DINING WITH DEMENTIA: CONTINUING TO FIND MEANING IN EATING-RELATED PRACTICES AS A SOCIAL EXPERIENCE AMONG FAMILY DYADS LIVING WITH TYPICAL DEMENTIA AND POSTERIOR CORTICAL ATROPHY.

A thesis submitted for the degree of Doctor of Philosophy

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Abstract

Dementia affects around 850,000 people in the UK. Whilst there is no cure, understanding how to support people to live well with this condition is important. There are ‘many faces of dementia’ and delineating experiences of living with different dementias in daily life is a key step towards understanding how to support people to live well with different symptoms. Supporting eating-related practices in a socio-relational context, referred to in this thesis as ‘dining’ experiences, may help promote the psychological needs related to living well with dementia, including inclusion, occupation and identity. This study aimed to understand how dining experiences and interactions were affected when living with typical dementia (tAD) and posterior cortical atrophy (PCA) and the processes involved in supporting dining experiences. Data collection included in-depth interviews with 20 family dyads (9 tAD; 11 PCA) and video-based observations of four dining interactions. An ‘informed’ grounded theory approach was used and Goffman’s (1974) Frame Analysis was identified to support understanding dining experiences in this study. Goffman’s (1974) theory provides understanding around how people structure and define their social experiences and coordinate these understandings in interaction. Findings revealed how dining could become disrupted when living with tAD and PCA, relating to vulnerabilities in this experience and eating-related practices becoming more about ‘management’. Interacting processes of revising frames, management strategies, optimising opportunities for continuity and engaging in supportive environments, were identified to support maintaining-meaning in dining. Video-based observations extended understanding in terms of contextual factors which shaped experiences and how people used the environment to support their dining interactions. Implications include supporting dining by using a balanced system of various processes to continue to create new meanings and experiences and using the environment to make ‘dining’ central, as opposed to focusing on eating-related practices as a ‘care-task’.

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Chapter 1: Introduction

1.1 Introduction

This chapter provides a background for this study and introduces the concept of living well with dementia, considering how a study on eating-related practices in a socio-relational context may support this. Secondly, the context is outlined as it is affiliated with a wider project and an introduction to the sample is also provided here. The development of this data-driven study is then outlined, describing how this study developed from a study focused around eating-related practices to a study on 'dining experiences' which is the term used to refer to the socio-relational experience of eating-related practices between two or more people. Goffman's (1974) Frame Analysis is introduced here as relevant for understanding micro-social interactions and the coordination of experiences within dining situations. The layout of the thesis is provided at the end of this chapter.

1.2 Background to study

In the UK, it is estimated there are around 850,000 people living with dementia and these numbers are projected to rise to one million by 2025 (Prince et al., 2014). Given these figures, there has been increasing public and research interest in dementia over recent years although this still lags-behind research into other diseases and conditions (Luengo-Fernandez, Leal & Gray, 2012). In terms of early-onset dementias there were over 40,000 people with this diagnosis in the UK in 2014, whereby symptoms arise before the age of 65 (Prince et al., 2014). Posterior Cortical Atrophy (PCA), originally Benson's disease, is a rare form of dementia which is typically early-onset with symptoms usually beginning between the ages of 50 and 65 years (Crutch et al., 2017). PCA is a visual-variant of dementia (see section 1.3). Any prevalence figures are likely to be an underestimate because of poor general awareness of the syndrome, however, Snowden et al. (2007) noted of 523 people who had Alzheimer's disease presenting to one specialist centre for cognitive disorders, 24 (5%) had PCA. When compared with other dementias, PCA is under-researched in terms of understanding the psychosocial impact, with much of the research to date focused on understanding the neuropsychological, cognitive and imaging profiles of those with the diagnosis (Crutch et al., 2017). Anecdotal and laboratory based research suggests ways in which PCA might impact on people's daily lives, including problems with eating-related practices, reading, driving and localising objects in space (Mendez, Ghajarania & Perryman, 2002; Yong et al., 2014;

Shakespeare et al., 2015), but there is a paucity of research focusing on the everyday experience of living with PCA for individuals and families.

Research which includes families living with dementia is important as around 63.5% of people with dementia live in the community, looked after by family or informal caregivers (Knapp et al., 2007). People with dementia who live in the community are thought to spend around 90% of their time with a spouse or close family member (Evans, 2003). Indeed, some researchers have suggested family caregivers are often like the invisible second patient (Brodaty & Donkin, 2009), as they become increasingly responsible for compensating for changes in functional abilities and dementia-related symptoms such as memory loss. A study by Jansson, Nordberg & Grafström (2001) observed 8 family dyads within the home environment and found activities of daily living such as hygiene, dressing and mealtimes were carried out together. For example, one couple showered together in the mornings so the husband could model the showering process to his wife with dementia. This suggests family members and people with dementia may come together in daily life more often than they did before the dementia. Indeed, some researchers suggest that there is a tendency in the research to “forget that there is a real living couple behind the disease” (Daniels et al., 2007, p. 162). However, given the amount of time people with dementia and family members spend together, experiences may be largely shared and interrelated, in terms of a ‘we’, when living with this condition, therefore it is important to consider this relational context.

The lack of understanding and knowledge of how less common dementias manifest often leads to delayed or incorrect assessment, diagnosis and support from health and social care professionals (Keage et al., 2012). Second generation research is beginning to disentangle the experiences of those with less common forms of dementias such as young onset dementias (e.g. Johannessen & Möller, 2013) and those with atypical symptom profiles such as behavioural variant frontotemporal dementia (e.g. Griffin, Oyebode & Allen, 2016). Visual impairments have a profound impact upon everyday life, with previous research demonstrating spatial perception is more strongly associated with independence in activities of daily living than episodic and verbal short-term memory (Glosser et al., 2002). However, there has been relatively little research into the impact of dementia-related visual impairments upon people’s everyday experiences. Furthermore, many people with typical amnestic presentations of dementia may also go on to have cortical visual impairment, likely later in their diagnosis and at such at a time when they may have more difficulty articulating their experiences (e.g. Paxton et al., 2007), therefore research with people with PCA may offer important perspectives on how people may experience dementia-related visual impairments.

At present, health care providers have greater opportunities to affect quality of life and wellbeing than to affect the course of the disease (Brod et al., 1999). In the absence of disease modifying therapies for people with dementia, environmental and psychosocial interventions to improve the quality of life and wellbeing of those living with dementia currently hold particular significance (e.g. Kasl-Godley & Gatz, 2000; Gilhooly et al., 2016). Better understanding and delineating the experiences of those living with various clinical phenotypes of dementia is a key step in developing tailored and specific environmental and psychosocial interventions for people.

Many studies have addressed living well with dementia, including concepts such as ‘wellbeing’ or ‘quality of life’. One of the most influential models of living well with dementia, has been developed by Tom Kitwood (1997) describing the concept of ‘personhood’, emphasising recognition, respect and trust for the person with the diagnosis. This concept also emphasises the idea of seeing the person before the dementia. Kitwood (1997) also outlined five psychological needs which he perceived to be important for all human beings, but which were more likely to be vulnerable among people with dementia. The needs Kitwood (1997) outlined, contributing to the expression of love are: comfort, attachment, inclusion, occupation and identity. Domains of living well with dementia in other research includes dignity, autonomy, choice, control, safety, security, enjoyment, meaningful activity, relationships and self-determination (Courtney et al., 2003; Kane et al., 2003).

As previously mentioned, not only does dementia affect the person with the diagnosis, but also those around them. Family members report experiences of loss in terms of the social connection and interaction with the person with dementia and the emotional burden of seeing them change over time (Etters, Goodall & Harrison, 2008). Family members are at increased risk of depression, stress and burn-out given the challenges associated for caring for someone with dementia (Papastavrou et al., 2007). However, as addressed in further detail in the literature review chapter (see section 2.2.2), experiences of caregiving are not always negative and vary depending upon a range of psychological and social factors. For many family members, positive experiences of caregiving have been reported such as enjoying togetherness, sharing activities, feeling a reciprocal bond and feelings of accomplishment and mastery (e.g. Sanders, 2005).

Dementia is increasingly being recognised as an inter-personal ‘we’ experience (Sällström, 1994; Perry, 1995). For example, some of the losses that people with dementia experience result directly from the responses of others rather than the dementia itself (Kitwood, 1997; Sabat, 2002; Patterson et al., 2017). For example, being devalued by others, social exclusion, depersonalisation and being perceived as ‘objects’ or having no subjectivity or personhood are experiences which occur in interaction with others (Kitwood, 1997). People in the earlier stages of dementia also often experience social isolation and withdrawal from others (Moyle et al., 2012). Furthermore, losses for the family member include more difficulties in communicating with the other person affecting the interpersonal relationship (Etters, Goodall & Harrison, 2008; Papastavrou et al., 2007). There can also be tensions within the dyad as people with dementia and family members transition into new roles (Adams, 2006; Atta-Konadu et al., 2011). Hellström et al. (2007) studied the way couples in the early stages of dementia maintained connection and maximised their quality of life. They found both partners played an active role, as they strove to maintain quality and closeness and create what they termed a ‘nurturative relational context’.

The present study focuses on eating-related practices in a socio-relational context, referred to in this study as dining experiences and some studies suggest this relates closely to the concept of living well with dementia (Keller et al., 2010; Genoe et al., 2010). Eating-related practices such as mealtimes are not just a space for tasks, but a place for identity formation, belonging and confirmation of social connection (through conversation and shared engagement in eating). Eating-related practices play an important role in family life, indeed they may be the ‘machine’ of family life (Keller et al., 2010), providing an important space to nurture identities and relationships within families (Fiese et al., 2006). Engaging in successful dining interactions may protect against separation and loneliness in dementia, supporting families to stay connected through change.

It is well documented that people with dementia often experience problems with eating-related practices, even in the mild stages of the disease. This includes problems with eating and drinking (Keller et al., 2007), weight loss (Soto et al., 2008), conversational difficulties (Orange, Lubinski & Higginbotham, 1996) and tensions for family members in providing care (Fauth et al., 2016). Many family caregivers provide assistant with eating and up to two-thirds report behavioural disruptions when supporting people with dementia (Fauth et al., 2016). Changes to eating-related practices also differ across various clinical phenotypes of dementia. For example, people with dementia with Lewy bodies score higher than people with typical Alzheimer’s disease on difficulties with swallowing, loss of appetite and needing support (Shunichiro, 2015). In behavioural frontotemporal dementias changes in social behaviour have been reported to be more predominant than in typical Alzheimer’s (Mendez et al., 2014). A study by Shakespeare et al. (2015) compared the differences between everyday functioning ability among 32 people with PCA and 71 people with tAD. People with PCA were significantly more impaired in everyday skills ($p<0.001$) and self-care ($p<0.001$), as well as in eating habits such as declining table manners. People with tAD were significantly more impaired in stereotypic and motor behaviours. This includes rigid and fixed ideas and opinions, routines which cannot easily be discourage and repeatedly using the same conversations. As well as this, motivation was reported to be more impaired for people with tAD, including less enthusiasm for usual interests. These differences may relate to important distinctions in dining experiences when living with these two different dementias.

Returning to Kitwood's (1997) model of psychological needs, engaging in eating-related practices together may be a space to nurture these needs for people living with dementia. For example, 'inclusion' may be supported by engaging in 'commensality' or the process of eating and drinking together (Kerner, Chou & Warmind, 2015), promoting belonging and inclusivity. 'Occupation' may also be nurtured through opportunities to be involved in purposeful roles such as preparing the meal. This is particularly important for people with dementia which relates to decreased opportunities to 'be useful' and involvement in purposeful activities can support quality of life for people with dementia (Phinney, Chaudhury & O'Connor, 2007). Finally, 'identity' may be nurtured within dining situations by emphasising choice and opportunities to express the self, for example, choosing to eat out at favourite restaurants or with particular social groups and having opportunities to express the social self during dining conversations. These opportunities may be vulnerable, in different ways, when living a visual-variant of dementia (PCA) and amnestic presentations of dementia (tAD).

1.3 The Seeing What They See project

This study is affiliated with a wider project (grant code: ES/L001810/1), funded by the National Institute of Health Research (NIHR) and the Economic Social Research Council (ESRC), called 'Seeing what they see: compensating for visual dysfunction in Alzheimer's disease' (Seeing What They See). Seeing What They See is a four-year study which aims to understand the impact of dementia-related visual loss and develop home-based interventions for people with dementia, to help people interact more successfully with their environments. This is a multi-disciplinary project which includes a team of occupational therapists, social workers, neuropsychologists, clinical psychologists and engineers across several research sites including University College London (UCL) and Brunel University London. The project is original as it involves people who have a diagnosis of PCA. The core features of PCA include insidious onset and gradual progression, prominent visuo-perceptual and visuo-spatial impairments not related to problems with eyesight-vision, relative preservation of memory and personal insight into changes and evidence of complex visual disorders (Crutch et al., 2017). At the time of this study, it was identified there was a lack of research on experiences of living with dementia-related visual impairments, despite this being a common symptom of dementia and people with PCA may offer novel insights into how dementia-related visual impairments affect quality of life and how they compensate for these difficulties. There are ‘many faces of dementia’, with ‘dementia’ being an umbrella term for a collection of syndromes, however existing literature has largely focused on dementia of the amnestic type. The Seeing What They See study developed as there was a need to understand how people experienced dementia-related visual impairments, as a rarer symptom of dementia, compared with more typical amnestic-type dementias. All the people with tAD in this study met the criteria defined by Dubios et al. (2010) including gradual progression and episodic memory impairments related to changes in the hippocampal area as the key early and defining feature, remaining predominant in the course of the disease. Less specific changes in executive functions, naming abilities or attention resources may also be apparent.

A diagram of the different study strands for the Seeing What They See project and aims of the various studies is provided in appendix 1. The researcher was involved in preparatory study 3 of the Seeing What They See project, led by researchers at Brunel University London. This included in-depth interviews with 37 family dyads (20 living with PCA and 17 living with tAD), involving both dyadic and separate clinical interviews with the person with the diagnosis and a family member. These interviews investigated difficulties and coping strategies related to living with PCA compared to more typical Alzheimer’s among people living at home (see appendix 3 for the interview schedule). The interviews for the Seeing What They See project were all carried out by the researcher and another researcher (either a fellow PhD student or co-investigator for the project). The study which is reported on in the following chapters developed from preparatory study 3 as a stand-alone study. The data collected specifically for this study is distinguished from the Seeing What They See project data-collection in appendix 1 using orange text-boxes. This separate study was supported by a Brunel University London Isambard Kingdom Research Scholarship, provided for the researcher to carry out a separate study. The research interests for this study emerged inductively from analysis of the first few interviews which were carried out for preparatory study 3 of the Seeing What They See study.

This study used a data-driven methodology which meant the researcher was initially open to the topic of investigation. From the initial Seeing What They See interviews, the researcher became aware that both people living with PCA and those living with tAD were reporting significant changes and concerns related to eating-related practices which led to the focus upon this activity for this study. Other activities of daily living (ADL)s such as bathing, dressing or shopping were also considered. However, they appeared less of a concern than eating-related practices from the Seeing What They See interviews, particularly given these practices related to family dyads coming together around three times daily for a significant portion of time.

Not only did being attached to the wider Seeing What They See study support the development of the interests for this study, but it also served a number of practical benefits. In terms of the sample, it afforded an opportunity to gain access to participants with the rarer dementia, PCA, through recruitment via the Specialist Cognitive Disorders clinic at UCL hospital, which specialises in rarer dementias (see section 3.4.3 for sample and recruitment). This provided an opportunity to explore how significant differential diagnoses was in terms of people's everyday dining experiences, comparing how different symptoms of dementia, including perceptual and spatial impairments (PCA) and memory impairments (tAD), affected dining. Secondly, PCA is typically a younger- onset dementia, which usually begins around a person's mid-50s to early 60s (e.g. McMonagle et al., 2006; Mendez et al., 2002). Given participants in the Seeing What They See study were age-matched, this meant that the sample of people with both PCA and tAD who were available for this study included a range of ages including early- and later- onset dementias. This provided a diverse set of family dyads with which to explore dining experiences which was deemed useful as the study aimed to provide an explanatory understanding of psychosocial processes related to various dining experiences, as outlined in sections 1.5 and 1.6.

Another practical benefit was that given the researcher had met participants previously to discuss difficulties and coping throughout the day for the Seeing What They See interviews, this provided a suitable platform with which to focus upon a particular day-to-day activity i.e. eating-related practices, in more detail. Had the researcher not already explored other day-to-day difficulties and coping strategies, family dyads may have felt they had not had an opportunity to discuss broader difficulties which concerned them, for example the diagnosis process or difficulties with bathing or other activities. Therefore, these initial interviews provided a suitable basis to then focus upon an aspect of daily life without ignoring the overall experience of living with dementia. Furthermore, the researcher had already built a rapport with these participants which may have supported them to be more open within the dining interviews than if this were the first time they had met the researcher.

Finally, being attached to the Seeing What They See project provided access to a wealth of data and interactions within the wider project team, including professionals from multi-disciplinary backgrounds. The researcher attended regular multi-disciplinary team meetings, which supported a wider perspective than if this were a stand-alone project. Furthermore, consent and ethical advice was gained via the Seeing What They See project, as outlined in the methods chapter (see section 3.3). The researcher also presented and discussed findings with this wider research team and multi-disciplinary discussions supported the analysis process and development of this study. The researcher also learnt from conducting the initial Seeing What They See interviews about useful methodological approaches for gaining access to participant's experiences. It was deemed that the format from the Seeing What They See interviews of interviewing family dyads first and then interviewing people with dementia and family members separately was an effective way for gathering rich data,. Furthermore, this may have provided some consistency for the participants as they were already familiar with this style of data collection.

1.4 Development of this study

Given the lack of current knowledge around dining experiences for people living with different clinical phenotypes of dementia, particularly when living with dementia-related visual loss (PCA), this study used a data-driven methodology. As outlined in the following literature review chapter, at the time of the Seeing What They See study and the start of this study, no research was identified which compared daily experiences of living with PCA and tAD from a qualitative perspective (see section 2.2.4). Furthermore, it was deemed important to make central the interests and concerns of people living with this diagnosis, as opposed to imposing pre-existing hypotheses which may not be relevant to their experiences. Data collection and analysis occurred simultaneously so that emerging themes could inform subsequent data collection and the research interests developed over time. As outlined in the methods chapter, this study also used an 'informed' approach, using abductive reasoning which is a process of comparing data, theory and literature as the study unfolded (see section 3.5.5).

The initial interests for a study on eating-related practices developed further as the researcher wanted to understand more about how people living with the two dementias interacted with the physical and social environment and compensated for any difficulties using the environment. Given people with PCA particularly experienced difficulties interacting with the physical environment, for example in terms of eating conduct, whereas people with tAD experienced other difficulties such as in social connection with others, this initially appeared a useful comparison to delineate experiences when living with these distinct clinical phenotypes of dementia. Over time, as this study developed using a constant comparative approach to compare dining experiences among people living with PCA and tAD, the symptom-specific differences in functioning appeared less important than the researcher may have expected in terms of overall appraisal of experiences. What appeared important was how people perceived the dementia-related changes impacted upon their opportunities to express their social selves and relationships within social eating-related practices. This meant that what was made central was the person, as opposed to the dementia and how the changes affected opportunities for people to be who they were within this space. This was supported by the reading of the literature, particularly the data-driven Eating Together study by Keller and colleagues, which found that mealtimes mirrored the way people were and revealed “what it was to be human” when living with dementia (Keller et al., 2010, p. 193). On reflection, the development of this study supported the researcher’s own learning about the importance of considering the person’s self-concept and on how dementia symptoms interact with this, as opposed to the diagnosis or symptoms per-se.

The focus of this study developed from an initial interest in eating-related practices as an ADL, to dining experiences as defined in section 1.1. Viewing eating-related practices as ‘dining’ helped to focus the lens upon this activity as a social activity, an opportunity to present the self and connect with others. Eating-related practices for the families who were interviewed for this study often became necessarily social as the person with dementia required assistance from family members and they thus co-depended on one another within this space and thus eating-related practices were largely an interaction. Where participants viewed changes as disrupting their ability to present themselves or there were tensions in social interactions, this appeared to relate to more negative experiences and a collapse in meaning of this integral aspect of daily life. Therefore, as the title suggests, this study focuses on ‘dining with dementia’ as opposed to eating-related practices as a functional activity.

The data-driven nature of this study meant that the questions the researcher asked participants evolved over time as the research interests developed alongside the analysis of the initial interviews. The first few interviews appeared less rich and informative as the researcher’s initial focus was largely upon eating-related practices as an ADL, to be managed. However, this lacked meaning in terms of the central concerns of participants around eating-related practices as a social experience. Over time, interviews became about how changes affected people’s dining experiences and interactions with others particularly in terms of how they could express the self, express identities and have social connection with others in this space. For example, more time was spent discussing how changes impacted on eating out experiences and social dining occasions with others, as well as how the changes impacted the way the participants conversed when dining together. This is where eating-related practices as a dining experience could be closely linked to ‘living well’ with dementia, as outlined in section 1.2.

Another development of this study included the movement from understanding perceived ‘dining’ experiences overall towards also understanding how actual micro-social elements of dining unfolded. This related to looking more closely at how dining interactions were managed for individuals living with either PCA or tAD and to understand how people living with these different dementias supported them. This informed the second stage of data collection, which used video-based observations of four different dining interactions. Understanding dining experiences at the micro-social level was also supported theoretically by Goffman’s (1974) Frame Analysis theory. Goffman’s (1974) Frame Analysis was identified to support the micro-social understandings of how people made meaning from their dining experiences and negotiated and managed these definitions in interaction with one another. This theory is outlined in detail in chapter 5.

The interests and academic background of the researcher also influenced the way this study developed. The researchers training and background is in Psychology (B.Sc.) and this study evolved in a way which met the interests of the researcher as well as participant’s voiced concerns. The initial focus was around considering the impact of the physical and social environment on people’s eating-related practices, however over time the study became more focused around psychosocial issues such as how individuals presented themselves through dining and how they perceived or ‘framed’ their experiences within various eating-related situations. Goffman’s (1974) Frame Analysis also considers micro-social meanings and people in interaction and his approach has been termed a kind of ‘structured social psychology’ (Verhoeven, 1993, p. 322). Engagement with these topics and Goffman’s work may have been influenced by the researcher’s background in Psychology. Although she did not come across Goffman’s (1974) work in her undergraduate study, the researcher came with an interest in ‘existential’ perspectives of reality and how people understood the self, as well as how people experience micro-social relationships and interactions. Although the researcher attempted to stay grounded within participant’s reported experiences, for example, through in-vivo, open coding (see 3.5.2), aspects such as level of intrigue and theoretical considerations may in-part also pertain to the interests of the researcher. Had the researcher not come with a background in Psychology, the study may have developed in a different way, for example focusing upon nutritional aspects of eating the meal or the physical management of eating-related practices, had she had an alternative background such as in Nursing or Occupational Therapy.

1.5 Layout of thesis

Chapter 1: Introduction

Chapter 1 has presented the background of this study, it provided a brief outline of the literature in relation to 'living well' with dementia. It described how this qualitative study developed from a study on mealtimes as a food-related task, to a study on dining with dementia. This chapter also explains the context of this study, as attached to a wider study and introduces the two types of dementia, tAD and PCA which feature in this research.

Chapter 2: Literature Review

Chapter 2 follows to outline the literature which is relevant to this study. It firstly outlines the broader literature on experiences of living with dementia overall and discusses how a study on 'dining' can both provide a window of opportunity to explore socio-relational aspects of living with a dementia diagnoses and the potential of dining to support the needs of people living with a dementia diagnosis. The second section of the literature review then appraises the literature on eating-related practices from a sociological perspective, including experiences among people living with dementia, as well as living with other diseases and conditions as there was a lack of studies in dementia and particularly atypical dementias, so it was deemed important to consult this wider literature. Chapter 2 concludes with outlining the research questions for this study and a justification in relation to the existing literature.

Chapter 3: Methods

Chapter 3 outlines the methods used to meet the research aims of this study. It describes the data-driven methodology and a justification for this approach, including the 'informed' grounded theory approach. It includes an appraisal of existing literature on living with dementia which use grounded theory approaches. Details of the sample and recruitment are included and ethical considerations. It also outlines the data-collection methods, firstly in-depth interviews and secondly observations of dining scenarios. Data analysis processes are outlined in detail. An evaluative framework and various criteria for appraising the quality of this study is also suggested.

Chapter 4: Goffman's (1974) Frame Analysis

In chapter 4, a justification for using Goffman's (1974) Frame Analysis to support understandings of dining with dementia in this study is provided. A discussion of the relevance of this theory for understanding dining experiences is provided. There is also a discussion on how his theory relates to a study on dining experiences of people with PCA and tAD. The reader is also referred to appendix 15 which contains a glossary of Goffman’s (1974) concepts which have been applied in this study.

Chapter 5: Interviews on Dining Experiences

Chapter 5 presents the findings from the interviews. It firstly addresses how people perceive changes to their dining experiences when living with PCA and tAD, showing how some individuals appeared to continue to find meaning in eating-related practices as a dining experience, whereas for others eating together could become more of a care-task as opposed to opportunity for enjoyment. Secondly this chapter addresses how people living with PCA and tAD who took part in this study supported changes to their dining experiences to maintain meaning in these experiences. The findings are conceptualised using Goffman’s (1974) Frame Analysis concepts.

Chapter 6: Observing Dining Situations

Chapter 6 reports on findings from the observations. It particularly addresses how actual dining interactions were affected when living with tAD and PCAand how people supported these interactions. It both compliments the interview chapter and highlights some key differences. This chapter particularly shows how props within the physical and social environment supported the diners. As in the previous chapter, the findings are conceptualised using Goffman’s (1974) Frame Analysis concepts.

Chapter 7: Discussion

Chapter 7 brings together the findings from the interviews and observations, relating them back to the original research questions as outlined in section 2.4. The findings are tdiscussed in relation to the existing literature, including what this study adds. The research is critically appraised using the evaluative framework laid-out in Chapter 3. Strengths and limitations of this study are discussed. Finally, this chapter concludes with areas for future research, implications and a conclusion of this work.

1.6 Summary of chapter one

This introduction has outlined the development of the research focus from ‘mealtimes’ to ‘dining’. Overall, studying dining experiences may provide an important avenue for understanding the way family dyads can manage and cope with dementia-related changes from a socio-relational perspective, to support family cohesion, meaning and connection and to help people to live well with dementia in their daily lives. Mealtimes may be one of the 'simple pleasures' (Hellström et al., 2007) which can contribute to retaining quality of life for both people with a diagnosis of dementia and their family members. Phull, Wills and Dickinson (2015) suggest that for a meal to be enjoyable "a group needs to play by the rules of sociable interactions to construct a pleasant eating event" (p. 979). This study explores what happens when different dementia-related symptoms (dementia-related visual loss and amnestic symptoms) disrupt the ability to 'play by these rules'. As people with dementia may come to spend more time with family members, given they may increasingly rely on others for support, this study looks at how people coordinate coping and meaning-making at the relational level, exploring how each member of family dyads contribute to one another's dining experiences.

Chapter 2: Literature Review

2.1 Introduction

As outlined in detail in chapter 3 (section 3.5.5), the literature has been reviewed throughout the development of this study, as the study used an 'informed' grounded theory approach. This meant the literature has been approached from the beginning of the study, through to the end-stages of the analysis and write-up stages to support the development of the study.

This chapter covers two areas of literature. Firstly, it provides an overview of the wider literature on experiences of living with dementia, in terms of the psychosocial impact of dementia upon people living with dementia and strategies people use to support their experiences among people living at home (section 2.2). It was outside the scope of this study to systematically review this research given the vast amount of literature available (Gilhooly et al., 2016). However, this section is intended to provide an overview, providing a justification and context for a study on dining experiences which may support living with dementia. Much of this synthesises existing systematic reviews to provide an overview of the main themes related to experiences of living with dementia. This section is organised into literature with people with dementia, family members, dyadic experiences and the limited literature on experiences of living with different types of dementia.

A more systematic approach has been applied to the literature review in the following section on qualitative studies on sociological aspects of eating-related practices when adjusting to a disease or condition in adult or later life (section 2.3). As well as reviewing this literature throughout the development of the study, a systematic search has been carried out to ensure all the relevant literature has been covered. Although there is literature available on eating-related practices in residential settings, this literature was excluded as this was outside the scope of this study focusing upon experiences for people living at home. The literature available on eating-related experiences for families adjusting to other conditions was also reviewed as limited research was identified which included the dementia voice and no studies were identified which included people with the atypical dementia PCA, therefore this wider literature was consulted to provide an understanding of how different symptoms may impact experiences of eating-related practices and insights into potential experiences for the person with changes to their functional ability as opposed to family member or dyad experiences, providing a suitable background for this study. The research questions are presented at the end of the chapter, following a discussion of the areas for research development in the appraisal of the existing literature.

2.2 Experiences of living with dementia

2.2.1 Experiences among people with dementia

This section provides an overview of the literature on experiences for people with a dementia diagnosis living at home and strategies to support experiences. One of the main experiences reported among people with a diagnosis of dementia is loss. Steeman et al. (2007) conducted a meta-synthesis of 33 qualitative studies on living with early-stage dementia and found the post-diagnostic phase was characterised by loss of control, leading to feelings of incompetency, low sense of self-esteem and a changing sense of self which may hinder a person further from being motivated to engage in certain meaningful occupations or tasks. Loss of meaningful relationships was also identified in the review by Steeman et al. as opportunities to socially connect with others was lost, for example, in terms of social conversation where people with dementia may lose track within the interaction and have difficulties expressing themselves. Feeling misunderstood and ignored by others could also relate to experiences of alienation and loneliness. Similarly, another study by Sørensen et al. (2008) with 308 people with dementia found evidence of low social participation, as estimated by the primary caregiver. They found low activity engagement predicted this, whereby when family members took over activities of daily living, people with dementia became passive. Loss in terms of sense of reality among people with dementia was also identified whereby cognitive loss could cause unpredictable “gaps in the flow of their day-to-day lives” (Phinney, 1998, p. 11). However, Steeman et al. (2007) also outlined that these experiences were not always felt and both positive and negative experiences were reported across their sample. Another study by Miranda-Castillo et al (2010) with 152 people with dementia and their family members, found that the most frequent unmet needs for people with dementia were daily activities (50.7%), company (39.5%) and help with psychological distress (30.9%).

In terms of coping with loss, Steeman et al. (2007) found that people with dementia simultaneously struggled to hold onto their identities whilst trying to adjust for changes, oscillating between self-maintenance and self-adjustment. They found people with dementia could seek opportunities to maintain meaning by engaging in purposeful activities and moving on with life despite dementia. Although not referred to in Steeman’s review, eating-related practices may be a suitable space whereby people may be able to engage in self-maintenance roles such as cooking. Han et al. (2016) also found connectedness was key for coping whereby being connected to others, doing activities with others and being connected within a familiar physical environment were supportive for maintaining continuity. In relation to this study, the dining space may support and facilitate connectedness, i.e. by promoting engagement in a familiar daily activity within a familiar environment, for example, by eating in restaurants people had dined in before they had dementia. As outlined in section 1.2, the concept of “commensality” refers to the process of eating and drinking together at the same table, which is thought to support relationships (Kerner, Chou & Warmind, 2015), therefore this may further promote feelings of connectedness for people with dementia. People with dementia have also been reported to use confabulations, discussing fabricated or mistinterpreted memories without conscious intention to deceive, to facilitate social conversation, remain included and maintain personal identity in interaction with others (e.g. Örulv & Hydén, 2006).

Steeman et al. (2007) also identified the importance of social interaction for coping with loss, citing Kitwood’s (1990) concepts around dementia as a socially-embedded phenomenon. They found that people viewed having a sense of belonging, being accepted and being loved and valued by others protected against experiences of loss. More recently, Han et al. (2015) and Moyle et al. (2012) also found people living with dementia in the community desired maintaining meaningful relationships and a loss of this was a source of loneliness. Maximising eating-related practices as dining events may support experiences of connectedness and maximise interaction with family members for people with dementia. Overall, promoting dining opportunities, such as dining out, may not only maximise the sense of belonging within family dyads, but also promote wider social connections with one’s community, including family and friend networks.

Another experience associated with living with dementia is changes in self-identity (Caddell & Clare, 2011) and difficulties in terms of maintaining personal dignity and value (Sørensen et al., 2008). Caddell and Clare (2011) found among 10 people with dementia, they still felt they were the same person, however, described specific changes to their sense of self in terms of the impact symptoms had on their ability to do things as they did before, as well as having an impact upon identity indirectly by affecting communication and thus weakening connections with family and friends. Overall, the researchers found there were tensions between continuity and change, leaving people with dementia in a state of flux regarding their sense of who they were. They suggested this might underlie the desire of people with dementia to maintain their lifestyle and activities, to prevent anxieties that could come from these tensions between continuity and change. As described in more detail in Chapter 4, Goffman (1974) views the ‘self’ as a malleable process which is expressed to others through engaging in everyday activities and roles. Therefore, engaging in eating-related tasks in social dining situations, similar to roles a person had in the past, may help to ease tensions in a person’s sense of self. Indeed, Sørensen et al., (2008) found great importance was attached to being involved in useful domestic activities among people with dementia helping to protect against a decline in personal dignity and value. Other studies support this, whereby opportunities for continuity have been reported as a ‘safe space’ to regain emotional equilibrium for people living with dementia (Pearce et al., 2002; Logsdon et al., 2007; Steeman et al., 2007; Wolverson, Clare & Monz-Cook, 2016).

Overall, many of the existing studies on living with dementia emphasise maintenance of meaningful aspects of life as a key component to promote wellbeing and quality of life. For example, in a meta-synthesis of studies on living with dementia (Eriksen et al., 2016) they found maintenance of social aspects of daily living such as supportive interactions, maintaining friendships, support from others and meaningful activity engagement was key for supporting quality of life when living with dementia. Meaningful activity engagement was also emphasised by Phinney, Chaudhury and O’Conner (2007) whereby they found “the single most important driving force in their lives was being active, doing as much as they possibly could” (p. 384). Being involved in household chores and social engagement was part of the range of activities which were meaningful, suggesting dining involvement could be supportive.. Phinney et al. also found the physical and social environment played an important role in facilitating involvement in meaningful activities. This is an important consideration for this study, whereby the physical and social dining environment may help promote involvement among people with dementia.

2.2.2 Experiences among family members of people with dementia

This section considers the literature on experiences associated with living with dementia for family members and strategies to support experiences. As outlined in the introduction (section 1.2), family members also experience changes when living with dementia and may be described as the ‘invisible second patient’. Much of the research has focused upon stress and coping among family members suggesting caring for someone with dementia involves ongoing stress and frustration, relating to poorer quality of life and wellbeing (Gallagher-Thompson & Powers, 1997; Bell, Araki, & Neumann, 2001; Butcher, Holkup & Buckwalter, 2001; Gilhooly et al., 2016). Family members have been reported to experience high levels of burden and may be at increased risk of depression, stress and burn-out given the challenges associated with caring for a person with dementia (Papastavrou et al., 2007). Some studies suggest rates of depression range from 23% to 85% in family members caring for people with dementia (Adkins, 1999; Clare, 2002; Papastavrou et al., 2007).

As the literature suggested for people with dementia one of the main experiences reported for family members is also loss (Evans & Lee, 2014; La Fontaine & Oyebode, 2014). Loss is reported particularly on the relationship level in term of loss of the partner/parent as they were prior to dementia, loss of the relationship as it was previously, loss of emotional and practical support and loss of shared understandings (Baikie, 2002; O'Shaughnessy, Lee, & Lintern, 2010). Loneliness has also been reported for family members, particularly because of a loss of companionship with the person with dementia (Ablitt, Jones & Muers, 2009), as well as social exclusion from friendship groups and difficulties maintaining a social life due to increased care responsibilities (Beeson, 2003; Nay et al., 2015). However, the experience of loss is complex and varies across family members, for example, some family members have reported the relationship continues to be present, while others talk of moving on from the relationship and making new friendships (Evans & Lee, 2014; La Fontaine & Oyebode, 2014). Dining together may foster social connection and prevent family members from feeling estranged from the person with dementia, providing mutual benefits in terms of protecting against experiences of loss for both the person with the diagnosis and family members.

One criticism of work with family members is that there has been a preoccupation in the research with the negative or pathological aspects of care (Twigg & Atkin, 1994). If the focus is on the caring role being one of burden and stress this may affect the discourses for family members meaning-making around their experiences of living with dementia. Some studies have highlighted that caring is more complex and experiences vary, shaped by factors such as culture, context, relationship dynamic, support structures, personal coping resources and meanings people ascribe to their situations (e.g. Hayes, Boylstein, & Zimmerman, 2009; Hibberd, Keady, Reed, & Lemmer, 2009; Lin, Macmillan, & Brown, 2012). Understanding multidimensional factors which affect experiences of dining together is an important consideration for this study.

Positive aspects of caring have been reported in existing research. For example, some family members have reported coping well with the challenges and rewarding and satisfying experiences (Farran et al., 1999; Cohen, Colantonio, & Vernich, 2002). Lloyd, Patterson and Muers (2016) reviewed 14 studies on the positive aspects of caregiving and found this included mastery or increased self-esteem, a sense of pride and purpose in new roles, emotional rewards, personal growth and increased self-awareness and mastery in learning new skills. In terms of coping, acceptance of the situation was found to be particularly important supporting family members to view their situation with a positive attitude and be compassionate and empathic towards the person with dementia. Furthermore, they found it important that family members created meaningful opportunities for the person with dementia empowering them to continue caring. Eating-related tasks may be one area whereby family members can promote meaningful engagement for people with dementia. Another study by Nolan et al. (1996) found caregivers reported continuing to find simple pleasures in daily life was supportive for positive caregiving, suggesting they should be encouraged to build enriching and fulfilling activities into their daily routines. In relation to this study, one enriching activity could be promoting dining, where family members could maximise meaning around eating-related practices as a social event.

2.2.3 Experiences within a socio-relational context

As outlined in the introduction (section 1.2), dementia is largely a socio-relational experience. In a study on the positive aspects of caregiving, Peacock et al., (2010) found having a family member with dementia provided an opportunity for families to spend more time together and become closer in ways that otherwise may not have been possible. However, this appears to contrast with the literature outlined earlier which suggests both people with dementia and family members experience loss in terms of their social connection (e.g. Baikie, 2002; O’Shaughnessy, Lee & Lintern, 2010). Some of the literature suggests that although people with dementia and family members are spending more time together, tensions may exist between the needs or perspective of the spouse and the person with dementia (O’Connor, 2007; O’Shaughnessy et al., 2010). In a study on mutual engagement in everyday activities among 26 cohabiting couples, Vikström et al. (2008) identified tensions in coordinating behaviours, for example, where the person with dementia could still wish to perform complicated tasks, whilst family members felt this could not be performed safely. The found increased nearness could also hold different meanings, indicating a burden for caregivers and/or feelings of loneliness when there was less mutuality in experiences. This suggests that although people with dementia and family members are coming together more, for example within the dining space, this does not necessarily relate to more experiences of closeness. There is a need to understand further how experiences and behaviours are coordinated within this socio-relational context, to understand how people may be able to support opportunities of being together as successful interactions.

Another aspect of the socio-relational experience which has received less attention in the literature but which relates to many of the problems reported by family members (Eggenberger, Heimerl & Bennett, 2013) is changes to conversation. Changes to conversations when living with dementia have been reported to relate to a disruption in perceived marital closeness among family dyads, making a partner see their relative as a different person than before (Boylstein & Hayes, 2012). Early symptoms of dementia include word-finding difficulties, repetitiveness and random topic shifts affecting conversational flow (Harley, 2001; Müller & Mok, 2014; Müller & Guendouzi, 2005). Conversation is particularly relevant to this study given that a fundamental element, or perhaps the fundamental element of dining together is conversation. Given that the literature suggests people living with dementia spend more time together, but that these interactions can be tense and exacerbate stresses, understanding how communication contributes to this and strategies to support communication within shared spaces is key.

Some studies have looked at conversation when living with dementia. For example, one study by Jones (2015) investigated day-to-day conversations between a mother with dementia and her daughter and son-in-law. This study found clear communication difficulties and diminishing capacity to communicate was not solely related to symptoms such as semantic and short-term memory impairment, but also related to the way the daughter and son-in-law responded in the interaction. Two main communication difficulties were identified, firstly when questions presupposed memory and secondly when the mother's conversation was exposed as being incorrect. In this study, Jones (2015) found the mother developed strategies to display interactional competence, such as answering without knowing to prevent disruptions to the interaction. An earlier study by Bohling (1991) which is described in more detail in chapter 4 (section 4.3), also described how people with dementia could change the topic or meaning of conversations where this may not meet typical conventions for conversation and family members could either establish effective communication by joining the person with dementia's frame of reference or fail to pick up on their cue, relating to people with dementia becoming frustrated. Hamilton (2005; 2008) studied the sociolinguistic aspects of language in dementia and found others had a significant impact on motivation and engagement in conversation among people with dementia. She likened this to a 'dance' (Hamilton, 2005) whereby people with dementia may be poorer (communicative) dancers, but with the appropriate dance (communicative) partners they are still able to execute the dance (conversation) effectively, demonstrating the interrelated experience of living with dementia. Other research suggests strategies including giving more information (Orange et al., 1996), verbatim and paraphrased repetition (Wilson et al., 2012) and simplifying sentences (Small et al., 2003). Studying dining as a social activity may offer an opportunity to examine further how families living with dementia facilitate successful communication.

One strategy to support interaction among people with dementia which has already been mentioned is confabulations. There is some debate in the literature about how family members should respond to this in terms of truth-telling (Spector et al., 2000). For example, reality orientation suggests truth-telling, however, this approach has been criticised as it can lead to suspicion and mistrust when the person with dementia's reality perspective is being contested. In contrast, validation therapy works to validate the reality people with dementia experience to support their wellbeing. This topic is complex as for family members no longer being believed or ceasing to tell the truth to a family member with dementia has potential repercussions in terms of closeness and openness in the relationship. As suggested by Woods (2012) there is scope for more development of approaches that may help to maintain and improve relationships between people with dementia and family members.

2.2.4 Experiences among people living with different types of dementia

This section considers the existing literature on studies of experiences when living with different types of dementia. As outlined in chapter one, there are 'many faces of dementia' and there is a need to understand how different dementia profiles can impact upon people's experiences. There is some literature on the relative burden for family members when living with frontotemporal dementia, compared with typical Alzheimer's disease. In a review of this work, Caceres et al. (2016) found spouses of people with frontotemporal dementia experienced greater caregiver burden, distress and increased rates of depression. There are a small number of qualitative studies examining experiences of living with different types of dementia. For example, a study by Kumamato et al. (2004) found eating behaviours such as cramming food into the mouth and uncooperativeness were found to be considerably burdensome among family members. Another study by Oyebode, Bradley, & Allen (2013) found changes in communication, rigid routines and socially embarrassing behaviours related to unique experiences among family members. One study by Galvin et al. (2011) with family members of people with Lewy Body dementia also identified unique challenges and unmet needs related to living with this differential diagnosis. No qualitative studies were identified which explored experiences of living with PCA at the time of this study. Therefore, it is largely unknown how people experience living with dementia-related visual loss within their daily lives. However, this is an important consideration given the above studies suggest various dementia symptoms can impact experiences differently.

Few quantitative studies have been carried out with people with PCA. One study outlined in the introduction (see section 1.2) explored the impact of PCA and tAD on everyday functioning and neuropsychiatric status. This identified key differences in the way everyday activities were affected, including eating-related practices and interactions. There were a lack of studies identified which explored how such changes impact family members. For example, given PCA involves more physical difficulties with interacting with the environment at mealtimes (Shakespeare et al., 2015), family members may need to provide more practical support which could have impact upon their dining experiences than family members of people with tAD. In terms of the psychological impact, no differences were reported in mood by family members, however, it is unclear why this is the case. Another study contrasts with this and found among 15 people with PCA, they reported greater depression compared with people with tAD, which they related to more insight and awareness into symptoms than those with tAD (Mendez et al., 2002) However, in another study by Suárez-González et al. (2015) which compared the neuropsychiatric profile of 28 people with PCA and 34 people with tAD, they did not identify differences in measures of depression, irritability, apathy and anxiety, despite the very different profiles of symptoms. There is a need for further research which explores the impact a visual-variant of dementia can have on the quality of life and wellbeing compared with tAD.

Another important consideration is around experiences of living with early- compared with later-onset dementias. Some research has been conducted exploring the experiences of living with an early-onset dementia (i.e. under 65). For example, Johannessen and Möller, (2013) found people with early-onset dementias particularly experienced intrapsychic challenges where dementia affected their self-image and there were reports of social embarrassment with having this diagnosis. Some people with early-onset dementia also described how they felt dementia was more stigmatising as it affected them at a younger age and some discussed hiding this diagnosis from others to maintain social façade. Given this current study includes people with both early- and later- onset dementias this offers an opportunity to explore how dining as a social experience may be affected by age. For example, considering how dining out experiences with peers may be affected differently for those with an earlier-onset dementia and the types of coping strategies, for example, perhaps attempting to conceal difficulties when they are viewed as particularly stigmatising. Family members may also experience different challenges when living with early-onset dementias, for example, Arai et al. (2007) found they perceived greater difficulties with caregiving, as well as financial pressures and work-related responsibilities. Feelings of isolation and being marginalised have also been reported among family members (van Vliet et al, 2010). A qualitative study also reported family members had more grief for midlife projects when affected by early-onset dementia (Ducharme et al., 2013). In terms of dining, family members of people with younger-onset dementias may have particular difficulties, for example, if they are also pressured by work-related responsibilities, this may prevent them from having as much time to enjoy dining interactions with the person with dementia, than people who are retired.

2.2.5 Summary and relation to a study on dining with dementia

There is a vast amount of research on the experiences of living with dementia from both an individual and relational perspective. It is outside of the remit of this thesis to cover all this research in detail, however, this overview of the wider literature suggests many of the difficulties and changes to experiences when living with dementia may be supported through engaging in successful dining interactions. Many studies suggest engaging in meaningful aspects of life, which promote opportunities for purposeful activity engagement and activities with others could support can support living well with dementia. Dining then may be one space to promote engagement in meaningful roles, as well as social interaction with others. As with studies with people with dementia, studies with family members also suggest loss in terms of the relationship as it was previously, as well as burden and stress. However, other studies suggest positive aspects of caregiving include being involved in enriching and fulfilling activities in daily life (e.g. Nolan et al., 1996) and continuing to create meaningful opportunities for people with dementia. Supporting successful dining experiences may then also be supportive for family members of people with dementia. Some dyadic studies, however, suggest mutual engagement in activities such as dining together, could increase burden and feelings of social isolation, as people with dementia and family members take on different roles and could have different perspectives within shared activities, relating to tensions.

The literature on living with different types of dementia appears to be in its infancy, whereby only a few studies were identified which looked at experiences when living with different dementias. For example, some work has examined living with early-onset dementias, suggesting that dementia may be more stigmatising when younger, relating to retreating from social situations. There was a lack of qualitative work which explored the impact visual-variant of dementia PCA could have on experiences of people living with this condition. Studying dining across people living with differential dementia diagnoses may help further understanding of the impact various symptoms of dementia can have on people’s daily lives and interactions with others. The following section outlines the current literature on eating-related practices among people living with different diseases and conditions.

2.3 Experiences of eating-related practices when adjusting to a disease or condition in adulthood or later life

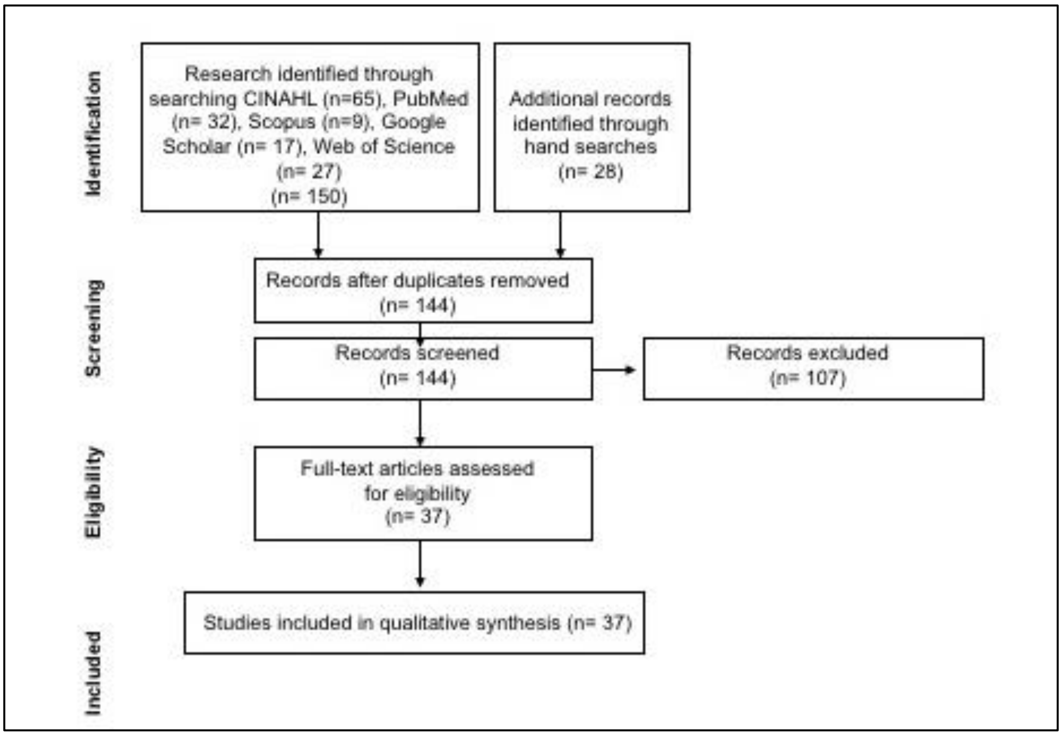
2.3.1 Literature search and overview

As discussed in the previous section studying eating-related practices as a shared experience may be supportive for living well with dementia as this activity may foster experiences of togetherness, inclusion in meaningful roles, identities and involvement in meaningful activities. This literature review examines the qualitative research available on studies of eating-related practices when adjusting to a disease or condition in adult or later life from a sociological perspective. This meant that studies addressing nutrition or feeding-related aspects of care were excluded. Studies including people living with other diseases or conditions aside from dementia were also included as there was a lack of studies with people with dementia, particularly with people with atypical dementias, therefore it was deemed important to consult the wider eating-related literature on adjusting or living with other diseases or conditions to provide a context for understanding the potential impact differential diagnoses can have in relation to eating-related practices.

Studies within residential or care home settings were also excluded as the focus of this study is upon experiences for families living at home. To be included in the review, studies had to be available in English. To identify suitable studies for review a search was carried out using electronic databases: Google Scholar, PubMed, Scopus, CINAHL & Web of Science, using the terms {'Dementia' OR 'Alzheimer's Disease' OR 'Posterior Cortical Atrophy' OR 'neurodegenerative' OR 'motor impairments' OR 'stroke' OR 'Parkinson's disease'} AND {'mealtimes' OR 'dining' OR 'eating' OR 'feeding' OR 'eating-related practices' OR 'eating out' OR 'cooking' OR 'meal preparation'}. There was no start date entered into the database so as not to limit the search and the end date was 29th June 2018 when this search was finalised and checked for the purpose of this write up. In addition, the reference lists of articles identified by electronic searching were manually searched for further relevant studies. Where literature included eating-related practices as a secondary outcome, these studies were also included. Studies which did not mention eating-related practices in any context, and referred broadly to activities of daily living, care tasks etc. were excluded on the basis it was not clear which aspects were relevant to this topic. Studies were screened for relevance based on the title and abstract.

The initial electronic search process identified 150 studies; of these, 107 were excluded, particularly as many of these studies addressed nutrition-related changes, or were conducted in care homes or residential settings. Quantitative studies were also excluded. The review process is summarised in figure 1.

Figure 1: Flowchart of study identification and the selection process



The 37 reviewed studies are summarised in a table in appendix 2. Regarding topic, 26 of the studies examined eating-related practices overall, one focused upon eating out, two studies looked at strategies to support eating-related experiences and 7 examined the experiences of changes to food-related roles. In terms of sample, 10 included family dyads living with dementia (8 of which were part of the same research project, the Eating Together study), 8 examined experiences for family members of people with dementia and only one study examined experiences for people with dementia. 7 studies examined experiences for people living with stroke, all but one included people who had had a stroke as opposed to family members, contrasting with the research with people living with dementia. Two studies examined experiences for people living with Parkinson's disease, with one including experiences for family dyads. One study looked at experiences for people with Chronic Obstructive Pulmonary Disease (COPD) and one with family members of older adults who had had a terminal illness. 4 studies included a mixed sample of people adjusting to a disease or condition in adult or later life, three of which excluded people living with dementia, suggesting the 'dementia voice' is largely lacking from the research. Regarding methodology, 25 of the studies used qualitative interviews, 6 used a combination of interviews and observations and 3 used focus groups. One study conducted an analysis of published autobiographies on experiences of having a stroke. The Eating Together study used a constructivist grounded theory approach, whereas most of the other studies used a descriptive design such as phenomenology, ethnography or thematic analysis. Regarding country, 14 of the studies were conducted in Sweden, 6 in the UK, two in Canada, two in Taiwan and one each in Iceland, Indian and Australia. One study did not specify country (Moloney & Walshe, 2018).

The review firstly appraises studies on eating-related practices overall. It appraises the largest study identified by the search, the Eating Together study by Keller and colleagues, and this is then compared with other research in dementia, across other diseases and conditions, and different contexts. The review secondly appraises the studies on changes to food-related roles. The final section appraises this literature overall before introducing the research aims for this study.

2.3.2 Eating related practices in a sociological context for people with dementia

2.3.2.1 The Eating Together study

The largest study identified on eating-related experiences from a sociological perspective is the 6-year ‘Eating Together’ study. This Canadian longitudinal study involved dyadic and individual semi-structured interviews with 26 family dyads living with dementia (Cassolato et al., 2010; Keller et al., 2010, 2015; Genoe et al., 2010, 2012; Lam & Keller, 2015 & Wong et al., 2015). Much of the previous research addressed nutrition-based aspects of eating-related practices, however the researchers recognised the importance of considering the sociological aspect as related to quality of life when living with dementia (Keller et al., 2010). The study aimed to explore how mealtimes were important in the caring relationship when living with dementia (Keller et al., 2010). Participants included 25 dyads living with Alzheimer’s disease, 1 dyad living with frontal-temporal lobe dementia and 1 dyad living with vascular dementia. The researchers did not distinguish between experiences for people living with these differential diagnoses. The Eating Together study used a constructivist grounded theory design, founded within symbolic interaction (Charmaz, 2006) to develop the resulting Life Nourishment Theory.

The Life Nourishment Theory describes that although challenges were experienced by many of the participants the mealtime, for the most part, was considered “a potential place for positive interaction” (Keller et al., 2010, p. 198). Three key themes were identified in this study: ‘being connected’ including being face to face, participating psychologically and getting and giving support; ‘honouring identity’ including protecting dignity, having meaningful roles and reaffirming self in the world; ‘adapting to an evolving life’ including triggering awareness, assigning meaning and responding to changes. Overall, they found mealtimes could be supportive for nurturing and strengthening attachments when living with dementia (Keller et al., 2010, p. 207).

The Eating Together series largely focused upon positive experiences. For example, the sub-study by Wong et al. (2015) looked at the emotional resilience of one mother-daughter dyad from the Eating Together study who were chosen based on their resilience and ability to adapt to changes to eating-related practices over the 6-year study. They found the dyad focused on positive gains and personal growth, and balanced past pleasures whilst adapting to the new normal. Adapting included developing positive strategies and continuing to learn about changes. They also found this dyad identified meaningful alternatives when the person with dementia could no longer complete mealtime related tasks, for example, eating out rather than cooking as a way to enjoy eating together without the burden of preparing food. They emphasised humour as one of the key coping strategies to support a positive appraisal of changes.

The Eating Together series of studies did not differentiate experiences among people with dementia and their family members which may be related to the grounded theory approach that was applied in terms of identifying a core concern, as opposed to highlighting more divergent themes. This is a consideration, particularly as the study reported on dyadic experiences and some researchers have suggested this can leave the person with dementia’s voice relatively unheard given family members may hold the dominant voice and people with dementia often report less in interviews (Murphy et al., 2015). In the Eating Together study, interviews with family members were reported to be around an hour whereas interviews with the person with dementia were around 20 minutes-45 minutes (Keller et al., 2010), suggesting they had less to report in relation to their experiences or may have had difficulty communicating their perspectives. This suggests it may be useful to use other means of data collection, such as observations, which do not rely on language ability or people reflecting upon recent experiences which may be more difficult for people experiencing short-term memory difficulties.

The Eating Together series of studies also used existing theoretical models such as the family adjustment and crisis (FAAR) model (Patterson, 1988), Kitwood’s (1997) person-centred care and attachment theory (Bowlby, 1979) to provide a conceptual understanding of the mealtime experiences among their participants (e.g. Genoe et al., 2010; Keller et al., 2012). For example, the FAAR model describes a continuous cyclical process of adjustment-crisis and adaptation when living with a chronic condition. According to this model, adjustment includes the use of available coping resources and crisis is where existing resources fail and adaptation is needed which involves redefining situations and adapting to new circumstances. The model also emphasises that subjective meanings, as opposed to organic symptoms, explain variability in family member's reported experiences. For example, whereby some people are situated in a phase of 'adjusting' hoping independence and social etiquette may return. Attachment theory (Bowlby, 1979) was also used to highlight the potential impact of food and mealtimes for the development and maintenance of relationships. Person-centred care (Kitwood, 1997) was used to focus upon the abilities and strengths of people with dementia and suggests dementia involves a continuous interplay between neuropathological factors and psychosocial factors. The use of these models appears to provide a deeper understanding of the experiences for people living with dementia. It is also worth noting that these theoretical models largely support a positive perspective in terms of successful adaptation and eating-related practices as a space to promote connection. This may be because the Eating Together study aimed to address *maintained* meanings of mealtimes and there is less understanding around the psychosocial factors related to losses and difficulties at mealtimes when living with dementia.

One sub-study from the Eating Together series examined eating out experiences for family dyads living with dementia (Cassolato et al., 2010). This was the only paper identified in the literature review which focused upon eating out. Cassolato et al. (2010) found that among the participants in the Eating Together study, eating out was meaningful for maintaining a balanced life. This was in relation to 'social balance', i.e. maintaining connections with social groups and acting as 'binding glue' for relationships and 'environmental balance' i.e. spending time in other eating environments and 'spicing up life', for example by trying different foods and minimising meal preparation demands. This supports the suggestion that eating out may help to protect against low social participation and social isolation which is reported in dementia (e.g. Sørensen et al., 2008). Cassolato et al. also reported changes influenced the experience of eating out, such as difficulties with crowds and noise as well as loss of social capacity resulting in eating out less. They identified several strategies found to support and restore balance such as going to familiar restaurants and at 'off-times' of the day, as well as ordering easy-to-eat meals.

Overall, the Eating Together study presents the value and role of mealtimes in maintaining the stability of the family unit when living with dementia. It highlights the potential of families to be able to continuously adapt and maintain meaningful experiences, and opportunities for eating-related practices to be a place for 'life nourishment' (Keller et al., 2010). The study also emphasised the social aspect of mealtimes as chiefly important, in terms of fostering connections and bonds as well as maintaining identities relating to the needs highlighted in section 2.2. They suggested that “eating meals together on a frequent and routine basis can develop and maintain relationships in the face of dementia and prevent depression and early institutionalisation” (Keller et al., 2010, p. 209). A list of strategies to support positive mealtime experiences in terms of social engagement and continuity is summarised by Keller et al. (2015) including conversation aids e.g. using the physical environment as an aid for conversation, creating a calmer atmosphere, doing tasks together, role engagement, negotiating capacity and being flexible. Overall, despite changes, they suggested that mealtimes could be used as an intervention for families living with dementia, providing a natural connection point for family dyads to maintain cohesion. They suggested "mealtimes provided a time when social interaction was often easier for families" (Keller et al., 2015, p. 5).

In summary, the Eating Together study focused upon the maintained meanings associated with mealtimes, as opposed to loss of meaning and difficulties for family members. This focus away from a problem-orientated approach helped to explore the positive aspects of life when living with dementia, but perhaps also overlooks some of the more difficult aspects, for example, where meanings may be lost and interactions stressful when eating together. For example, as mentioned earlier, the sub- study by Wong et al. (2015) examined the resilience of one mother-daughter dyad, chosen on the basis of positive experiences. As well as this, after 3 years, from the original 26 family dyads, 18 continued to participate in the Eating together study. As the researchers noted, the people who agreed to participate and stay in the study may have been different from the average family living with dementia with superior coping skills that support resilience and continuation in the study (Keller et al., 2015). Whilst the Eating Together study can be seen to support narratives around living positively with dementia which help to challenge negative stereotypes and stigma (Harris & Keady, 2008), there is less of an understanding around psychosocial factors related to eating-related practices becoming a more stressful occasion when living with dementia.

2.3.2.2 Other research on eating-related practices for families living with dementia

Most other studies identified by the search were with family members of people with dementia (n=7), excluding dyadic perspectives. Only one study explored the self-descriptions of eating-related practices for the person with the diagnosis (Johansson et al., 2011). This may limit understanding of eating-related experience both including the ‘dementia voice’ and from a socio-relational perspective, understanding how people coordinate and negotiate their practice and understandings. As outlined in section 2.2.3 people with dementia are thought to spend around 90% of their time with a spouse or close family member (Evans, 2003), therefore including dyads in research on eating-related practices is important.

Of the studies with family members there were more negative experiences reported than in the Eating Together study. The study by Keller et al. (2006) described the theme ‘throwing in the dishtowel’ to demonstrate how dining experiences became stressful and tiring for family members in their study with 23 caregivers. Another study by Hsiao et al. (2013) identified family members tended to have negative attitudes and behaviours regarding changes to the person with dementia’s eating conduct and deviations in eating behaviour. These authors suggested “the burden of dealing with an older person with dementia increased along with the progression of the disease” (p. 365), thus presenting the idea of an inevitability of a distressing experience for family members of people with dementia, as opposed to being able to successfully adapt. The researchers aimed to look at problematic eating behaviours using semi-structured interviews with 13 family members and asked participants “what bothers you about the care recipient’s eating habits?” (p. 362) which differed from what was asked in the Eating Together study in terms of maintained meanings of mealtimes. This suggests it is important to consider the influence of researcher bias upon the way people appraise their experiences.

Other studies found that mealtimes related to a loss of social connection for family dyads (Keller et al., 2006; Hsiao et al., 2013; Papachristou, Giatras & Ussher, 2013; Johansson et al., 2014). For example, Papachristou, Giatras and Ussher (2013) conducted semi-structured interviews with 20 family members and concluded that their findings conflicted with the Eating Together study, whereby family members began conducting eating-related practices alone and ate out less together, relating to a loss of opportunities for togetherness. They reported some variations in strategies, for example, whereby some found it important that the person with dementia assisted in food preparation such as laying the table, although this could be more difficult or stressful for family members. In the study by Johansson et al. (2014) with 10 family members there were also reports of stressful interactions when engaging together in eating-related practices. Family dyads could lose the day-to-day conversation which related to experiences of loss and sadness when appraising mealtime experiences. Johansson et al. reported that changes in conversation meant family members had to adjust to silence and difficulties with the person with dementia following the on-going dialogue. Keller et al. (2006) also talked about the loss of social mealtimes where eating together as a social activity could be neglected and a ‘food as medicine’ type attitude could come to dominate. These findings again contrast with the Eating Together study in terms of the opportunity of mealtimes as a time for being connected and eating out being a resource for family dyads (e.g. Keller et al., 2010; Cassolato et al., 2010). These studies used descriptive, qualitative design and lacked explanatory hypotheses, for example in how or why conversations may change or why family members use different coping strategies.

It is also apparent that none of the studies distinguished experiences for family members when living with different types of dementia. Only one of the studies (Keller et al., 2006) identified by the search specified the type of dementia, including probable Alzheimer's (14), senile dementia (2), mixed dementia (2), frontal temporal lobe (3) and Parkinson's related dementia (1), but did not differentiate experiences within this sample. Other studies reported including people with 'dementia' overall and did not specify type. No studies were identified which included family members of people with PCA.

One study was identified which solely addressed mealtimes as described by people with dementia. This study by Johansson et al. (2011) looked at managing mealtime tasks among 15 people living with dementia in Sweden. They found that people with dementia normalised their situations and largely described preserving the self by engaging in mealtime roles. Themes in this study included preserving the self whereby people with dementia discussed using familiar habits as usual and being able to manage whereby participants expressed they did not have difficulties preparing or eating food. Overall they found "experiences were that memory loss did not affect their mealtime tasks in any great way" (p. 2557). These findings contrast with the research with family members which describe more changes, stress, burden and taking over meal preparation. There is a lack of understanding around how these perceptions may be coordinated with family members within shared eating-related situations. Johansson et al. (2011) also found that self-reports were not necessarily consistent with their observations, whereby individuals reported memory problems were not affecting mealtimes but may forget in the interviews what they had recently eaten or steps in the cooking process. This suggests the interview approach may be limited in capturing the complexity of experiences among people with dementia and observing behaviours may provide another layer of understanding around these experiences. Overall, given the study by Johansson et al. focused upon managing mealtime tasks, there is a lack of understanding around how people with dementia self-report their experiences of the social elements of mealtimes, such as conversations with family members and co-ordinating roles. The study also included 9 people with dementia living alone, therefore, the study may also be more about the mealtime as an individual eating-related activity, as opposed to eating-related practices as a shared activity with others.

2.3.2.3 Supporting eating-related practices among people living with dementia

Many of the studies identified by the literature review detailed strategies to support eating-related practices. However, across all the studies it was unclear how effective strategies were and in which contexts. For example, the study by Keller et al. (2006) stated that some families adapted by employing strategies listed, however, some did not resolve their mealtime problems. It is unclear what factors related to the variable usefulness of such strategies. Listing strategies in this way is relates to the methodological approach of descriptive qualitative designs as opposed to explanatory-based studies.

Many studies suggested the physical environment could be supportive, such as putting a glass of water by the side of the person with dementia to encourage them to drink (Papachristou, Hickeys & Iliffe, 2016). In the study by Ball et al. (2015) they identified strategies such as providing regular snacks and finger foods could support eating. However, they found strategies described by family members could also exacerbate caregiver stress and burden, which may then impact upon their social enjoyment of eating-related practices. In line with this, strategies such as food shopping alone and eating out less with people with dementia to manage symptoms also relates to loss of social dining experiences and opportunities for togetherness (e.g. Keller et al., 2006; Papachristou, Giatras & Ussher, 2013; Johansson et al., 2014). In the study by Keller et al. (2006) they listed strategies such as cutting up food before the meal, keeping environments non-distracting such as no music, convenience foods, pureed food and plastic-coated metal utensils to support eating conduct changes. However, such strategies may disrupt the social enjoyment of the meal and relate to more of a ‘food as medicine’ attitude (Keller et al., 2006). Many studies did not appear to distinguish between strategies which support mealtimes as a social opportunity compared with the management of eating as a care task. Furthermore, it may be important to consider the social definition strategies such as eating aids can carry for people and how their use impacts upon the dining experience.

Other studies focused upon strategies to support eating-related practices as a social activity. For example, Johansson et al. (2014) found having the radio on or discussing past family memories with the person with dementia could be helpful. In the study by Papachristou, Hickeys & Iliffe (2016) they developed and evaluated booklets with 20 family members on eating-related practices. They found social strategies such as telling others about the condition when eating out could also be helpful. In a focus group study by Johansson et al. (2015) with 22 staff working in the community, they found strategies such as enabling meals at home, taking over, moving meals outside the home, and people with dementia preparing food were recommended to maintain abilities and independence. It is worth noting this advice differs from some of the strategies suggested in other studies with family members such as eating out less and taking over cooking roles (e.g. Papachristou, Giatras & Usshet, 2013). This may be related to different motivational relevancies, for example, whereby family members may find it more stressful and time consuming to enable the person with dementia to take part, whereas home-help staff may recognise this as important for the person with dementia. This demonstrates the importance of including the dementia voice in this research. Should people with dementia hold different perspectives around their experiences as suggested in the study by Johansson et al. (2011) they may value conflicting strategies such as being involved to support their reality, in contrast to family members who may find it more advantageous to employ other strategies. How these strategies are then negotiated and impact on each other's experiences is an important consideration.

2.3.3 Research on eating-related practices across other diseases and conditions

This section compares literature on eating-related practices across other diseases and conditions to the research described above with people living with dementia. One of the key differences is most of this research has been conducted with people with the condition and only a small number included family member or dyadic accounts. This suggests a difference in the way people with dementia are perceived in terms of their agency over their eating-related practices and/or barriers in accessing the person with dementia's voice. Of the studies with people living with other diseases and conditions, all emphasised difficulties with the social aspects of eating-related changes. For example, Miller et al. (2006) found psychosocial consequences concerned people more so than the physical difficulties with eating. Another study by Nyberg et al. (2016) found that people could withdraw from certain social occasions or food types which may be used to demonstrate "proper food and mealtime behaviour, to maintain the façade and act according to perceived norms" (pg. 1). This supports focusing upon the psychosocial consequences of changes to eating-related practices.

Some of the studies with people living with other diseases and conditions used multiple methods for data collection, such as combining interviews with observations. For example, the study by Klinke et al. (2014) found observation supported the inclusion of 7 people with communication difficulties who had had a stroke whereby communication through behaviours and body language could be investigated. These methods combined with interviews also provided novel insights into strategies which supported eating-related practices. For example, with observation Klinke et al. found that some participants maintained a good outward façade by pretending to drink from a cup in the presence of the researcher. Another of the studies by Nyberg et al. (2016) found observations facilitated understanding of eating difficulties as participants commented whilst interacting with their meal. For example, one participant switched from a knife and fork to a spoon at the end of the meal to support the eating process and muttered that this was bad table manners, suggesting he was embarrassed and this was ‘improper’ behaviour. In some of the studies, despite using a combined approach including observations it was unclear where this translated into the findings. For example, in one of the studies they used observation and interviews but did not comment on the observations in their paper (Carlsson, Ehrenberg & Ehnfors, 2004). Furthermore, often in these studies details of the complex interactions which were observed, including non-verbal and verbal behaviours were not included. This may be related somewhat to the way this data was collected, i.e. relying on notes from the observations. Other methods such as video-recording may help in capturing the complex and multi-faceted behaviour which can be observed in face-to-face interactions (Knoblauch, 2012). One of the studies reviewed by Jones and Nasr (2017) on eating among 8 people who had a stroke used photography as well as interviews which revealed complex difficulties with eating-related activities such as eating out. The researchers emphasised the need for these types of research methods which peel back the layers of complexity related to eating as a multifaceted phenomenon.

In reviewing literature with people living with other diseases and conditions many of the studies reported many difficulties and stresses in terms of the social aspect of eating-related practices. For example, in the study by Westergren et al. (2016) with 19 people with Parkinson’s disease they found participants presented overwhelming challenges, helplessness and loss of control over the mealtime, as well as not being able to participate socially. In another study by Moloney and Walsche (2018) which examined 10 autobiographies of people who had a stroke, they found individuals discussed feeling embarrassed and worried about the perceptions of other people and the impact that this has on them psychologically. This suggests that whilst eating together can be therapeutic when adapting to a disease or condition (Keller et al., 2015) it may also be a difficult social experience which reveals one’s impairments through engaging in eating-related practices. In the study by Odencrants, Ehnfors and Grobe (2005) with 13 people with COPD they found respondents described eating with others at home or in a restaurant in more diverse ways. For some it was an event and reason to eat more and for others they ate smaller portions and were ashamed when eating with others. Some reported eating with others made them nervous to the point they started to cough.

It is worth noting that social embarrassment was not a key theme which came out of the study with people with dementia (Johansson et al., 2011). Several possible reasons may account for this. Firstly, many of the participants in the Johansson et al. study lived alone and therefore they may have reflected more upon food-related tasks as a solo experience as opposed to in a social context. Alternatively, people with dementia may have had more difficulty reflecting on their recent experiences due to short-term memory problems and thus did not recall feeling embarrassed. Another reason may be experiences are unique to living with this diagnosis. Johansson et al. (2011) drew on Goffman's (1959) presentation of self to explain their central theme of 'meals as normal' among people with dementia. They suggested people with dementia attempted to display themselves as competent and having control over the situation to protect their identity and fear of being dependent on others, therefore presenting the idea that they were satisfied and able to manage (e.g. De Witt, Ploeg & Black, 2009). However, this explanation may be limited as one may expect then that people with Parkinson's as another neurodegenerative condition may also present changes in this way whereas the study by Westergren et al. (2016) described in the previous chapter suggests more loss and challenges. Further research is needed to elucidate the dementia voice around experiences to their social eating-related practices.

Other studies emphasised mealtimes as an opportunity to anchor to normality, relating more so to the study with people with dementia (Johansson et al., 2011). For example, Jones and Nasr (2017) found among 8 people who had had a stroke that sustaining eating activities regardless of their disability was important for wellbeing. They found that people sought opportunities to participate in occupations revolved around eating. Wallin et al. (2013) also conducted a study with 9 family members of people who were terminally ill with eating deficiencies and found ways to be together around food helped to maintain ordinariness in everyday life for family members.

As with some of the studies in dementia many with people living with other diseases and conditions emphasised subjectivity in experiences. Disability appeared to be related to the way people interpreted what changes meant as opposed to the objective changes themselves and related to the way people managed eating conduct difficulties, for example hiding symptoms when they viewed changes as non-normative (Perry & McLaren, 2003; Carlsson, Ehrenberg & Ehnfors, 2004; Odencrants, Ehnfors & Grobe, 2005; Miller et al., 2006; Medin et al., 2010). For example, Perry and McLaren, (2003) found level of impairment did not translate to how much this impairment was a handicap or perceived as a problem in relation to eating-related experiences. They provided an example of this, whereby a wife in one couple was hemiplegic, ate one-handed, had impaired chewing and swallowing, was dysphasic and hemianopic and despite these impairments, still carried on eating in restaurants and enjoyed this experience with friends. They contrasted this with the case of a man who had a loss of tactile recognition in one hand and would only eat out if shielded from view in a restaurant (Perry & McLaren, 2003). The researchers highlighted the importance of exploring participant's perceptions towards symptoms as opposed to the objective impairments themselves, as they appeared to relate more closely to social handicap and risk for social isolation. Similarly, a study by Medin et al. (2010) which involved interviews with 13 people who had a stroke found that the use of different strategies to support eating-related practices varied from individual to individual and was related to what was important to each person and how they used to eat before their stroke. Others could be viewed as either facilitators or barriers to supporting eating situations according to the persons' values and previous habits. These studies support the concept that understanding experiences of eating-related practices is complex and largely relates to psychosocial processes and individual appraisals of situations.

Unlike the studies presented with people with dementia, some studies in other diseases and conditions differentiate experiences across samples. For example, Gustaffson et al. (2003) differentiated experiences when living with stroke, Parkinson's disease and rheumatoid arthritis. Another study by Miller et al. (2006) differentiated experiences between the person with the condition and family member's experiences. The study with 37 family dyads living with Parkinson's disease found "what might help the person with PD [Parkinson's disease] could be an added burden for the carer" (p. 617) suggesting some coping strategies could cause tensions and difficulties affecting the other person. In including family members accounts they also reported how swallowing problems encroached on family members' experiences, whereby they often felt guilty with seeing their partner struggling and worried about them choking, thus highlighting the way such diagnoses can be viewed as an experience for the whole family. Of the studies with people living with dementia, where dyadic perspectives were included studies reported on shared experiences as opposed to differentiating experiences which also appears important.

Another strength of the study by Miller et al. is in looking at the effects of specific symptoms, i.e. swallowing difficulties, as opposed to a broader diagnostic label. Another study by Odencrants, Ehnfors and Grobe (2005) also considered factors specific to living with COPD. For example, they found general factors relating to all people such as a desire of having company, as well as findings associated with the ageing process, such as altered intake of food and decreased activity level and finally some themes of a more disease-specific nature (e.g. breathing, positive and negative feelings and the need of time). Differentiating experiences in this way, i.e. related to symptoms, may be particularly important in being able to provide tailored support and advice and is an important consideration when conducted a study with people living with dementia where there are 'many faces' related to this diagnosis (see section 1.2).

Four of the studies identified by the literature search explored eating-related practices across various contexts when living with different diseases and conditions (Brijnath, 2011; Klinke et al., 2013; Lam & Keller, 2015; Chen et al., 2016). The study by Klinke et al. (2013) was the only study identified which included experiences among younger-people (aged 34-64) adapting to changes in their eating practices with 7 younger-stroke survivors. Key findings included social embarrassment and participants wanting to escape in the company of others. They reported social embarrassment may be more of a difficulty for younger people as they felt they stood out more in relation to their peers than their older counterparts who may be able to normalise their experiences in relation to their peers. Strategies such as using humour and attempting to conceal their difficulties was identified. This relates to the study by Johannessen and Möller, (2013) described in section 2.2.4 where people with early-onset dementias experience intrapsychic challenges including social embarrassment and stigma, relating to hiding their difficulties from others. Age is an important consideration in terms of social eating experiences which appears to be yet to be addressed.

The other three studies considered cultural differences. The study by Lam and Keller (2015) was a sub-study of the Eating Together study with 8 Chinese immigrant families with dementia. They found although the life nourishment theory (see section 2.3.2.1) was generally supported there were some important cultural differences such as taking on the role of the elder, transferring culture across the generations, and keeping culture. They also found older care partners also willingly accepted help from adult children. This differs from some of the other research with people from Western backgrounds from individualistic cultures whereby people reported more difficulties with accepting family support (see section 2.3.3). Another study by Chen et al. (2016) examined experiences of people in Taiwan with low-literacy skills living with COPD. They found people held a passive, fatalistic perspective about eating with heart disease and felt insecure about eating activities and preparing food. The researchers suggested this was a unique challenge because participants had difficulty accessing education or support around eating. This set of studies highlights the importance of considering individual situations in understanding experiences of eating-related practices.

2.3.4 Food-related roles in a sociological context

The research appraised in the previous two sections (2.3.2, 2.3.3) examined experiences of eating-related practices overall. This section appraises the existing literature specifically on food-related roles including in dementia and other diseases and conditions. 7 studies identified by the search focused upon food-related roles when adjusting to different diseases and conditions including 5 with people with dementia (Gustaffson et al., 2003; Russell, 2007;

Fjellström et al., 2010; Atta-Konadu et al., 2011; Kullberg et al., 2011; Papachristou, Giatras & Ussher, 2013; Boyle, 2014). All these studies considered the impact of gender-role ideologies.

All studies suggested gender-role ideologies impacted experiences and types of strategies people used to adjust to changes in cooking roles. For example, the study by Papachristou, Giatras and Ussher (2013) with 20 family members of people with dementia (10 male; 10 female) found cooking and preparing meals was particularly challenging for male family members who took on this role, given they were not necessarily familiar or skilled in food preparation compared to female family members who had these roles previously. This related to different coping responses, for example, male family members bought ready meals, selecting items that were less complicated and stressful, helping them transition to these new roles. One paper from the Eating Together study also explored changes in food-related roles (Atta-Konadu, Keller & Daly, 2011). From the analysis of 3 years of interview data they identified a central theme of ‘sliding into food-related roles’ driven by a gradual process of moving back and forth through steps and strategies to retain meaning as food roles shifted. Overall, they described the process of coming to terms with changes and working things out. As with other studies they found gender played an important role, for example, where wives who perceived food preparation to be related to the feminine identity saw a loss of these roles as failing to live up to expectations and losing part of their identity. Kullberg et al. (2011) conducted a study with 18 men with somatic diseases, used continuity theory to explain why consistency in patterns of thinking about mealtimes and cooking roles were important for participants in their study. They found the use of adjustment and adaptation techniques were influenced by driving forces of continuity in their lives as opposed to adjusting for the disease itself. They found factors such as gender-related roles, as well as civil status, personal interests, and skills and habits were important factors in the participant’s approaches to food-related activities.

Some studies found people were able to successfully adapt whereas others presented changes as difficult and stressful. For example, Fjellström et al. (2010) found men struggled to take on new cooking roles, in contrast the study by Papachristou, Giatras and Ussher (2013) found men could transition to these new roles. One factor which may relate to variations in findings across the studies is the methodological approach. The study by Fjellström et al. used focus groups which included male and female family members. This design may have related to male family members reporting more difficulties taking on the cooking roles, given they may have positioned this as non-normative compared to females in the focus group who may have perceived they had stronger cooking role identities as a traditional western gender role ideology. The study by Papachristou et al. used 1:1 interviews, whereby male family members may have had more freedom to express a new cooking role identity which was not influenced by group dynamic. Thus, it may be important to consider how the social context and approach to data collection could be impacting the way eating-related practices are appraised.

Another study by Gustaffson et al. (2003) found type of disease or condition impacted on the way changes to food-related roles was appraised. This study involved semi-structured interviews with 72 women with different diseases and conditions. They found people who were not disabled (i.e. the control group) highly valued independence, people with rheumatoid arthritis tried to live a normal life and ignore their disease, people with Parkinson's disease wanted to cook their own food for as long as they could and people who had experienced a stroke engaged in food-related training and worked at becoming their own masters again. This relates to research how different symptoms and disease types have an impact on the way changes are experienced and the types of strategies people use to support their experiences (see section 2.3.3). This study excluded people with dementia, therefore there is a lack of understanding of differences related to living with this condition. The researchers did not specify why they excluded people with dementia.

Two studies were unique in using observation to examine dyadic interactions when managing food-related roles. Boyle (2014) looked at how men approached cooking when their wives developed dementia. They used a combined approach of observing 21 couples going about their mealtime and food-preparation, as well as semi-structured interviews. They found husbands exercised choice and control over whether they cooked and often exercised control over whether their wives cooking depriving them of decisional autonomy. Through the combination of interviews and observations this provided a deeper understanding of behaviours, including embodied expressions. For example, they found although women were unhappy about their exclusion from cooking they did not verbally challenge their husbands and instead expressed their resistance more subtly through their behaviour, such as trying to enter the kitchen and joining in when their husband started cooking. These observations appeared to have revealed important understandings around perhaps more socially undesirable behaviours which people may be less likely to report in interviews. Another study by Majlesi & Ekström (2016) also used observations but with video-recording to capture interactions among one couple living with dementia when preparing food. They found people with dementia actively used the material environment (including physical cues and their partners) to compensate for challenges and difficulties in the task in order to partake in the activity. The researchers reported this approach added understanding about actual performance and interactions, as opposed to just reflections on performances using interviews.

2.3.5 Appraisal of the literature

Overall, the 37 studies reviewed highlight the complexity of experiences related to changes to eating-related practices across different diseases and conditions. The research shows how dining experiences become affected both for the person with the condition and those they interact with and the complexity of coping across different individuals, as they adapt, not just to changes in physical eating or nutritional changes, but also to social, cultural and psychological changes. Existing research shows the importance of considering eating-related practices from a psychosocial perspective, considering issues such as stigma, social embarrassment, need for social adjustment, and the psychological impact of changes to roles in terms of self-identity. The most comprehensive of studies identified with people living with dementia, the Eating Together study, suggested the therapeutic potential of mealtimes for Life Nourishment, however, other studies also suggest eating-related practices can become stressful and people with dementia and family members may spend less time together eating, eating out and engaging in social conversation, losing the therapeutic potential. Themes of social embarrassment, stress with taking over cooking roles, valuing independence and adjusting were reported to be related to adjusting to changes.

In terms of research with people living with dementia there was a lack of studies identified which compared eating-related practices when living with different types of dementia. Although some of the studies reported including a mixed sample of people with different clinical phenotypes none distinguished between experiences, treating the sample as homogeneous. As outlined in the introduction, ‘dementia’ is a broad term for a set of symptoms, and differentiating experiences across different types of dementia is important for identifying at-risk groups and providing tailored support. In some of the research with people living with other diseases and conditions experiences related to swallowing difficulties (Johansson & Johansson, 2009) and breathing difficulties (Odencrants, Ehnfors & Grobe, 2005) were reported providing more specific understandings of experiences related to these symptoms. Furthermore, one study explored the social impact of eating difficulties related to living with younger-onset stroke (Klinke et al., 2013), and there is a need for further research in dementia which includes people living with early-onset dementias and how they experience changes to eating-related practices.

From the review, it appears there is also limited research which includes the ‘dementia voice’. For example, three of the studies which have explored the impact of eating difficulties in different diseases and conditions chose to exclude people with dementia from taking part despite the fact it is well-known people with this diagnosis experience eating-related difficulties. One study included people with dementia but the majority lived alone (Johansson et al., 2011), therefore there is a need for further understanding around how people with dementia perceive and cope with changes to social aspects of eating-related practices. It may be important to outline differences in experiences among people with dementia and family members particularly as cognitive losses can relate to difficulties identifying shared perceptions (e.g. Phinney, 1998; Vikström et al., 2008). For example, the Eating Together study, included people with dementia and family members, however, reported on the dyadic experience overall. It is important to report on diverse experiences as opposed to just shared dyadic experiences as this can leave the person with dementia’s voice unheard where family members perspectives can come to dominate. Another concern is how best to access a person with dementias experiences where they may have more difficulties reflecting on recent eating-related practices, particularly in amnestic-type dementias. As highlighted by Klinke et al. (2014) other data collection methods such as observation can help maximise inclusion for people with communication difficulties in research.

Overall, the research paints a complex picture of experiences of changes to eating-related practices. This includes reports of a wide range of experiences and strategies to support changes. Most the studies identified by the literature search used descriptive, qualitative methods which described *what is* happening as opposed to *by which* it is happening. Given the variations in reported experiences, from eating-related practices being a high point of the day for family cohesion and enjoyment, to a time of tension, stress and estrangement from the ‘typical’ experience, there is a need for more explanatory research to provide potential insights into *why* these different experiences may be reported. The Eating Together study used grounded theory to explore the meaning of mealtimes for family dyads living with dementia. This methodology is particularly useful for moving understanding towards *why* and exploring inter-relationships between themes, providing a conceptual understanding of processes related to experiences. The Eating Together study used a constructivist approach (Charmaz, 2006) which is useful for understanding the way people reflect upon their experiences. The study also used existing theoretical frameworks which supported understanding of the complexity of coping and processes by which individuals adapt to the behavioural, psychological and social consequences of living with dementia. Many of the studies reviewed were a-theoretical which limited understanding of these complex psychosocial processes.

Another area for further research development is in understanding more about actual micro-social interactions which take place when engaging in eating-related activities when living with dementia. For example, studying conversation as a key aspect of the social element of eating-related practices. This is important considering that although people with dementia and family members may spend more time together this increased nearness can exacerbate tensions within the couple (see section 2.2.3) therefore understanding these interactions is important. One reason much of the research has not looked at the actual interactions which take place may be that many take a constructivist or symbolic interactionist approach, as in the Eating Together study. Much of the research uses interviews to focus upon abstract meaning-making and how people reflect upon experiences, as opposed to behaviours and coordinating actual actions. Related to this, understanding how people living with dementia utilise the physical and social environment is an important area for research development, considering how this may promote opportunities for involvement among people living with dementia.

2.4 Research questions

This study has developed using a grounded theory approach to address how perceived dining experiences and actual interactions are affected for people living with two types of dementia, tAD and PCA and how people living with these diagnoses support their experiences and interactions. By ‘dining’ the researcher is referring to the social aspect of eating-related practices with two or more people. This study includes the whole process of eating-related practices where it involved social interactions such as food preparation and clearing away the meal, as well as typical aspects of dining such as eating together. By ‘living with dementia’ this refers to the person given the diagnosis and a close family member, given the study takes the approach of dementia as a socio-relational experience (see section 1.2). In comparing PCA and tAD, the broad aim is to understand how dining experiences and interactions can be affected and supported when living with a visual-variant of dementia versus amnestic symptoms of dementia as well as identifying similarities in terms of adjusting to a dementia overall.

Specifically, the research questions for this study are as follows:

1. How do people perceive their dining experiences when living with tAD or PCA?
2. What strategies support maintaining meaning in dining experiences when living with tAD or PCA?
3. How are dining interactions affected as they unfold when living with tAD or PCA?

(4) How do people facilitate successful dining interactions as they unfold when living with tAD or PCA?

The following chapter outlines how grounded theory and both interviews and video-based observations have been selected and utilised to meet the aims of the study.

2.5 Summary of chapter two

Chapter two has set the context for this study. It firstly explored the wider literature on living with dementia and provides a justification for a study on eating-related practices as a social experience, relating to supporting needs such as inclusion, occupation and identity (Kitwood, 1997). The review of literature on eating-related practices has also identified the complexity in understanding experiences from a psychosocial perspective, including the importance of considering individual contexts which shape experiences, the methodological approach, and considering variations across different clinical phenotypes. Existing studies with people with dementia described eating-related practices from being a high point of the day for family cohesion and enjoyment, to a time of tension, stress and estrangement from their typical dining experience. Overall, it appears there is a need for more explanatory research to provide potential insights into *why* different dining experiences may be reported by people living with dementia and the processes which contribute to various experiences. Furthermore, there appears to be a need for further research which includes the ‘dementia voice’, as well as a second-generation of research which considers experiences across different types of dementia, including PCA and early-onset dementias. Finally, the literature review highlights a need for further research which focuses on the micro-social environment and interactions which take place within dining spaces. Existing studies have used in-depth interviewing and often take a constructivist angle which focuses upon meanings-made from experiences as opposed to actual behaviours. However, it is important to consider behaviours within dining spaces and how physical and social environments may promote opportunities for involvement among people living with dementia, as well as how people coordinate their behaviours within shared dining situations. The research questions have been outlined and the following chapter outlines the methodology selected to address these questions.

Chapter 3: Methodology

3.1 Introduction

As outlined in the previous chapter, this study aims to understand how people living with tAD and PCA perceive and support their dining experiences and interactions. This chapter describes the methodology selected to meet these aims. It outlines the data-driven methodological approach which was undertaken and provides a justification for this. Although not a grounded theory study, procedures from grounded theory were drawn upon and the rationale behind using an ‘informed’ grounded theory approach is described. This chapter outlines the data collection methods; firstly, dyadic and separate interviews and secondly, video-based observations of various dining scenarios. It is important to note for organisational purposes that data collection and analysis are presented separately in this chapter, however, these procedures were not conducted separately but simultaneously as recommended for grounded theory research.

3.2 Qualitative methodology

3.2.1 Rationale

A qualitative approach was identified as most suitable for this study providing an in-depth exploration of participant’s experiences in their own words. Qualitative approaches also allow participants to talk about changes which are significant for them, as opposed to imposing pre-existing measures which may not capture personal concerns. This is important for this study as it includes people with the rarer-dementia PCA and standardised quantitative measures have been developed with people with typical Alzheimer’s and thus may not be so appropriate for people with PCA. A qualitative methodology allows people to explain their perspectives and rich-meanings they give for their experiences (e.g. Carr, 1994), making it useful for understanding dining experiences.

This study has been informed by grounded theory methods (Glaser & Strauss, 1967; Charmaz, 2006). The grounded theory methodology has not been applied in the ‘purist’ sense, given the aim was not to develop a grounded theory of dining, but rather to understand how dining experiences change and the strategies related to supporting these changes. A rationale for using this approach is described in this section, followed by an outline of grounded theory and application of grounded theory in other studies in dementia.

Firstly, the focus of the grounded theory approach is not on ‘what is’ happening, but ‘by which it is’ happening (Strauss & Corbin, 1998; Corbin & Strauss, 2008). This emphasis on process particularly supports the development of an explanatory understanding as to why dining experiences may vary for different individuals, which was an important aim of this research. This contrasts with other qualitative approaches such as phenomenology which focus on describing experiences (Starks & Trinidad, 2007). Secondly, given dementia is a degenerative disease whereby family dyads are experiencing on-going changes to their everyday lives, the emphasis on change and social processes in grounded theory helps capture changing experiences among participants. Grounded theory suggests researchers use coding procedures which emphasise processes in-flux, for example, using ‘-ing’ gerunds, to reflect processes in action, as opposed to providing static understandings of experiences (Charmaz, 2006). Thirdly, grounded theory is particularly suited to “the study of local interactions and meanings as related to the social context in which they actually occur” (Allen, Oyebode & Allen, 2009, p. 458). As outlined in the previous chapter, there is a need for research which addresses the micro-social experiences of dining, including how they interact with the physical and social environment.

Grounded theory was also initially identified as useful for this study, given there is a lack of qualitative research with people living with PCA and limited research which includes the dementia voice (see section 2.3.5). Grounded theory methods provide a data-driven approach, useful for when little is known about the phenomenon of interest (Charmaz, 2006). It was deemed important that the concerns of participants were made central to dictating the interests and direction of the research rather than imposing hypotheses which may not fit with their experiences. Therefore, the data-driven approach of grounded theory was identified as useful, providing a way of studying eating-related practices from participants’ perspectives. Initial open, flexible coding procedures as outlined in section 3.6.2 allowed for an exploration of the key areas of concern among participants to be made central. The guidelines of grounded theory constantly refer the researcher back to participant’s accounts, so emerging themes are grounded in their experiences. This informed the development and refinement of the data collection and analysis over time. The simultaneous nature of data collection and analysis also relates to the researcher shaping future data collection. In this study, this procedure supported the development of interests from eating-related practices as a management task towards their potential as dining interactions, as described in the introduction (see section 1.4), it also supported the identification of using video-based observation of dining situations as an appropriate next stage to help refine and understand themes arising from initial interviews with participants.

This study also included a comparative sample of people living with a diagnosis of tAD and PCA. The central methodological procedure of grounded theory is the constant comparative method, which is useful for comparing across and between participant's accounts (e.g. Harmer & Orell, 2008). Given grounded theory uses constant comparison across and between groups from the beginning of data collection, this approach allowed differences and similarities across the sample to emerge. For this study, by comparing the experiences of people with PCA, tAD and family members this established patterns associated with the effects of specific symptoms on dining experiences between the two dementias, as well as similarities in terms of adjusting to living with a dementia overall. As well as this, the constant comparative approach supports integration between themes, as in the Life Nourishment theory developed by Keller and colleagues (section 2.3.2.1), providing a useful example of how grounded theory can be useful for providing a more integrated understanding of eating-related practices.

This study also utilised existing sociological theory to enhance understanding and interpretation of data. More recent versions of grounded theory often suggest engaging with the literature during data analysis as it can enhance understanding and conceptualisation of the data (e.g. Dey, 2004; Bryant & Charmaz, 2007; Locke, 2007; Bryant, 2009). Thornberg (2012) presents an 'informed' version of grounded theory which utilises abductive analysis. Abductive analysis involves a recursive process of comparing data, theories and literature. Researchers who support the process of abduction suggest that in-depth knowledge of multiple theories is necessary to find out what is missing or the anomalies in existing research. Rather than engaging with literature at the end of the project, as classic or traditional approaches suggest, informed grounded theory suggests engaging with multiple theories and searching for explanations for emerging concepts stimulating an understanding of the data. This process was deemed useful for this study whereby different theories were used to inform understanding and were approached critically for their relevance in understanding dining experiences for participants in this study. As presented in the following chapter, Goffman's (1974) Frame Analysis was identified as the most relevant and comprehensive theory which aided understanding of the data within this substantive area.

Overall, grounded theory methods were identified as useful for meeting the aims of this study. However, they were not adopted in the purist sense as the aim was not to develop theory but produce a comprehensive understanding of dining experiences, grounded in participants accounts, for people living with PCA and tAD. The guidelines of grounded theory are malleable, as Glaser and Strauss (1967) invite readers to use grounded theory strategies flexibly and in their own way. Furthermore, Charmaz (2006) views grounded theory as a set of principles and practices to guide the researcher through a process as opposed to being adopted as packages. Therefore, it was important the researcher was guided by the research aims and interests for this study. Overall, for this study, grounded theory procedures were selected as they were particularly useful for referring the researcher back to participant’s accounts, exploring social processes, comparing across and between the sample and the ‘informed’ version (e.g. Thornberg, 2012), provided guidelines for using existing sociological theories to help provide explanatory understandings of participant’s dining experiences. These rigorous procedures were identified as useful for providing a comprehensive understanding of dining driven by participant’s accounts.

3.2.2 Grounded theory methods

By definition, grounded theory is “a qualitative research design in which the researcher generates a general explanation (a theory) of a process, action, or interaction shaped by the views of a large number of participants”’ (Creswell, 2007, p. 63). Grounded theory was initially developed by sociologists Barney Glaser and Anselm Strauss (1967). This approach was developed in response to criticisms of sociological studies of the time that appeared to be concerned with verifying theory as opposed to discovering it. Glaser and Strauss argued that research in sociology often tested existing theories, which could be ill-applied and did not always fit with participant’s experiences under study. Instead they provided a ‘bespoke’ data-driven approach for research in a substantive area. This approach suggests working from the ground upwards and supports the generation of theory as opposed to testing existing hypotheses. Grounded theory emphasises movement, for example, through coding using ‘-ing’ gerunds to emphasise change and thus as mentioned in the previous section, is particularly useful for understanding experiences where people are adapting to change (Benoliel, 1996; Schreiber & Stern, 2001; Corbin & Strauss, 2008).

Briefly here and further elaborated on and discussed in relation to how they have been adopted in this study (see section 3.6), the basic processes of grounded theory are cyclical and repeated processes of: open coding (line by line coding to identify incidents and initial concepts), constant comparison (comparing incidents across different cases as the data comes in), memoing (writing notes on thoughts about the data and theoretical concepts throughout the study), theoretical sampling (using emerging areas of interest to make decisions about where to go next in data collection), theoretical coding (coding, memoing and using diagrams to identify the ways in which concepts relate to each other), sorting (organising codes and memos to support conceptual development) and writing (numerous cycles of writing to support the development and presentation of the data and links between concepts).

The process is unique to grounded theory, labor intensive and involves working with the data from the outset of the study.

There is some debate among grounded theorists about the use of existing theory during data analysis, whereby some suggest this can cause researchers to 'force' the data and commit themselves to preconceived doctrines or pet theories, going against the original purpose of grounded theory as an inductive methodology (Glaser & Strauss, 1967, p. 46). However, among more recent versions of grounded theory, there is a suggestion that existing theory can enhance understanding of emerging themes and concepts in the data analysis (e.g. Dey, 2004; Bryant & Charmaz, 2007; Locke, 2007; Bryant, 2009). Rather than engaging with literature at the end of the project, as classic or traditional approaches suggest, informed grounded theory (Thornberg, 2012) suggests engaging with multiple theories and searching for explanations for emerging concepts to stimulate an understanding of data during analysis. This approach was selected for this study, as people's dining experiences were complex and varied and existing theoretical frameworks were deemed useful for further elucidating psychosocial processes which related to the way people understood their dining experiences and interacted within these dining spaces.

Since the initial outline of grounded theory, many different strands and schools of grounded theory have developed, with various tools and procedures which can be adopted depending upon research aims and the epistemological and ontological position of the researcher. Various schools include: classic grounded theory (Glaser & Strauss, 1967), Straussian grounded theory (Strauss & Corbin, 1998), constructivist grounded theory (Charmaz, 2006, 2014), feminist grounded theory (Wuest, 1995), as well as informed grounded theory (Thornberg, 2012). All grounded theory approaches utilise the basic processes of constant comparison, memoing, theoretical sampling, theoretical coding, sorting and writing. As will be discussed in the next section, whilst there are various 'schools' of grounded theory, many researchers in practice use a mixture of various grounded theory approaches which suit their research interests, whereas some aim to stick to a particular school and follow the procedures outlined in a particular approach. For some studies, it is not clear the exact methodological approach they have taken, using 'grounded theory' as an explanation, whereby this term is ambiguous as a descriptor.

3.2.3 Application of grounded theory procedures in other studies in dementia

Studies which have used grounded theory to explore experiences of living with dementia among people at home are reviewed here to provide an understanding of how grounded theory has been applied in previous work within this field to situate the researcher's approach with this existing research. Studies were identified using electronic databases; Google Scholar, Scopus, CINAHL & Web of Science, using the terms "Dementia" OR "Alzheimer's" AND "Grounded Theory". Studies were reviewed covering the time-period from 1970 to 30th May 2017. This was selected as an appropriate time-scale as grounded theory was first developed in 1967 (Glaser & Strauss, 1967) and its application and use in health sciences research began around the 1970's. The final date reflects when studies were reviewed for the purposes of this write up. Studies were included which were available in English, mentioned grounded theory in the abstract and included experiences of living with dementia among people living with dementia at home as opposed to people living in institutional settings, as the focus for this study. The Eating Together study has already been described in detail in the previous literature review chapter. A table of the 44 reviewed studies can be found in appendix 4, detailing the topic, type of grounded theory used, the approach and the research product.

Overall, it appears from this review that grounded theory has been utilised for three broad research interests (see appendix 4). Firstly, the experiences of living with dementia overall (n=33 studies), including day to day experiences, experiences of the diagnosis, changes in the relationship, end of life, help seeking and respite for family members, social participation, self and identity and experiences of hope. More recently, the experiences of dementia within specific activities has been explored (n=7), including experiences of dressing, leisure activities, grocery shopping, navigating at a zebra crossing and eating-related experiences. This set of studies on specific activities particularly relates to this study on eating-related practices, i.e. focusing in on a specific aspect of the day to identify how people living with dementia both experience and cope with changes within this context. As discussed in section 3.2.1, the grounded theory approach is particularly useful for studying experiences within the actual social context they occur in (Allen, Oyebode & Allen, 2009) and thus may be particularly helpful in studying eating-related practices. Thirdly, the experience of dementia across and within different cultural contexts has also been examined using grounded theory (n=4). No studies were identified which used grounded theory to compare experiences across people living with different types of dementia, as in this study which includes people with tAD and PCA. However, the fact it has been used to explore different experiences across cultures suggests it is useful for exploring similarities and differences across various groups, facilitated by the constant comparative method (Harmer & Orell, 2008). For much of the studies reviewed, as in this study, grounded theory methods were selected due to a lack of information or knowledge gap concerning the research interests, with grounded theory providing a data-driven, open approach to analysis.

Grounded theory has been used to explore the experiences of family members (n=19), people with dementia (n=11) and experiences of dyads, i.e. family members and people with dementia (n=11). These dyadic studies did not differentiate between experiences of people with dementia and family members but looked at commonalities or shared experiences across them both, as in the Eating Together study (see section 2.3.2.1). In this current study, both the dyadic perspective has been addressed as well as separate perspectives among people with dementia and family members. The procedure of doing dyadic interviews and separate interviews in this study, supported the harnessing of multiple perspectives to be presented (Kendall et al., 2009). As well as this, the fact the researcher did not aim to present an overall ‘grounded theory’ or ‘core concern’ per se, supported the identification of both similarities and differences across experiences. This is similar to the study by Lawrence et al. (2008) which did not integrate a theory around a core concept but rather presented similarities and differences in experiences across three ethnic groups in the UK. Traditionally, grounded theory emphasises the use of constant comparison to identify a core concern across the sample (Glaser & Strauss, 1967). Although this is useful for dyadic studies in terms of understanding shared perspectives around living with dementia overall, it may also be important to outline differences in terms of a person with dementia’s perspective and family member’s perspective, as opposed to overlooking differences in the process of identifying a core concern.

From the studies reviewed, various schools of grounded theory have been utilised. 19 indicated using Straussian grounded theory procedures, 16 used classic grounded theory, 5 used constructivist grounded theory and 4 used a mixed or unspecified approach (see appendix 4). A mixed approach refers to when two or more schools of grounded theory were discussed in the study. Despite indicating these ‘schools’ of grounded theory were followed, many of the studies did not meet their original criteria. For example, only 31 of the studies produced a theory which is typically outlined as the main criteria for a grounded theory study. The other 13 studies used grounded theory methods to describe experiences for people living with dementia. Furthermore, 10 of the studies consulted the literature before analysis, which for many grounded theory schools is contested. Therefore, it appears grounded theory is a rather broad term and when applied practically different studies adopt these methods in different ways. In reviewing the studies some did not describe the exact coding procedures they used, making it difficult to determine if they followed all the approaches recommended by that ‘school’. For example, Chung, Ellis-Hill and Coleman (2008) suggest they used Straussian grounded theory, however only outlined using constant comparison when describing their analysis as opposed to open, axial and selective coding and the coding paradigm which is outlined by Strauss and Corbin (1998), meaning it was unclear if these procedures were indeed used.

As previously mentioned, another ambiguous element of grounded theory is when to approach the literature. Grounded theory was originally outlined as an inductive methodology whereby existing literature should be reviewed at the end stages of data analysis and conceptualisation (e.g. Glaser, 1978). However, more recent grounded theorists emphasise the co-construction of theory by the researcher and participants and suggest an informed approach is most prolific, utilising the literature to support understanding and conceptualisation of data (see Thornberg et al., 2012). From the reviewed studies, 10 indicated approaching literature and existing theory at the beginning of the data analysis. For example, Brown and Alligood (2004) indicated using Newman's (1986) theory of health as expanding consciousness to interpret their findings, which supported the development of the substantive theory of 'help seeking choices: taking one day at a time' among wives caring for husbands with dementia. This approach appeared particularly useful for integrating findings with the literature to provide explanations around the phenomena investigated. The other studies did not indicate when the literature was approached making it difficult to understand how 'informed' the analysis was. As outlined in section 3.6.5, for the purposes of this study, an informed use of the literature and theory during data collection and analysis has been used to support interpretation of the psychological and social processes related to dining.

From this review, several important considerations have been highlighted. Firstly, given ambiguities around how researchers have used the term 'grounded theory' including the various 'schools', the researcher has been mindful to provide an exact outline of the methodology used for this study. The researcher takes the stance that she did not want to dogmatically follow one school of grounded theory, but be flexible and open to the various methods suggested by different schools, guided by the research questions. Thus, for this study, the approach may be best described as a mixed grounded theory, following the basic principles of grounded theory but not prescribing to one particular school. Secondly, it is unclear in many of the existing grounded theory studies on living with dementia when the literature was approached or why, therefore the researcher has been mindful to be transparent about when literature was approached, how it has informed or guided the analysis and a justification for this. Finally, the researcher considered various approaches to grounded theory, however, over time it became clear the aim was not to follow a particular 'school' or to develop a grounded theory *per se* but to utilise grounded theory methods to generate an integrated understanding of eating-related practices as a social experience for families living with PCA and tAD. For this study then, grounded theory methods were not adopted in the strictest sense, as with some of the other grounded theory studies. The aim was not to identify an overall ‘core concern’ or central theme but to capture a broader understanding of dining experiences. The ethical considerations which are important for this study are highlighted in the next section followed by the procedures which were used in this study.

3.3 Ethical considerations

This section provides an overview of the ethical considerations for the study which involved interviews and video-based observations. Ethical considerations are important for determining the correct values and best practice with any given situation or actions (Leino-Kilpi & Tuomaala 1989). This study has received ethical approval via an NHS ethics application to the University College London Hospitals NHS Foundation Trust (UCLH). This was gained for the whole Seeing What They See project (appendix 1). Brunel University’s Research Ethics committee were also consulted for ethical advice for this study and agreed that no further ethical approval was required for these interviews as they were included within the scope of the UCLH application. Brunel University’s Research Ethics committee were also consulted for ethical advice for this study and agreed for all ethical consent for these interviews to be gained through the UCLH application (see appendix 5 for the approval letter). As part of the ethics protocol, it was required the researcher attend Clinical Governance, Good Clinical Practice training at UCLH. This training outlined data protection legislation and local information governance policies when conducting research with vulnerable clinical populations. The Seeing What They See research team also has experience in conducting research with people with dementia. The researcher’s supervisory team also had a higher degree in medical law and ethics and the other was chair of the Brunel University Clinical Sciences research ethics committee. Ethical considerations were discussed in supervisory meetings. Each discipline also has their own code of practice for human research ethics. Given the researchers background in Psychology, the British Psychological Society (BPS) code of human research ethics (bps.org.uk, 2014) has been used to guide best practice.

Firstly, as in the BPS code of ethics, researchers should endeavour to identify and assess possible risks and develop a protocol for risk management. Research involving people with dementia is ethically acceptable provided it is directed towards the understanding and treatment of dementia and presents a negligible degree of risk whereby all research with humans involves some risk in relation to psychological damage. A protocol for risk management was developed which included the researcher informing the supervisory team when she went on a home-visit as a lone worker and were contactable should any concerns arise. One consideration for this study was around potential risk that dyad interviewing could pose in terms of tensions or conflict within the dyad (Valentine, 1999). This was particularly a concern as people with dementia often appeared to have a different perspective on changes then their spouse. Sensitivity of the researcher was considered important and it was key to avoid ‘siding’ with one of the participants. The researcher deliberately did not use any confrontational techniques despite the fact this may have resulted in more data. The boundaries of family dyads were respected and it was deemed important they decided what was shared. This meant that at times people revealed information that seemed to be new to the other person, resulting sometimes in signs of unease. It was important the researcher was sensitive to this unease and at times moved the conversations on. This was a delicate balance between this control as the researcher as well as respecting the boundaries of dyads and allowing them to decide what to share. The researcher also debriefed participants afterwards ensuring she left participant’s homes on a positive note. Although there is psychological risk with dyad interviews, having opportunities for openness and sharing may also have supported closeness in the relationship (Morgan et al., 2013).

Family dyads also had the opportunity following joint interviews to discuss separately their perspectives. The researcher deemed it useful to do these separate interviews afterwards which may have related to less confrontation in the dyad interview as they were aware they had this opportunity to speak individually with the researcher. However, it can also be anxiety provoking as this approach might imply secrets exist and that the person is willing to share these secrets with the researcher (Morris, 2001). It was crucial to maintain the confidentiality of all participants, and not to disclose any information shared separately. Furthermore, the fact each member of the dyad had this opportunity may have supported people to feel equally listened to. They were also familiar with this format of interviewing from taking part in the Seeing What They See interviews, perhaps supporting them to feel more at ease.

Another consideration regarding risk was around how questioning can be anxiety provoking for people with dementia (Novek & Wilkinson, 2017). As outlined by Johansson et al. (2011) interview studies which include people with dementia have shown they are able to contribute in a meaningful way but it is important to establish a trustful and relaxing relationship to facilitate these interactions and lessen anxiety for the person with dementia. They suggested to provide a safe context, interviews at home are advised and this was deemed important for this study. Furthermore, the trusting relationship may have been supported as this was the second research visit the researcher made following the interviews for the Seeing What They See study.

In terms of video-based observations as the second stage of data collection, the researcher was mindful that videoing could be awkward for those involved and this psychological risk needed to be minimised where possible (Luff & Heath, 2012). It was deemed important to discuss the use and benefits of it before recording, as well as introducing it and setting it up with participants, so that they could become familiar with the camera being in the room and with being recorded. The researcher also chatted with participants before setting up the video camera. Furthermore, the researcher made clear the camera could be turned off at any point during the dining observations at participant's requests. Given the researcher was asking participants to observe an element of their home lives, this was an unusual situation for participants and therefore it was also deemed important to given family dyads as much control over the way these observations were conducted as possible. For example, family dyads dictated whether they would prefer a lunchtime or evening meal to be observed and how the researcher would be involved, i.e. as an observer or as a dining participant. The participants also helped decide where to set the camera up in their dining space. Furthermore, given the researcher had visited these family dyads on two occasions already for the Seeing What They See and mealtime interviews, a rapport had been built with these family dyads which may have supported participants to feel more comfortable with being observed during a dining situation. Debriefing was a key element where the researcher had a discussion following the end of the video-recording sessions asking participants how they found being videoed and if they had any questions or concerns. None of the participants raised any concerns following the video-recording of their dining situations.

The researcher also decided not to share transcripts of the interviews or observations with participants for checking purposes as some qualitative researchers suggest (e.g. Page, Samson & Crockett, 2000). The researcher understood this data as a process, as a constantly changing experience, particularly given these participants were living with a neurodegenerative disease. Therefore, the interviews were understood as reflecting perceptions about dining at a single time-point during the interview. Sharing these transcripts later may not then be relevant at a different time-point and may have affected the way family dyads continued to process and shape their dining experiences. Especially where participants reported distressing dining experiences or these were observed, from an ethical perspective sharing the related transcripts may have caused unnecessary harm and exacerbate negative experiences, affected the way they went on to cope and adapt to changes to their dining situations.

Secondly, researchers should ensure that participants consent freely to the process on the basis of adequate information. As outlined in the BPS code of ethics where capacity to consent is in question, it should be assessed using a systematic procedure such as engaging the potential participant in a dialogue to explore their understanding of what it is that they are consenting to. The researcher adhered to the legislation laid down in The Mental Capacity Act (2005) regarding the involvement of people who lack capacity when they enter the study and those who lose capacity during the study. Any part of the consent process can be problematic when a person experiences cognitive impairment (Bartlett & Martin, 2001). The nature of qualitative research also means consent procedures are not a single event but a continual process between researcher and participants, especially when the person may forget they have consented to participate (Kayser-Jones & Koenig, 1994; Bartlett & Martin, 2001). Therefore, consent was re-negotiated on every visit as recommended by Bartlett and Martin (2001). Furthermore, informed consent was gained with the person with dementia and family member in the same room before each study visit. This is recommended to facilitate the process of communication of information and understanding, where family members can co-operate and participate in this process (Bartlett & Martin, 2001).

Capacity was assessed firstly by the research manager for the Seeing What They See project using a combination of neuropsychological test scores, discussions with participants and spouses/relatives, and qualitative assessments of willingness and ability to continue to participate in the study. Informed consent was then gained by the researcher when visiting participants for the Seeing What They See interviews (appendix 1) aided by the information sheets and consent forms. Standard procedures were adapted where necessitated by the participant’s cognitive impairments. For example, information sheets and consent forms were read to individuals with PCA in the presence of their family member and the family member or researcher filled the name and date if the individual with PCA was unable to write, then asked them to sign after explaining what was written on his/her behalf. Information sheets were given to participants to keep which included contact details of the research manager.

For the dining interviews, participants were not required to sign new consent forms following the Seeing What They See interviews as participants had already provided written consent to be audio-recorded and interviewed about difficulties and coping strategies. Instead consent was re-negotiated with family dyads where the information sheets/consent forms were revisited. The researcher provided a new written copy of the information sheets which included the debrief contact numbers (appendix 9). The researcher also ensured participants understood the purpose of the dining interviews by providing visit description sheets which provided clear information about all aspects of this relevant to their decision about whether to participate (appendix 6) as recommended in the BPS code of ethics. Careful drafting of this visit description was done to ensure this information was provided in an understandable form.

These sheets were provided at the end of the Seeing What They See interviews when inviting potential participants to take part. They were also reviewed with participants when entering their homes for the dining interviews before taking part. Verbal consent was gained and the researcher engaged participants in a dialogue to check their understanding of what they were consenting to. This involved discussing the aims of the project, why the research was being carried out (for a PhD project), method of data collection, type of data to be collected and confidentiality/ anonymity conditions. As recommended, joint consent procedures were conducted with family members present who could facilitate communication if needed. It was explained their participation in these separate interviews were entirely voluntary and they were free to withdraw at any time. The visit description also included contact details for the researcher in case of any queries. These procedures were adapted where necessitated by the participant's cognitive impairments as above.

For the video-based observations, an amendment to the existing ethics application for the Seeing What They See project was required which included permission to observe and video-record observations within participant's homes, given this was not included on the information sheets/consent forms or covered in the original ethics application. The amendment was completed collaboratively by the researcher with the project manager for the Seeing What They See study. The amended information sheets, consent forms and ethical approval letter are included in the appendix (appendix 9). The researcher was mindful that the information sheets and consent forms applied to the whole Seeing What They See project and thus lacked specificity in terms of detailing the exact aims, purpose and approach of data collection for the video-based observations. Therefore, as with the information sheet for the interviews (appendix 6) invitation letters were carefully drafted to ensure this information was provided in an understandable form. These invitation letters (appendix 10) were sent out to potential participants and reviewed with participants when entering their homes before taking part in the observations. This included the purpose of the observations and how the videos would be used. It was explained the videos would only be shared among researchers on the Seeing What They See project. It was reiterated their participation was entirely voluntary and they were free to withdraw at any time. The invitation letter also included contact details for the researcher in case of any queries.

Thirdly, as outlined in the BPS code of ethics participants in psychological research have a right to expect information they provide will be treated confidentially and, if published, will not be identifiable as theirs. To maintain confidentiality, all participants were given a pseudonym and all possible identifiable information was removed during transcription of both the audio-recordings and videos. This included specific details such as locations, family member's names and events. Audio-recordings and videos were uploaded to a password-protected computer and deleted from the device immediately following each visit. Also one of the reasons the researcher did not share transcripts with participants was to help protect the anonymity of participants in the individual interviews as they were often sharing hidden perspectives from the other member of the dyad, therefore from a confidentiality perspective it may have been difficult to manage sharing data with each member of family dyads separately.

Other ethical considerations detailed in the BPS code of ethics (2014) include giving advice, deception and debriefing. In terms of giving advice, caution was exercised whereby the researcher only offered support or advice relevant to the study, for example, sharing information about eating aids that other people may have been using. This was only done at the end of the interviews and/or observations. This was deemed appropriate support particularly for people with PCA, where there is little formal advice or support for these individuals (Crutch et al., 2017). Any other advice participants required, the researcher signposted them to the contact details for the research manager for the Seeing What They See project or the PCA support group at UCLH. In terms of deception, it was not required to deceit participants for this study. Finally, in terms of debriefing the researcher spent time at the end of a research visit discussing how participants found the process and engaging in conversation to ensure she left on a positive note before leaving participants homes. Rapport building was considered important, particularly as participants were giving their time voluntarily.

3.4 Data collection: In-depth interviews

3.4.1 Rationale

Home-based qualitative interviews on people’s dining experiences was selected as the appropriate first stage of inquiry for this study. Interviewing allows for open flexibility and exploration of an experience, which is particularly well-suited where little is known about the phenomenon of interest (Charmaz, 2006, p. 29). Furthermore, participants were familiar with this research design from taking part in the Seeing What They See interviews with the researcher (see section 1.3), providing some continuity in which to situate a follow-up discussion on eating-related practices. As identified by the literature review presented in the previous chapter, no qualitative studies were found which compared experiences of dining when living with PCA and tAD, therefore interviewing as an exploratory line of enquiry was identified as a useful approach. Furthermore, as Charmaz (2006) describes, interviews allow the researcher to go beneath the surface of the described experience and ask about participant's thoughts, feelings and actions, therefore this approach provided a suitable avenue with which to provide an in-depth understanding of the meanings people made around their dining experiences.

Paired interviews were deemed useful for understanding how family dyads worked together to address issues and conflict and to capture how the pair coordinated their shared dining interactions (Taylor & de Vocht, 2011). It was also useful as interviewees could fill in gaps, supporting each other's memories in their storytelling (Wilson, Onwuegbuzie, & Manning, 2016). This was particularly useful for people with tAD given they often had memory lapses relating to what happened at mealtimes and the other family members could support their memory of recent experiences. It was also useful for allowing the researcher to observe interactions between the pairs and observe how they co-created meaning and how they managed conflicting perspectives. Separate interviews were also used as these allowed concealed perspectives to be shared, which they may not have shared with the other person, as well as elaborate on their perspectives from the dyad interview. Having this opportunity to share these individual perspectives was identified as useful from the Seeing What They See interviews as it meant where perspectives differed, individuals had an opportunity to voice these views in the separate interviews. This may have supported family dyads to be less confrontational than if only dyad interviews were conducted. Overall each approach complements the other in harbouring multiple perspectives around mealtime experiences (Taylor & de Vocht, 2011).

The order of the interviews always involved the dyadic component first, whereby family dyads discussed experiences together, followed by separate interviews with each member of the dyad which were conducted away from the other family member. This configuration was identified as most appropriate by the researcher for several reasons. Firstly, eating-related practices as a dining experience are a shared activity, therefore the interview mirrored the idea of eating-related practices as dining, providing an opportunity to interact and negotiate perspectives. Secondly, the researcher could pick up topics which arose in the dyadic interviews to explore these further on an individual basis in the separate interviews. Thirdly, on a practical level on visiting the participant's homes it felt more natural to see the family dyad together first as this was their shared abode and this arrangement flowed on from the consent procedures. Lastly, the fact the participants were also familiar with this structure from the interviews for the Seeing What They See study may also have supported them to feel at ease.

3.4.2 Sample and recruitment

Recruitment for this study was facilitated by the Seeing What They See study. For the Seeing What They See project participants had attended the Cognitive Disorders Clinic at the National Hospital for Neurology and Neurosurgery (NHNN), London (UK) and were invited to take part in the research. This is a secondary/tertiary referral centre, with attending patients often presenting with younger or atypical presentations of dementia. All of the participants underwent a clinical and neuropsychological assessment as this was a requirement for participation in the Seeing What They See study. People who had evidence of an ischaemic stroke or brain tumour were excluded. All PCA participants fulfilled clinical criteria for PCA (Tang-Wai et al., 2004) and probable Alzheimer's disease (Dubios et al., 2010). The tAD participants fulfilled research criteria for a diagnosis of typical amnestic Alzheimer's disease (Dubios et al., 2010) (see section 1.3). Participants were excluded from the Seeing What They See study if they were deemed to lack capacity to make an informed decision about taking part in the research (see section 3.3.3)

Purposeful sampling was used to recruit for the interviews for this study, whereby family dyads with either a diagnosis of PCA or tAD were asked at the end of the Seeing What They See interviews if they would like to take part in this study on eating-related practices. Participants were handed an information sheet by the researcher about these interviews at the end of taking part in the Seeing What They See interviews if they indicated they were interested (appendix 6). They were contacted within a week to see if they wanted to take part and to arrange for the researcher to visit them at home. The researcher liaised with the project manager for the Seeing What They See interviews to agree a suitable time to visit participants. For some, if they were taking part in other research, it was decided to hold off on interviews until they had completed those to minimise the possibility of interviewer burden. The researcher also tried to ensure flexibility around participant's availability around their other commitments. All the interviews were conducted with 1-3 months of the Seeing What They See study interviews.

Given this study aimed to compare across people living with tAD and PCA around an equal number of participants with each type of dementia were sought. In addition, the researcher aimed to recruit people both with earlier-onset and later-onset dementias, given PCA is typically an earlier-onset dementia and as outlined in the literature review, having dementia at a younger age may present unique challenges and disruptions to dining which was an important consideration. Given the aim was not to achieve a 'representative' sample, but rather capture diverse situations and experiences, the sample was not restricted to spousal relationships and included one mother-daughter dyad who were living together (see table 2, section 5.2). Given this study aimed to establish causal explanations around various dining experiences, a diverse sample was sought for understanding dining experiences under a range of different conditions.

Overall, twenty family dyads took part in these interviews and participants from the Seeing What They See interviews (n=37) stopped being invited once theoretical saturation had been reached i.e. when nothing new was being said about the concepts and categories which were emerging in the analysis. All the participants who were approached agreed to take part in the subsequent interviews on their eating-related practices. The sample included 9 family dyads living with tAD and 11 family dyads living with PCA. All family dyads who took part lived at home with one another and dined together for most mealtimes, as well as often being together for other eating-related practices such as preparing the meal. This supported the researcher to focus upon eating-related practices as a social dining experiences.

Recruitment occurred through the Specialist Cognitive Disorders Clinic at UCLH and many of the participants were active volunteers in various research projects at the clinic and those with a diagnosis of PCA had access to specialist support and advice, for example, through the PCA monthly support group which is organised by the clinic. Although not all the participants who had a diagnosis of PCA attended this group, they were all aware of its availability and most were in travelling distance to attend should they wish to do so. People, particularly with PCA, may have felt more supported, given this access to specialist knowledge and education around their symptoms from the specialist clinic. Having said this, people with tAD in the study had access to a wider range of support and knowledge, given this is a more well-known dementia, for example, from local support groups such as through the Alzheimer’s society.

One weakness of the sample is that most participants recruited through this process happened to be from a similar socio-cultural background. All but one family dyad was White-British, with many being highly educated. This is an important consideration when interpreting the results of this study. For example, Hulko (2009) is critical of studies which include samples largely comprised of mainly white, well-educated, high-class, married professionals in the early stages of dementia. In Hulko’s study she identified that social location (including age, class and geographic location) had a substantial impact on the way people go on to cope with and experience their diagnosis. This is a key limitation of the sample who were included in this study. However, there was some variability across participant demographics including age, gender and type of dementia. As presented in the results chapters, a diverse range of dining experiences were reported among this sample, allowing for some understanding of how these different contexts shaped dining experiences. Despite the limitations of the sample recruitment through the clinic provided access to a significant number of individuals living with the rarer dementia, PCA, which would not have been feasible without this recruitment path, given the rarity of this diagnosis.

Another consideration in relation to the sample, is comparing between the two types of diagnosis as a fairly arbitrary comparison, given people can differ in the types of symptoms they experience. For example, some people with PCA had impaired cognitive awareness and some people with tAD also reported perceptual difficulties. It is important to consider that dementia is a ‘syndrome’; an umbrella term to describe a range of experiences of cognitive impairment. Although distinguishing between PCA and tAD helped to understand patterns of experiences related to mainly memory difficulties versus perceptual and spatial awareness impairments, it is important to be mindful that the line between these dementias could be blurred. This message has been echoed elsewhere (e.g. Cotrell & Schulz, 1993; Epp, 2003) suggesting that whilst it might be useful to diagnose dementia and the various types, it is important to be cautious in viewing individuals with dementia as individuals, demonstrating limitations with grouping people within their diagnostic label as a basis for comparison. However, comparing across these specific types of dementia can provide a more accurate understanding of potential experiences related to various clinical presentations of dementia. As discussed in the previous chapter, this supports a development in the research in terms of beginning to distinguish dining experiences when living with different symptoms, as opposed to just dining with ‘dementia’ as a very broad syndrome.

3.4.3 Procedure

The interview structure largely replicated that of the Seeing What They See project. Interviews were carried out with the person with dementia and a family member, first interviewed together and then separately on difficulties and coping with dementia. Given this structure worked well for gathering rich data on shared and individual experiences for the Seeing What They See interviews and this format had been piloted with two family dyads for that project, it was not deemed necessary to carry out further pilot studies for this study. However, the researcher was prepared to alter the interview guide or format of the interviews should there be any issues or concerns following the first few.

Interviews on dining experiences were conducted over a period of 9 months. The first interview commenced on 11/12/2014 and the final interview on 28/09/2015. All interviews were conducted within 3 months of participants taking part in the Seeing What They See interviews, with the majority within the same month. The interviews for this study were conducted individually by the researcher at family dyads homes and lasted approximately 1-1 ½ hours. Given mealtimes largely took place in this context for participants, this provided a relevant background to stimulate memories of dining activities and with which to discuss various coping strategies. For example, some participants showed the researcher various eating aids they had at home and often explained their dining situations by showing the researcher the space they typically dined in. However, interviews in participants own homes caused some unanticipated difficulties, for example, they could become distracted by several things when interviewed in this environment (Bowling, 1997). Distractions such as interruptions from other family members, unexpected visitors and phone calls all occurred. Another issue with home interviewing was having appropriate space to be able to conduct the individual interviews without the other member of the family dyad overhearing or participating in these conversations. Given the researcher had visited participant's homes previously for the Seeing What They See interviews she was aware that appropriate space was available. However, should there not have been, alternative space at the Dementia Research Centre was available for participant interviewing if needed. Given interviews took place in the participants own spaces, it was deemed important they were given control over how these situations were managed, for example if they wanted to stop the interview to answer a phone call. The researcher ensured she allocated enough time for each interview (at least two hours) allowing flexibility in case any unanticipated distractions occurred.

On meeting participants at their homes, the information sheet was revisited (appendix 6) and any further questions answered to ensure the participant dyads understood the purpose of the visit. The researcher also revisited the information sheets and consent forms from the Seeing What They See interviews with participants. Whilst they were not required to sign new consent forms as they had already consented to take part in home-based interviews, the researcher spent some time gaining verbal consent and checking they understood the process as outlined in section 3.3. All participants stated willingness to take part in the study and did not raise any concerns with the process for the interviews. The researcher also had an informal discussion with participants before commencing the interviews. This included being asked if there had been many changes since the last visit for the Seeing What They See interviews to check in with participants after the time-lapse since the last interview, re-establish rapport and provide a suitable basis to begin a focused discussion on eating-related practices.

Interviews involved a dyadic and separate interview component with the person with dementia and a family member, exploring both interrelated and individual perceived dining experiences. These interviews were all conducted in one visit. It was explained to participants that the procedure for the interviews would follow the same structure as the Seeing What They See interviews. It was decided with participants what format this interviewing would take where the researcher said to participants they could decide who went first for the separate interviews and participants negotiated this between themselves. This both gave them some element of control over the interviewing process and the researcher worked with participants to negotiate where and how these separate interviews would be conducted. One issue was that the researcher visited family dyads alone for the dining interviews whereas for the Seeing What They See interviews there were two researchers. The other member of the dyad then had to entertain themselves whilst the researcher was interviewing the other separately. For the majority, this did not appear problematic as the other member of the dyad busied themselves in other areas of the house and two of the participants went out for a short walk whilst the researcher was with the other. However, for two dyads the other family member stayed in closer proximity which may have affected the quality of the data collected. For example, Tanya became frustrated because she noticed her husband Alastair was listening at the door when the researcher was interviewing her and asked him to leave the room a few times. This affected the flow of the interview and the researcher broke off from questioning whilst Tanya liaised with her husband to avoid his listening affecting the interview. Another example, was where Bob, Sarah’s husband, was sat in the conservatory adjacent to the living room where the researcher was talking with Sarah. It was not until the interview commenced that it became clear that Bob had sat next to the door and was listening and at one point he verbally involved himself in the discussion. Both Sarah and the researcher then spoke in a lower tone for the rest of the interview, however, Sarah may have been more concealed in her response as she may have been cautious of Bob overhearing in the adjacent room. Given the researcher chose to take a non-confrontational stance and work with participants to allow them autonomy in the interview process it was not deemed appropriate to tell the other family member they could not listen as this could have caused distress around the idea of having secrets (Morris, 2001).

Interviews were semi-structured, whereby an interview topic guide was used (appendix 7), however, this was used flexibly where the ordering of questions and additional questions could be added as the study developed and led by the concerns of the participants. The use of a flexible topic guide is recommended by grounded theorist Charmaz (2006) for novice researchers supporting researchers to return to the key topics. The interview guide was not intended to impose a rigid structure but provided a guide to the main areas to be explored, helping to keep interviews relevant. Topics which were addressed included experiences related to changes, the eating environment, dining out, social issues such as changes to conversations and eating with others, food preparation and clearing away.

Over time, key areas of concern for participants began to emerge with initial transcription and analysis of the earlier interviews, as analysis of the interviews and data collection occurred simultaneously. Conversations became more in-depth and focused on key areas of concern, i.e. around ‘dining’ as a social experience. This included more discussion with participants around dining out experiences e.g. in public dining settings and managing concerns of stigma and embarrassment associated with not meeting expectations for ‘correct’ dining behaviours. This type of theoretical sampling is recommended by grounded theorists (e.g. Glaser & Strauss, 1967), where interview discussions are dictated by the emerging areas of interest from the data analysis which is occurring in conjunction with data collection (see section 3.8). As well as this, the interests of the researcher with a background in Psychology may have influenced the development of the topics of interest as outlined in section 1.4. At the end of each interview, participants were asked if there was anything they had not covered in relation to eating-related practices, maximising the opportunity for collecting rich data.

Field notes following each interview were written with initial thoughts on the interviews. These were written as soon as practically and conveniently possible, usually within an hour post-interview. These included notes such as observations from the visit and thoughts about the interview, information about setting and context, how interviews related to previous ones and what information was new or similar and notes of conversations which were not captured in the audio-recording, for example, if participants added any comments such as on the researcher leaving once the audio-recorder had been switched off. See below for an example field note (figure 2) from an interview.

Figure 2: Example field note following a mealtime interview

Date: 11/12/14
Type: field note
Susan and Terry, mealtime interview

Have conservatory room at the back of the house and chair in living room. Mainly eating in there and spending most of time in that chair. Light coming through at back.

Susan very articulate about issues faced at mealtimes

Lack of choice/ makes it an easier task, only eating certain things.

Terry quite straight-talking, likes things done ‘properly’

Lots of aids around the house/ doesn’t necessarily support enjoyable mealtimes

Don’t seem to enjoy each others company/ mealtimes not social activity

Next visit think about taking pictures of dining environments

3.4.4 Audio-recording and transcription

The interviews were audio-recorded and transcribed by the researcher following each interview. To maintain confidentiality, all participants were given a pseudonym and all possible identifiable information was removed during transcription. Audio-recordings were uploaded to a password-protected computer and deleted from the audio-recorder following each visit. Transcribing is useful for data-driven methods of inquiry which allows the researcher to become familiar with the data and begin to explore emerging areas of interest from the outset of data collection. As grounded theorist Charmaz (2006) suggests “as a novice, you can best study your data from the very start by transcribing your audio-tapes yourself or through writing your own field notes… by studying your data, you learn nuances of your research participants’ language and meanings. Thus, you learn to define the directions in which your data can take you” (p. 36). This initial stage of transcribing was found to be helpful for familiarisation with the data as well as informing the nature of inquiry within subsequent interviews as the areas of concern began to evolve. Furthermore, given this study was data-driven it supported an in-depth understanding of dining from participant’s experiences and early analysis. Some researchers who use data-driven grounded theory approaches suggest transcribing can be time wasting and encourages description rather than conceptual of the data (Glaser, 2002). However, the process was found to be useful by the researcher for staying open to different areas of concern for participants rather than forcing the data with pre-existing hypotheses. Furthermore, on a practical level, transcribing was key for organising the data electronically and comparing across interviews. There was a large amount of data for this study, i.e. three interviews per family dyad, totalling 60 interviews. Therefore, it was important this was organised electronically, by typing-up interviews and uploading them into a qualitative analysis software package (see section 3.6.1). An example of a transcribed interview of one family dyad in this study is included in appendix 8. As outlined in section 3.3 the researcher did not share these transcripts with participants for checking purposes.

3.5 Data collection: Video-based Observations

3.5.1 Rationale

As described in further detail in section 3.6.2, interview transcripts were analysed as each interview was conducted which helped identify gaps in understanding and inform further data collection. Importantly, interviewing served as the primary method of data collection for this study, given this provided access to richer information on perceptions around dining from participants and some understanding of behaviours. Video-based observations were selected as a second stage of data collection, supporting further understanding of actual dining behaviours. As outlined in the literature review (section 2.3.4), much of the existing research comes from a constructivist perspective, whereas the use of video-based observations assumes a scientific realism, assuming people are existent and that they have been conducting in ways open to research (Knoblauch, 2012). This realist perspective is supported by the theoretical framework of Erving Goffman (1974) which is explained in the following chapter and which has been used to support conceptual understanding of data in this study.

Video-based bservations were selected for several reasons. Firstly, this method was thought to support inclusion of the dementia voice in the research. As several researchers have highlighted, dementia can impact on a person’s ability to articulate their views and perceptions verbally posing unique challenges for researchers when conducting interviews (Hubbard et al., 2003; Lloyd, Patterson and Muers, 2016). In the study by Johansson et al. (2011) presented in the literature review (section 2.3.2) they described “detailed descriptions were seldom given; instead, answers were often short and important experiences might have been left out” (p. 2558). Similarly, in this study it was found interviews with people with dementia were often shorter and less detailed around recent dining experiences than with family members. Klinke et al. (2014) found observations can facilitate the inclusion of people who have communication difficulties in their study on eating-related practices with people who had had a stroke. Similarly, in an article on methods for gaining access to experiences of people with dementia, Nygård (2006) suggests combining interviews and observations to elicit rich data, enabling researchers to observe behaviours which may escape conscious awareness.

Secondly, observation may be useful in collaboration with interview techniques (Jamshed, 2014). For example, observations can provide further understanding of less socially desirable behaviours which participants may be less willing to report in interviews. This was identified in the study by Boyle (2014) (see section 2.3.3) whereby they found evidence for behaviours related to power and control among family members of people with dementia which they did not discuss in interviews. Participants may wish to display themselves in a certain way, e.g. as a 'good carer' and thus only discuss aspects of dining experiences which support a desirable image in interviews.

Thirdly, as identified in the literature review, there appeared to be a gap in understanding the micro-social element of dining, such as conversations which took place in this space. As this study developed, the questions evolved to include dining interactions and how people supported these interactions in situ. As Wills et al. (2016) suggests, understanding everyday social practices is challenged by the fact these activities are often mundane and important behaviours and perceptions may be taken for granted and therefore difficult to recall. These nuanced aspects of the practice itself, can be revealed through observation. Goffman (1959) suggests "what people say often differs from what they do. Thus, he [Goffman] preferred to observe actions and to listen to what people say in their natural settings than to rely on interviews'' (p. 982).

Goffman is talked about in more detail in the following chapter, including the relevance for this study. Goffman (1974) primarily used observations for understanding micro-sociological everyday encounters and how misunderstandings and breakdowns in meanings arose in interaction. As the researcher became more familiar with Goffman's (1974) work and its relevance for understanding dining experiences for people in this study, observation was identified as useful to facilitate understanding of these misunderstandings and breakdowns that can occur when dining with dementia.

After some deliberation and reading of the literature, video-based methods were selected as the best approach to capture observations. Although the researcher recognised the presence of the camera could affect how natural dining encounters were, the benefits appeared to out-way limitations in terms of this approach capturing the rich multi-faceted behaviours and interactions which took place. As Knoblauch (2012) describes in his book on qualitative video-based approaches, this approach provides a “microscope of interaction” (p. 9). Video recording provides the opportunity to meticulously examine and re-examine sequences of events as they take place in real-time (Heath, Hindermarsh, & Luff, 2010). Videoing allows for instances to be replayed and subtleties in body language and action to be drawn out from observations (e.g. Sundin & Jansson, 2003). Furthermore, as shown in the study by Majlesi and Ekström (2016) (see section 2.3.3), the use of video-recording dining interactions can support understanding of how people with dementia use the physical and social environment, including cues, to compensate for their difficulties. A small number of dining situations were recorded in this study, given that the data was rich and multi-faceted, providing a large amount of data with which to analyse and compare with the interviews. This process was labour intensive and it was important to be cautious of not collecting too much data which then can harbour the process of developing a conceptual understanding of the data (Glaser, 2001, p.192).

3.5.2 Sample and recruitment

For this next stage, as with the interviews, purposeful sampling was used whereby the researcher observed dining scenarios among people living with PCA and tAD who were available after taking part in the dining interviews. Given the researcher was interested in comparing experiences of dining in terms of living with PCA and tAD, an equal number were approached. The researcher sought four scenarios where participants were reporting a range of dining experiences and the initial reasons for selection are described in more detail below.

Four family dyads were contacted by letter informing them of the purpose and nature of the video-based observations (appendix 10). They were then contacted a week later to see if they were interested in taking part. For one family dyad living with PCA whom the researcher initially planned to contact, the person with dementia sadly passed away just before they were contacted. Another dyad living with PCA was approached and the other three family dyads whom the researcher had planned to contact agreed to take part. The research visit to their home was arranged for a time and date which suited them.

Below is a description of the four family dyads, the reasons for selection and the context of each scenario. The pseudonyms used are the same as for the interviews and demographic information regarding these participants can be found in section 5.1.

1. **Alastair and Tanya:** Alastair who has a diagnosis of tAD and his wife Tanya were approached as Alastair appeared to have impaired insight into changes and was

defensive in the interviews when Tanya discussed changes relating to the diagnosis. There were discrepancies and conflicts in Alastair and Tanya's accounts of changes and ways of coping. These frame disputes are described in more detail in chapter 5. The researcher wanted to explore how these different perspectives were coordinated through behaviours and actions during a dining scenario and understand more about Tanya's approach to this, as well as how Alastair presented himself during dining in action given he was reporting little changes in the interviews.

2. **Burt and Denise:** Burt, who has a diagnosis of tAD and Denise were approached as Burt was more aware and less defensive about changes than Alastair. He appeared to accept that he was having difficulties and embraced dementia in some ways; for example, he spent a few days a week at a day centre with others with dementia. Burt and Denise reported positive mealtime experiences in the interviews, for example, they reported working together to prepare meals and compensating for memory loss. The researcher wanted to explore how this openness about tAD affected how eating-related practices were managed and how this related to the way Burt presented himself in a dining scenario, as well as Denise's behaviours. The scenario with Burt and Denise was also unique as they dine with Denise's mother who also has a diagnosis of dementia. She was consented into the study as a family member and thus the analysis considers how her involvement affected the interaction with Burt, as opposed to analysing her behaviour independently of this.

3. **Trudy and Edward:** Trudy, who has a diagnosis of PCA and her husband Edward were approached as they were reporting positive dining experiences in the interviews. Despite Trudy having an early-onset dementia, at 58yrs old, Trudy and Edward reported no social difficulties and going out to eat 'now more than ever', suggesting they maintained meaning in their dining experiences. The researcher wanted to understand more about the behaviours and the set-up of their eating-related practices which may have influenced this experience. It was clear from the interviews that Trudy was experiencing substantial changes in her abilities, for example she now had difficulty cutting up food and had stopped preparing meals.

4. **Louise and Richard:** Louise who has a diagnosis of PCA and her husband Richard were approached as they were reporting more negative mealtime experiences in the interviews. Louise reported feeling uncomfortable eating out due to difficulties managing the meal and spilling food, had stopped going to 'formal' dining functions with her husband and reported embarrassment with these difficulties. Richard

presented these difficulties as wrong in relation to how eating-related practices 'should' be managed. The researcher wanted to learn more about dining behaviours in action which may have related to these types of appraisals, as well as how the dyad were interacting during dining which may have related to a breakdown in the dining experience.

3.5.3 Procedure

As described in section 3.5.2, following initial analysis of the interviews, video-based observations within participant's homes were selected as the next stage for data collection. This required an amendment to the existing ethics application to include permission to observe and video-record observations within participant's homes, given this was not covered in the original ethics application for the Seeing What They See study (see section 3.3). This process took some time and it was not until over a year following the dining interviews that the researcher entered the field to conduct the observations, following both the analysis of interviews and decision to use observation and ethical approval from London- Queen Square Research Ethics Committee. The dates for observation and interview for each of the families is included in table 1. Ideally these observations would have been carried out earlier, directly following the interviews, so they reflected a similar time-point, however, on a practical level this was not possible and therefore they were conducted at this later date. As with other sociological research, it was regarded important to 'go where the action' is, (Nygård, 2006), collecting data within the specific context i.e. at home, to provide an understanding of how participants used this setting to support their dining interactions

Table 1: Dates of interviews and observations with the four dyads who took part in the video-based observations

	Date for interview	Date for observation
Tanya and Alastair	16/01/2015	01/06/2016
Burt and Denise	12/02/2015	08/06/2016
Trudy and Edward	23/04/2015	10/06/2016
Louise and Richard	14/04/2015	29/07/2016

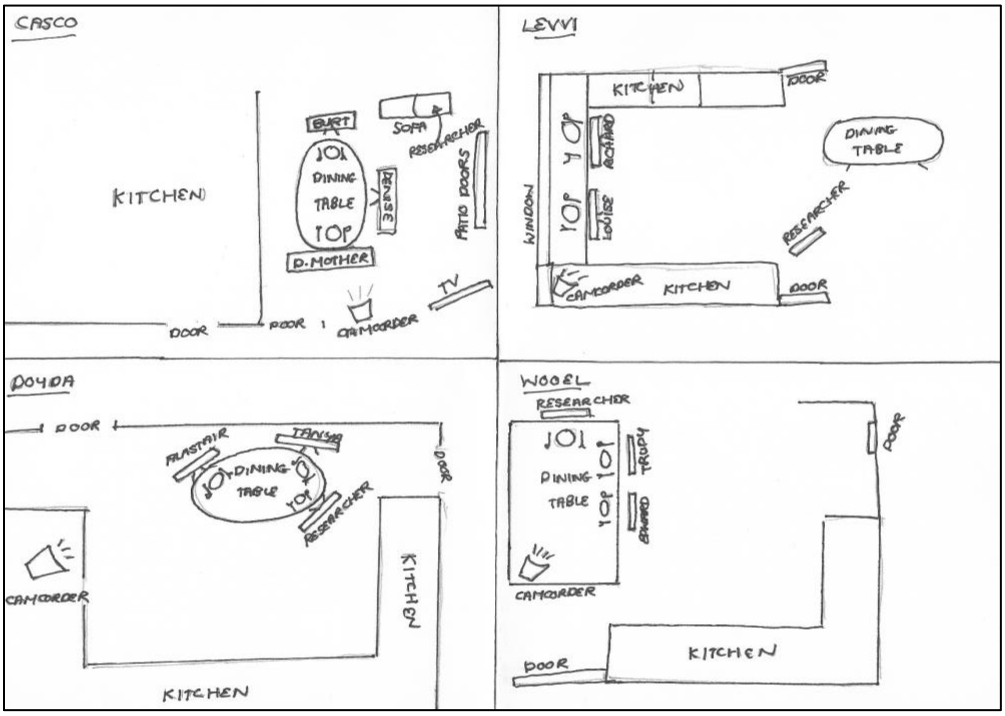
For the observations consistency or reliability was not important but rather observing scenarios which were controlled by the participants, in terms of how they wished to carry out their dining interactions. This meant the researcher was flexible in the procedure and encouraged participants to carry out and coordinate their behaviour in a way that suited them.

When family dyads were contacted by phone to arrange a suitable date and time for the observation, they were asked whether they would prefer a lunchtime or evening meal and how they would prefer the researcher to be involved i.e. as an observer or as a dining participant, depending upon what they were more comfortable with. It was explained to participants over the phone that the researcher wished to observe the meal preparation aspect as well. However, on arriving at people's homes some had already began this aspect. This highlights the lack of control researchers can have when conducting research in natural settings, however, it may also have been more naturalistic in the sense that this maybe the way participants managed situations when having a guest round for mealtimes.

When the researcher arrived at participant's homes, information sheets were provided for participants to keep and consent was gained for taking part in this observation stage (see appendix 9). The purpose of the visit was explained to participants as observing an- as natural as possible under the circumstances- dining situation to understand more about experiences and coping strategies when living with dementia. The researcher took a copy of the invitation letter and read through it with the participant dyads to ensure they understood the purpose of the visit. Participants were encouraged to ask any questions they may have at this stage. It was made clear to participants that taking part was entirely voluntary and they could stop the video-recording at any time should they wish to. Participants were also encouraged to discuss any changes to their situation prior to being observed given time had lapsed since the interviews.

Following this, participants were introduced to the camera and it was explained videos would be anonymised during transcription and analysed by the researcher. The participants were reminded that recordings would be used for research purposes only and may be shared among the research team for the Seeing What They See project but these recordings would not be shared publically. The researcher was mindful that video-recording could potentially be awkward for participants (e.g. Luff & Heath, 2012) therefore spent some time discussing the use and benefits of it, introducing it and setting it up with participants, so that they could become familiar with the camera being in the room and with being recorded. Where possible, families helped set the camera up in a suitable space and check the frame-view was suitable to support their control and ownership in this situation. Placement of the camera is an important consideration in video-based research (Jewitt, 2012). It is important to consider that filming is room-limited and to the framing the camera could capture. This did not present as an issue for the observations with Trudy and Edward, Alastair and Tanya and Richard and Louise as they had open-plan kitchen and dining spaces meaning most the interactions including preparation, clearing away and the mealtime together could be captured. However, for Burt, Denise and her mother, the kitchen was in a separate room and therefore some of the interactions, such as during meal preparation, were not captured as the camera was set up where the dining table is. The researcher decided not to move the camera around to minimise distraction, particularly as the camera was a larger compact cinema camera and may have interrupted the interactions. Instead the researcher took note of some of the conversations with Denise and Burt which occurred in the kitchen space which were not captured on the video-recording, however this lacked the richness of the data captured using the video-camera (see figure 4). Placement of each participant, the camera and the layout of the physical environment for each of the dining situations is included in figure 3. The camera was turned on as early as possible following the consent procedures and placement of the camera to support participants to become familiar with being filmed.

Figure 3: Pen-picture of dining environments for the four dining situations, CASCO refers to Burt and Denise, LEVVI refers to Louise and Richard, DOYDA refers to Alastair and Tanya and WOOEL refers to Trudy and Edward (these were the original code names from the Seeing What They See study)



Given the researcher allowed for flexibility in terms of dining situations being led by the participants, this approach produced four very different scenarios. The dining scenario with Alastair and Tanya who were living with tAD involved a lunchtime meal, including a main meal and dessert, where the researcher was invited to dine with the couple. Therefore, the research was acting as ‘participant as observer’ (Gold, 1958) i.e. being part of the scenario. The meal took place around a dining table which was in the kitchen area. The scenario with Burt and

Denise who also were living with tAD was unique in that (as previously mentioned) Denise's mother who also had dementia ate with the couple. Their meal involved an evening meal, including a main meal and dessert, where they requested the researcher observed the meal and sat on the sofa adjacent to the dining table during their scenario. Here the researcher was acting as 'observer as participant' (Gold, 1958) i.e. with minimal involvement in the social situation but acting as an overt observer whom the diners could interact with as they wished. The meal took place around a dining table which was situated in the living room, adjacent to the separate kitchen area. For the scenario with Louise and Richard who were living with PCA, this involved a lunchtime meal with a main meal and yoghurt for Louise afterwards. The researcher sat behind the couple at the other end of the room whilst they ate their meal and as in the scenario with Burt, Denise and her mother acted as 'observer as participant'. The meal took place on a low kitchen breakfast bar facing out to a window. Louise and Richard had their back to the researcher whilst eating, but chose to turn their chairs around after Richard had finished the main meal and Louise was still eating and discussed changes since diagnosis with the researcher. The scenario with Trudy and Edward who were also living with PCA involved an evening meal prepared by Edward, involving a main meal and pudding. The researcher was invited to dine with Edward and Trudy, acting as 'participant as observer' as in the scenario with Tanya and Alastair. The meal took place around a dining table which was situated in the kitchen. The role of the researcher's presence in the dining interactions is further discussed in the observation chapter. It was important that these variations were part of the analysis. As grounded theory researchers suggest 'all is data' (Glaser, 1998, p.8) and it was important to consider the situational variations which related to various dining interactions.

As previously mentioned, another way the situations varied was in how much meal preparation was carried out before the researcher arrived. For example, Denise started cooking from scratch when the researcher arrived after a busy day out, whereas for Trudy and Edward the meal was already in the oven and did not require much additional preparation. This contextual variation was another important consideration in the analysis.

The length of the dining scenarios also varied and depended upon the participants and the way they chose to carry out their activity. For two of the dyads, after-dining conversations were had at the dinner table and the camera was kept running during this. Video recordings of the observations lasted from 41:58 minutes up to 01:07:59 minutes across the four dyads. Once the camera was switched off, the researcher had a discussion with participants, asking how they found being videoed and if they had any questions or concerns. All four dyads had taken part in another study as part of the Seeing What They See project which involved video-recording in a simulated visual environment (preparatory study 2; see appendix 1), therefore they may have been slightly more at ease with being recorded, compared with if this was new to them. However, one participant (Trudy) said at the end of the recording that she felt like a monkey in a cage, suggesting her behaviour was perhaps affecting by the cameras presence. However, she did say this in a humorous tone suggesting she did not experience too much anxiety with being recorded, and when questioned further about this she said she got used to the camera being in the room and the meal was fairly typical for their interaction. The other participants talked about forgetting the camera was there after a while. As previously mentioned these contextual variations were part of the analysis as ‘all is data’ (Glaser, 1998) and are included in the results.

Following each visit, field notes were made of conversations which were not captured in the videos and the researcher’s reflections on the dining scenarios. This included conversations before and after recording began. For example, Edward mentioned on arrival that the researcher may notice a significant decline for Trudy in terms of her functioning ability since the previous visit and this was recorded in the field note. An example of a field note from the observation with Burt, Denise and her mother is provided in figure 4.

Figure 4: Example field note following observation

Date: 08/06/2016
Type: field note
Burt and Denise observation

Wife wanted to see me separately in the kitchen: ‘it’s absolutely soul-destroying’, she discussed grappling with helping them maintain their identity whilst seeing performance in everyday life is diminishing, She thought he might be talking less due to trying to appear normal (said in kitchen)- sitting up straight idea, engaged less over time, suspicion over what is framing him?

‘it’s lovely to see him engaging and chatting with you’ (he doesn’t do this normally and didn’t in the observation)

Separate/ boundary, ‘do you want to record in here this is where it’s ‘all happening’’

‘welcome to the chaos’/ stressed/ ‘mad house’
Humour element for wife

Feeling out of control- whatever?! idea

Some humour used around it, particularly by her

Much more openness about dementia with me separately

Mother has dementia too, mother and Burt playing each other off, didn’t interact with one another

He’s happy when engaged but quiet overall/ suspicious of what frames him?

Important of engaging socially/ lack of social aspect but birds connection and TV connection

Disengaging as own coping strategy/ preserving self

3.5.4 Video recording and transcription

As outlined in section 3.5.1 video-based data collection was used which allowed the researcher to review the dining situations back, re-examining. Furthermore, it allowed the researcher to be present during the observation as opposed to being concerned with noting down behaviours and conversations during the scenario, acting as a participant and part of interactions where necessary. As embodied perceptions became a theoretical interest, observing these subtleties, for example in facial expressions or body language, could also be explored via the playback features. Subtle strategies to support dining interactions could also be observed and noted from these videos. On a practical level, the researcher used a camcorder which was available to her through the research team. This was a compact cinema camera (Panasonic AU-EVA1 5.7K). The camera was portable but due to the bulky size it was deemed it may distract dining interactions if the researcher moved it around and thus it was mounted in a suitable place within each setting as shown in figure 3. The camera also has a microphone attached which captured the audio data.

Videos were uploaded and stored on a password-protected computer and deleted from the camcorder following each research visit. During the transcription process of these observations, personal details were anonymised and the pseudonyms which had been used for the interviews were also used for the transcripts. Video-recordings were watched once following each visit and rough notes were made of key instances and first-thoughts related to themes from the interviews. The videos were subsequently watched repeatedly and transcripts included details of the conversations and behaviours of participants, as well as a summary of the setting and context. Given the data-driven nature of this study and the fact there has been little research using video-based observations of eating-related practices when living with dementia it was deemed important to transcribe qualitatively. A non-standardised approach to transcribing was used where interactions, actions and social situations were transcribed as described by Knoblauch (2012). This contrasts with more systematic approaches to analysing video such as dementia care mapping (Brooker, 2005). The process was found to be laborious given the multi-sensual nature of the data and difficulties with capturing subtle facial expressions in the interactions. There was little literature identified on how to transcribe such details from video-based data. For example, although the study by Majlesi & Ekström (2016) on eating-related practices used video-based observations and transcribed these qualitatively they did not outline how they transcribed and analysed their multi-sensual data. The researcher was guided by the recommendations from Knoblauch (2012) in his book on qualitative audio-visual analysis whereby actions and interactions were sequentially transcribed including how actions were being performed. This includes all talk and visual conduct in as much detail as possible. However, given the researcher was new to this type of transcribing and analysis the amount of information captured in the transcripts may have been limited. Furthermore, it is also important to consider the transcripts of video data are a version of events by the viewer, open to interpretation as with other sources of data (Gibson et al, 2005).

Transcripts were organised into three key phases: *'meal preparation'*, *'the mealtime'* and *'clearing away'*. Theoretical notes about the data were also included in the transcripts (see example transcript in appendix 11). These transcripts were then uploaded into Atlas.ti 5.0 with the interview data. Video transcripts were coded using the codes which had been established from the initial stages of analysis of the interviews, as well as these codes being refined and added to with additional codes where appropriate. For presentation purposes, the quotes used in the observation results chapter (chapter 6) were re-formatted and therefore appear slightly different to the original transcripts (as in appendix 11).

3.6 Data analysis

3.6.1 Use of CAQDAS for analysis

Analysis of the transcribed interviews was carried out using computer assisted qualitative data analysis software (CAQDAS), Atlas.ti (version 5.0). The researcher attended an Atlas.ti training workshop with Dr Christina Silver, an Atlas.ti consultant, whereby the main functions and uses of Atlas.ti were demonstrated. From this it was identified this programme was useful for grounded and data-driven analysis given the flexible coding functions and the ability to move across different documents for constant comparison. This software is useful for storing large amounts of data and organising each data file as 'documents'. In addition, the software is useful for the coding process, whereby codes are developed freely and can easily be edited, removed or merged, supporting initial open and focused coding and renaming of codes as analysis develops. Another helpful feature of Atlas.ti is that it supports the ability to group 'families' of documents in the 'document manager'. This feature was useful to compare across groups of people with PCA, tAD, people with dementia and family members by grouping their documents and comparing codes for each 'family'. Constant comparison across the data set and within interviews and observations is also facilitated by the programme whereby it is possible to compare quotations for each code using the 'code manager'. Each of these functions was used within this research, to refine and sort the codes, as well as group codes into themes to support the developing analysis. An example screenshot of the Atlas.ti programme and the functions described here which were used for this study is included in Appendix 12. As well as this, in the results (chapters 5 and 6) codes from Atlas.ti 5.0 for quotes and related documents are used which provide an audit trial to the raw data.

3.6.2 Coding

Analysis was not carried out in a linear process but rather as a cycle of ‘double back steps’ and from the initial stages of data collection through to the write up of this study as recommended by grounded theorists (e.g. Glaser, 1978, pg. 16). Coding, constant comparison and memoing were carried out throughout the analysis process. Open coding involves coding data with an initial open mind. As recommended by Charmaz (2006) line-by-line coding was used, staying close to participant’s words, by using ‘in-vivo’ codes which use phrases or words from the participant to code that section of data. Codes were also generally labelled with ‘-ing’ words to emphasise the active process and change or movement in experiences as opposed to treating them as fixed instances (Glaser, 1998; p. 143). This data-driven approach allows for codes to ‘earn their way’ into the analysis as opposed to being imported from pre-existing theories or hypotheses (Charmaz, 2006). Overall, 937 codes were created in relation to the interviews which stayed close to the interviewee’s accounts of their dining experiences. This approach was important for capturing the voices of participant’s experiences to identify their main concerns, thus ensuring analysis was data-driven.

The initial 937 open codes from the interview analysis were collated into focused codes which were then applied to the analysis of the observation data and further refined with this new data. This resulted in 104 focused codes. Whilst the researcher transcribed and analysed the entire sequences of the dining observations as described in the previous section, they were considered with an interpretative lens of Goffman’s (1974) Frame Analysis concepts and with the codes from the dining interviews. In this way, the analysis was more focused for the observations, for example, upon misunderstandings and how these were coordinated and the various devices people used to coordinate their behaviours. However, the use of non-standardised qualitative transcribing supported the process of staying grounded with the data, supporting openness to new concepts and conflicting data (Charmaz, 2006).

Memos (as described in section 3.6.4) were hand-sorted and arranged into groups. Theoretical links between concepts were identified, which conceptualises how focused codes relate to one another (Glaser, 1978). Memos on links and nuances were made and links between concepts were considered. The 104 codes were grouped into overarching themes which included changes to dining experiences, processes related to maintaining meaning in dining and how these processes were interrelated. A list of the codes and their associated groups from Atlas.ti is provided in appendix 13. Writing was another important stage in solidifying key themes and concepts, some concepts were renamed during this process to capture and present the content of each theme more accurately.

3.6.3 Constant comparison

Constant comparison is the process of comparing across incidents and codes to identify underlying patterns across a data set, as recommended in grounded theory (Glaser & Strauss, 1967). Constant comparison across documents is the central tenant of the grounded theory method, which is carried out during data collection and analysis, until the themes and resulting concepts have been saturated. Atlas.ti 5.0 was found to support this process whereby concepts could easily be compared to identify similarities and differences across and within cases (see section 3.6.1). For example, Atlas.ti allows the researcher to look at codes and compare quotations for each code across different interviews. As well as this, the families function allowed the researcher to compare the codes for each group including people with PCA and tAD, family members and people with dementia. This process was used throughout data analysis, helping to establish overarching themes by exploring similarities and differences across cases from the open coding phase through to the focused coding phase described in the previous section. As in the Eating Together study (see section 2.3.2.1) the use of constant comparison procedures supported a more interrelated understanding of the data.

3.6.4 Memoing

Memoing is another key tool recommended by grounded theory researchers which was also used throughout the data analysis process to record the development of thinking and capture ideas about codes and the way they relate to each other (Glaser, 1978, 1998). Memos were hand-written throughout the data analysis process and typed into a Microsoft Word document for later review during theory generation. They included notes about the data, field notes, notes about related literature and theory to support understanding of the data.

The researcher decided to hand-write memos, type them up and label them in Microsoft Word as this was perceived as less restrictive than the memoing function in Atlas.ti. Firstly, hand-writing memos could be done anywhere and did not rely on having the Atlas.ti programme available, allowing them to be recorded as and when thoughts came up. Secondly, memos could be viewed chronologically which was useful for observing movement within the analysis and continuing to grow and develop ideas and conceptualisation of the data. As well as this, because they required typing up, they could also be refined and modified during this process. Memos became more theoretical over time, for example, regarding relationships between categories and relationships between themes and Goffman's (1974) Frame Analysis (see chapter 4) as the analysis developed. Memos about the similarities and differences between living with PCA and tAD were also recorded to support comparisons between dining experiences across these two dementias. Examples of memos are included in appendix 14.

3.6.5 Abductive reasoning

As outlined in the previous chapter (see section 2.3.5), many studies on mealtime activities for people living with dementia have been a-theoretical. Given the various dining experiences reported in the literature and for participants in this study, from mealtimes being a high point of the day for family cohesion and enjoyment to a time of tension, stress and estrangement from the 'typical' dining experience, it appears dining is a complex psychosocial experience when living with dementia. Theoretical explanations could help to elucidate the complex psychosocial processes by which individuals adapt to the behavioural, psychological and social consequences of living with dementia (Menne, Kinney & Morhardt, 2002). As previously outlined, this study used an informed version of grounded theory to identify relevant theoretical frameworks to support understanding of the data . Different sociological theories were 'tested' against the data as the analysis developed towards abstraction in understanding.

From reviewing the memos on existing theories which were considered in relation to the data, these included the following: symbolic interactionism (e.g. Blumer, 1986); behavioural settings theory (Barker, 1968); person-environment fit (Edwards, Caplan & van Harrison, 1998); the stress-process model (Judge, Menne & Whitlatch, 2009); symbolic interactionism (Blumer, 1986); stress and cognitive appraisal (Lazarus & Folkman, 1987); social order, power and conflict theory (Marx, 1976); presentation of self (Goffman, 1959) and stigma (Goffman, 1963); selfhood theories (e.g. Kitwood, 1997; Sabat, 2002); social facts (Durkheim, 1982); ethnomethodology (Garfinkel, 1967); field theory (Bourdieu, 1977); corporeal schema (Merleau-Ponty, 1945) and finally Goffman's (1974) Frame Analysis theory (1974). Goffman's (1974) Frame Analysis and his taxonomy of terms was identified as the most comprehensive and relevant theory to support a conceptual understanding of the data and this theory is outlined in the following chapter.

3.7 Rigour

Although qualitative methods of inquiry are useful, a criticism of this method includes lack of methodological rigour (Sandelowski, 1986). Some researchers suggest quality in qualitative research is difficult to explain, but is recognised when it is seen, therefore in this respect it is more like an art than a science (e.g. Corbin & Strauss, 2008). Alvesson and Sköldberg (2017) suggest that qualitative research requires a creative and open mind and an acknowledgement of blurriness, complexity and subjectivity by its nature. Some researchers use evaluative criteria for establishing rigour in qualitative studies. Criteria should be selected which is most applicable to the research interests and approach of the research (Mays & Pope, 2000).

Having considered various criterion for this study, the following criteria is proposed. Firstly, Lincoln and Guba's (1985) constructs are proposed as a widely accepted criterion for qualitative research and naturalistic inquiry (Pandey & Patnaik, 2014). Lincoln and Guba (1985) suggest that trustworthiness of a study is important in evaluating its worth. They suggest that qualitative researchers should consider four criteria of trustworthiness in their work. These criteria are outlined here and used to evaluate the trustworthiness of this study in the discussion chapter (see section 7.4.1). As well as this, the researcher has also added the criteria of 'relevance' and 'work' from grounded theory (Glaser & Strauss, 1967), as these relate to developing explanatory understandings of experiences, as in this study. Other criteria from grounded theory, i.e. fit and modifiability, have not been proposed as although grounded theory procedures have been used to support this study, the study did not intend to develop a grounded theory per se (as described in section 3.2) and thus these criteria are not applicable.

3.7.1 Credibility and relevance

Credibility, Lincoln and Guba (1994) suggest, is the most important factor in establishing trustworthiness. Credibility deals with the question "How congruent are the findings with reality?" (Merriam, 1998, p. 201). It is an attempt by the researcher to demonstrate confidence between their findings (reconstructions) with that of participant reports (constructed realities).

This criterion is similar to 'relevance' as a key criterion in grounded theory studies (Glaser, 1998), A relevant grounded theory should have 'grab' (Glaser, 1998) and should be understood and recognised in relation to those who it refers to. Although the researcher did not develop a grounded theory, this criterion can be used to judge how relevant the explanatory findings are for understanding variations in dining experiences for people who took part in this study.

3.7.2 Transferability

Another criterion for assessing the quality of qualitative studies is ‘transferability’. Transferability should be viewed with caution in relation to qualitative research, given small sample sizes and importance of contextual factors which impinge on individual cases (Gomm, Hammersley & Foster, 2000). However, Lincoln and Guba (1985) suggest that for a quality study, qualitative researchers should provide a sufficiently thick description of the phenomena under study to allow readers to have a thorough understanding of the boundaries of the study, allowing them to make judgements of how the instances of the phenomenon described may transfer to other situations.

3.7.3 Dependability

Dependability closely relates to credibility (Lincoln & Guba, 1985) as described in section 3.7.1. Dependability refers to the consistency of the inquiry processes used over time. It also emphasises the uniqueness of human situations and reporting variations in experiences rather than identical repetitions (Pandey & Patnaik, 2014).

3.7.4 Neutrality

Freedom from bias in the research process and end-product is the objective here (Guba & Lincoln, 1994). This relates to ensuring that as far as possible the works findings are the result of the experiences of participants as opposed to characteristics and preferences of the researcher (Shenton, 2004).

3.7.5 Work

The grounded theory criterion of ‘work’ refers to the ability of the findings to account for the way in which participant’s difficulties or concerns are resolved (Glaser & Strauss, 1967). It refers to how the data can “explain what happened, predict what will happen and interpret what is happening” (Glaser 1978, p4).

3.8 Summary of chapter three

In this methodology chapter, the methodological approach has been outlined which includes a data-driven, qualitative investigation, utilising grounded theory techniques to support the analysis. The aim of this study was not to develop a grounded theory of dining experiences, but rather utilise the flexible, data-driven methodological tools of grounded theory to understand and analyse dining experiences. The study was data-driven in terms of allowing participant's accounts to drive the on-going interests and development of themes and analysis. A justification for using grounded theory processes has been outlined including the lack of current understanding around dining experiences for people living with PCA and tAD, thus requiring a data-driven approach and the usefulness of the constant comparative method for both comparing between groups of participants and supporting a holistic understanding of dining experiences by comparing across concepts and themes. This study also utilised a theory-based 'informed' version of grounded theory for analysis, whereby abductive reasoning was used throughout the research process. This meant different concepts from existing sociological theories were tested against the data to enhance understanding of the emerging concepts. The procedures have been outlined which include in-depth interviews on eating-related practices with 20 family dyads living with either PCA and tAD and video-based observations of four dining scenarios with an equal number of people living with PCA and tAD. The analysis process including cyclical and repeated processes of open and focused coding, memoing, constant comparisons and abductive analysis has been presented. Proposed evaluative criterion has also been outlined and is used to evaluate this study in the discussion chapter. The following chapter presents Goffman's (1974) Frame Analysis (1974) which was identified through the process of abductive reasoning as the most relevant and comprehensive theoretical framework to support a conceptual understanding of dining experiences within this substantive area.

Chapter 4: Goffman's (1974) Frame Analysis

4.1 Introduction

As discussed in the previous chapter, this study utilised an informed version of qualitative analysis, using abductive reasoning to 'test' the data against different sociological theories. The researcher stayed open to a variety of sociological theories which supported the data analysis process and Goffman's (1974) Frame Analysis was identified as the most comprehensive theory which helped to explain dining experiences for people who participated in this study. Goffman's (1974) Frame Analysis provides a close observation of behaviour and interactions in everyday social contexts. This chapter provides an overview of the Frame Analysis theory and the main principles from his works which are relevant to this study and which been used to conceptualise understanding of the themes presented in the findings chapters. The relevance of Frame Analysis to conceptualise an understanding of dining experiences for people living with tAD and PCA is also outlined. Given Goffman's (1974) Frame Analysis contains a taxonomy of new terms, these terms are defined in this chapter and where presented in italics the reader is referred to a glossary of Goffman's (1974) terms in appendix 15. Where these terms are used in subsequent chapters, the reader can refer to this glossary for a reminder of their definitions.

4.2 Goffman's (1974) Frame Analysis

4.2.1 Rationale

Goffman's (1974) Frame Analysis was identified through abductive reasoning as the most supportive theory to facilitate understanding of dining experiences. Firstly, he emphasises that engaging in ordinary, everyday conduct is an opportunity for social expression and expression of the self. He viewed the self as an aspect of social and cultural arrangements as opposed to an isolated concept. This supported an understanding of how different changes to eating-related practices could affect the opportunity to express the self within this space as a social interaction. Goffman (1974) also describes how social experiences can become vulnerable with change and the pathways towards experiences becoming vulnerable in this study which appeared to be relevant to the experiences of people living with tAD and PCA.

Secondly, the philosophical lens Goffman takes also complimented the research interests of this study in terms of understanding actual dining interactions. This contrasts with much of the research in the literature review which took a constructivist or symbolic interactionist angle, focusing on meanings-made as opposed to actual experiences (see section 2.3.4). Although Goffman's (1974) philosophical standpoint is not easily described and he does not align himself strongly with a particular perspective, he described his ideological viewpoint as a kind of "structural social psychology" (Verhoeven, 1993, p. 322). With this lens, he explores the structure of social interactions and behaviours. He acknowledges symbolic interactionist perspectives whereby people co-create meaning through social interactions and individual contexts which influence the way people behave and perceive their experiences. However, he also criticises symbolic interactionism on the grounds that people do not enter everyday situations with empty heads. Goffman also acknowledges structural patterns at the societal level, where there are various norms and ideal standards for behaviour and people bring this knowledge to guide their everyday doings. This perspective compliments looking further at how people behave within dining situations as opposed to purely the meanings-made around experiences as has been the focus in many previous studies on dining experiences. Furthermore, this structural aspect of Goffman's theory compliments this study as many norms and ideals for dining behaviours appeared to inform the way people understood their experiences. For example, the observation that the majority of people in Western cultures pick up the knife and fork to eat at the dinner table suggests there are some structured definitions or frameworks for these actions. His theory supported an understanding of how these 'ideal' standards for behaviours affected the way people perceived their behaviour when it deviated from these 'norms'.

Not only this, but Goffman's (1974) Frame Analysis was identified as the most comprehensive theory which provided an understanding of a range of social phenomena including normality, stigma, embarrassment, feelings of uselessness, exclusion and misunderstandings in meaning, which were key areas related to dining experiences for people who took part in this study. His theoretical concepts provide a sociological lexicon for interpreting the way people behaved and coordinated behaviours within shared social situations and the way people framed their experiences to maintain meanings around dining. The relevance of Goffman's (1974) Frame Analysis is further addressed in the subsequent sections.

4.2.2 Overview of Frame Analysis

Instead of what is real, Goffman (1974, p. 2) approaches William James' philosophical question 'under what circumstances do we think things are real?' Goffman constructs and deconstructs the notion of experience by suggesting that people unconsciously monitor situations by asking, 'what is going on here?', whereby *frames/frameworks* provide these meanings and typically are confirmed by the situation, rendering a smooth flow of activity and the world coherent. This is relevant to living with dementia whereby cognitive losses can cause losses around a person's sense of reality (see section 2.2.1). For Goffman, reality is dependent upon how it is framed and *frames* permit and motivate actions in everyday life. In a book by Scheff, Phillips and Kincaid (2006) 'Goffman Unbound!', they explain Goffman's (1974) notion of *frames* as 'defining contexts' whereby "individuals and groups organize their experience of a situation by shuffling through their vocabulary of words, phrases, propositions and images… so that the situation becomes meaningful for them" (p. 90). This highlights the subjectivity in experiences, whereby individuals bring their own assembly of *frameworks* to everyday situations. In relation to this study, this supports an understanding of the individual contexts and experiences that people bring to their dining situations, acknowledging the highly individual *frames* which govern different people's dining activities. *Frames* help people organise their social worlds and make sense of what would otherwise be confusing and meaningless situations; with these understandings informing and permitting action in everyday situations. Goffman suggests *frames* are fundamental to our daily lives, they provide social order and understanding and permit action; "we press these stories to the wind; they keep the world from unsettling us" (1974, p. 15).

Goffman's (1974) work has been described as both social constructionist, in terms of the building up of meaningful frame assemblies through a lifetime of socialisation, as well as deconstructionist in terms of displaying how reality can easily break down relating to confusion and misunderstandings in framing (Davis. 1975; Clough, 1990). In relation to this study, dining activities are particularly well-framed given we are socialised into them from birth and typically conduct them daily, thus they provide a sense of normality, where activity generally flows predictably from the established frameworks. This supports understandings of the therapeutic value of mealtimes as identified in the Eating Together study (e.g. Keller et al., 2010), in terms of anchoring people living with dementia to a relatively normal aspect of daily life. However, the 'deconstruction' element of Goffman's (1974) theory helps to illuminate the way the expectant frameworks could be disrupted by changes related to dementia, relating to the potential for negative dining experiences and confusion when engaging in these activities and finding framed expectations are not being confirmed.

Given living with dementia often involves changes to 'typical' behaviours, this threatens the smooth flow of activity for both members of the family dyad when dining together, where pre-dementia *frames* for dining may not be met. Goffman also presents the idea that situations can be layered with different frames of reference; whereby one situation could be transformed in many different ways by people in interaction e.g. from a 'serious' *frame* to a 'joke' or play scenario (see section 4.3.4). These notions open-up variability and ambiguities in meanings, whereby Goffman presents the frequent misunderstandings which can arise in social encounters, where the wrong frame can easily be applied or individuals can *layer* situations differently. These multiple realities are particularly relevant to experiences of living with tAD, for example, where people with dementia may confabulate and bring different perspectives into interactions, relating to tensions within family dyads when one member has dementia (see section 2.2.3). Goffman provides some understanding around how different realities are managed by people in interaction.

As previously mentioned, Goffman's (1974) theory can be described as a kind of "structural social psychology" (Verhoeven, 1993, p. 323). He rejects symbolic interactionism in that it is limited if one is to consider social order and patterns in people's behaviour. The structural elements have largely been overlooked in existing studies which as previously mentioned tend to take a constructivist perspective to understanding dining experiences (section 2.3.5). Goffman discusses the structural aspect of his theory in an interview suggesting social order is possible given there are culturally defined 'norms' or frameworks for behaviour which relate to patterns which can be observed in behaviour across groups of people:

"As soon as you relate and identify a couple of processes, or try to relate them, or provide a systematic picture of something, you have to pull away from the very abstract approach of symbolic interactionism which doesn't provide any patterns. The argument would be that there are no patterns, that patterns emerge through persons taking each other into consideration, in moving in and around each other. But there is no structure to the way they are supposed to interpenetrate into each other's course of action." (Verhoeven, 1993, p. *334-335)*

In this way, Goffman's (1974) Frame Analysis has some similarity to Durkheim's (1982) concept of social facts which exist at a cultural level, with a well-defined framework through which people negotiate daily life and generate required responses. This allows society and social order to continue in a relatively structured fashion. This relates to a relatively conservative element to framing which may not be easily modified, for example, eating with a knife and fork has been a common tradition since at least the 4th century and may not be easily modified (James, Thorpe & Thorpe, 1995). It also allows people to coordinate their behaviours when in interaction with others. As Misztal (2001) suggested in a discussion of Goffman's (1974) work, engaging in collective frames of behaviour in situations such as eating-related activities helps to build connection and trust among interactants. However, individuals also have some agency over framing and Goffman also emphasises subjectivity, individual contexts and interactions in co-creating meanings.

4.2.3 Situating Frame Analysis with Goffman’s (1974) earlier works

Goffman was primarily concerned with micro-social, face-to-face interactions in everyday life throughout his work (Crossman, 2017). This was useful for this study, in terms of providing conceptual understandings around the micro-social elements of dining experiences, such as dining conversations. Goffman perceived Frame Analysis to be his masterwork, bringing together many of the concepts described in his earlier publications (Fine & Manning, 2003). In his earlier work, Goffman appeared to define various frames which people used to structure their experiences. Goffman developed a sociological lexicon, revealing a socially concealed world and highlighting the smallest details of everyday behaviours and interactions. Goffman’s (1974) earliest and arguably most popular work (Crossman, 2017) developed from his doctoral dissertation, ‘the Presentation of Self in Everyday Life’ (1959), whereby Goffman used dramaturgical analysis drawing on imagery from theatre, presenting the idea ‘all the worlds a stage’ and suggesting all actions are social performances to give off desired impressions to others. In this book, he first defined terms such as ‘concealment’, ‘performance’, ‘front region’, ‘backstage’ and ‘team collusion’, which he further discusses in Frame Analysis.

Many of Goffman’s (1974) earlier works also appeared to be focused upon the way situations are *framed*. For example, ‘Asylums’ (1961) was an ethnographic study which explored how behaviour was framed in psychiatric hospitals and Goffman described how ‘total institutions’ restricted people’s behaviours, yet people found ways to redefine their roles and reclaim their identities and create new norms. ‘Stigma’ (1963) also presented many of the concepts discussed in Frame Analysis, outlining how people managed impressions of themselves, often through ‘concealment’, in order to ‘pass at being normal’. ‘Behavior in Public Places’ (1963) also included important elements found in Frame Analysis (1974), for example, behaviour of people in daily circumstances is described where the actor takes account of the spatial environment and uses *frameworks* from this setting, acting accordingly to become an inclusive member of the gathering. Here Goffman describes differing norms for actors, for example, the level of familiarity with a person they are interacting with dictates the limits of the behaviour (p. 112ff.) ‘Strategic Interaction’ (1970) also consists of two essays which relate to Frame Analysis. In these essays Goffman describes conditions under which individuals receive, give and hide information. Here he introduces the concept of *frames* and describes terms such as *concealment* and *keying* which are further defined in Frame Analysis.

Frame Analysis, draws reference to many of these earlier works, bringing together some of the key concepts and the way people manage themselves in social situations. Frame Analysis (1974) also contains some novel insights about the organisation of experience, seeing a shift from the content of social events and social phenomena to their form and the nature of social meaning in general (Fine & Manning, 2003). In Frame Analysis (1974) Goffman writes about how conceptual frames structure an individual's perception of society. He moves understanding towards an existential perspective of the nature of reality itself, whereby the way social meaning is constructed and deconstructed in general is explored. Frame Analysis also acknowledges that social and cultural frames inform individual frameworks, which compliments an understanding of dining activities as a relatively structured daily activity. The following four sections outline the main concepts in Frame Analysis which are relevant to this study; *primary frameworks, frame anchoring, transforming frameworks* and *negative experiences.*

4.2.4 Primary Frameworks

Goffman's (1974) book, Frame Analysis, begins with a chapter presenting *primary frameworks* which are the actions which are said to be "real or actual, to be really or actually or literally occurring" (Goffman, 1974, p. 47). For Goffman, frames are the socially constructed, contextually bound, principles of organisation. Multiple *primary frameworks* go on at the same time and they inform a person's actions and their attentional focus. According to Goffman, frames typically filter into the flow of activity subconsciously, as they are ordinarily confirmed by behaviours and the external environment. The situation, or frames available in the external environment also provide an anchor for one's own frames' and behaviour. They allow for social inclusion when individuals engage in shared frames within situations, connecting individuals and coordinating behaviour in interaction. This relates to the concept of commensality around eating (see section 1.2) as a kind of anchor to normality when living with dementia as described in some of the existing literature (e.g. Keller et al., 2010; Johansson et al., 2011). The interaction requires knowledge of the appropriate frame, guiding appropriate actions. Goffman (1974) uses the analogy of a game of checkers to describe how individuals take acquired knowledge to situations, whereby they do not go into everyday situations with empty heads but are guided by cultural 'rules' of the game which have been learned over time. As well as this, individual's take personal knowledge, for example, past performance and knowledge of social relationships with others, motivating their frameworks and related actions as the game unfolds.

Goffman also distinguishes between the *main-track* or dominant storyline, as well as *dis-attended tracks* or activities. New frames can disrupt the main frame, providing new frames for the main-track of the activity. Disruptions are not always positive and Goffman discusses uncomfortable situations where *out-of-frame* acts can threaten the frame of an event, drawing on the analogy of a member of an orchestra playing out of key and threatening the performance (p. 571). This can be dis-attended to if the behaviour is not too obvious or repeated, or concealed by other players if they co-operate, or it can disrupt the activity and cause *negative experiences* (see section 4.7). This is particularly relevant in relation to living with PCA where perceptual and spatial impairments relate to difficulties in eating conduct (Shakespeare et al., 2015), which could disrupt the *main-track* of the dining interaction.

Goffman also distinguishes between *natural* and *social frameworks*. *Natural frameworks* are unguided and occur beyond human consciousness through natural forces. *Social frameworks* are those which involve human guidedness and are considered. Actions which are viewed in a social framework subject the actor to standards of social appraisal by others, given motive and intent are perceived to be involved (p. 22). However, distinguishing between whether to apply a *natural* or *social framework* is often ambiguous and the wrong frame can easily be applied. According to Goffman, individuals need two understandings: (1) understandings of the natural world by which they are encompassed and (2) understandings of the social world. People continue to use and negotiate these frameworks, also relying on accompanying signs such as setting, appearance and manner, helping to distinguish which frame to use. This is relevant to this study with people with dementia given that it may not always be clear whether to view changes in behaviour as intentional or as part of a *natural framework* as Goffman discusses in relation to mental disorders (p. 189). Given people cannot see damage to the brain, interpreting behaviour is more likely to be ambiguous and certain behaviours could be viewed in a fully intentional social framing, rending more judgement from others and the self.

Another key element is the *'person-role' formula* whereby a person is never completely free from the roles them play and the capacity in which they 'play' is always open to social accounting (p. 270). He discusses person's anchoring of doings into the world as an expression and outcome of the self, whereby the self is present behind the roles they play. Goffman discusses roles as 'styles' (p. 290) which are manners of doing things which are deemed 'appropriate' given age, sex, class etc.; a style which he says is modelled after something else, i.e. *framing conventions*. As outlined in the literature review, people with dementia often struggle with maintaining their sense of identity and engaging in daily roles can support this (e.g. Caddell & Clare, 2011; Miranda-Castillo et al., 2010; Sørensen et al., 2008). This may be linked to changes in the types of roles they are able to anchor into the world and the style with which they are able to carry out these roles. Difficulties in carrying out daily activities are a defining symptom of dementia and understanding changing roles as a social expression of the self, help to understand loss of self-identity, as reported in the literature (see section 2.2.1).

4.2.5 Frame Anchoring

Goffman (1974) also covers the issue of how people maintain trust in the reality of everyday *frames*. In his chapter on the Anchoring of Activity (p. 247-300), he uses the metaphor of the *anchor* to describe how *frames* are anchored towards familiarity through several frame devices, as if to prevent them drifting off into a sea of uncertainty. One such device is *bracketing* whereby boundaries in time and space, help individuals define the beginning and end of an activity. Goffman (1974) stresses that collectively organised social activity is especially likely to be *bracketed*, allowing individuals to coordinate their behaviour around a shared framework. This is particularly relevant to dining, as a collectively organised social activity, typically marked off from the ongoing flow of events by a set of boundary markers (pg. 251). The physical environment, with its *framing conventions*, acts as an important cue for generating the correct cognitive *frames.* Alexander (1979) notes that the physical environment "is, precisely, the pre- condition, the requirement, which allows the patterns of events to happen. In this sense, it plays a fundamental role in making sure that just this pattern of events keeps on repeating over and over again" (p. 92). For eating-related practices then, environmental cues such as the dishes and sitting at the table may generate the framework that it is a time to engage in a certain set of behaviours related to eating-related practices. In terms of social dining occasions for example, further environmental cues such as a candle, or music may anchor people to the framing around a social dining *frame*. This is an important consideration, whereby environmental cues may play an important role in generating frame-relevant cues for dining situations (e.g. Majlesi & Ekström, 2016). Another consideration, is that Goffman (1974) suggests the *anchoring* of frames is especially loose when individuals are framing informal interpersonal experiences, i.e. social occasions, where they may be less cues for framing (Sullivan, 2008).

With his concept of *anchoring* frames, Goffman discusses how frames 'box in' experiences, shutting in desired behaviours and shutting out intruding ones (p. 253). One way individuals attend to boxed in frameworks, is a device Goffman calls *unconnectedness*, referring to the idea that people can ignore aspects of the situation which are not relevant to the ongoing frame. For example, people in a meeting could ignore caterers, preventing disruption to the main-frame of the meeting. Goffman (1974) also discusses other *anchoring* devices, such as *resource continuity*, whereby the material traces left behind such as the dining room, anchor activity to the external world, relating to an enduring understanding of how to behave in these situations. In this way, sitting at the table and eating together may *anchor* people living with dementia to a relatively enduring aspect of daily life, supporting a sense of continuity (e.g.

Keller et al., 2010). *Frames* may also connect individuals to the broader social world. For example, *anchoring frames* towards a collective point of view (ibid., p. 290) may foster a sense of connectedness and reality with others, connecting individuals with society. Frames can connect families and communities and this is an important consideration in terms of how people with dementia perceive their dining experiences in relation to wider social networks and communities.

4.2.6 Transforming Frameworks

Goffman highlights that "meanings, in everyday life, are the projection of the structure or form of the experiences in which they are embodied" (ibid, p. 119) and through his concepts around *frame transformation,* demonstrates the depth of various forms or layers of different meanings (e.g. p. 83; p. 182). Firstly, *keying* transforms the meaning of an activity from what it literally appears to be to something else (p.44). Davis (1975) calls this structural aspect of Goffman's (1974) theory 'the onion skin', as an analogy to capture the 'peeling back' of realms of experiences for individuals. Goffman suggests that *frames* can be keyed-up or down from the *primary framework*. It is a means of understanding a *framework* in terms of another, which hinges on a *primary framework* representation (pg. 79). In relation to eating-related practices then, when the dominant frame is outcome-focused and practical, this relates to a *primary framing*, whereas when interactants have more time for social interaction, this may relate to room for other *keyings* of *frameworks*, such as humour or playfulness. Typically, interactants engaging in a transformed *key* are expected to be free of pressing needs. Transforming frameworks is relevant to living with tAD as people with this diagnosis often use confabulations, to support their social interactions (see section 2.2.1). Family members and those around them may then need to transform the *key* from a *primary* 'serious' *framework*, providing a supportive transformed understanding of the interaction.

Related to this, frames can be transformed through *fabrications*. This is a deceptive construction by others whereby a person disguises one experience in terms of another. Situations can be transformed to disguise and support the impression of others, inducing a false belief about what is really going on (p. 103). One type of fabrication is *benign fabrications* which are deceptive frames which are perceived to be in the best interests of the person 'contained' within them (p. 87). For example, paternal constructions are designed to comfort children (p. 99). This is relevant where a person with dementia may confabulate and family members may have a knowledge framing beyond the person with dementia's *evidential boundary* and using Goffman's (1974) concepts they are then contained within this deceitful framing. Therefore, family members often hold the *power of beliefs* in knowing the true *frame* within these situations, withholding information from the other and that person is then contained in a *frame trap*.

Morality and trust are important in the fabrication process. This is because whoever holds the power of belief are responsible for choosing when and how to reveal or *clear* the frame. This relates to the literature described in section 2.2.3 where there is some debate around the morality of truth-telling among family members and whether to engage in reality orientation or validation therapy when their relative with dementia confabulates (Spector et al., 2000). This is powerful because the deceiver is responsible for knowledge management, in relation to the control and blocking of information, relating to Goffman’s (1974) work on secrets (Goffman, 1974, p. 177). Through fabrications layered upon *primary frameworks*, a person is thus contained in a form of social control by others, a deceptive cognitive frame, whereby the deceiver can choose to disclose the true framework at any given moment (p. 369), *clearing the frame*. In this way, Jenkins (2008) suggests “we ought to think of Goffman as a significant theorist of power” (p. 157). Through containment there is a constant facilitation and constraining of cognitive interpretation and meaning, a battle of who holds the ‘true’ account of what it is that is *really* going on. This is an important consideration in this study, particularly in relation to living with tAD, where family members may withhold and conceal information from the person with dementia to support their reality, but the person with dementia is then at the will of others, i.e. in terms of others managing their knowledge frames.

According to Goffman, two or more people may be in the know and use what Goffman terms the *concealment track* to operate in collusive communication with one another (p. 234). By using *collusive communication* such as having a discussion out of ear-shot of the person contained within a deceitful frame, people can conceal the framing from a person’s understanding. Some tact is involved in that deceivers need to engage in these subtle conversations out of ear-shot of the person contained. This is an important consideration in relation to social dining activities for people living with dementia where understanding of changes may vary across different diners. This relates to Keller’s (2010) finding that at times people with dementia can be psychologically excluded in awareness when engaging in conversations with others over mealtimes. Related to this, Goffman suggests frames can be ambiguous and there is often “a wisp of doubt concerning the correct framework to apply” (p. 379-380). Suspicion and doubt arise when people perceive that another may be viewing the same situation with a different framing to their own.

According to Goffman, when situations are fabricated such situations are particularly vulnerable to collapse since they are based on a differential distribution of knowledge, therefore disruption may occur due to discrediting or doubt in the authenticity of the frame. This relates to Goffman's notion of *negative experiences*, when individuals are unsure as to the correct framing. Schutz (1989, p. 285) describes 'shock' experiences as individuals move from one realm of understanding to another. What was real to the interactants a moment ago is now seen as a deception; their frame has collapsed and all the interacts may then come to have a "workably correct view of what's going on" (Goffman, 1974, p. 338). Goffman suggests individuals are often aware of the *evidential boundary* they are contained within and acknowledge they are psychologically excluded from these frames. This is an important consideration for people with dementia, whereby in social dining situations they may acknowledge an *evidential boundary* beyond their cognitive framework, which could leave them feeling excluded.

Goffman also discusses self-induced deception in terms of fabricating framing of a situation. He suggests "some of those who are committed to differing points of view and focus may still be willing to acknowledge that theirs is not the official or 'real' one" (p. 8). Therefore, people may choose to focus their attention upon frames which confirm their reality, or turn away from unsupportive frameworks, whilst still acknowledging this does not mean they hold a power over the correct beliefs. Goffman stresses that self-induced misalignment is likely to involve mainly perception and not action and that there are various ways an individual may actively work against their own capacity for effective framing, setting themselves against their own ability to realistically orient themselves in the world. Goffman does not discuss the purpose of this but gives examples such as 'dissociated states', 'psychotic fabrications' and so-called 'hysterical symptoms' where an individual may act as if they were mentally ill to continue to reside in a psychiatric setting. Some researchers suggest people with dementia use denial of changes as a coping mechanism particularly if they view dementia negatively (e.g. Clare, 2002). Self-induced misalignment for people with dementia could involve focusing perception on what people are able to do in relation to eating-related practices as opposed to changes in functioning as found in the study by Johansson et al. (2011) on self-reports of eating-related activities among people with dementia (see section 2.3.2.2).

4.2.7 Negative experiences

Goffman explains *negative experiences* as those in which an individual does not have a viable response for the activity, or they cannot 'bind' themselves within the frame that apparently does apply in the situation (p. 379). Therefore, *negative experiences* to Goffman takes form from what they are not, i.e. having no appropriate frame or action relevant to the frame in the situation. Goffman (1974) dedicates two chapters in Frame Analysis (p. 378-495) to describing how experiences can become vulnerable in everyday life and discusses this further throughout the book.

The first pathway is related to participation in the activity, as frames organise involvement. Participation can range from boredom at one end to being fully engrossed at the other. A collapsing *framework* disrupts the activity, leaving people disorientated, uninvolved or intensely involved with whoever caused the frame to collapse. Relating to the previous literature, family members may report being burdened (see section 2.3.2 and 2.3.3) due to over-involvement in the frame, for example with stepping in to support the person with dementia should they perform *out-of-frame acts*. This first pathway particularly relates to the human body whereby it can “fail to sustain the frame in which it finds itself” (p. 349). Goffman (1974) suggests that an individual may “capsize as an interactant” (p. 350) and fail to organise themselves in terms of their role. An individual may then escape from the event, or in Goffman’s words *flood out* (p. 350). This may be more relevant to people living with PCA as opposed to tAD in this study, where they may have more difficulty with eating conduct given perceptual and spatial impairments (Shakespeare et al., 2015). For people with PCA engrossment in the frame then may be particularly difficult affecting engagement in frame relevant actions with others.

Some researchers have suggested Goffman has a primary concern with normality in his writings, where people work hard at maintaining normal appearances (e.g. Mistzal, 2001). To be ‘normal’ Goffman suggests in his earlier work (Stigma, 1963), is a prized cultural status for those “who do not depart negatively from the particular expectations at issue” (p. 5). People living with dementia may be constrained by dining norms which may not be accommodating to changing functional capacity, thus they may be more likely to perform frame breaks in these situations. Goffman suggests people experience social embarrassment and often attempt to maintain decorum, ignoring or suppressing out of frame acts, as such behaviours disrupt both the continuity of the frame, as well as how the self is viewed in terms of the role they are carrying out. He suggests that when an individual *floods out* they make an effort to conceal what has become of them, for example, by covering their face with their hands. This relates to some of the literature with people with other diseases and conditions affecting eating conduct (see section 2.3.3), which found they experience social embarrassment and attempt to hide changes in eating ability (e.g. Klinke et al., 2014; Nyberg et al., 2016).

Goffman discusses how people are pressed into the formalities of a role (p. 269), required to carry out the conventions of a frame. He discusses how life is not an imitation of art “but ordinary conduct… is an imitation of the properties, a gesture of the exemplary forms" (p. 562). These 'normal' frameworks provide expectations and influence how deeply and fully the individual is carried into the activity organised by frames (p. 345). When individuals stray from desired framing patterns, this relates to *normal deviation* which Goffman suggests is significant in undermining the intelligibility of everything individuals thought were going on around them, because of this uncertainty when individuals do not fit in with the norm, this can relate to negative judgements from others. In this way, *self* to Goffman is a malleable, changing process, whereby the self is a negotiated entity which is presented to others through engaging in everyday behaviours such as during eating-related practices, demonstrating where and how the individual will show through (p. 299; p. 573). This relates to his notions around the *person-role formula* (see section 4.2.4). This is relevant to people with dementia, whereby changing abilities may affect the way they are able to show a positive image of the self through engaging in activities such as dining.

The second pathway Goffman (1974) discusses is related to the cognitive sense of identifying the correct framework for what is going on. This includes mis-framing at the primary framework level and suspicion and doubt arising when frames have been transformed and layered with different meanings. This pathway is summarised by Goffman in the following quote:

"it is apparent that every individual must face at various times ambiguities regarding frame and suspicion regarding the role of the individuals in a frame; furthermore, he can expect to misframe events on various occasions. Similarly, occasionally he will be a victim of a deception and delusion and discover that these fabrications of reality have occurred" (p. 444)

This may be a particularly relevant issue for people living with tAD in this study whereby memory impairments may affect the correct identification of frame, making frameworks around dining more ambiguous and increasing the likelihood for mis-framing events. Similarly, fabrications and different perspectives towards shared dining situations may relate to more misidentifying of the correct *framework*. Mis-framing relates to engaging in a wrong stream of action based upon a mis-framed premise. Goffman describes how people can also become marginalised when they are misaligned to the correct *framework* and become psychologically outside of the scene which others are spontaneously involved in (p. 489). Marginalised people according to Goffman are likely to know what is 'really' going on and appreciate it just isn't going on for them (p. 117). This relates to the Eating Together paper by Keller et al. (2010) whereby people with dementia can become psychologically excluded. Goffman suggests individuals are likely to examine the setting to pick up information to settle matters, suggesting the physical environment may become increasingly important for cueing individuals when they have doubt over their own framing of events (p. 338). Given the various meanings people can take to situations, Goffman suggests “an individual’s sense of knowing what is going on is most often threatened is one in which other individuals are immediately present” (p. 379). This is an important consideration for this study which considers the social experience of eating-related practices with other diners.

Frame disputes (p. 323) are described by Goffman where individuals disagree as to the correct *framework* which relates to a situation. Where people with dementia lack insight or confabulate, this could increase the vulnerability for *frame disputes* given family members may come to hold a different perspective towards the same situation. Regarding inter-personal frameworks, Goffman discusses the democracy of the dyads suggesting two-person worlds can be vulnerable when differential framing patterns raise suspicion and doubt in the relationship (p. 462-463). If situations are fabricated, long-term consequences could leave individuals unsure of what is happening around them. An individual could come to suspect the sincerity of another’s actions and feel that everyday ordinary events involving them are fabrications, seeking to undermine their everyday world. A coalition is required between players to provide each other with expression of the existence of a desirable bond (Sabel, 1993, p. 1133), relating to the concept of validation therapy in dementia (see section 2.2.3). According to Goffman, a person will “seek out a class of persons who are committed to a framing of events that will support him” (p. 469). This begs the question as to which environments people with dementia may perceive their cognitive frameworks are supportive.

4.3 Relevance of Goffman’s (1974) Frame Analysis

The relevance of Goffman’s (1974) Frame Analysis is most easily addressed in the following two results chapters and the discussion, as concepts which have been defined here and in the glossary (appendix 15) are used to support the interpretation of findings. As presented in the methods chapter (section 3.5.5) abductive reasoning was used for this study to identify suitable sociological theories to support understanding of the emerging concepts during data analysis and Goffman’s (1974) Frame Analysis was identified as relevant through this process. Most importantly, Goffman’s (1974) Frame Analysis supports an understanding of engagement in everyday activities such as dining through a sociological lens, i.e. as an opportunity to express the self and engage in social interaction with others.

Through his many concepts related to everyday behaviour, Goffman provides a sociological lexicon to explain various aspects of behaviour and the way individuals organise their understanding of experiences when in interaction with others. Goffman was critical of grand theories and he provides a sociological lexicon which is flexible in its application, as opposed to forcing data into pre-existing hypotheses (Verhoeven, 1993). This allows the researcher to apply his terms flexibly to understand the emerging themes, as opposed to forcing the data into some pre-existing model or theory. Secondly, Goffman's (1974) philosophical worldview of a structural social psychology (Verhoeven, 1993) compliments the lens taken by the researcher, which both acknowledges agency in how individuals define and frame their dining experiences and create meanings in interaction, as well as recognising structural aspects of dining, such as behavioural norms which are relatively uniform across individuals, such as eating with a knife and fork, allowing the researcher to understand tensions in dining experiences and how people coordinate their frames and behaviours with others in collective situations.

In terms of application of Frame Analysis in other studies on dining, it appears from the literature identified and presented in chapter 2 that his theoretical concepts have not yet been applied to understand dining experiences in dementia, therefore this study offers a original interpretation in this area. Goffman's (1974) lens appears to promote an understanding of eating-related practices as dining opportunities, in terms of ordinary conduct carrying social meaning and concepts which relate to social interaction and the self. There is also little literature identified which used Goffman's (1974) Frame Analysis in detail to provide an understanding of illness experiences of living with dementia, therefore this study also makes a broader contribution to social theory and the field of dementia research.

Some studies have used Goffman's (1974) concept of *frames* to describe the context-laden meanings people living with dementia and memory problems use to *frame* their experiences (e.g.; Beard & Neary, 2013; Harnett, 2014; Marson & Powell, 2014; Håkansson, 2014 & Harnett & Jönson, 2017). For example, the study by Håkansson (2014) used Goffman's (1974) concept of *framing*, exploring how professionals *framed* using an iPad with people with dementia, identifying various frames such as a play-frame, work-frame or medical-frame. The study by Beard and Neary (2013) also applied Goffman's (1974) concept of *frames* (1974) and his earlier work around Stigma (1963) and described how people with mild cognitive impairment employed strategies to attempt to fit into 'normal' and minimise social disenfranchisement associated with *frameworks* around 'dementia'. However, none of these studies used Goffman's (1974) Frame Analysis beyond the concept of the *frame*, nor do they discuss particular *frameworks* which Goffman alludes to in his book such as *social* and *natural frameworks*, *frame anchoring*, mis-framing and misunderstandings. These studies using Goffman's *frame* concept also took a symbolic interactionist perspective to explore the abstract meaning-frames people applied to their experiences, as opposed to considering the structural aspect of Goffman’s (1974) work, considering the way *frameworks* guided behaviours and coordination of actions.

Goffman’s (1974) 586-page book, has more concepts and analytical descriptions beyond the *frame* which may be usefully applied to understanding illness experiences in dementia. For example, through his notions related to *transforming frameworks*, Goffman shows how framing *“*does not so much introduce restrictions on what can be meaningful as it does open up variability” (p. 238). This can open-up an understanding of how family members and people with dementia may apply different frameworks to the same situations, which guide their various responses, as well as strategies related to *transforming frames* such as *collusion, benign fabrications* and *frame traps*, helping to interpret the complex processes through which individuals manage their dining interactions. The syntactical element to Goffman’s (1974) concept of transforming ‘frames’ provides an opportunity to describe the different layers of experiences individuals bring to their everyday social encounters.

Only one study was identified by the researcher which applied transformational frames to understand living with dementia. The study by Bohling (1991) was introduced in the literature review in relation to experiences of conversations when living with dementia (section 2.2.3). Bohling (1991) used three of Goffman’s (1974) concepts- *frames*, transformational cues and *brackets* to describe the different ways family members responded to people with dementia in conversation. This study involved analysis of 26 episodes of conversation between 8 family members and 10 people with dementia in an adult day centre. Using Goffman’s (1974) concepts, Bohling described how people with dementia could change the topic or meaning of conversations where this may not meet typical conventions for conversations and family members could either establish effective communication by joining the person with dementia’s frame of reference or fail to pick up on their *framework*, relating to people with dementia becoming frustrated. Bohling found family members used *benign fabrications*, supporting the person with dementia’s *framed* ‘reality’, rather than exposing frame differences. The study by Bohling (1991) highlights the different realities people with dementia and family members could interact with. Goffman holds the perspective “the view that one person has of what is going on is likely to be quite different from that of another” (p. 8). These understandings may be particularly relevant to people living with tAD where frames of reference between people with dementia and family members may differ, as suggested in the study by Bohling. Goffman’s (1974) approach legitimises different framed realities and provides a language for understanding how different realities come into interaction and how they can be coordinated.

One may hesitate in thinking how applicable Goffman's (1974) concepts around cognitive *frames* is to people with dementia where cognition is impaired. However, it was found for this study that his concepts helped to explain much of the analysis, in terms of the difficulties people living with tAD and PCA faced in their dining interactions, as well as helping illuminate processes to maintain meaning within these experiences. In this study, it was identified that people with dementia still applied cognitive frameworks within their everyday lives, after all, frameworks permit one to act and people with dementia have agency and engage in purposeful actions, particularly in the early stages of their diagnosis (Roach & Drummond, 2014). Furthermore, Goffman highlights two pathways towards vulnerable daily experiences which are chiefly relevant to the two dementias in this study. Firstly, the pathway related to the body and physical performance, particularly related to living with PCA and secondly, meaning-frames and mis-framing events, particularly relevant to living with tAD. Goffman's (1974) concepts then provided a common language with which to describe changes in dining experiences and processes to support maintaining meaning across the two dementias.

4.4 Summary of chapter four

In this chapter, Goffman's (1974) Frame Analysis has been outlined and contextualised in relation to his previous works. His main concepts are explained including *primary frameworks*, *frame breaks, natural* and *social frameworks, frame anchoring* and *bracketing*. Secondly, this chapter outlines how *frames* can be *transformed* and layered with different meanings through various *keyings* and *fabrications*, demonstrating the complexity of experiences in interaction. Finally, *negative experiences* in Goffman's (1974) terms are described in relation to *normal deviation* and *breaking the frame*; particularly relevant to PCA and the physical performance of eating-related practices and mis-framing; particularly relevant to tAD and cognitive knowledge related to mealtime situations. Overall, this theory supported the research questions for this study in terms of understanding experiences and interactions in relation to dining when living with tAD and PCA, as well as strategies to support dining experiences (see section 2.4). It supported the focus upon eating-related practices as social interactions and self-expression . Overall, the relevance of Goffman's (1974) Frame Analysis has been outlined in this chapter and is further demonstrated through application in the following two results chapters and the final discussion chapter.

Chapter 5: Interviews on Dining Experiences

5.1 Overview of findings

This chapter begins by presenting the demographics and background of people who took part in the interviews. Following this, the chapter deals with the first research question (see section 2.4) in terms of how people in this study perceived their dining experiences, firstly for people living with dementia overall and secondly how they were perceived in different ways for people living with PCA and tAD. The findings show how some individuals appeared to continue to find meaning in mealtimes as a dining opportunity when living with dementia-related changes, whereas for others, these understandings could breakdown, relating to tensions in dining interactions and this becoming more a management task as opposed to an opportunity for enjoyment. Where dining experiences became vulnerable when living with PCA and tAD, the pathway towards this appeared to differ in relation to the presenting symptoms. The way dining experiences became vulnerable is explained using Goffman’s (1974) Frame Analysis concepts.

The second section (5.4) of this chapter deals with the second research question in terms of how people supported changes or disruptions to their dining experiences to maintain meaning in these experiences. A number of psychosocial processes for coping with these disruptions were identified across the sample to support successful dining interactions, which were broadly similar across people living with PCA and tAD. This suggests that whilst the pathway towards disruptions to dining experiences can differ across different dementias, similar psychosocial processes can be used to support maintaining meaning in dining, regardless of the presenting symptoms. Five key themes of processes to maintain meaning in dining were identified in the interviews including management strategies, revising frames, co-creating dining experiences, external dining contexts and optimising opportunities for continuity. The way these different processes were used by people living with both PCA and tAD is addressed. Each process also appeared to be limited in its usefulness and these parameters are outlined in each section. Although the processes are presented separately for presentation purposes, each process interacted and overlapped with one another, relating to a dynamic and interrelated ‘coping system’. The way these different processes worked together to maintain meaning in dining experiences is presented in the final section.

Goffman’s (1974) Frame Analysis has been used to conceptualise how people experienced and maintained meaning in their dining experiences. Where concepts from Goffman’s (1974)

Frame Analysis have been used, the reader can turn to the glossary in appendix 15 for a reminder of the definition of these terms. Where quotations are used in this chapter, the Atlas.ti 5.0 code is provided at the start (pertaining to the document number and quotation number) and a reference to the type of dementia and type of interview which the quote refers to is provided at the end of each quotation.

5.2 Demographics

A total of 20 family dyads (9 tAD and 11 PCA) took part in this study. The demographics table below (table 2) details pseudonyms for the person with dementia and their family member as used in this write up for the interviews and video-based observations. Age of the person with the diagnosis, type and year of diagnosis and subjective year of diagnosis are included in the table. This information was made available to the researcher from the database of demographic information which was collected by other researchers for the Seeing What They See project. Age and year of diagnosis data was missing for Dawn from this database and they were uncontactable to gather this information. All relations were spousal, expect for Dawn and Alesha who were a mother-daughter dyad. All dyads lived together. The sample included people aged 53-80yrs, with an average age of 67yrs for both people with tAD and PCA. The subjective year of diagnosis (i.e, when the family dyads first noticed symptoms) has also been included in the table as for some participants it took many years until they received a formal diagnosis, particularly for people with PCA, which is common for this type of rarer dementia (Crutch et al., 2017). Severity of the dementia symptoms varied across people who took part in this study, however all the participants could manage eating independently and they also had adequate verbal fluency which supported their ability to take part and give informed consent for taking part in the interviews. Formal diagnosis date ranged from 0-7 years.

Table 2: Information about the sample

PwD (gender)	**FM (gender)**	**Age (yrs) of PwD**	**Diagnosis type**	**Years from diagnosis to interview**	**Year of formal diagnosis**	**Subjective year of onset**
Betty (f)	Elliot (m)	80	PCA	4	2010	2010
Susan (f)	Terry (m)	70	PCA	2	2012	2000
John (m)	Annabelle (f)	58	PCA	4	2010	2007
Alastair (m)	Tanya (f)	64	tAD	4	2010	2007
Burt (m)	Denise (f)	53	tAD	3	2012	2011
Amanda (f)	Mark (m)	58	PCA	4	2011	2010
Bob (m)	Sarah (f)	60	PCA	4	2011	2008
Bessie (f)	Gordon (m)	67	tAD	4	2011	2009

Louise (f)	Richard (m)	67	PCA	4	2011	2009
Jeffrey (m)	Sian (f)	72	tAD	6	2009	2005
Henry (m)	Juliette (f)	71	tAD	7	2008	2005
Fearne (f)	Harry (m)	68	PCA	3	2012	2008
Camilla (f)	Jack (m)	71	PCA	3	2012	2009
Celia (f)	Joseph (m)	76	tAD	1	2014	2011
Trudy (f)	Edward (m)	59	PCA	4	2011	2010
Dawn (f)	Alesha (f)	-	tAD	-	-	-
Claire (f)	Michael (m)	71	tAD	6	2009	2008
Peter (m)	Shirley (f)	77	PCA	1	2014	2011
Charles (m)	Peggy (f)	63	tAD	2	2013	2010
Bob (m)	Joyce (f)	71	PCA	0	2015	2014

PwD= person with diagnosis, FM= family member of person with diagnosis, m= male, f= female, - = data missing

An important consideration in relation to the sample is that although the researcher recruited people with a diagnosis of PCA and tAD as confirmed by the Specialist Cognitive Disorders clinic at the Dementia Research Centre, their symptoms varied somewhat. For example, some people with PCA had impaired cognitive awareness and some people with tAD also reported perceptual difficulties. To provide an example in this study, Charles who had a diagnosis of tAD appeared to have intact evaluative judgements whereas he had some spatial awareness difficulties and his wife, Peggy felt he was more likely to have PCA although he had not been given this diagnosis. Therefore, although the diagnostic label provided more specific understandings of experiences this label still offers a fairly arbitrary comparison, given people can still differ in the types of symptoms they experience under these diagnoses.

5.3 Dining experiences when living with dementia

5.3.1 Experiences when living with dementia-related changes

This section presents how dementia-related changes could come to affect dining experiences, whether living with tAD or PCA. Overall, dementia-related changes appeared to impact upon the ability to carry out roles such as cooking and eating, to social conversations and dining out experiences. Many dementia-related changes were not reflected upon as threatening to dining experiences and thus were presented as neutral or even positive changes in relation to experiences. It is important to emphasise the individuality of the frame expectations people had for what were appropriate or ideal dining behaviours across participants in this study. Different people in this study were found to view the same behaviours as acceptable or non-acceptable; shaped by their individual frames. This meant that some interviews were shorter than others and to the point, whereby dementia-related changes were not perceived to disrupt people's frame assembly of meaning for how they felt 'dining' should be. For example, Sarah and Bob and Celia and Joseph, discussed dining together as a relatively normal aspect of the day. In most of the interviews, this varied whereby some changes in behaviour were not perceived as disruptive to dining experiences, whereas others were. To provide an example of a dementia-related change being experienced positively in relation to dining frames, Denise appraises changes to Burt's eating habits in the following way:

6:65: "Denise: now it's just kippers. The whole week just kippers. It was quite…well its good because it's good for him." [Individual interview, family member tAD]

For Denise, this change did not appear to be distressing or negatively impact the meanings-made around dining situations. Denise appears to have the framing that people 'should' be healthy at mealtimes and therefore this change in Burt's food preferences was not seen to disrupt these understandings. Other people viewed narrowing food preferences as disrupting their expectations and this could disrupt their experiences of how dining 'should' be. Another example of this can be seen in the following interview with Trudy and Edward, whereby they share in the framing that although Edward has taken over the cooking roles this was not a problem for their overall dining experiences:

54:26 "Trudy: yeah I couldn't slice, I couldn't chop, I'd chop off my hands [laughs]… but we didn't worry about that and Edward didn't worry about doing the cooking cos he'd already taken his erm, his…
Edward: I was retired
Trudy: he was retired which was so weird everything sort of came into place" [dyad interview, PCA]

Trudy provides a humour framing to show her acceptance of the changes in her cooking ability. Both Trudy and Edward then share in the framework that they 'didn't worry' about Edward taking over cooking at the time, as it filtered into their life context, when Edward was retired and thus he had time for this new role. Across the sample, often where symptoms were mild or the changes filtered into life situations without upsetting the individual meanings they had for 'dining', these changes did not require coping with or disrupt their understandings of dining and were thus presented in this matter-of-fact way.

However, at other times, almost all the people in this study presented at least a few changes which threatened the frameworks they had for dining, either in terms of shared frames or individual frames. This relates to Goffman's (1974) concept of *negative experiences* whereby he suggests when people are unable to produce a viable response for an activity or cannot bind themselves within the frame that apparently does apply, they have a negative reaction. For people in this study, negative reactions in relation to not meeting expectations of the dining frames people had included feelings of low self-esteem, loss of identity or relationship with the other person, tensions within the dyad, guilt, helplessness, frustration and social embarrassment. To provide an example from the interview with Betty and Elliot, Betty discusses a negative experience in terms of losing the cooking role she previously had, due to her PCA symptoms:

45:10 "Betty: I was an enormously good cook and this hurts me, you know I can't do that anymore" [dyad interview, PCA]

Betty appears to have the framing around her self-concept that she is a person who can cook. Therefore, unlike Trudy in the previous example, Betty is "hurt" that she cannot meet these expectations through her actions within dining situations. Other changes, such as struggling to eat the food was not presented as threatening by Betty in her interview, but for other people, for example, Bob who had PCA, these changes threatened his understanding of how 'dining' should be, as he had a strong framing that one should be independent in eating the meal. For others, losing the cooking role was not presented as a problem if this was not a strong role that they defined their self-concept around. Goffman's (1974) Frame Analysis supports understanding of this, whereby individuals have built up expectant *frames* for dining based on a lifetime of encounters with everyday dining situations. In this way, self is a process built out of encounters. Betty had a particularly strong framing that she was a cook and when she found she could not meet the frame expectations for meal preparation, this threatened these meanings for her. As can be seen in the following example from this interview, as well as experiencing loss, Betty also appeared to experience a threat to her social self in relation to loss of her cooking roles:

45:38 "Betty: No one, no one… like, Gary, who's going to cook our Christmas dinner for us at their house and he said 'oh granny, when we came home from school and opened the doorand this smell from all these nice things you've been cooking'… I think he's the only one in that family who ever came to me and said 'you used to cook so well' [laughs]" [dyad interview, PCA]

This relates to Goffman's (1974) notion of the person-role formula (see section 4.2.4) as an anchoring device to one's sense of reality. Betty's symptoms appear to threaten her ability to socially present herself in terms of the enduring role she perceives herself to have, relating to a tension in framing and loss in terms of understanding who she was. This relates to Goffman's (1974) idea that the self is shown through engaging in roles and Betty appears to see that this opportunity is lost, which impacted the way she felt others viewed her. This also relates to Goffman's (1974) early work on Presentation of the Self (1958), whereby people can be seen as actors on a 'social stage', creating an impression of themselves for the benefit of an audience, with the audience being Betty's family. Across participants in this study, collective, macro-social frames, around gender-role ideologies as to who should hold the cooking roles, appeared to relate to more women seeing changes to their cooking roles as threatening the dining frame. For example, women including Claire, Dawn, Fearne, Susan and Bessie had some negative reactions to changes in their cooking ability, threatening their sense of self. However, the degree to which this was a problem varied across individuals and did not appear to simply relate to gender-role ideologies or if people held these roles in the past. For example, Trudy had a strong-cooking role identity but did not appear to view changes in her cooking roles as threatening towards her sense of who she was as in the example towards the beginning of this section. This relates to the idea of frames as 'defining contexts' (Scheff, Phillips & Kincaid, 2006) whereby individuals bring an assembly of frameworks to understand their everyday situations and gender-roles may be just one individual context which interacted with many other individual frames of meaning.

As well as gender, many other individual contexts appeared to influence the way changes were appraised, such as age and relationship type. For two of the oldest couples in this study, Betty and Elliot and Celia and Joseph, many dementia-related changes were reflected upon as less disruptive to social dining situations, as Joseph said "we're all slowing up". Another example, was in terms of relationship type whereby Dawn and Alesha had a mother-daughter relationship, as opposed to the rest of the sample which included spousal relations. This appeared to impact some changes being perceived as more threatening, compared with spousal transitions. This can be seen in the following example from Alesha where she discusses her new cooking role:

2:35 "Alesha: I think it being food, it's kind of more central to like the roles of a mother and the roles of a child, so not to say ok I'm older now you know I'm not like, I'm in my 20s but the mother that's part of a nurturing role for the mother to cook the food" [dyad interview, tAD]

Alesha appears to view the changes as threatening to her self-concept as 'daughter', although she also attempts to revise her understandings of her role as daughter, i.e. whereby she is "older now". Dawn appears to encourage Alesha in the dyad interview and support her to revise her frames in the interview, for example, normalising their situation by saying "it's up to the individual homes”. These strategies are outlined in sections 5.3.2 and 5.3.3. Alesha also reported that Dawn was often unaccepting of meals prepared by Alesha and instead would snack on plain bread and hot chocolate as food items she was able to provide for herself. Both Alesha and Dawn may have had more difficulty reshaping their roles, given it related to a reversal of mother-daughter anchored expectations, relating to tensions when transitioning to new roles, threatening the sense of reality around who they both were in relation to one another. Spousal relations may then be less threatening, whereby roles are typically more balanced prior to dementia-related changes. However, again this was not a hard-and-fast rule, as many of the spousal couples also found transitions in roles difficult.

Also, changes were more likely to be perceived as disruptive to people’s expectations for dining when they were viewed in a social framework as opposed to a natural framework. This appeared slightly more likely among people living with tAD than PCA. For example, people with tAD sometimes appeared not to think of a dementia-based explanation for behaviours and may thus become more defensive when changes were presented. This relates to Goffman’s (1974) notion that when changes are perceived in a socially intended framing they then render more judgement as intended actions. How people with tAD were able to manage such social framings of changes is further discussed in section 5.4.2. Family members also sometimes viewed changes in a social frame, subjecting the person with dementia to more standards of appraisal. This can be seen in the following example from Gordon:

9:7 “Gordon: Bessie’s got it in her mind now that I am the waiter, or I’m the person to wait on her and that annoys me a lot of the time because we’ll go round my daughters and soon as she walks in and goes ‘anything I can do for you’ and it really bugs me to think she’ll go round there and give her hand but it seems like round here I’m the only one doing anything” [individual interview, tAD family member]

This example shows how Gordon views Bessie’s actions in a socially guided framework, suggesting motive and intent are involved and Gordon becomes frustrated with Bessie for ‘choosing’ not to help with meal preparation at home. He appears to resent Bessie for her lack of involvement in the meal preparation and perceive his new role as a burden. However, it may be that Bessie does not have these frames for supporting Gordon in their home environment, due to the symptoms of her diagnosis and these changes may be more appropriately viewing in an unguided, natural framing. However, given the lack of consistency in Bessie’s behaviour, Gordon views the changes in a social framework. Indeed, as Goffman (1974) suggests when people cannot see the changes which are related to behaviours (e.g. in mental health) it is easy to interpret them incorrectly in a social framework. This example also shows how taking on new roles can be a burden for family members, related to over-engrossment in meal preparation.

Related to this ambiguity in interpreting changes in either a natural framework or social framework, dining out was reported as particularly challenging by some people living with dementia, related to the idea that an ‘audience’ (Goffman, 1959) of diners in a restaurant do not have the frames of a natural, dementia framing to interpret changes in. This can be seen in the following example from Juliette:

14:22 “Juliette: People might look at him and think oh why’s she lauding over him, you know what people are like but as I say because there’s no recognisable symptoms, you know he doesn’t have a badge saying ‘I have dementia’… so it does become more difficult eating out it’s not something I think ‘oh let’s go and eat out…’, it’s something where I think oh well, let’s not bother, you know” [individual interview, tAD family member]

This example suggests Juliette was worried about the impression both her and her husband were giving off in their management of difficulties when socially dining out. Without others having a natural, dementia framing, people were perceived to be more judgemental and as found with others in this study, people living with dementia could see themselves as being unable to meet the frame standards which governed dining out situations. This suggests dining out could be a kind of ‘on-stage’ performance (Goffman, 1959). However, other people described dining out as a resource for sustaining eating-related practices as a dining experience, exemplifying the subjectivity in framing and how people brought different frame assemblies to their dining experiences (Scheff, Phillips & Kincaid, 2006).

The following two sections outline how the different symptoms of living with amnestic-led tAD and visual-variant PCA, could disrupt the nature of dining experiences for people living with these diagnoses. As discussed in section 5.2 the distinction between the two diagnoses was not always so clear-cut, for example, some people with PCA experienced some amnestic type difficulties (such as short-term memory difficulties or fluctuations in insight) and some people with tAD experienced some perceptual or spatial awareness changes which were more in-keeping with a PCA diagnosis. Therefore, the following sections, are broadly speaking in terms of the main changes which distinguished between dining experiences when living with these two dementias.

5.3.2 Experiences when living with tAD

Overall, people living with tAD appeared to have difficulties identifying the relevant cognitive framework for defining what was going on, which could affect their dining experiences and interactions. In the words of one person with tAD, Burt, he described this in terms of not being able to “picture things up”. These difficulties related to some negative dining experiences in terms of marginalisation, misunderstandings and lack of engrossment within shared dining frames. For example, Charles discusses this in relation to social dining occasions:

20:20 “Charles: There’s times where I genuinely would not be able to work out what was going on and then you think mmm, everything goes that way that way and then you’re sort of moping round the room thinking who should I talk to you know” [individual interview, tAD person with dementia]

In the above example, Charles discusses his difficulty in social situations where he just cannot “work out” what is going on i.e. he does not know the correct frame that applies to be able to engross himself in the social dining experience. He uses the term “moping around the room” to show the aimless manner in which he presents in this situation when he does not have the correct cognitive frames to engross himself in the situation. However, Charles is aware there is a social framing that exists beyond his evidential boundary suggesting he perceives himself as socially excluded from this. In the interviews, Charles and Peggy discussed how Charles chooses to eat out less than he did before dementia. This flooding out response may relate to Charles’ own fears around being unable to identify and therefore meet framing conventions which govern these social dining occasions. This may also relate to Goffman’s (1974) notions that the anchoring of frames is especially loose when individuals are framing informal interpersonal experiences (see section 4.2.5). This informal interpersonal dining scenario appears to leave Charles unsure of what to do as the framing conventions are unclear (e.g. Branaman, 1997) perhaps more so than engaging in the eating aspect. Some family members of people with tAD also gave examples of people with tAD appearing as if they were unsure of how to act within certain dining situations, or ‘not knowing what to do with themselves’ (Tanya), such as when family members were engrossed in preparing the meal. This suggests people with tAD experience difficulties in identifying relevant frames for dining and this lack of frame understanding relates to a lack of engrossment within dining situations.

As well as difficulties identifying the correct framework in dining interactions, some people with tAD also appeared to mis-frame situations and enter into a wrong stream of behaviour based on a mis-framed premise. An example of this change with meal preparation can be seen in the following example from Denise, Burt’s wife:

4:7 "Denise: You might be able to do a bowl of soup or something might you, but we have to be careful because sometimes the soup gets opened, so Burt might be able to open the soup but then he'll put the whole tin in the microwave" [dyad interview, tAD]

This type of difficulty was reported in many of the interviews by family members of people with tAD, as well as observed in the video-based scenarios with people living with tAD, as presented in the following chapter. This relates to Goffman's (1974) concepts around primary frameworks being guided by previous knowledge of the 'rules' which govern a situation. The success of one's actions are informed by gearing a correct framing into the situation, which Burt and many others (particularly with tAD) appeared to have difficulty with at times. The above example shows how Denise appeared to present this change as a neutral experience, something which is not particularly problematic towards their dining interactions. This may be because Denise had revised her frames (see section 5.4.2) and has adopted this as a new normal, or may be because these changes did not cause tensions in her frames for 'dining' in the first place. In contrast, the following example from Michael, shows how this type of change could be detrimental to meaning-making around dining, affecting his experience:

18:17 "Michael: She can't even make a cup of tea… for a start off she was out here forever, forever and then she came back after god knows how long, with two cups, with warm water that she'd obviously got out the tap and milk in, that was the cup of tea… she has no idea" [individual interview, tAD family member]

Michael appears to see Claire's actions as completely unintended, almost as if she is acting unconsciously, stating she has "no idea". This relates to Goffman's (1974) concept of the person-role formula (see section 4.2.4) whereby Michael appears to be using the role Claire has to judge her person. Given Claire does not meet Michael's framing conventions of making a cup of tea, this relates to his interpretation that "she has no idea". However, this behaviour may have been a management strategy by Claire, whereby she was engaging in an action which perhaps confirmed her frame reality (see section 5.4.1). However, Michael views these behaviours as discordant with his primary framework of how to make a cup of tea, therefore this act related to a deconstruction of meaning and a negative experience for him. In this study, it was found that often family members viewed such changes in behaviour among people with tAD as lacking meaning in this way. This example also suggests that the dining experience is interdependent and dynamic, whereby each dining participant can affect one another's experiences. It suggests what might be a management strategy to anchor one person to their sense of reality, could work to detach another person from theirs.

Difficulty identifying shared frames of meaning in conversation was also widely reported among those living with tAD, as opposed to among people living with PCA in this study. Family members of people with tAD including Sian, Tanya and Michael reported that conversations had become more difficult as they often struggled to identify a relevant, shared framework. This can be seen in the following example from Sian:

24:22 "Sian: we chat less cos actually sometimes I just, it's too complicated to talk sometimes, cos always when I just say anything it's 'what did you say?', if I pause, he then answers but it's a kind of reflex and I sometimes find it very trying, so I just switch off and watch the news" [individual interview, family member tAD]

Sian suggests her conversations with Jeffrey have been complex and thus they talk less when dining together. She discusses her own frustration when Jeffrey says, "what did you say?" repeatedly in conversation and how she then retreats from this and "switches off". Similarly, many other family members of people with tAD reported difficulties in conversations when dining together, in terms of anchoring behaviour to shared frames for interaction.

Across the family dyads living with tAD, it appeared more often that family members reported changes and frustrations, as opposed to people with tAD who often reported little changes to their dining experiences. For example, Jeffrey perceived that conversations with Sian were the same as they had always been. The following example from Jeffrey and Sian around food preparation shows how these differential understandings caused social tension in coordinating behaviour:

24:31 "Sian: No I mean I let him but he gets in the way… he makes the squash and he kind of opens every cupboard to try and find, what are you looking for and he doesn't know what he's looking for cos he's got the glasses there and he's got the orange there but he's opening cupboards looking for he doesn't know what… I let him so called lay the table, he might put a mat on and he might put a couple of forks on and knifes on but then I do the rest of it, I just do it, occasionally I'll ask him to grate a carrot, erm, wash the tomatoes" [individual interview, family member tAD]

Goffman (1974) suggests one's cognitive impingement on the world informs the cognitive response to it and Jeffrey's framing that he can prepare meals appears to guide his motivation to be involved in it. Engaging in meal preparation tasks may have supported Jeffrey to anchor himself to his sense of reality. However, given Sian framed Jeffrey was unable to cook, these same behaviours were seen by her as "getting in the way". This shows how frame realities could differ among people with dementia and family members. Sian appears to use *benign fabrications*, letting Jeffrey “so called” carry out tasks which may have supported and honoured his reality. However, this related to Sian viewing these behaviours in a different keying, i.e. as carrying little ‘serious’ meaning in terms of a primary framework and relied on her seeing value in this for Jeffrey’s wellbeing. However, this appeared to conflict with Sian’s primary, outcome-focused framing of making the meal, which related to her becoming frustrated with Jeffrey “getting in the way”. Struggling to find shared meanings meant that people with tAD and family members could work at cross-purposes, relating to a tension in the interactions between them. Therefore, although people living with tAD in the study were spending more time together than they had in previous years, this was not always supportive for their sense of togetherness and their relationship.

The varied understanding around changes among dyads living with tAD in this study also related to more misunderstandings and frame disputes in the dyad interviews. Family members often appeared to use benign fabrications and view the person with dementia’s behaviour in a transformed frame. Goffman (1974) suggests this makes interactions particularly vulnerable to collapse in meaning. To provide an example, see the following *frame dispute* between Henry and Juliette:

13:71 “Henry: I do a bit of washing up occasionally don’t I
Juliette: mm you don’t have to, we have a dishwasher
Henry: I can’t even score points on that, I know where the dishwasher is…
RW: any other changes do you think around mealtimes?
Juliette: hmm not that spring to mind, erm,
Henry: well I mean we’ve got this park immediately behind us here and I use it every day with the dog, erm, or I might go further afield somewhere else
Juliette: we’re talking about mealtimes Henry
Henry: oh yeah, ok, but it’s not only mealtimes is it, I mean if I go for a walk somewhere…
Juliette: no but that’s what we’re talking about
Henry: ok sorry…” [dyad interview, tAD]

In the example, Henry appears to be caught in a kind of frame trap, whereby Juliette as the fabricator of Henry’s reality has a sort of power of beliefs and Henry is thus contained within her frames (see section 4.2.6). For example, when he talks about washing up, Juliette suggests this action is not particularly useful, demonstrating how she has transformed her own understanding of this behaviour, whereas Henry has applied a serious primary framework to these same actions. He then changes the conversation to dog walking as a separate role where he perhaps feels he can express his sense of purpose through this role. However, Juliette undermines this to bring him back to mealtimes as the relevant frame for the conversation. Many people with tAD appeared to experience this difficulty of being undermined by others, relating to some people with tAD retreating from conversations, for example echoing other people's speech, as opposed to inserting their own frameworks into the interaction. This was both observed in the interviews and video-based observations presented in the next chapter. A key difficulty for people with tAD then appeared to be other people, whereby a person with tAD's cognitive sense of the frame was more threatened when engaging in shared, social interaction with others.

Overall, it appeared living with tAD particularly related to difficulties at the dyad level in identifying shared frames to anchor and coordinate behaviours to within dining situations. Section 5.3 addresses how people living with tAD (and PCA) who took part in this study could maintain and support maintaining-meaning within their dining interactions. The following section outlines changes to dining experiences among people living with PCA, again using Goffman's (1974) Frame Analysis to provide a conceptual understanding of their experiences.

5.3.3 Experiences when living with PCA

Overall, negative experiences for people with PCA appeared to be related to the engrossment pathway which Goffman (1974) describes, in relation to the physical body failing "to sustain the frame in which it finds itself" (p. 349). Negative experiences were particularly related to eating conduct difficulties for people with PCA, including more reports of social embarrassment, frustration and useless, at "failing mealtimes as a performance" (Nyberg et al., 2016). Meeting the expectations of the frame through the correct bodily actions appeared to be less of a difficulty for people with tAD, compared to those with PCA in this study. However, people with PCA were more likely to identify the relevant frames within dining situations, relating to less misunderstandings and frame disputes as highlighted in the previous section for people living with tAD. As one person with PCA (Camilla) stated "even if I can't do it, I know what *it* is" when comparing herself to a neighbour who has tAD and was diagnosed at a similar time to herself. In other words, people with PCA knew what style they wished to carry out their roles in and the framing conventions which informed these behaviours (e.g. Goffman, p. 270), but they had difficulty carrying out this image. Overall, there appeared to be more mutual awareness of changes among dyads living with PCA, however symptoms affected the physical performance aspect for people with PCA relating to frame breaks which threatened the dining experience for people living with this diagnosis.

Feeling useless was a key problem reported by people with PCA in this study. People with tAD also struggled to maintain the perspective of being useful, however this was less pronounced than for those with PCA. This may be because people with tAD often compensated by doing other purposeful tasks such as taking the dog for a walk or doing the dishes. However, people with PCA were more restricted in what they were able to do, meaning many people with this diagnosis reported felt helpless and useless given a lack of engrossment in roles. One person with PCA, Louise, described herself as “the dibdob of the crowd” (Seeing What They See interview) in relation to her friends and a family member, Annabelle used the word “spare part” (dyad Seeing What They See interview) to exemplify this idea of her husband, John being out of the main framing of everyday activities. According to Goffman, knowing the framework relates to an understanding of how much a person is carried into it as a participant. Given people with PCA could often ‘think to do it, but could not’, this may have related to more reported experiences of uselessness or social exclusion from the frames than for people with a diagnosis of tAD.

Some people with PCA such as Fearne, Trudy and Louise, reported experiences of a type of battle with the physical aspect of the meal because of dementia-related changes. This difficulty can be seen in the following example from Louise:

46:20 “Louise: Actual getting it together is the worse bit, by the time I’ve picked up that bit and put it down I’m not seeing the second bit so it can be frustrating… I’ve got to get the filling, I’ve got to get the bread, I’ve got to get the sandwiches into the toaster and then I’ve got to find myself a drink, that’s all…” [individual interview, person with dementia PCA]

It appears Louise is aware of the frames she wishes to anchor her behaviour to, but she is blocked by her perceptual and spatial awareness symptoms, making the process frustrating and effortful for her as she attempts to coordinate her behaviour to meet this framework. These types of difficulties could affect the dining experience for the person with PCA, as well as affecting social interactions at the dyad level. For example, many people with PCA appeared concerned about their symptoms entering the main frame of social dining encounters, fearful of embarrassing themselves or others around them. This can be seen in the following example from Fearne:

49:2 “Fearne: I find it hard work, social, you know, it’s something to, be wary of if you know what I mean, you don’t relax, it’s not that I don’t like the food, it’s just, you are not relaxing because you’re watching things all the time and I think that’s one of the things about PCA, is you can’t, you’re aware, you can’t just relax and just do things automatically, you think about *things all the time the effect of doing everything." [individual interview, person with dementia PCA]*

Goffman suggests embarrassment and becoming self-conscious is due to participants sensing what sort of conduct ought to be maintained as the appropriate thing and failing to meet these normative expectations. This may have related to Fearne's reports of struggling to 'relax' during dining interactions. Similarly, other people with PCA in this study reported struggling to 'relax' during dining interactions, as they were attempting to control the extent of their symptoms entering dining interactions. This relates to the concept that people attempt to maintain decorum by suppressing their out-of-frame acts (Goffman, 1974). Goffman sees these acts as both disrupting the continuity of the frame, as well as how the self is viewed.

These social difficulties also appeared to impact family member's experiences of dining, whereby they often attempted to support frame continuity and attempted to keep PCA symptoms from breaking the social dining frame. One family member, Mark, described this in the interview as being like a "defender in football' whereby he was attentive to 'defending' Amanda's eating conduct difficulties from entering their dining interaction. This relates to Goffman's (1974) idea that a collapsing framework can leave people more intensely involved with whatever caused the frame to collapse. For family members then, their own experiences could be affected when PCA symptoms threatened the dining framework and they may become more engrossed in preventing this. As with family members of people with tAD, over-engrossment in the frame also related to burden and stress for some family members of people with PCA.

Some people living with PCA reported becoming focused upon the physical aspects of managing the meal, relating to a lack of attentiveness to dining as a potential social experience. To provide an example, Anabelle discusses eating as a structured task, "geared up" in a certain way to manage John's eating conduct difficulties. Annabelle's framework is dominated by the practical aspects of supporting the meal as a management task as opposed to around social meanings. In a dyad exchange with Annabelle and John it appears John attempts to frame eating-related practices around a social framework, however, this framing is not the focus of attention for Annabelle:

30:27 "RW: is it an enjoyable time of day?
John: I think it is but I think it's rather like a erm, erm, erm, best to, erm, it's better to have erm the meal, a meal out, that's ideal, I think but of course that doesn't apply

Annabelle: well a meal out is more stressful because, is it going to be the right, are we going to find the right sort of thing for you
John: ahh
Annabelle: you know, will we remember to ask for the right things, noand then it will come and I've forgot to ask to cut it up and then I have to cut it up so it's more stressful, so it's probably better that it's here" [dyad interview PCA]

John discusses enjoying eating out which was reiterated in his individual interview where he discussed enjoying eating out for his birthday with his family. Annabelle, however, focuses upon the practical aspects which appears to alienate John's social frames, suggesting eating out is more stressful due to the symptoms of PCA. Eating-related practices appeared to lack an enjoyable social meaning for Annabelle, therefore eating out was 'stressful' as opposed to a social dining opportunity. This relates to Goffman's (1974) notions of unconnectedness whereby people do not consider aspects of a situation which are not relevant to the ongoing frame. For Annabelle, she appears to anchor her frames around eating-related practices as care, relating to a shutting out of frames related to a social dining activity and shutting in frames around managing PCA symptoms. This relates to Annabelle's report in the wider Seeing What They See interview that she perceived herself as more of a carer than a wife now. However, another explanation for this could be that Annabelle perceived the interview to be about PCA-related changes, as opposed to 'dining' particularly as this was one of the earlier interviews the researcher conducted whereby there was more focus upon eating-related practices as opposed to the social experience (see section 1.4).

Engrossment opportunities in many areas of daily life appeared to affected for people with PCA. In the words of Bob, eating could be "one of the only dignities you're left to" (dyad mealtime interview), therefore managing it oneself was reported as particularly important for many of the people with PCA in this study. Family members sometimes struggled with knowing when to take over and support the person with PCA and when to stand back and support them to attempt to carry out roles. This could affect the social dynamic between them when interacting in shared dining situations. At times people with PCA could feel over-managed and family members could feel as if there was an uneven distribution of roles with them having to do everything. These tensions can be seen in the following example from Joyce and Bob:

60:56 "Joyce: he does get embarrassed about spilling, so if the grandchildren are here and they say why did grandpa spill… we've kind of got a, got, that's his special cooks apron 'grandpa Bob' so we've kind of got to have a special apron for him, so it doesn't look like he's got a bib on or anything [laughs],

RW: yeah so would you wear that at every meal?
Joyce: well if it’s something sloppy… [laughs]
RW: are you happy to wear that then Bob?
Bob: no choice, same with this, no choice, they’re just plonked on top of me
Joyce: otherwise I’m washing shirts every day you see and this was what I was talking about previously, the washing load, gets more and more so he’s been wearing this every day, because I like him to look clean not with spills or things like that, I just plonk it on his head [laughs]” [dyad interview PCA]

This example shows how Joyce tries to support her husband when he spills food at mealtimes by providing an apron for him. When asked if he is happy to wear this, Bob states he has “no choice” and feels it is “plonked” on top of him. The use of the word ‘plonked’ suggests it is a heavy action from others, perhaps reflecting his feelings around being over-managed and lack of control over this frame. Joyce attempts to justify the reasons for providing this aid for Bob such as not having to wash his clothes each day, making the management easy for her and because she likes him to look clean. These eating aids may also have affected how Bob was able to show himself through his dining interactions. Bob was described in the interviews as a proud man who was concerned about table manners and eating in a conventional way. The eating aids may have gotten in the way of this image and related more to managing the symptoms of PCA as opposed to supporting Bob to show his self through this activity. As Goffman suggests, the external environment can also act as a cue for the relevant frames within situations, therefore these eating aids may have distracted from the framework of eating-related practices as an enjoyable social experience, instead reflecting this as a management task. These tensions in management appeared to affect the social enjoyment of dining experiences for Joyce and Bob as can be seen in the following example:

60:53 “Interviewer: and does that affect the enjoyment for both of you…
Bob: yeah, I’ve got to the end, I’m safe…[laughs]
Joyce; [laughs]… see in many ways this illness has brought us a lot closer, in other ways it’s caused tensions that never used to be there” [dyad interview PCA]

When asked if the difficulty in negotiating roles affected their enjoyment of mealtimes, Bob agrees in terms of getting to the end and being ‘safe’, wanting to escape and retreat from eating together, perhaps somewhere where a framing around his symptoms was not dominating the main-frame for their interactions. The example suggests dining is a bracketed activity, with an ‘ending’, suggesting it is a type of on-stage performance (Goffman, 1959), with which Bob wishes to escape from, perhaps as his role was disconfirming his sense of who he was. This dyad also reported retreating from eating out which used to be an enjoyable activity for them both, suggesting these difficulties related to a breakdown in opportunities for successful dining experiences. In the example, Joyce also discussed how not only does this affect eating-related practices but it has caused tensions within their relationship overall, showing how understanding dining may provide a ‘window’ of understanding family coping on a broader level (Keller et al., 2010). The extent to which tensions in the management of difficulties occurred for family dyads living with PCA appeared to vary across participants in this study.

In summary, for people living with PCA, engrossment in frames relevant to eating-related practices appeared to be affected, relating to frame-breaks and disruptions to dining experiences. The social dynamic during dining could be threatened by these changes, as eating conduct changes could relate to a new frame anchoring towards managing the symptoms, as opposed to frames of social enjoyment around dining. The following section reports on the processes people living with PCA and tAD appeared to use to support constructing meaningful dining experiences. Although the pathway towards dining experiences becoming vulnerable appeared to differ for people living with PCA and tAD as presented in the current and previous sections, themes related to overcoming these negative experiences were largely shared across the two dementias, therefore they are presented together, with examples from people living with both PCA and tAD.

5.4 Processes involved in continuing to find meaning in dining experiences

5.4.1 Management strategies

Management strategies were symptom-specific, problem-based strategies which appeared to be used to adjust the actual situations people engaged in. These strategies could protect against negative experiences in dining by controlling the extent to which dementia-related symptoms entered the main-track of the dining experience. Management strategies such as eating aids, simplifying the environment, collusive communication and benign fabrications were used. However, as discussed towards the end of this section, management strategies needed to be carefully considered in terms of how and whether they supported the dining experience or could be detrimental to this.

Many people with PCA reported using management strategies, particularly given eating conduct difficulties could come to dominate the main-framework and affect dining interactions for both the person with the diagnosis and family members (see section 5.2.3). Management strategies people living with PCA reported included: choosing easy to eat foods, using compensatory aids such as a bowl and spoon to eat, slowing the eating practice, feeling around for food e.g. tapping the plate or moving the fork around on the plate, cutting up food beforehand, slowing the practice and eating in the corner of restaurants. Props to manage the performance such as bright cutlery, using a bowl or plastic clip around the plate, or having bright lighting over the plate were also used by some participants. An example of using a management strategy can be seen in the following quote from Jack and Camilla when they discuss how they compensate for worrying about Camilla knocking a drink over when eating out:

42:66 "Jack: it's not worth the worrying that she's going to knock it down, knock it over, so we just don't do it… we just go afterwards and have a drink don't we [laughs]" [dyad interview PCA]

By simplifying the physical environment, this supports Camilla to engross herself comfortably into the social dining frame, preventing her from disrupting the frame by spilling a drink. This strategy appears to be effective, as Jack laughs after discussing this, perhaps suggesting a state of satisfaction and that their dining expectations are now better met with this adjustment. Strategies to support dining out experiences appeared to be particularly important, given as discussed in section 5.3.1, dining out could become complex as strangers in restaurants did not have frames around dementia to interpret behaviour in a natural framework.

Family members of people with PCA and tAD often strategically used the concealment track to manage changes from disrupting the main-track of dining interactions. For example, given the person with PCA often had perceptual difficulties, family members could conceal physical support strategies such as putting food back onto their plate without them noticing. Another example is where family members managed the physical environment so the person with dementia could comfortably engross themselves in the frame, as can be seen in the following example from Sarah:

38:6 "Sarah: I think twice before I serve up something for him, you know to make it easier for him, because if there is something he struggles with like he would with spaghetti bolognaise and makes a mess he gets so uptight about it, it's just not worth the aggravation, so I just make sure the pasta's cut, so when it goes on the spoon, it's already easy to eat" [individual interview, family member PCA]

Sarah appears to recognise that physical difficulties may threaten Bob's dining experience as he gets “uptight” which would “aggravate” the dining interaction for them both. Sarah discusses managing this by providing an easier dining situation for Bob to enter, cutting up food beforehand. At other times, management strategies were used more openly, such as providing a spoon or in-curve clip on for the plate. However, these could exacerbate problems in terms of the dining experience, as these objects could carry social definitions for people which affected their dining experiences. This limitation of eating aids as management strategies can be seen in the example from Bob in section 5.3.3 and in the following example from Amanda:

36:58 “Amanda: erm, not in a sort of dinner party type thing… I don’t think I would like to be eating with a spoon when everybody else is using a knife and fork
Interviewer: and what about if it was just you and Mark here?
Amanda: that’s not a problem [laughs]” [dyad interview PCA]

This example shows how eating aids such as using a spoon could perpetuate social exclusion and embarrassment, particularly in social occasions with other people, where people appeared to be more concerned about maintaining social façade. For Amanda, it appears using a spoon holds different social definitions in different contexts, whereby it would be acceptable at home but would threaten the dining frame when eating out with others. Similarly, other people with dementia, reported various management strategies differed in their usefulness for the dining experience based upon the context of the situation they were engaging in. Such contextual considerations are further addressed in the following chapter (see section 6.2.4).

For people living with tAD, management strategies to support dining interactions slightly differed to those for people living with PCA, as management strategies were symptom-specific. As outlined in section 5.3.2 one of the difficulties was lack of awareness of changes in functioning among people with tAD. A key management strategy to support this reality appeared to be engaging in familiar frames which supported their sense of reality. These were often reported by family members and included behaviours such as people with tAD attempting to cook or choosing easy to eat foods from the kitchen. This is discussed in the following example from Alesha:

1:3 “Alesha: I don’t think it’s snacking because she’s a snacker, I think it’s snacking because she can’t prepare a meal so that bread would go down today if it’s left out” [individual interview, family member tAD]

Using Goffman's (1974) Frame Analysis to interpret this behaviour, perhaps Dawn struggles to identify the correct frameworks for cooking meals when entering the kitchen and so compensates by choosing easy to eat foods, with this behaviour confirming her reality which she reported in the interviews of being able to provide meals for herself. However, as discussed in section 5.3.2, these types of behaviours could also cause negative experiences for family members as they may lack meaning in terms of their differing frame understandings of what the person with dementia was able to do.

Given people with tAD often appeared to have difficulties identifying the correct framework within dining situations, family members often provided visual or verbal prompts to support their frameworks. For example, Gordon discusses pouring out a drink for Bessie as a visual prompt to support her framing 'to drink':

9:6 "Gordon: Yeah, I'll always put it in a glass for her, because you know seeing it's there on sight is, you would know the old saying, Bessie will go to the cupboard, she can't see for looking so if the can was there she'd think that was finished so if I pour it in a glass she'll see that it's to be drunk" [individual interview, family member tAD]

By pouring out the drink from a can, Gordon makes obvious there is a drink to be drunk. This prop cues Bessie's response of taking a drink. Many family members exaggerated the physical environment in similar ways, to guide the frames and behaviours of people with dementia to help them remain engrossed in the relevant frames. This is supported by Goffman's (1974) notions that the physical environment acts as an important cue for generating relevant frames.

Some family members discussed concealing their support to confirm the person with dementia's sense of reality. For example, Sian discussed discretely re-ordering food in a restaurant after Jeffrey placed an order for food she knew he did not like. This supported Jeffrey to perceive he had made the order and also ensured he received food he liked to eat. Another example, was in conversations, where family members fabricated their social interaction to support the person with dementia. This can be seen in the following example from Sian:

24:25 "Sian: [the conversation] I would say it's much worse… I think basically his mood reflects mine… It's pure reflectionand I'm a good actor you know, mealtimes I can put on a good show but it doesn't mean it's a good experience for me" [individual interview, family member tAD]

Sian discusses putting on a “good show” for Jeffrey to fabricate an enjoyable social context. This relates to Goffman’s (1974) (1958) concepts around presentation of self, whereby Sian is attempting to give off a desired impression to Jeffrey that she is having a good time. However, this act appears to lack meaning for Sian, whereby this was not seen as an authentic act in terms of her frame reality, whereby she was not enjoying the social conversations. This further demonstrates the complexity of supporting dining interactions for people living with tAD, as what could be a management strategy to support one dining participant, could perpetuate negative experiences for another.

Another way people living with tAD reported managing changes to the social conversation was to provide external props to support a social, mutual anchoring for the dining interaction. For example, Joseph and Celia discuss listening to the radio for shared enjoyment:

10:10 “Joseph: well we always sit down, we don’t chat a great deal do we
Celia: no
Joseph: I think we talk enough
Celia: yes but if it’s the archers we’re in the archers aren’t we or telling the radio that that’s a silly part or so and so’s a bad actress or a good actress” [dyad interview, tAD]

Joseph appears at first to discuss a lack of social interaction during dining, however, Celia moves from this framework, to discuss how they listen to the archers on the radio. She appears to frame this in terms of a shared ‘we’ experience whereby they are both “telling the radio” their feelings about the programme. This may have supported Celia and Joseph to distance their frameworks from being around management of symptoms and instead focus upon anchoring their frames around the mutual experience of listening to the radio programme. This relates to Goffman’s (1974) concept of unconnecteness, whereby Celia may be attempting to ignore aspects of the situation (i.e. difficulties in social conversation) as irrelevant to understanding their dining experiences, whereas enjoying listening to the radio show together was the anchor point.

Management strategies were however, limited in their usefulness and it appeared important family dyads balanced using these strategies with other processes described in the following sections. Where management strategies were not balanced with other strategies, this could relate to hypervigilance and stress in terms of trying to control changes, relating to a breakdown in the dining experience. The following example shows this difficulty for Joyce as she attempts to manage her husband’s difficulties during eating-related practices:

60:36 "Joyce: I do tend, as a carer to be watching him all the time, in case it spills, so sometimes I'm on edge because if I can see something going wrong I kind of jump up, so it's not as relaxed as it used to… where we'd chat and say what are we going to do today, what are we going to do tomorrow, because I'm always watching, like with this spatial awareness around the house, I'm just watching that he gets to the chair, that his cup goes on the red mat" [dyad interview, PCA]

Joyce appears to have fairly rigid frameworks for how behaviour should be within the mealtime situation. For example, ensuring the "cup goes on the red mat" and worrying about Bob spilling food. These frameworks appeared to motivate Joyce's behaviour in terms of attempting to manage the extent these difficulties entered their experience. However, she may be over-managing this situation, meaning this situation was not relaxed as she would "jump up" to prevent difficulties entering the frame. Joyce may also be focused upon managing the eating difficulties Bob experiences, which relates to anchoring her frames around the practical elements of eating the meal. Joyce also appears to frame her role "as a carer" as being responsible for managing changes. This may partly relate to a society-level framing of what 'being a carer' involves, whereby some researchers suggest there is an over-emphasise upon functional 'problems' and problem-focused management in dementia care (e.g. Klinke et al., 2013). However, coping with changes mostly in this way appears to be detrimental to Bob and Joyce's dining experience, as outlined in section 5.3.3.

The usefulness of management strategies appeared to depend upon the individual frameworks people had for what was acceptable for their dining situations. For example, some people had the framing that they should be able to manage their meal independently. This can be seen in the example from Susan,

31:14 "Susan: well it would be a change to have you know, whatever it is that she's bought for me, but it means I'll need help and it's just better not to have help" [individual interview, person with dementia PCA]

The above example shows how Susan frames she should not have support from her daughter and instead decides choosing easy to eat foods is a more suitable strategy which supports her own frameworks for how she should present herself within dining interactions. However, Susan appears to come up with further tensions in framing as she perceives that "it would be a change" to have a variety of food, implying she is dissatisfied with this management strategy of choosing easy to eat foods, related to a sense of helplessness in managing her experience. This example demonstrates how management strategies interact with further frameworks of meaning and could be limited in their usefulness depending on the individual frameworks people had. As one family member (Denise) stated, dementia and associated changes could not be “fixed” and strategies such as revising frames as outlined in the next section also appeared to be important for supporting people to continue to find meaning in their dining interactions.

5.4.2 Revising frames

Another process which was identified as important for maintaining meaning in dining experiences across all the people in this study was revising frames. This appeared to be an ongoing process and may have related to some changes being presented as neutral as outlined in section 5.3.1, whereby frames around these changes may have already been revised to incorporate them into dining interactions as acceptable. Revising frames refers to the coping process of reshuffling, reorganising, reframing or adding to frameworks of meaning, to incorporate changes as acceptable and normal into understandings around dining experiences. This appeared to be both an emotional process of accepting losses in functioning into the main-track for dining situations, as well as a cognitive process of reasoning and rationalising around changes to incorporate changes as acceptable, as opposed to disruptive to the meaning of dining. This can be seen in the following example from Bessie and Gordon:

“7:42 Gordon: yeah before you had the Alzheimer’s it was like she’d just chat and eat but nowadays she’s eating but listening to other people but not going into the conversation because it… just muddles her up a little bit…
Bessie: … makes no difference to me because most times, by the time the end of whatever that period is when you’ve been with people, I’ve forgotten it all anyway so I try not to let it worry me… it used to worry me but I’ve got over it now, just take it for granted, whatever I remember, I remember, whatever I don’t, I don’t
Gordon: I think you enjoy going out and eating though don’t you, picking from a menu and all that” [dyad interview, tAD]

Bessie uses her understanding of dementia and symptoms of forgetting to lower her expectations for herself in dining out occasions and not let it worry her when, as Gordon states she becomes muddled in conversations. This framing supported Bessie to continue to go out and enjoy social dining occasions with others, as opposed to retreating from these environments due to not being able to meet the dining out frameworks. Many people in this study appeared to be creative in the way they revised their frameworks around the existing frames they already had for dining, recreating expectations for themselves which supported changing behaviours.

Particularly among people with PCA, revising frameworks often involved rationalising changes around one's symptoms and for some, using humour. This can be seen in the following example from Trudy when she discusses difficulties with making a sandwich:

54:59 "Trudy: I tried to make a sandwich, I went out into the kitchen, got the bread and everything, stuff like that and erm, I was sort of cutting them up, but then I was cutting up another one next to it and it was like half a one and it was just a mess [laughs] a child could of done it but I just couldn't do it [laughs] because if I look away from anything you see, it's gone" [Individual interview, person with dementia PCA]

Trudy firstly uses a humorous, self-deprecating style of framing, to present changes in her ability to cut food up, suggesting "a child could have done it" but she could not. Trudy reconceptualises her frames, incorporating changes as acceptable by using a natural framework, explaining the perceptual symptoms she had which then causes difficulty in cutting up food. Goffman (1974) suggests humour is often a reaction to acting in a way which is not seen to be totally intended or guided, naming these situations muffings (see section 4.2.4). Given people with PCA were often aware of their symptoms and could interpret changes in a natural framework, humour was used to accept such muffings given they were not perceived as purposeful acts but within a natural frame. This supported Trudy to prevent perceiving these changes as threatening to her self-concept and accepting Edward taking over cooking roles. This demonstrates the importance of being appropriately educated around symptoms and difficulties so people could reconceptualise expectations for behaviour around these new, natural frameworks. Telling other people about the diagnosis was reported to be particularly helpful to support others to revise frames within a natural frame, supporting behaviour changes to be accepted within dining interactions. This can be seen in the following example from Edward:

54:51 "Edward: it makes life an awful lot easier… because otherwise people will say is there anything wrong with Trudy or you know, she doesn't seem ok, but now everyone knows they don't say anything… they just accept it for what it is" [dyad interview PCA]

Edward discusses other people accepting "it for what it is", suggesting the symptoms are a separate "it" from Trudy herself, supporting others to revise their frames for Trudy's behaviour. As mentioned in section 5.3.2 rationalising changes around symptoms appeared to be used less frequently among people with tAD than people with PCA. This may be due to a lack of insight related to this condition, or an impaired ability to recognise the severity of symptoms among people with tAD (Starkstein, 2014). To maintain meaning, it appeared people with tAD were often creative in the way they revised frames to support changes. An example of this can be seen where Dawn and Alesha discuss changes in eating conduct:

2:17 "Alesha: yeah unless I put the cutlery on the food then I've noticed she's started eating with hands… it's just a reminder that that's obviously the tool that, you know how we're kind of without thinking you know your fork goes in your left hand, so just yeah sometimes I can see it's a bit of a difficulty
Dawn: it's not a problem, it's not a problem, because there's so many left-handed people in the world you see
Interviewer: yeah, are you left handed?
Dawn: no… it depends, it depends, so even then it's not now I think right from the day I was born I think I was doing that" [dyad interview, tAD]

Alesha discusses the changes she has noticed with her mother "eating with her hands"and frames this as a difficulty. Dawn defends this as "not a problem", putting herself in a group with people who are left-handed despite the fact she is not left-handed herself. This helps her interpret the change as acceptable in dining interactions, however when the researcher asks if she is left-handed, she is then unable to incorporate the change as acceptable and presents instead she has always done things this way, allowing her to accept this behaviour her daughter has presented. This shows how an illness framework is not used in this situation. Other explanations such as ageing, changes to the physical environment, retirement etc. were often used by people with tAD to revise their frames to support changes. This suggests assimilating changes and explaining them using a natural framework could be affected for people with tAD and such creative attributions could be useful for people to make sense of changes. In the above example, this supported new behaviour not to be perceived as threatening to Dawn's anchored understanding of what she was able to do, supporting her to maintain her sense of reality. Given people with tAD often did not revise frames in a natural framework around dementia, they appeared more defensive than people with PCA in discussing changes, perhaps as they were perceived within a socially guided frame and thus open to more judgement from others than if they were viewed in a natural framing (Goffman, 1974). Some family members of people with tAD appeared to see it as more appropriate to revise their own frames using a natural dementia framing and use benign fabrications to support the person with tAD's sense of reality.

There were some limitations with revising frames. For example, revising frames around symptoms could be upsetting to a few of the people in this study, particularly when they had negative frames around dementia overall. This can be seen in the example from Jeffrey whereby when he attempts to revise expectations for his behaviour around Alzheimer's disease, he becomes upset:

23:75 Jeffrey: I haven't thought of having that point of view, erm, did Alzheimer's… yes by the time I had Alzheimer's, erm, my social situations were differentand Sian was doing most of the cooking by then… I wouldn't say I miss [cooking]… I miss the fact that err [crying] … carry on" [dyad interview, tAD]

Jeffrey reported a particularly negative perception of dementia and it appears in this example that considering his loss of cooking roles in a dementia framing was distressing for him. Jeffrey discusses how he has not thought of it from "that point of view" suggesting he typically unconnects from this frame anchoring for his behaviour. From the interviews, Sian largely appeared to support Jeffrey's reality by using benign fabrications as much as possible to prevent dementia-symptoms and this awareness around changes entering the main-track of their dining interactions. In the individual interview, Sian discussed Jeffrey enjoying mealtimes when Sian could promote opportunities for continuity, however, when his difficulties disrupted the frame on occasion, she reported he became upset as in the example above. This example suggests there is a close interaction between individual frameworks and the processes which are effective for supporting dining experiences (see section 5.4.6).

Where people viewed changes as threatening to their self-concept, this also appeared to relate to more difficulties revising frames around these changes. For example, for Peter he frames the dining activity as being about having conversations and given he has difficulty with word-finding, this sought to undermine the whole dining experience for him.

55:12 "Peter: you might think oh you know, I might do that, I might say so and so, but you can't put that to another person because it just won't come out … I really do miss having conversations over a meal, you know, either me and Shirley, or with the family, or with anyone really you know because that's what life is all about, you're… you're trying to send [laughs] well, it's like I feel like the man in the iron mask you know…" [individual interview, PCA]

Peter's framing that life is "all about" having conversations appears to contribute to him feeling excluded and isolated from the main-frame as he is unable to meet these expectations during dining interactions given his word-finding difficulties. He provides a powerful metaphor of his negative experience, as like the “man in the iron mask”, showing how blocked off he felt in social dining occasions given he could not meet this frame anchor of life being “all about” conversations. Peter appears to be stuck in this framing pattern, viewing his behaviours as discordant with the ideal frames for dining, as opposed to revising frames in a similar way to Bessie as presented in the start of this section. Considering the wider context of Peter’s situation, Peter discussed being a strong conversationalist in the past, whereas Bessie described she had always taken a “back seat” in social groups. Therefore, difficulties with word-finding for Peter may also have been more threatening to his self-concept and how he was able to express himself through the person-role formula. Sometimes people appeared to prefer to be dissatisfied with their dining experiences and retain their sense of self and understandings around how dining experiences should be, then revise frames to bring new behaviours in as acceptable.

5.4.3 Engaging in supportive social environments

Framing meaning in dining situations appeared to be largely informed by the way those around them framed behaviour. People’s frames appeared to cue other’s frames and set the tone, or anchor for the main-track of the dining experience. In this way, the social environment was one factor which could support people to continue to have successful dining experiences. Given the dyads in the study most often dined together, they appeared to have a key influence on one another’s framing of shared dining situations. For example, the following exert shows how Susan frames her husband, Terry’s understanding of eating-related practices:

31:28 “Susan: You go through that, the meal comes, sits on your plate and you eat it or doesn’t eat it. And unless I’ve done something in the process of eating that’s caused him annoyance. Then, you know, he’s not passing the time of day, or telling me something that happened at the swimming pool or, it’s not an event” [individual interview, person with dementia PCA]

This framing appeared to have a direct impact on Susan’s understanding of her dining experience with Terry. Indeed, Terry appears to have an outcome-focused, pragmatic understanding of interactions as he says in his individual interview “food is a function, it’s not an enjoyment”. The fact that dining interactions were largely framed in this functional way when Susan and Terry interacted related to difficulties for Susan as her PCA symptoms meant she often ‘failed’ this aspect of eating-related practices as a physical performance (Nyberg et al., 2016). This can be seen in the following example from Susan:

33:8 “Susan: I get shouted at because I haven’t eaten my vegetable, or I haven’t done whatever” [individual interview, person with dementia PCA]

Given Terry appeared to be focused upon the physical aspects of eating the meal as opposed to an opportunity for social connection and interaction, this may have related to him “shouting” at Susan when she did not meet his frame standards in terms of the physical eating of the meal. Given they dined together on most occasions, this had a significant impact on their overall enjoyment, where Susan reported in her interview she did not enjoy mealtimes anymore and had chosen only to eat a very small selection of foods, such as toast, which she could manage without disrupting the frames of eating itself. This helped Susan to keep PCA-related symptoms out of the framework, however, this diet lacked nutritional value and did not relate to enjoyable dining experiences for either Terry or Susan. For many other people in this study, family dyads appeared to work together to co-create meanings around ‘dining’, supporting social, inclusive dining situations.

Not only did family dyads co-create meaning around dining together, but meanings were co-created in group dining situations, whereby supportive social contexts were important to continue to frame dining situations so dementia-related changes were acceptable and not seen as disruptive within interactions. For example, Peggy discusses a supportive social context whereby friends compliment Charles’ conversational input:

21:11 “Peggy: Of course you’ve only got certain people if we are out with two or three friends or even with the family we’ll all be chatting awayand Charles will be, you know we’ll all be having banter and then Charles will come in with something completely bizarre nothing to do with anything that we’re talking about at all because he clearly wants to say something and of course without being rude it stops the… because you all think ok where are we going with this, you know and you’ll see everyone’s brains ticking along, my sisters brilliant, she’ll pick it up and wander off with Charles into a conversation wherever it’s going and we are all getting better at this wandering off in conversation but if you’ve got other people, they get embarrassed by that and think what an earth is he talking about instead of going with the flow” [individual interview, family member tAD]

In this example, Peggy discusses the importance of “going with the flow” in conversations, “wandering off” to discuss other topics around Charles’ frames. Peggy sees value in this in that these deceptive frames are comforting for Charles to remain engrossed and included in the interaction. However, as Goffman (1974) suggests, these frame transformations also rely on others not exposing Charles’ conversational errors. Overall, many of the family dyads were motivated to dine with supportive and understanding others who were perceived to be flexible in their expectations for dining, i.e. those who could revise their frames (see section 5.4.2). When dining with groups of people, other individuals could also help to revise frames to incorporate changes into dining interactions. This can be seen in the following example from Mark:

36:61 "Mark: The first thing I did was get a sharper knife, thinking if Amanda had a sharper blade, she could cut… and then it was the woman that said why don't you cut it up in the kitchenand I'd thought that myself and decided that that might be a bit embarrassing and I wouldn't want to do that, but then when she said why don't you do that, it was as if that was giving me permission to do it…" [dyad interview, PCA]

In this example, the dinner guest appeared to help Mark to accept the management strategy into the situation, providing room and "permission" for Mark to use this strategy and revise his own frameworks of what was acceptable in the situation, as opposed to attempting to conceal Amanda's difficulties or retreat from the social situation. This shows the dynamic process of framing and learning through engaging in dining experiences and revising frames with one another, showing how framing conventions can be revised over time. Another finding in this study was how often grandchildren were discussed as particularly supportive to dine with when living with dementia. For example, Sian, Juliette, Susan and Fearne reported people with dementia (tAD and PCA) engaged and interacted more when grandchildren were dining with them. This may partly be because their presence helped to establish a non-threatening environment, where frame expectations for behaviours may be more relaxed then perhaps more formal dining situations. This relates to the next section on external dining contexts to support maintaining meaning within dining interactions.

5.4.4 Engaging in supportive external contexts

As previously mentioned, people's frames appeared to change in different contexts as to what were acceptable and unacceptable behaviours for various dining situations. For many participants in this study, they reported being able to comfortably engross themselves in some situations but not others, where they may attempt to hide their difficulties. Therefore, the external dining situations people entered influenced the frames which informed their dining experiences. This overlaps with the previous theme of engaging in supportive social contexts. To provide an example of the impact of the external dining context, Denise discusses how Burt's behaviour changes across two different dining situations:

6:39 “Denise: He will [talk] at the Alzheimer’s group, I think cos they’re all on the same level but when we’re out socially, eating, I’ve noticed he takes a step back… he’s there and he’s listening but I sometimes think he feels left out but I can’t get him to, I can’t get him to express that” [individual interview, family member tAD]

Denise suggests spending time with people at the Alzheimer’s group seemed to be supportive for Burt, i.e. when cognitive understandings were “on the same level” and he could comfortably engross himself into the frames which applied and thus participate in conversations. However, he was unable to meet frame expectations with these same conversational abilities when dining out socially with friends and thus Denise reports he had negative experiences as he was socially excluded. According to Goffman, a person will “seek out a class of persons who are committed to a framing of events that will support him” (p. 469). Many people in this study discussed retreating from formal dining occasions where there were more expectant frameworks within these situations. This relates to Goffman’s (1974) notions around being pressed into the formalities of a role (p. 269), whereby more formal occasions may provide expectations which mean people with dementia are excluded from the activity organised by the formal frame expectations.

Another example of this theme is where John, who had PCA, ate with a spoon at home, whereas when eating out, this was perceived as an unacceptable behaviour. This also relates to the example with Amanda in section 5.3.1 whereby she discussed she would not want to eat with a spoon when dining with friends, but this would not disrupt her dining experience when eating at home with her husband. The standard frames which governed these situations then differed. For Annabelle and John, Annabelle discussed choosing to sit in the corner of restaurants as a management strategy, away from the watchful eyes of other diners in the restaurant. This positioning in the restaurant may then have related to the activation of different frames, where changes in behaviour were perhaps seen as less disruptive in terms of the frames which governed this situation. This further shows how contextual dining experiences were and this is further discussed in relation to the observations (see section 6.2.4).

In contrast to the example with Burt at the beginning of this section where he enjoyed eating at the day centre with other people with dementia, this was not perceived as supportive for Peter who has a diagnosis of PCA. This can be seen in the following exert from Shirley and Peter whereby they discuss Peter’s physical difficulties with eating conduct leading to him retreating from eating at the day centre with others:

57:19 “Shirley: well this was another reason why you stopped having dinner at the dementia club because he would struggleand also you’d end up with…
Peter: most of it in me lap
Interviewer: is there no other people there with dementia who have difficulties at mealtimes?
Peter: yeah, there’s only about erm one or two others who are the same as me… the rest are either very old, or a bit deaf, things like that, but not useless like me” [dyad interview, PCA]

This example shows how Peter perceives himself as physically inadequate and “useless” when he reflects upon his inability to meet the frames for managing the meal in dining occasions at the dementia centre he attends. This exemplifies the differences in how dining situations could become vulnerable for people with PCA and tAD. Peter appears to struggle with engrossing himself in the relevant physical frameworks, relating to a lack of a commensality experience of eating and drinking together (section 1.2) with others at the day centre. Peter compares his own dining performance to others at a dementia day centre who presumably had a more typical Alzheimer’s which made him feel ‘useless’ when he found he was unable to anchor his behaviour to the frames which applied in this situation. This shows how the external contexts people engaged in could relate to the assemblies of frameworks around the dementia-related changes which were activated.

5.4.5 Optimising opportunities for continuity

The final process to support maintaining meaning in dining experiences and interactions which was identified as a key process among people who took part in this study was optimising opportunities for continuity. Revising frameworks and coming up with management strategies and implementing them could be both an emotionally and cognitively challenging processes and participants in this study often balanced this with optimising opportunities for continuity through changes. Johansson et al. (2014) refers to this strategy as a way of ‘charging the batteries’ whilst adapting to a new life. For people living with tAD, optimising opportunities for continuity appeared to be particularly important, for supporting a shared sense of reality within the dyad. This may be because they often had difficulty reflecting upon and assimilating changes into shared understandings, therefore focusing on continued aspects in terms of maintained abilities, roles and traditions, could provide an anchor to reality and a sense of normality away from misunderstandings and frame disputes when reflecting upon changes. For example, a sense of continuity appeared to support Claire to maintain meaning in her dining experiences with Michael. This can be seen in the following exert:

17:21 "Claire: well if we sit here and eat that's what we do, you know same is if you were to sit and eat a meal you know, but once we've eaten from here, we would move into our TV room and settle ourselves down then" [individual interview, person with dementia tAD]

Focusing on continuity appeared to support Claire to anchor to a sense of normality, as well as connection with the researcher as she comments "same if you were to sit and eat a meal", to emphasise this as a normal aspect of daily life. This relates to Goffman's (1974) notions around anchoring activity and how frames can connect individuals to the broader social world, fostering a sense of connectedness with others. However, sadly this contrasted with Michael's experience as he reported the opposite experience in dining with Claire, as can be seen in the following example:

18:34 "Michael: just make the meal and put it on the table, I don't actually think about well what are we going to do when we're having the meal, it doesn't come into my brain it's empty,
Interviewer: yeah so is Alzheimer's affecting your enjoyment of the meal?
Michael: well of course it is 100% it affects… because I don't enjoy meals anymore because not only am I cooking, I don't get any conversation because of the Alzheimer's, I'm cooking because of the Alzheimer's, I'm washing up and clearing up because of the Alzheimer's… so my life has changed full wack" [individual interview, tAD]

It appears from this example, that Michael struggles to find a sense of continuity through engaging in dining situations with Claire. This may be because he is more aware of changes and compensating for them and thus his anchored understanding of mealtimes has shifted to one of a management task. Michael may then have unconnected to elements of continuity in dining and he may attend to behaviours and experiences which confirm this reality that eating-related practices have completely changed for him. This is an extreme example, whereby although other people living with tAD in this study appeared to have a different understanding around changes, often family members were still able to perceive elements of continuity in their experiences. This example also begs the question as to how dining experiences may unfold in real-time when people living with tAD can have such different perspectives around changes and this issue is addressed further in the following chapter on the video-based observations, demonstrating how different situations could be layered and transformed with different meanings.

People living with dementia could also provide props in the external environment to support a sense of continuity. From the example with Claire she discussed the television as one possible element to maintain a sense of continuity. The following example shows how Tanya actively works to create a sense of continuity for her husband, Alastair who has tAD:

27:71 "Tanya: But he's come from such an intelligent place… you know, yes I continue buying the New Scientist but he only looks at the pictures, if you asked him what was in it he wouldn't be able to tell you, but in his mind he's enjoying all these… and that's fine, there's no problem with that." [individual interview, family member tAD]

Tanya appears to attempt to support Alastair's continuing sense of self by providing the science magazine he has always enjoyed and placing it within their dining space. This may have supported Alastair to have a sense of continuity when engaging in the dining situation, as well as reminding Tanya of this enduring aspect of Alastair's self. This relates to Goffman's (1974) notions around resource continuity, whereby material traces in the dining environment could anchor activity and meanings-made around continued aspects of the self.

For people living with PCA, looking beyond the physical barriers that people had could pose also supported maintaining continuity, as well as resilience in terms of maintaining meaning in dining experiences. This can be seen in the following example from Mark:

36:50 "Mark: Yeah because if you start thinking oh PCA then you're just sitting in, you wouldn't go out would you and I think we do try to do what we can and I mean it's just if we're going around a shop or working our way around a restaurant I'll probably just put my arm round Amanda, which is pretty normal isn't it, most chaps put their arms around their… when they're walking out together [laughs] so it doesn't look odd" [dyad interview PCA]

This example suggests that in many ways, framing could be an attentional process and people had some element of control over where they focused their attention. This shows how denial of changes (e.g. Clare, 2002) and self-induced misalignment was not just a coping strategy for people with the diagnosis, but family members as well. This also relates to Goffman's (1974) notion of unconnectedness where people could ignore aspects of situations which were not relevant to the anchor of the frame. Mark discusses thinking past PCA and trying to "do what we can" to maintain focus around the social aspects of dining. Mark appears to balance this with considering management strategies, such as putting his arm around Amanda to support her walking ability when going into a restaurant.

However, there were limitations to optimising opportunities for continuity and this strategy needed to be balanced with other processes. Continuity could relate to denial, which appeared to be maladaptive for coping and moving forward with changes. This relates to Goffman's (1974) notions of self-induced perception whereby participants could work to align themselves to a particular perspective, which could differ from reality. As one participant said, too much of this strategy, could be like having their "head in the sand" (Joseph), so as not to deal with the changes in their situation. Continuity in terms of denial related to some defensiveness when changes did enter the dining frame, as can be seen in the following example when Sarah attempts to discuss changes in Bob's abilities:

38:17 "Sarah: I left him some apple juice, in a glass and he hadn't drunk it when I got backand I guess it's because I don't think he saw it… he left it next to his plate of lunch so
Bob: [from next room] don't like it [angry tone]
Sarah: doesn't like it, what you don't like apple juice
Bob: no, it wasn't apple juice
Sarah: it was apple juice
Bob: I don't like it
Sarah: fine, but anyway it's not a problem, it's not a problem… ask us again in a year's time and it might be a problem but you know at the moment it's fine." [dyad interview, PCA]

This example shows how Bob is dismissive of changes being related to the diagnosis and becomes angry when he can hear Sarah suggesting changes relate to his symptoms. Sarah supports Bob's framing to suggest it's not a problem and appears to focus upon continued aspect of mealtimes and retained abilities throughout the rest of the interview. This may be useful early in the diagnosis, however, as more changes arise, opportunities for continuity may become more limited and facing up to changes and allowing them into the main-frame may be important for gradual adjustment and finding ways to continue to enjoy dining together.

5.4.6 An interconnected system of maintaining meaning in dining experiences

Overall it appeared each of the processes presented to support maintaining meaning in dining experiences- management strategies, revising frames, co-creating meaning, external dining contexts and optimising opportunities for continuity- were not distinct but more often overlapping, dynamic and interconnected, contributing to people's reflections on their dining experiences. This section shows how two or more of these processes often appeared to work together.

To provide an example of how individual frames, revising frames and management strategies worked together, Trudy appears to revise her frames around using certain eating aids, but not others, contributing to their acceptability for dining interactions:

52:4 "Trudy: even though I'm enjoying the actual food, it's the fact that I have to, erm, try and get it in my mouth rather than down my front, Edward said he's going to get me one of those plastic things [laughs] but I'm never that bad… but it's like I said we'll come in, we get all our, we call them the doggie clothes, because when the dog comes in he's all hairy and everything so we have our old gear for that and every time we come in from being out, we come in and take our decent clothes off." [individual interview, person with dementia PCA]

This example shows how Trudy is able to maintain social value and connection with Edward when using the management strategy of changing clothes before eating the meal. This prevents the change in clothes carrying a social definition around "spilling", or Trudy's symptoms, to being about the dog and a shared strategy they openly use together to manage spills. She contrasts this with the idea of having a "plastic thing" but says she's never "that bad", suggesting this type of strategy would be detrimental to her sense of self and could threaten her dining experience, in terms of providing a frame that she is "that bad" if she were to engage with these types of eating aids. This shows how strategies worked dynamically with frame assemblies of meaning and the importance of understanding the individual frames people had to understand different management adaptations.

To provide another example of this interconnected and dynamic system, Gordon discusses in the following exert how his wife, Bessie, moved from revising her frames around a change, to seeing these revisions as threatening towards her sense of self and instead using withdrawal as a management strategy:

9:21 "Gordon: [sighs] when all this first started it used to be a joke because it was just a bit of forgetfulness but now it's getting serious now, erm, yeah, we used to make a joke out of it but no, you wouldn't make a joke out of it now she'd get the hump over that, but we both made a joke out of it… yeah we used to go away on holiday and first thing Bessie would say to somebody 'if I keep repeating myself it's only because I've got a bit of a memory problem and all that and that sort of broke the ice with everybody, but now, she's withdrawing now, definitely withdrawing now, she don't make conversation, she'll mix in with the conversation but she won't make conversation" [individual interview, family member tAD]

This example shows how Gordon notices that they first used humour to revise their expectations around forgetfulness and incorporate this into interactions. This related to the management behaviour of telling others about Bessie's diagnosis, allowing her to comfortably engross herself into social dining frames. However, Gordon then notices Bessie started to perceive changes as threatening and "serious", perhaps towards her enduring anchor in terms of role continuity and her sense of self, which he relates to an abandonment of this previous coping strategy. When these changes were then not accepted into the main frame during dining, this appeared to relate to reports of avoidant management strategies such as hiding or attempting to cover up difficulties to maintain social façade. It appears from this example, Bessie sees it as more advantageous for her self-concept, to choose to retreat from conversations. Goffman (1963) discusses this 'hiding' strategy in his text on 'Stigma' whereby people who perceive themselves in a negative stigma frame, may avoid, hide or attempt to pass at 'being normal' in situations, thus maintaining a social façade.

Among family members, revising frames provided more room for changes, relating to strategies of empowering the person with dementia to carry out dining-related roles, as opposed to jumping in and attempting to take over where they may feel uncomfortable when dementia-related changes enter the main-track of the dining experience. This can be seen in the following exert from Mark:

36:18 "Mark: I can feel myself being irritated… you knowand sometimes I might want to just do it, cos it's quicker if I do it… I try not to interfere, where it's something that Amanda can do because even if it takes longer… so I just chew the edge of the table quietly [laughs]
Amanda: [laughs]
RW: are you aware Amanda that Mark's getting frustrated?
Amanda: [laughs] yeah there's a certain amount of blue in the air [laughs]" [dyad interview, PCA]

Mark presents the idea of "chewing the edge of the table quietly" to physically exemplify the struggle with stopping himself from inserting his own framing into the situation and allowing Amanda's PCA symptoms to be present in the interaction. This further demonstrates the role of humour in revising frameworks, making something previously unacceptable, acceptable. Amanda shares Mark's humour framework, showing how dyads co-created frameworks. This in turn, appears to relate to the management strategy of empowering Amanda to attempt to manage some aspects of food preparation herself. As well as this, Amanda and Mark discussed in the interview how they had always used humour throughout their relationship, demonstrating how this may be a strategy which also optimises a sense of continuity.

Overall, what appeared to be effective in maintaining meaning in dining experiences among people who took part in this study was a balanced and realistic use of different processes related to the various frameworks people had around dining. This whole system can be seen in this final example from the interview with Gordon:

7:48 "Gordon: To be honest it's one of the good parts in the day time I think, you know when you're sitting down and having a meal together even though, erm… really I say even though I'm having to cook 24 7 I should look at it the other way round and when Bessie was well that she cooked 24 7 and you know, she never ever complained about oh blimey I've got to cook this meal and that sort of thing… when I go shopping I have to start planning what we're having on a Monday, what we're having on a Tuesday… never thought about that beforeand it does come a bit of a bind… that's why we go out, that's why I like to go out … takes the edge of it a little bit" [dyad interview, tAD]

In this example, Gordon firstly discusses the therapeutic value of dining as being "one of the good parts in the day" where there are opportunities for continuity and connection between him and his wife, Bessie. He then discusses the threat the change in cooking roles has on his enjoyment framing stating, "even though", suggesting changes threaten his pre-change expectations for how dining interactions "should" be. He then appears to engage in a cognitive process of revising his frameworks by comparing these new roles to his wife's previous situation, stating "she never ever complained", as a guide for his own framing of his role. This shows the interrelatedness of framing, whereby one person's framing patterns influenced another's, relating to the usefulness of supportive social contexts. Finally, this process of revising frames interacts with the use of the management strategy of eating out to "take the edge off" the potential burden of preparing meals for Gordon, supporting a social enjoyment framing. This example shows how people living with dementia appeared to work hard, utilising numerous processes in order to maintain meaning within their dining experiences.

5.5 Summary of chapter five

This chapter firstly presented perceptions around dining experiences among people living with tAD and PCA, relating to the first research question (section 2.4). For people living with tAD, dining experiences could become vulnerable as there were difficulties identifying the relevant cognitive framework in dining situations, relating to misunderstandings and difficulties in the social interaction with others. However, for people with PCA, there appeared to be more difficulties in terms of engrossment in the physical frames for the dining performances, relating to disruptions and frame breaks in the dining experiences, relating to social embarrassment and feelings of uselessness for people with PCA. Family members could also begin to focus on these difficulties and feel burdened by their new roles, relating to the frame anchor being around dementia-related symptoms, as opposed to dining as an opportunity for meaningful social connection.

The second section dealt with strategies to support dining experiences, relating to the second research question (section 2.5), presenting five themes of processes which were identified: management strategies, revising frames, optimising opportunities for continuity and engaging in supportive social and physical external contexts. It appeared these processes were not separate, but interacted with one another in a co-creation of dining experiences. The findings were interpreted using Goffman's (1974) Frame Analysis concepts, providing an understanding of how changes could relate to negative experiences, as well as how individual frameworks could be recreated to support and maintain dining experiences under the new and changing circumstances. What appeared to be important for family dyads was not being stuck in a framing pattern where their behaviours were not meeting frames for dining, but that frames were continually shaped and changed to allow for the progressive changes in functioning into dining experiences. Overall, the ability to cope with changes appeared to be largely non-disease specific and unrelated to severity of the dementia itself, but rather influenced by the individual and shared frames of meaning which governed various dining situations.

Another finding was that dining experiences were largely contextual and situational. Different situations constituted different frames and in turn how well the individual could be carried into these different dining interactions and coordinate their understandings with others. The social and physical environment appeared to play an important role in dining experiences among people in this study and the following chapter explores this in more detail by comparing four dining interactions. The final discussion chapter follows and brings the findings from the interviews and observations together to provide an overview of 'dining with dementia' for people living with tAD and PCA, as well as integrating these findings with existing literature.

Chapter 6: Observations of Dining Situations

6.1 Introduction

This chapter follows on from chapter 5, reporting on findings from the video-based observations of four dining scenarios, extending understandings particularly in relation to the third and fourth research questions for this study in terms of how dining interactions are affected as they unfold and how people facilitate these interactions when living with either tAD or PCA (see section 1.5). It shows how many of the strategies reported in the previous chapter work in action, such as benign fabrications and collusive communication to support dining interactions. The observations also highlighted some important differences from the interviews. For example, people appeared more likely to attempt to conceal difficulties and dis-attend to them when being observed and this sometimes differed to how they reflected upon their experiences in the interviews. Furthermore, a number of props in the external social and physical environment appeared to impact dining experiences, some of which were not reported in the interviews. An important consideration was that for two of the situations, the researcher dined with the other interactants as a ‘guest’ and this chapter outlines how that generated various social frameworks around dining compared with when the researcher observed. How different contexts appeared to affect the engrossment opportunities in the dining situation is presented in this chapter.

The structure of this chapter follows a similar format to the previous chapter, whereby the first section addresses changes to dining experiences for people who took part in the observations and the second section outlines the main processes which were used to support and maintain meaning within the dining interactions. The reader is referred to section 3.5.2 for a description of each of the four dining contexts observed and section 5.2 for the demographics information whereby the same pseudonyms have been used for the participants. Again, Goffman’s (1974) Frame Analysis concepts have been used throughout this chapter and the reader is referred to the glossary in appendix 15 for a definition of these concepts. As in the previous results chapter where examples are used from the original data, the Atlas.ti 5.0 code is provided at the start of the example (pertaining to the document number and quotation number).

6.2 Dining interactions when living with dementia

6.2.1 A new normal?

A key finding from the observations was how many dementia-related changes largely seemed to filter into dining interactions. It may be that people had revised their frames (see section 5.4.2) around many of the new behaviours, relating to a new normal within these dining situations. On reviewing the field notes from the visit with Burt, Denise and her mother, Denise said “welcome to the mad house” on the researcher’s arrival and Burt later also said “it’s a mad house this”. This may have related to the idea that they had adopted a new normal for their dining interactions and as a pre-warning for the researcher to be flexible in her own frame expectations. This may relate to Goffman’s (1974) ideas around frames connecting individuals to their broader social worlds, whereby Denise and Burt may have felt disconnected from framing conventions for dining within the wider community. However, they appeared to say this humorously, which also suggested they had come to accept this new normal. In terms of how these new frames related to their dining experiences, take the following example:

40:46: Denise’s mother: [starts moving the chairs from around the table into a line in the centre of the living room space]
Denise: [comes into the room] Do you want… Oh!... that’s normally Burt’s job… what are you doing with the chairs [laughing]
Denise’s mother: erm [blushes]
… Denise: put the chair back… [Denise’s mother shifts a chair slightly forward] no… put the chair… that’s normally Burt’s job isn’t it… shifting the furniture

In this example, Denise appears to have new understandings that Burt’s “job” is to “shift the furniture” in the room. Presumably, Burt had not done this previous to having dementia, however, this role now had new meanings to Denise as a practical job which Burt could engross himself within. Denise’s mother who also has dementia then does Burt’s “job” for him in the above example which appears to activate non-normative frameworks for Denise as she is surprised to see her do it as opposed to Burt. She exposes this frame understanding which appears to embarrass her mother. This shows how new behaviours can become an everyday norm, whereby Denise saw meaning in Burt randomly shifting the furniture as one of his “jobs” at mealtimes, yet when her mother engaged in this behaviour, this disrupted her understandings for their dining interaction.

The following example shows how a PCA-related change, which the researcher viewed as perhaps atypical for dining interactions, filtered into the dining interaction for Louise and Richard:

62:43: Richard: do you want, erm… pepper

Louise: no thanks [she puts food on her fork and then moves the fork up and down repeatedly, as if weighing how much is on there]
Richard: it's hot so you best be careful with it

This example shows how changes in eating practices, such as Louise moving the fork up and down appeared to filter into the dining interaction as a normal aspect of their interaction. Furthermore, this practice had not been mentioned in their interviews, despite Louise using this strategy on several occasions in the observation, suggesting perhaps it filtered into their 'normal' understandings of dining. However, to the researcher when watching back these videos, this appeared an atypical practice, disrupting frameworks for the researcher's own understanding of 'normal' dining behaviours. To provide a final example of this new normal, take the following example from the dining interaction with Alastair and Tanya:

07:31: Tanya: right… enjoy!
Alastair: [stamps his knife and fork on the table loudly a few times]
Tanya: [to the researcher] so you have a busy time in London?

In this example, Alastair stamping his fork up and down could have been viewed as inappropriate for 'dining', however, it does not appear to disrupt the framework whatsoever, filtering into the interaction. Tanya appears to support the researcher's understandings of this behaviour as normal as she carries on with the social conversation. These examples may help to explain why many of the difficulties in dining reported in the interviews were related to dining out or with people they did not know so well, whereby their frameworks for 'normal' dining behaviours may not have been revised to include dementia-related changes.

6.2.2 Disruptions to dining frames

As found in the interviews, dementia-related changes were observed to, at times, disrupt the main-track of the dining experience. For two couples living with PCA, as found in the interviews, physical eating difficulties could relate to collapsing frameworks and a focus upon PCA-related symptoms. This appeared to be more pronounced for Trudy than it was for Louise, whereby it appeared her perceptual and spatial impairments were causing her greater difficulties with eating conduct. On visiting for the observation, Trudy had experienced further deterioration in her functioning since the interviews. As recorded in the field notes, Edward mentioned when the researcher arrived at the house "you'll be surprised when you see how much worse she's got". On visiting, Trudy appeared to have more difficulties with word-finding and exhibited substantial difficulties eating the meal during the observation. Often, difficulties were dis-attended to by all the diners in the interaction, as discussed in section 6.3.1 and prevented from entering the main-track. However, at times the difficulties became particularly pronounced, causing a frame break and affecting the smooth flow of the activity. This can be seen in the following example:

64:29: Trudy: I don’t like parsnips
Edward: you don’t like parsnips do you
Trudy: they’re like sweets if you do them properly
Edward: [Edward is watching Trudy eating her meal, Trudy’s fork is upside down and she has difficulty putting food on the fork]… turn your fork around [she turns it slightly the wrong way]… the other way [Trudy turns the fork the right way round]… that’s it… [he looks at the researcher]… I have to prompt her
The researcher: yeah… you’ve started twisting the fork round as you’re getting to the end of the meal
Trudy: bored [laughs]… bored probably

The focus of the main-track of the dining interaction appears to move from a conversation about food Trudy enjoys, to a focus upon her difficulties with eating the meal, whereby an illness framing comes to dominate this interaction. Prior to this example, Trudy’s difficulties were less apparent, as the researcher and Edward were still eating their meal and the attention was then not focused around Trudy’s eating practice. Both Edward and the researcher appear to focus the interaction around Trudy’s difficulties and Edward begins to discuss his caring role of needing to prompt Trudy. The context of dining with the researcher may have related to more focus on symptoms, perhaps as this was a familiar framework they had used with the researcher previously on visiting for the interviews. The role of the researcher in influencing the dining interactions is further discussed in section 6.2.4. This exchange appears to disrupt Trudy’s enjoyment and the social conversation and she appears slightly defensive as she says she is “bored” when a discussion around her difficulties enters the main-track of the interaction. This reported experience of boredom may be related to lack of engrossment in the eating frame, whereby Goffman discusses when someone is less involved in the framework, this relates to boredom. As Edward takes over managing the eating of the meal, the level of involvement Trudy experiences diminishes, which may relate to these feelings of boredom. Alternatively, Trudy may say she is bored, to normalise this behaviour and protect against feelings of social embarrassment, maintaining social façade that she would be able to manage this role but she is bored and therefore turning the fork around as a socially-guided response. This relates to Goffman’s (1974) notions around Presentation of Self (1958), whereby Trudy may be attempting to give off a desired impression to the other diners.

Following this interaction, Trudy continues to have difficulties which then appear to cause tensions in the social interaction between Trudy and Edward:

64:31: [Trudy’s knife is upside down]
Edward: turn it round the other way
Trudy: No… because I’m alright”
Edward: fair enough [laughs]
Trudy: No, see Edward wants to have everything perfect
Edward: No it’s just so you can pick some food up love
Trudy: I knowww… but I’ll get there eventually

In the previous example, Trudy attempted to dis-attend to her PCA-related difficulties, to maintain a social façade in front of the other diners that she was able to manage her meal. However, she continued to have difficulties eating which Edward attempts to support by providing verbal prompting. This appears to exacerbate stresses in terms of the dining interaction, as Trudy then appears resentful towards Edward, blaming his “perfect” frame expectations for how her eating practice should be, causing a disruption in framing. There appears to be tensions in the relevant frame, whereby Trudy has her own frame expectations for her engrossment, making clear she will get there herself eventually, again perhaps as this person-role formula was important to Trudy for maintaining her sense of self in this interaction. Importantly, these types of disruptions were not reported in the interviews with Trudy and Edward. As outlined in section 3.5.2 the reason this dyad were selected was because of their reported positive interactions and experiences of dining. Trudy talked about accepting social support with meals, such as when Edward cuts her food up for her. She also discussed not being embarrassed in social dining occasions when she requires this kind of support. It may then be that these frameworks of meaning only become apparent when participating within dining situations and these frames may be operating at an unconscious level. Alternatively, Trudy may have revised her frames in the interviews, making them acceptable in reflecting on living with PCA, but not in experiencing symptoms in everyday life. Furthermore, the context of the situation with the presence of the researcher as a relative stranger within the activity, may have related to more of a focus upon wanting to maintain a social façade in-front of an audience, as well as the presence of the camera perhaps adding to this on-stage performance. It appears Trudy did feel under-pressure as if she was ‘on-stage’ as at the end of the meal she stated “it’s like being a monkey in a cage isn’t it”, suggesting she perceived herself as carrying out a dining performance in front of an audience.

As found in the interviews, for the two scenarios with people living with tAD more misunderstandings and frame disputes arose in terms of identifying a shared framework of meaning during dining interactions than for the two people with PCA. Family members were more likely to notice changes and when they revealed these understandings to the person with dementia, this could result in tensions as to the correct framing which applied. This can be noted in the following example from Tanya and Alastair:

63:10: Tanya: Put it a bit nearer to you so it doesn't hit the floor
Alastair: [frowning and smirking, looking over at the researcher] that obviously happens many times
Tanya: No it doesn't… Right would you like any sauce or anything?

Tanya reported in the interviews that Alastair often drops food on the floor and appears to attempt to manage this anticipated difficulty by asking Alastair to move the meal closer to him. However, there is clearly a disagreement in terms of Alastair's own framing for his eating practice. Alastair appears to attempt to manage the impression created by Tanya by responding sarcastically and smirking to the researcher to suggest Tanya's framing is mistaken. Tanya manages this by going on to support his framing, concealing her own frame understanding in this interaction, perhaps as a type of benign fabrication to support his reality. Tanya draws reference to the sauce in the environment, as a prop to anchor the conversation towards a mutual conversation topic to repair the conversation (see section 6.3.3). These frame disputes appeared much less frequently than in the interviews, perhaps as in the interviews people living with dementia were specifically asked about dementia-related changes and there were more frame disputes when reflecting openly on these changes. In the dining interactions, it may have been more about maintaining a social façade and upholding the dining performance (Goffman, 1974).

On various occasions, the two people with tAD who were observed appeared to engage in a wrong stream of action, perhaps based upon a mis-framed premise. This was also reported in the interviews with people living with tAD (see section 5.3.2). At times, Tanya and Denise appeared embarrassed or frustrated by these behaviours. For example, Alastair is seen to lick his knife a few times and Tanya blushes at this, suggesting she is embarrassed by his eating practice. The following example from the observation with Denise and Burt, shows how behaviours could also be perceived as frustrating for the family member:

61:44: Denise: have you finished? [Burt hands Denise his plate and then he switches the knife and fork around repeatedly on the table]… are you going to give them to me? [Denise is poised

ready to take the knife and fork from Burt]… is that it? [Denise takes the knife and fork from Burt's hands, looks away and rubs her arm]… Does it matter what fruit it is?
Burt: no

This interaction suggests Denise and Burt are working at cross-purposes. Burt may want to have some control and a role in clearing away the meal and thus starts to move the cutlery around. However, it appears Denise is working in a primary, outcome-focused frame in this instance and becomes frustrated as Burt is perhaps getting in the way of achieving her goal of clearing away the meal. The physical action of Denise rubbing her arm may be a strategy she is using to manage herself from becoming more frustrated or clearing the frame. Relating this to Goffman's (1974) Frame Analysis, Goffman suggests that interactants engaging in a transformed key are expected to be free of pressing needs. Denise reported feeling particularly stressed and rushed to the researcher before their dining observation took place, which may have been further pressurised by the presence of the researcher. This may have given her less time to see Burt's actions in a transformed social framework, judging his actions in a serious, primary framing and becoming frustrated when they got in the way of the outcome-focused frame of providing and clearing away the meal. These frustrations were also reported in interviews, particularly among family members of people with tAD when they viewed changes in a primary-outcome focused framing (see section 5.3.2).

6.2.3 Engrossment in dining frames

As well as disruptions to dining frames, another change which was reported in the interviews was exclusion, or lack of engrossment in dining frames among people with dementia and over-engrossment among family members. Indeed, from the observations there appeared to be less opportunities for people with dementia to be involved. For example, for all the observations, the family member had taken over preparing the meal and there appeared to be less, if any, opportunity for engrossment in these preparation frames for the person with dementia. Related to this, within the observation with Denise and Burt, Denise appeared to make decisions for Burt, as opposed to including him in this decision-making process. The following example shows how Denise decides where Burt is sitting for their dining situation:

61:11: Denise: shall I sit Burt over this end, that's where he normally sits, so if I sit him up that end… you'll just have to swap places tonight Mum if that's alright

It appears Denise largely perceives herself as having agency over where Burt will be sat, suggesting she has a more dominant role within the dining interaction. She talks about 'sitting him' as an action decided by her, as opposed to including him in this decision-making process. This may give Burt less autonomy and opportunity to engross himself into the dining situation. It is also important to consider contextual factors such as Denise may be more anxious about controlling how the dining situation occurs due to being observed and this may thus relate to these behaviours.

Furthermore, for the two scenarios with people with tAD, there also appeared to be different layers of understandings as to what was going on within the dining situations, affecting engrossment opportunities. In this way, people with tAD could be psychologically excluded from the frame, as reported in the interviews (see section 5.3.2). The presence of the researcher appeared to influence this, whereby there were different layers of understanding between the various interactants. This was not observed among the two dyads living with PCA. To provide an example, on several occasions, Burt is excluded from the evidential boundary whereby Denise engages in collusive communication with the researcher, indicating the frame Burt is operating in should be transformed by the researcher. Take the following example of a conversation between Denise and the researcher, in the separate kitchen area away from Burt:

13:30: Denise: Rachel… the fun could start now, or it could just go swimmingly
Denise's mother: yes [laughing]

Denise is exercising some tact by collusively communicating with the researcher and her mother in the separate kitchen area. Denise is suggesting that the researcher transforms the keying from a primary framework of a dining situation, to a "fun" framing, modelled on a primary, serious framework of dining (see section 4.2.6 for keying frames). This suggests Denise operates in a transformed frame, different to the one Burt applies in their dining interaction. However, Burt may be aware that there is an evidential boundary he is excluded from, as he is alone in the living room when this conversation is going on, but the exchange is audible from the living room as it was captured on the video which was placed in this area. This type of interaction could make the person with tAD suspicious over the correct frame. Burt said very little during their dining interaction and perhaps this was related to anxiety and uncertainty over the relevant framing, given the collusive communication which had been going on around him before they are engaging in the dining experience.

Layers of different meanings also appeared to affect the dining interaction with Alastair and Tanya, as can be seen in the following interaction:

63:19: Tanya: I don't remember that… how long have we been here?
Alastair: hmm… [he looks up, he looks at Tanya and then the researcher]… [he laughs]… can we do the vague sort of thing?
Tanya: [laughing] the vague sort of thing is we've been here for 37 years… very vaguely [she frowns and looks over at the researcher]

Tanya appears to engage in collusive communication with the researcher, frowning over when she says "very vaguely" perhaps to indicate this is a transformed framework and not a serious primary framing, ensuring the researcher is aware of this. It appears Alastair is slightly suspicious of this as he looks to both dining participants with a questioning "hmm" suggesting suspicion and doubt. This relates to Goffman's (1974) suggestion that when marginalised people are unsure of the correct framing which applies, they will examine the setting to pick up information to 'settle matters' (p. 338). This type of benign fabrication is designed to support Alastair and his reality, however, it also excludes him from understanding what is really going on within this situation. This shows how social dining situations, i.e. where there is two or more others, could be vulnerable experiences for the person with dementia as they could become excluded from knowledge frameworks around them. As Goffman suggests: "an individual's sense of knowing what is going on is most often threatened is one in which other individuals are immediately present" (p. 379) and suspicion and doubt arise when people perceive that others may be viewing the same situation with a different framing to their own.

In the dining scenarios with the people with PCA, they appeared at times to be excluded in terms of engrossment opportunities, such as in preparing the meal or eating independently. This can be noted in the example in section 6.2.2 whereby Edward attempts to take over Trudy's management by verbally prompting her when eating the meal, providing less opportunity for engrossment in this frame. The uneven distribution of roles can also be noted in the following example from Louise and Richard:

62:41: Louise: am I waiting for you or what? [looking around]
Richard: [from the pantry] are you talking to me? I can't hear you…
Louise: I said am I waiting for you?
Richard: what are you saying? No carry on, do what we normally do, I eat mine half cold [laughing]
[Richard is clearing up in the kitchen]

Opportunities for shared engrossment here are lost as Richard is busy clearing away the kitchen and Louise is excluded from this preparation frame as she is unable to participate in this role as reported in the interviews. Louise may have wanted a social, dining experience as she asks Richard whether he wants her to wait to eat their meal together, however, Louise is left sitting alone eating her meal alone as Richard is focused upon frames related to his new role. This relates to Goffman's (1974) notions around unconnectedness, whereby Richard may have been anchoring his behaviour towards an outcome-focused, meal preparation frame, which may have related to him not paying attention to opportunities for social interaction with Louise. Louise discussed later in their dining scenario, following the meal, feeling on the "fringes" all the time. These types of lack of engrossment opportunities may relate to this experience of feeling socially excluded in everyday life.

Trudy appeared to experience word-finding difficulties, which was not observed in the other dining scenarios, but which acted as a barrier towards her being able to socially interact with the other dining participants:

64:43: Trudy: mm yeah… I think it must be a treat… a trite… a… I can't remember the word, aaa, oh what's the word… erm, I'll come to it in a minute when I've eaten a bit of greenery, my brains might go a bit better then [laughs]
Edward: feed the brain

In this example, Trudy appears to become frustrated as she cannot get out the words she wishes to say in the dining interaction, disrupting the flow of this exchange. She manages this in a humour framework to maintain an appropriate social façade and prevent disruption to the enjoyment frames, demonstrating the effort she works at to maintain socially appropriate appearances, around a collapsing framework (Goffman, 1974, p. 353). However, Trudy is still blocked from socially conveying what it is she wishes to say as the conversation moved to another topic following this exchange, demonstrating how dementia-related symptoms could disrupt opportunities for engrossment. A few other people in the interviews also reported experiencing word-finding difficulties which impacted on dining interactions, for example see section 5.4.2 for Peter's experience of word-finding difficulties.

Overall, this section shows how people with PCA and tAD in this study could be excluded from the frameworks which applied in the dining interactions as they unfolded. For people with tAD, they were often excluded from knowledge frames in terms of 'what was really' going on, whereby family members engaged in collusive communication with the researcher, trapping the person with tAD in a different frame perspective. For people with PCA, their physical difficulties with managing the meal, meant they were often excluded from being meaningfully engrossed within the relevant frameworks for dining.

6.2.4 Contextual differences relating to dining interactions

Lastly, in this section around changes to dining interactions, the way dementia-related changes were perceived largely related to many contextual factors which made-up the individual situations which were observed. For example, as previously mentioned Denise was particularly rushed after a busy day out and needed to prepare a meal from scratch for both her mother and Burt (see section 6.2.2). Surrounding this, as noted in the field notes, Denise also worked part-time and discussed feeling particularly stressed generally when the researcher visited the family triad at home. This context appeared to shape the frames which Denise took to this dining situation, relating to certain behaviours in the dining interaction:

61:12: Denise: [enters the living room] you alright in here? [Denise starts setting the table]
Burt: mm, yeah… did you have custard?
Denise: Did I have custard [laughs]… no… [laughs]... why would we be having custard?!
Burt: [chuckles]
Denise: We might be having custard for after's

In this example, Denise is attempting to do two things at once, whereby she is focused upon getting the table ready, the meal prepared and she is also attempting to have a conversation with Burt. She appears to undermine Burt's conversational input and expose that he has inserted an irrelevant framework into the interaction as she shows surprise and laughs at his input. This may be because Denise was largely operating in a primary, serious framework, in terms of preparing the meal, affecting her ability to transform her frames to support Burt's perspective. Denise appears then to revise her frames to support Burt's conversation by talking about dessert. However, this initial undermining appears to embarrass Burt as he becomes aware he has not met the norms of the conversational frame. Following this, Burt said very little during their dining situation and largely repeated what Denise said, which may have related to his own worries about being unable to meet the frames for the social interaction. However, this conversational style from Denise did not appear to reflect how she perceived she should manage changes from the interviews whereby she discussed concealing difficulties from Burt to support his frame understandings and using benign fabrications. However, within the dining situation, she undermines Burt and his mis-framing in conversation. This suggests the strategies which were discussed in the interviews may not always be available to people as they go about their day-to-day interactions. Having time to revise frameworks appeared to be important to be more flexible in conversations, relating to

Goffman's (1974) notions that interacting in transformed frameworks depends upon there being no pressing needs present.

The context of having a guest, i.e. the researcher, in the scenarios with Alastair and Tanya and Trudy and Edward also appeared to influence the dining interactions, whereby in both these situations, the family dyads appeared to frame the dining scenario within a social frame. This influence can be noted in the following example with Alastair and Tanya:

63:39: Alastair: when I come I always make sure I amuse everybody when they come… says me [laughs]
Tanya: Rachel thinks your funny don't you
The researcher: I do
Alastair: how much was it [pretending to count out money]… 10 quid

Alastair frames the dining situation as social, suggesting he tries to "amuse" people when they visit, joking about charging a fee for his entertainment. Tanya supports a social framing and does so throughout their dining interaction, for example using benign fabrications and ensuring she sits down to eat at the same time with the other dining participants. However, Alastair's behaviour within the dining scenario differed to how Tanya described their dining interactions with just the two of them in the interviews:

27:64: "Tanya: it just happens. He doesn't talk he just sits, he sits down for his, you know he just sit down… so I get everything, I run around get everything" [individual interview, family member tAD]

Tanya appears to suggest that typically during their dining interactions there is no social element, however, this differs to what was observed when the researcher dined with them. It appears then that dining situations were exactly that, situational and largely dependent upon variable contextual factors, such as whether a guest was also present for the meal, cueing the relevant frames for the interaction. The presence of the researcher may have motivated a social framing, whereby both Tanya and Alastair worked at creating an inclusive, social dining interaction. As well as this, Tanya and Alastair had their grandchildren staying with them that week, which may have influenced dining becoming more of a social experience over the week as they all had been eating together over that time. These situations may also have supported Alastair to more confidently insert his own cognitive frameworks, as grandchildren were reported to be particularly supportive in the interviews (see section 5.4.4).

Similarly, Trudy and Edward appeared to work at creating a social dining experience which may have differed from how typical dining situations were for them. This discrepancy can be seen in the following description from Trudy:

64:42: Trudy: when I was… normal… I was very slow as well because I would be talking all the time at the table at the table, chatter, chatter, chatter but I don't do that now
The researcher: you've been talking quite a lot today
Trudy: mm yeah… I think it must be a treat

Given Trudy and Edward had not dined with the researcher before, Trudy appears to view this situation as novel as she says it must be a "treat", suggesting this scenario was not typical of their usual dining situation. Both Trudy and Edward may have made an extra effort to create a social framing to support an enjoyable dining experience for the guest. However, Trudy suggests a more practice-focused framing where she focuses upon her management of the meal operates on a day-to-day basis, perhaps losing the opportunity for social interaction as her effort becomes focused on meeting frame expectations of consuming the food. Furthermore, they ate at the table in this scenario whereas usually they reported eating in front of the television in the living room, suggesting this was a more novel context which may have influenced the types of frameworks which operated to produce this dining experience.

The presence of the researcher appeared to impact the dining interaction with Louise and Richard in a different way. The researcher was invited to observe from a distance and sat behind the family dyad, at the other end of the room. This may have related to less of a social framing, whereby the researcher was seen not as a dining guest but as a researcher. In their dining scenario, Richard turned his chair around once he had finished his meal and began discussing changes in their dining experiences, as they had done in the interviews:

62:18: Richard: [turns chair around to talk to the researcher who is sat behind Louise and Richard at the back of the room] Louise's function, main function is that she will clear up… that's the deal, I prepare it and cook it and Louise washes it up
The researcher: ah, that's a good deal
Richard: I'm not sure for who… at least I haven't got to do both
The researcher: how's washing up Louise?
Louise: fine, fine
Richard: I frequently find though, plates in wrong cupboards and knives not where the knives should be but where the forks should be so that aspect of coordination isn't there you know…

she knows what draw they go in but they're not always… I can find two knives in with the spoons

This conversation shows how the presence of the researcher, related to a unique context whereby Richard turns his chair around as soon as he finished his meal, leaving a potential social dining interaction with Louise and focusing attention on the social interaction with the researcher, whilst Louise is still eating her meal. This shows how the dementia-related changes are brought into the main-track of the experience, changing the framework to one similar to in the interviews. Richard appears to be interacting in an illness framing whereby he clearly discusses the changes he has noticed to Louise's abilities. This may have been influenced by the fact the researcher had visited them previously to discuss changes and thus the researchers' presence acted as a cue for this type of interaction, relating to a disconnection from the social dining situation. This may differ from how the dining interaction would be without the researcher, whereby there may be less of an illness framing and more of a framing around the social dining experience. Overall, then dining experiences appeared to be largely situational and governed by the various frameworks which made up each unique dining situation.

6.3 Maintaining meaning in dining interactions

6.3.1 Concealing disruptions to dining frames

This section addresses the processes which appeared to support maintaining meanings within dining interactions as they unfolded. A key process which was identified in all the observations, was dis-attending to dementia-related difficulties as they unfolded. This relates to the strategy of optimising opportunities for continuity as identified in the interviews (see section 5.3.6) and this process appeared more important for dining in action than when reflecting upon their experiences after they occurred. This may be because the behaviours which unfolded in the observations constituted a type of 'dining' performance and thus the interactants were more concerned about keeping changes disrupting the main-track of this 'on-stage', dining performance (Goffman, 1959), as opposed to when reflecting upon changes. Not only was this discrepancy apparent in the interviews, but also in the observation with Trudy, whereby she appears to use strategies to dis-attend to dementia-related difficulties as they unfolded, but would bring in to the conversation PCA-related changes which occurred at another point in time. This can be seen in the following conversation:

64:12: Trudy: I was saying about how I tried to put the… kni-kni- knifes and forks, when you went out to get the fish and chips and I put loads of them on top of each other or something [laughs]… what did I do?
Edward: yeah you piled them altogether [laughing]
Trudy: cos I thought I was being really good… [laughing]… I just had to put them into the draws… that's all I had to do [laughs]

This example suggests openness about changes and revising frameworks around changes in a humorous way may be more of a reflective coping strategy following difficulties that have occurred and may be less useful when these difficulties actually occur in real-time, whereby this situation is governed by certain dining conventions for behaviour. Trudy may subconsciously hope to give off the desired impression that she is able to perform the role of managing her meal and therefore uses dis-attending strategies to cope with any difficulties. The following example shows how Trudy attempts to conceal her difficulties from both Edward and the researcher:

64:15: Edward: Do you do much cooking? // Trudy: [Trudy blows on her fork and puts it into her mouth with nothing on it, she looks wide eyed around the room]
The researcher: I'd say I'm learning
Trudy: did your mother show you?

In this example, Trudy looks around the room as if to check no-one has noticed her difficulties. She prevents her difficulties from disrupting the social conversation and continues to join in with conversations with the other diners. Neither the researcher nor Edward appeared to notice these difficulties as they were attending to frames related to the social conversation and their own eating practice. As well as this, Edward also appeared to co-operate to support Trudy to keep difficulties with managing the meal from entering the main-track of the shared dining experience by using the concealment track:

64:35: [a leaflet is posted through their letterbox]
The researcher: who's delivering at this time?!
Edward: I don't know [he gets up to retrieve the post]… Brexit post [he hands the leaflet to the researcher]
[whilst the researcher is reading the leaflet, Edward sits down and quickly pushes food back onto Trudy's plate which had fallen onto the table]

Edward appears to strategically use the concealment track whereby he can support Trudy's eating practice without this management strategy entering the researcher's own frames. He exercises some tact to support Trudy whilst the researcher is reading a leaflet, discretely pushing food back onto her plate. This management strategy is concealed from the researcher's own evidential boundary as it was only when the researcher watched the video back that this strategy became known. This shows how family dyads could work together to conceal difficulties to maintain social façade in dining.

However, there were limitations to this process, whereby it sometimes appeared more difficult to ignore or suppress out-of-frame acts. As Goffman (1974) suggests behaviour can be dis-attended to if it is not too obvious or repeated. For Trudy, she appeared to have more opportunities to conceal her difficulties during the beginning of the meal when both the researcher and Edward are also eating. This relates to the idea of commensality, whereby all the diners are attending to shared frames of eating and drinking together. However, Trudy's practice is slower than the other diners and towards the end of the scenario she is the only person eating, separating her practice from the other diners. Here she appears to have less opportunity to conceal her difficulties, as the researcher and Edward move their attention towards her practice. This related to frame breaks and disruption to the main-track of a social dining experience and a focus upon Trudy's difficulties, as can be seen in the example in section 6.2.2. This shows how, whilst dis-attending was a useful coping process to maintain frames of dining around the social interaction, this coping process was not always available.

Dis-attending to PCA symptoms as a coping process can also be seen in the following two examples of the dining interactions between Richard and Louise, whereby Louise appears to ignore Richard's verbal prompting to support her consumption of the meal:

62:57: Richard: Your knife's upside down
[Louise turns her knife around]
Richard: that's it [Richard sits back in his chair and observes Louise's eating]
Louise: it's stringy this

62:46: Richard: you haven't touched any of your wine
Louise: what was I saying…

In these examples, Louise gives a minimal response towards Richard's support and appears to quickly change the subject. In the first example, Louise appears to use the physical food as a prop to anchor the conversation away from her difficulties (see section 6.3.3). This shows how the eating environment could be used as a resource. Perhaps Louise is also resentful towards Richard bringing her difficulties into the main-track, as in the first example she is also presenting her own dissatisfaction with the meal Richard has prepared. This shows how both members of the dyad could affect one another's dining experiences, in terms of supporting one another's changes in roles, relating to the theme of engaging in supportive social environments from the interviews (see section 5.4.3).

This dis-attending strategy was also observed for people living with tAD, particularly in terms of dis-attending to incorrect actions or entering the wrong stream of action. As identified in the interviews, other dining interactants appeared to use benign fabrications to support the person with tAD's framed reality, keeping changes in behaviour from disrupting the social dining interaction. This can be seen in the following example from the dining situation with Burt, Denise and her mother:

61:61: Denise: can I have my knife please? [laughs]
[Burt looks and passes the knife to Denise from next to his plate]
Denise: thank you
Denise's mother: did you get your knife?
Denise: it's alright! I've got it… what do you think of the new sausages?

Denise appears to respond to Burt taking her knife in a normative way, simply asking to have it back. This suggests Denise is attempting to dis-attend to Burt's mis-framed practice, to support his sense of reality and inclusion in the situation. However, Denise's mother threatens the dis-attendance to this mis-framed practice by bringing it back into the conversation and suggesting that this framework is incorrect by asking Denise if she got her knife. This relates to Goffman's (1974) suggestion that "an individual's sense of knowing what is going on is most often threatened is one in which other individuals are immediately present" (p. 379). Denise uses a warning tone with her mother, as if to tell her to keep this in the concealment track and then uses the physical eating environment as a prop to anchor frames towards the food (see section 6.3.3). In the interviews, Denise and Burt were more open about discussing changes to their dining experiences together and this was one of the reasons they were selected to be observed (see section 3.4.3). This further suggests that when engaging in actual dining situations, dis-attending to dementia-related difficulties appeared particularly useful and diners could co-operate to support this. However, as Goffman (1974) suggests deceivers are responsible for knowledge management and could clear the frame as Denise's mother appears to do in the above example. This relates to the next section on how dining experiences were largely co-created by individuals in interaction.

6.3.2 The impact of the social environment

Following on from the example with Burt and Denise in the previous section, it appeared important that other diners in the social environment co-operated in terms of dis-attending to dementia related difficulties. This can be seen in the following example from the observation with Tanya and Alastair:

63:15: Tanya: can you pass that to Rachel please Alastair?
Alastair: [Alastair puts the sauce onto his drinks coaster and slides it across the table towards the researcher]
Tanya: thank you very much
The researcher: thank you

The diners in this situation could have questioned Alastair as to why he was using his drinks coaster to pass the sauce over and clear the frame in terms of him entering a wrong stream of action. However, given Tanya and the researcher had awareness of Alastair's diagnosis, they may have appropriately interpreted this behaviour in a natural framework and perceived it as part of the condition, as opposed to a socially guided response. Therefore, rather than clearing the frame and telling Alastair this was 'incorrect', both diners appear to collusively let this behaviour slide into the interaction, whilst they may hold transformed frameworks as to what this behaviour represents. As reported in the interviews, this also opens-up variability across experiences and shows how dining interactions could become vulnerable to disruptions in framing and misunderstanding given people were often interacting under 'multiple realities' within the dining space.

Another way the social environment played a fundamental role in dining experiences was the way it shaped the framing of situations and influenced the actions of others. Overall, the social environment appeared to cue relevant behaviours to maintain social inclusion and co-ordination with other dining interactants. To provide an example see the way the diners in the observation with Burt appear to cue each other's behaviour towards the relevant framework:

61:45: Denise: [in the kitchen area washing up and clearing away]
Denise's mother: [in the dining room] nothing on the floor is there… no I haven't dropped anything [looks under the table]… [she picks up the mustard] so I'll go and put it down there, put that there… errr [looks around]

Burt: [sat at the table watching mother-in-law]… [he begins switching the glasses around on the table and moving them back and forth]…
Denise's mother: you've got that one there, that drink that drink yours yeah
Burt: yep, that one's there and that one's there [he slowly points to two of the glasses which he has been moving around]

In the above example, Denise is busy in the kitchen washing up and clearing away the meal. This appears to activate Denise's mother's framing to engage in clearing the table, signalling to Burt that clearing away is the correct framework to anchor one's behaviours to. These external cues may then have supported Burt's own response, whereby he begins to move the glasses back and forth on the table. This appears to give Burt the experience of having a purposeful role, co-ordinating his behaviours with the other participants. He says, "that one's there and that one's there" to his mother-in-law, appearing to make it clear that he is handling this part of clearing away. This shows how people with tAD could engage in familiar frames which may relate to the main anchor of the situation, i.e. in this case clearing away. Although this had no pragmatic, outcome-focused purpose, it may have psychologically supported Burt to feel purposefully and socially included in the dining situation. It appeared important the other dining interactants accepted this type of behaviour into their framing, supporting the experience of the person with tAD.

The social environment also played a crucial role in inclusion in dining conversations, particularly for the two dyads living with tAD. Whereby diners created a non-threatening social interaction, this appeared to support inclusion in conversations. For example, in the dining situation with Tanya and Alastair, Tanya appears to use uncertain frames to support Alastair to insert his own cognitive understandings into the interaction. This was a strategy which Tanya did not discuss in the interviews suggesting perhaps it was a new strategy she was using since the interviews, or this strategy was unconsciously operating to support Alastair's inclusivity. This strategy was also not picked up in interviews with other people living with tAD. The following example shows how Tanya uses these uncertain frameworks to support Alastair's participation:

63:15: The researcher: Eddie the eagle?
Tanya: He's the man who…didn't he want to be an Olympic downhill skier… he wanted to be an erm… downhill skier… downhill… skier? [she looks at Alastair]
Alastair: yeah, something like that yeah
Tanya: and erm, there wasn't anyone who'd been downhill…

Alastair: yeah, there was a film about it [nodding head]… there was a sort of story about it but they'd made it a bit clever but it was very good, very enjoyable
The researcher: He was a bit of an amateur wasn't he… is that what the story is?
Alastair: mmm

This strategy appeared effective for Alastair to add his own understandings about a movie they had recently watched in an unthreatening environment. Rather than Tanya making it clear she holds the power of beliefs which may be threatening to Alastair, she appears to use vague and uncertain frames herself, allowing room for Alastair to share in guessing at the correct frames in the interaction. This appears to be a type of benign fabrication whereby Tanya knows the frameworks but is 'play-acting' to support Alastair's more uncertain frames of reference. This contrasts with interactions between Denise and Burt where it was clear Denise had frames beyond Burt's own understandings and he has difficulty engrossing himself within these interactions:

61:66: Denise: This time last Wednesday it was really cold
Burt: it was very cold
Denise: it was horrible wasn't it… we had a stew because it was so cold
[Burt's holding knife and fork whilst Denise's mother and Denise are still eating their meal. He looks around, takes a sip of his drink. He looks at his drink. He puts it back down. He grabs hold of the knife and fork again. Burt looks down and moves things around.
Denise: was it nice?
Burt: mm… it was very nice
Denise: "I'll have to phone Harry later cos he said he was going to come and do the ceiling"
Denise looks at Burt…
Burt: what did you say?
Denise: Well I text him a few days ago and he text when we were in hospital and he said can I come tomorrow so I text him back, yes, cos obviously we couldn't do very much in hospital…so I'll try and phone him now and make sure he's coming and then we'll only have one loft hatch
Burt: silence [starts moving knife around]
Denise: won't we!
Burt: mmm

In this example, Denise inserts her own frames into the conversation and Burt appears to struggle to insert frames which meet these understandings. This relates to reports in the interviews of difficulties with social conversations among family dyads living with tAD (5.3.2).

Burt appears uncomfortable within this situation as he starts twisting his knife and shuffling items on the table, suggesting he is perhaps embarrassed and uncomfortable as he is aware the frame is vulnerable to collapse. Furthermore, Burt is unable to engross himself in the physical aspect of eating the meal as he has finished his food at this point before the other diners. This may relate to further vulnerabilities as he cannot engross himself in the commensality aspect of eating the meal. Denise attempts different frames for the conversation e.g. about the weather, about his meal and the loft, however Burt does not engage in these, perhaps as they rely on short-term memories and Burt may not have these frames to bring to the dining conversation. Denise appears to become increasingly frustrated with Burt's lack of input as she says "won't we!", suggesting her own frame expectations for conversation are not being met here and there is a disruption in framing for her. This shows how dementia affects both the person and those they interact with as they can struggle to co-create meaning and identify shared understandings. Overall, the social environment appeared to have a key impact on how Burt was included in conversation. In relation to this, in the interviews, Denise also reported that Burt does converse with others at the dementia day centre (see section 5.4.4). Relating this to the example with Tanya and Alastair, perhaps Burt feels less cognitively threatened in this environment, and may feel more confident to insert his own cognitive frames into these interactions.

Familiarity in the social environment also appeared to play an important role in the way people with tAD could be supported in their engrossment in the social conversation. The following example shows firstly the struggle Alastair has in conversing with the researcher and the way he uses Tanya to support his memory:

63:33: Alastair: Funny houses these… it's a street which was… the land and err, out in county and out in the… country all around… err [Alastair scratches his head]… people who've got 'we've got ordinary… who've got ordinary word… work… [holds his head and looks down at the table]… yeah… [he looks over at Tanya who is doing the dishes]
Tanya: I can't hear what he's saying
The researcher: lots of houses on the street
Alastair: yeah well they were new houses relatively, yeah
The researcher: [looks over at Tanya]
Tanya: well they're not huge, large houses down with big gardens and there are almost 12 houses up here… with big gardens, see how big our garden is, we didn't mind did we
Alastair: no as I say… quite narrow these houses are, very long and just on the street there, it was long like that… and all the houses go like that

This example shows how all the diners in this exchange are working to find a shared framework in the dining interaction. It appears to be particularly useful that Tanya has many shared experiences with Alastair, meaning she had more memories with him and she could work with Alastair to fill in gaps in his frame knowledge and anchor the conversation towards a shared understanding.

In the dining situations with the two couples living with PCA, the social environment also appeared to play an important role, influencing the way dementia-related changes were perceived. In the dining situation with Louise and Richard, at the very start of the dining situation, Richard frames Louise's eating practice as 'wrong', which appears to relate to the way Louise also perceives her own practice and the way she manages difficulties. This framing from Richard can be noted in the following example:

62:2: Richard: That's the other thing about Louise she's left-handed… well she eats that way, rather than eating the other way… I always blamed her parents for not correcting her when she was a child

Richard provides this framing at the beginning of their dining interaction, suggesting that her eating practice is 'wrong' and that this is another thing, along with the dementia-related changes. It appears Richard has the framing that there is a 'right' way to do things at mealtimes and largely views Louise's practice as not meeting these anchored expectations for dining. This framing may have influenced Louise's own non-acceptance frames of the dementia-related difficulties she has, as can be seen in the following example:

*62:8: Louise: "I hate these things [cutting up food]… [food drops off the fork three times]… b*** things…"*

Louise appears to be frustrated in this example when the meal is not handled as it 'should' be and food drops off the fork numerous times. She says these words very quietly to herself, it appears out of earshot from Richard in the video. This shows how Louise attempts to conceal her difficulties and maintain a social façade, as these behaviours may be perceived as disrupting frameworks for acceptable dining behaviours. Similarly, Louise may have her own frames that these behaviours are unacceptable, showing how dyads can work together and share the frames they have for dining. Throughout their interaction, she also appears to manage difficulties with eating conduct herself and dis-attends to any support Richard tries to offer as can be seen in the example in section 6.3.1. Wanting to suppress or hide difficulties and maintain decorum, also related to the types of management strategies Louise reported using in the interviews such as retreating from eating out in formal environments, which could be related to a shared framing that changes in her eating practice were ‘wrong’.

Not only did family members appear to influence the person with dementia’s dining experience, but people with dementia also appeared to play a role in the way other diners experiences were affected by dementia-related changes. The following example shows how Trudy works to help the researcher and Edward frame dementia-related difficulties in a humorous framing and accept the changes into the dining interaction:

64:40: Trudy: [Trudy picks up a large portion of broccoli with the end of the fork which hangs off the end of the fork]… very healthy… OH, OH [Trudy struggles with getting the piece of broccoli into her mouth which she balances against her lips]… See! I can balance them! [laughing]… I’m good at doing that

Trudy manages potential social embarrassment with her difficulties entering the main-frame by using humour, negotiating the potential discomfort of others through this strategy. This may be a strategy to keep a social, enjoyment framework in the main-track of the dining situation as opposed to an illness framing seeming to disrupt this experience. This may have been particularly important to Trudy and Edward as the researcher was also dining with them as a guest. It was obviously difficult to dis-attend to these changes given they were so pronounced in this example and so Trudy manages the frame disruption by using humour to help others around her incorporate such changes as acceptable.

Another way Trudy appeared to influence the dining interaction was by emphasising a social frame as the main-track for the dining situation, as opposed to a pragmatic, ‘mealtimes as a function’ framing. As found in both the interviews and the observations, outcome-focused frameworks could exclude the person with dementia when they were unable to meet the framing conventions for this. In the following example, Trudy appears to encourage a social framing of the dining interaction as when Edward is clearing away she emphasises this as the wrong framing for their dining situation:

64:67: Trudy: so well… in this country [she says to the researcher]… oh
Edward: [Edward is in the kitchen area, can hear the pans clattering as he is clearing away]…
Trudy: Oh Edward shut up!
Edward: I’ll be done in a minute

Trudy appears frustrated with Edward when he is clearing away, emphasising that this is not the relevant framework and it is disruptive towards the social framing of their interaction. This supports Trudy to suitably engross herself within this social framing, suggesting Edward is the one who is excluded by clearing away. This relates to Goffman's (1974) notions around unconnectedness as an anchoring device whereby Trudy is encouraging Edward to ignore aspects of the situation which are not relevant to the ongoing social frame. This supported the dining experience whereby Trudy could remain included with the other diners, as whilst she may have 'failed mealtimes as a performance' (Nyberg, 2016) she was able to engross herself within a social, enjoyment framing. Overall, then it appears the social environment plays a key role in dining experiences, shaping the meanings-made and influencing behaviours of others.

6.3.3 The impact of the physical environment

The use of the physical environment for supporting dining interactions became particularly apparent in the observations. The environment appeared to provide props and opportunities for meaningful engrossment in the dining situations. For example, for the two couples living with PCA creating a simpler physical environment appeared to be important so that physical difficulties did not disrupt the social dining frames within the situation. Furthermore, the physical environment could be simplified for all the diners, creating a mutually exclusive situation and sense of commensality within the dining interaction. For example, in the dining observation with Trudy and Edward, Edward provides just a fork for the meal and cuts up the meal beforehand for all the diners within the interaction. This may have helped Trudy feel socially included within the situation, providing an inclusive situation where everyone had equal participation status. This type of strategy may support people with PCA to feel 'part of the team' as opposed to standing out as different or excluded from frames the other diners may be engrossed in. The following example shows how Richard also discusses he is mindful of the physical environment in supporting Louise with engrossing herself within the eating activity:

62:49: Richard: Do you want to eat this yoghurt?
Louise: oh yeah
Richard: it wouldn't have been a good idea… but perhaps I should have left the top on the yoghurt… because she'd never have got that off
The researcher: but you'd usually take it off
Richard: yeah

Here, it appears Richard sees the impact of the physical environment on Louise's' ability to manage her meal, as well as his own impact upon these engrossment opportunities. Richard firstly discusses how he could have left the top on the yoghurt, whereby Louise's' symptoms may stand out more, but makes clear that he would typically take the top off, whereby Louise can engross herself into this framework. This shows how the physical and social environment interacted, whereby Richard had some responsibility over the engrossment opportunities for Louise.

As previously mentioned, the physical environment could also be used as an important resource for anchoring to shared conversations. This was particularly useful for the two dyads living with tAD, whereby finding shared frameworks for conversation could be more difficult. The use of the physical environment as a cue for social interaction can be seen in the following example:

63:43: Tanya: I used to eat only 2 eggs a week cos of cholesterol and now they say that's not right
Alastair: do you like the glasses?
The researcher: I do like the glasses, yeah
Alastair: I had to say that
Tanya: Which one's your favourite?... this one or this one?
Alastair: Well I always liked the Romans… you know the romans the romans they're very ancientand they made beautiful glasses like that… they're absolutely beautiful
Tanya: You picked these glasses didn't you at Ikea

In this exchange, Alastair appears to use props within the physical environment as a conversational tool to interact with the other diners. He appears to move the conversation from Tanya's utterance about lowering her cholesterol, to asking the researcher about the glasses on the table. Tanya then appears to join Alastair's conversational frameworks, by asking him which glasses on the table he likes best, providing an opportunity for Alastair to meaningfully engross himself in social interaction with the other diners. Again, this shows how both the physical and social environment were useful for maintaining meaning in dining interactions, relying on both Tanya being flexible in responding to Alastair's movement in the conversation, as well as Alastair using props in the environment to stimulate conversation which did not rely so much on stored frameworks. This supported the diners to anchor their activity around a shared external framework.

Tanya also appeared to use the physical environment as a cue to socially connect with Alastair and provide a sense of continuity through changes. The following example shows how the physical environment both connect Tanya and Alastair, past and present:

63:24: Tanya: you like peas don't you… do you remember when I met you and your favourite was fish fingers, chips and peas
Alastair: probably yeah… from when I was about 3 probably yeah
Tanya: [laughs] Alastair gave us a really good date… took me out for fish fingers, chips and peas
Alastair: hang on... now, now, now, now

Tanya uses the peas from the meal as an important anchor for her to sustain a sense of continuity in the relationship between her and Alastair. Tanya uses this prop to socially connect to her husband and convey a story to the researcher about when they were first dating and Alastair shares in a humorous framing with his wife around this. This relates to the concept of resource continuity, whereby material traces in the environment can help individuals verify past events and may provide both Tanya and Alastair with a sense of continuing togetherness when experiencing changes related to living with dementia.

The physical environment was also identified as an important resource for conversation in the observation with Denise and Burt. For example, Denise reported that she usually has the TV on during dining, but they had not turned it on during the main meal when they were being observed. This relates to section 6.2.3 whereby contextual differences shaped the dining interactions. As Denise said during their dining situation "it's quiet in here tonight, there's no telly on is there", suggesting this was an important prop they typically used within the dining environment to anchor and coordinate their interactions. Denise then turned the TV on for the dessert-part of their meal in the observation. The following exchange shows how this external prop supported social connection among the diners:

61:53: Denise: [turns TV on]
Burt: ohh… that's that guy isn't it [he moves his body forward closer towards the TV]
Denise's mother: oh is that that man
Denise: yeah
Burt: he's the one that erm… actually got. What's he got?
Denise: I don't know what he's got… something motor neuron… he's a scientist isn't he
Burt: yeah, he's a scientist guy

In this example, rather than Denise inserting her own frameworks which Burt appeared to have difficulty connecting with (section 6.3.2), Burt is able to use the physical environment i.e. the entertainment on the television to insert his own frames of understanding. This appears to be a supportive social situation for all the diners as they participate on an equal, uncertainty level, guessing at who the person is on the television, rather than any of the diners having a power of beliefs over the other interactants.

Another use of the physical environment to connect people in the dining situation was consuming the meal itself, in other words engaging in commensality in the eating practice. For example, Burt appeared engrossed in consuming the meal and had no difficulty inserting the correct frames for consuming the meal alongside other diners, however, once he had finished eating he appeared unsure of what to do, in terms of identifying the relevant frames to insert into the interaction. This relates to Goffman's (1974) notions around frames being looser in informal interpersonal experiences given no formal apparatus governing these situations. Therefore, engaging in eating could support people with tAD to engross themselves in relevant frames. Where the meal did not pose barriers for the two dyads with PCA, this commensality experience was also observed. However, when people with PCA had difficulty with the physical eating practice, their engrossment in the eating frame appeared more vulnerable and the physical environment could instead act as a barrier in the social connection with others. For example, Trudy appeared to talk less as she struggled to manage the meal and it took her longer to eat than the researcher and Edward, relating to her standing out as separate or excluded from the commensality frameworks with the other diners. Overall, many of the uses of the physical environment presented in this section were not discussed in the interviews, suggesting observing interactions is useful for understanding how people use the environment to support their everyday interactions.

6.4 Summary of chapter 6

Overall, the dining observations showed how dining experiences were largely situational and varied depending upon the different frames which constituted moment-to-moment interactions. There appeared to be some discrepancies between the way people sometimes reflected upon their dining experiences within the interviews, compared to when they engaged in dining when observed. This may be related to dining behaviours being an 'on-stage' performance, a bracketed activity which is marked by its own frame conventions, particularly as these dyads were being video-recorded, therefore it may have been more difficult for participant to accept dementia-related changes into the main-track of the dining interactions. Each dining situation also appeared to be heavily influenced by context, for example, whether the researcher was dining with them as a ‘guest’, or how stressed family members perceived themselves to be before the dining situations unfolded. Overall then this chapter shows how dining experiences often fluctuate.

Across all four observations, dining interactions appeared to be disrupted by dementia-related changes relating to experiences such as social embarrassment, frustration and difficulties establishing what was going on (Goffman, 1974) during exchanges. However, largely changes were dis-attended to and filtered into the dining interactions, relating perhaps to these dyads creating a new normal around their changing behaviours. Participants used strategies such as collusive communication, props in the physical environment and the social environment to support maintaining meaning within their dining interactions. For people with PCA, as found in the interviews, disruptions were largely related to the physical eating performance and engrossment in dining frames were affected. Family dyads often worked to create inclusive eating environments, for example, simplifying the eating environment. For people with tAD, as found in the interviews, disruptions were largely related to social conversation and establishing ‘what was going on’ at any given moment. Family dyads often worked to support mutual frames for dining interactions, for example, by using the physical environment as a prop for anchoring shared frames to. Family members of people with tAD could also use benign fabrications to support the person with dementia’s understanding as to what was going on and use uncertainty-type frames to support engrossment in conversations in a non-threatening cognitive environment.

The final discussion chapter brings together the findings presented in this chapter and those presented in the previous chapter. It also relates the findings to the existing literature and discusses the use of Goffman’s (1974) Frame Analysis for providing a theoretical framework to support understanding around how people living with dementia both experience and can maintain meaning in their everyday dining interactions.

Chapter 7: Discussion

7.1 Introduction

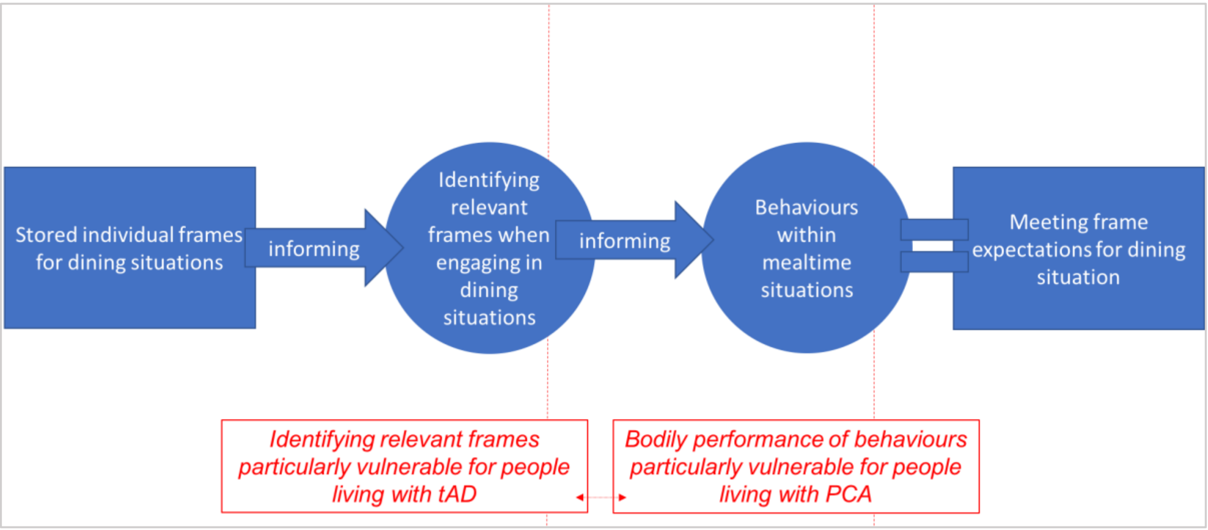
In this chapter, the first section provides a summary of the findings from the interviews and observations in relation to the research questions. This is followed by a discussion of the findings in relation to the existing literature. Rigour of this study is also outlined using the qualitative evaluative criterion as set out in chapter three (section 3.7). The strengths and weaknesses of this work in terms of what it brings to the literature on dining experiences for people with dementia is then provided. Finally, implications and ideas for future research in this area are outlined. The chapter ends with the conclusions for this study, summarising the study and value of this work overall.

7.2 Summary of findings

In Section 2.4, four research questions were outlined for this study. How these research questions have been answered will be summarised within this section and the findings from the interviews and observations are brought together in more detail following this. The first question was concerned with how people perceived their dining experiences when living with tAD or PCA. This question was particularly addressed in the interviews and the findings suggested that expectations people had for their dining experiences could become disrupted when living with either type of dementia. For some, this tension in their expectations meant eating-related practices could lose meaning as a social, dining experience and people could begin to anchor their frames around eating-related practices as management tasks. The second question was around strategies people use to maintain meaning in dining experiences when living with tAD or PCA. Various psychosocial processes were identified, particularly in the interviews, and observed somewhat within the dining scenarios. A balanced, interconnected process of revising frames, management strategies, optimising opportunities for continuity and engaging in supportive social and physical environments appeared to support people to continue to find meaning in their changing dining interactions. The third question was concerned with how dining interactions were affected as they unfolded when living with tAD or PCA. This question was addressed through the video-based observations, which revealed how dining interactions could become complex and misunderstandings arose as family dyads coordinated various meanings in their interactions and these frames, at times, conflicted. The observations also revealed that in many ways dining interactions did not appear to be affected by dementia-related changes as families appeared to have adopted a ‘new normal’ for their interactions. The final question for this study was concerned with how people supported successful dining interactions as they unfolded when living with PCA or tAD. The observations revealed how families often dis-attended to disruptions to the dining frames, for example, using the concealment track and collusive communication to maintain social façade. The observations also showed how props in the physical environment were often used to anchor frames towards a mutual understanding and repair conversations over the dining interactions. The social environment also appeared to play an important role in shaping the unfolding dining interactions, where individual's frames of diners had an influence over one another's frames in these unfolding encounters.

The first key aspect of this study was understanding how dining was for people with two different types of dementia (research questions 1 and 3). Both the interviews and observations revealed important differences in how these two dementias could affect dining experiences and disrupt interactions. Diagram 1 summarises these differences as well as showing how there could be some degree of overlap between the two dementias. For people living with tAD the main vulnerability appeared to be related to difficulties with identifying the correct cognitive frames within dining situations to inform relevant behaviours (Goffman, 1974). This related to difficulties such as entering the wrong stream of action, being undermined by others in social situations and difficulties finding shared frames for social interaction at the dyad level. Family members often used benign fabrications to support the person with dementia's sense of reality. However, transformed frames also meant people with tAD could become marginalised and excluded from the evidential boundary of the frame which others were included in. Family members could also experience a lack of meaning and frustration when they did not transform their frame perspective from a primary framing of the person with tAD's behaviours. As well as this, transformed frames also related to more frame disputes and working at cross-purposes when interacting with one another during dining. Given that people with tAD were less likely to notice changes to their functioning than family members, often the problem for people with tAD was other people, whereby their frame perspective may be disconfirmed by others framing patterns, calling into question 'what was going on' at any given moment when engaging socially within shared dining spaces, relating to suspicion and doubt. In this way, the sense of reality and realness was affected, where some dining experiences lacked this quality.

Diagram 1: Pathways towards vulnerable dining experiences, whereby people living with tAD tended to have more difficulties identifying relevant frames whereas people living with PCA tended to have more difficulties engrossing themselves into the relevant frames.



Rather than difficulties identifying the frame, as shown in diagram 1 people with PCA more often appeared to 'think to do it', i.e. they were aware of the frame with which they wished to anchor their dining behaviour to, but often could not, relating to frame breaks and disruptions to the experience. This related to more feelings of social embarrassment, frustration and uselessness and over-engrossment and burden for family members as they often stepped in to support the person with PCA. When people with PCA 'failed mealtimes as a performance' (Nyberg, 2016), this related to an illness framing coming to dominate the main-track of the dining situation. This could relate to unconnectedness from the anchoring of dining as a social experience, to an anchor towards dining as a management or care-task.

Although there were important differences when comparing experiences of living with tAD and PCA, overall it appeared that dining experiences varied across the sample and largely related to different contexts aside from the symptoms themselves. Goffman's (1974) Frame Analysis (1974) helped to explain this, whereby frames are informed by many stored knowledge frames which people bring to their dining interactions, including frames for the 'self'. Therefore, it did not appear to matter so much what the nature of the changes were for people with dementia or family members, but whether they disrupted individual's expectations for how dining situations *should* be. Context appeared important, whereby different dining situations related to the activation of different frame assemblies which informed the way dementia-related changes were appraised. This was particularly apparent from the observations, whereby dining experiences appeared to be largely informed by the physical and social environments people were engaging in. From the interviews, changes were often reported to be more threatening when they were perceived in a socially guided framing, than when they were perceived in a natural framework. For some, this led, to more difficulties with dining out, where when other people in restaurants did not have a ‘dementia’ or natural framing available, dementia-related changes were thought to be judged with more social scrutiny.

The second aspect of this study was to identify processes related to maintaining meaning in dining experiences and suppporting dining interactions when living with tAD and PCA (research questions 2 and 4). Whilst comparison between the two dementias was initially the focus, the constant comparison process revealed how the processes people used to maintain meaning, regardless of type of dementia, largely overlapped. Five key processes were identified from the analysis of the interviews with 20 family dyads living with both tAD and PCA and these are summarised in table 3. As can be seen in the table, each process appeared to be both useful and limited in supporting dining experiences. For example, whilst management strategies could help control the extent of symptoms, strategies such as eating aids often carried their own social definitions and could be seen to further disrupt dining if they did not compliment frame expectations. Furthermore, if they were not balanced with other strategies this could relate to over-management and hypervigilance affecting the dining experience. The use of these processes appeared to be interconnected and a balanced system of different processes, continuing to shape and recreate the meaning of dining, appeared to be particularly effective to support maintaining meaning in experiences. It appeared important that family members and people with dementia were attuned to the way the other person used these different strategies and coordinated their processes of maintaining meaning accordingly.

There were some differences in the use of strategies to support maintaining meaning in dining experiences, for example, revising frames for people with PCA more often appeared to be related to using a natural framing related to symptoms of the diagnosis to incorporate changes as acceptable. Family members of people with PCA and tAD also appeared to use this process. However, for people who had tAD, it appeared they were less likely to assimilate changes within a natural frame and may use social frames or more creative attribution styles, such as normalising changes around their situation to incorporate them as acceptable. This appeared to make it more difficult for people with tAD to revise frames, as they were viewed as more socially guided and thus more likely to be judged than if they were viewed in a natural framing. Therefore, some family members of people with tAD appeared to see it as more appropriate to revise their own frames and use benign fabrications to support the other’s sense of reality.

Table 3: Summary of the processes identified to support maintaining meaning in dining experiences among people living with PCA and tAD

Strategy	**Definition**	**Usefulness for dining**	**Limitations for dining**
Management strategies	Symptom-specific solutions e.g. cutting up food, simplifying the meal, providing ‘props’ in the environment, verbal prompting, slowing practice, cooking together, benign fabrications, collusive communication, discussing known frames of reference etc.	• For controlling the extent that dementia-related changes enter the main-track of the dining experience	• Over management or over-control of symptoms, could lead to unconnectedness to the ‘social element of dining • Some management strategies used to control symptoms perceived as not meeting frame expectations for dining
Revising frames	A cognitive and/or emotional process of reshuffling, reorganising, reframing or adding to frames around dining	• Accepting new behaviours into the dining experience • Developing a new norm • Openness about changes	• Relied on having knowledge frames to rationalise behaviour • Could be upsetting or representing loss • Less useful when revising frames conflicted with self-identity • Less useful when changes conflicted with dominant dining frames
Co-creating dining experiences	The social environment informing one another’s frames in dining situations	• Learning together to incorporate changes as acceptable • Learning from wider social networks • Entering supportive social contexts	• Others dining frames having a negative impact on own frames around dining • Others misinterpreting changes in a social framework
External dining contexts	The external environment informing frames in dining situations	• Engaging in supportive external contexts, e.g. where less formal expectations for behaviours such	• External environments having a negative impact on own frames around dining e.g. when eating in public

		as day centres or eating with grandchildren	places such as ‘formal’ restaurants
Optimising opportunities for continuity	Identifying aspects of dining which connect people with their pre-dementia lives	• Anchoring to continued sense of reality • ‘Recharging the batteries’, or a break from coping with changes • Resilience in dining environments	• ‘Head in sand’ or not dealing realistically with changes, relating to denial • Defensiveness when changes arise in dining situations

The observations largely complimented the interviews, for example, it was observed that dementia-related changes could disrupt the main-frame of dining interactions, and processes such as the use of management strategies, the physical and social environment and opportunities for continuity were observed. However, some important distinctions were also identified. Firstly, there were some discrepancies between the way in which people sometimes reflected upon their dining experiences in the interviews, compared with when they engaged in dining in the observations. It is suggested that the dining situations may have represented a kind of ‘on-stage’ dining performance (Goffman, 1959), with its own bracketed framing conventions, when participants engaged in these situations compared to when they reflected on their experiences in the interviews. People appeared more concerned about preventing changes from disrupting the main-track of the dining scenarios and worked at maintaining a social façade within these situations. Furthermore, the physical environment was also identified as useful in the observation as a prop for social conversation and to dis-attend from dementia-related changes. For example, people with PCA could use the physical eating environment as a prompt to move attention away from difficulties with eating the meal itself and people living with tAD often used the environment as a device for social conversations. This can be related to Goffman’s (1974) concept of resource continuity whereby resources within the environment provided enduring frame conventions and for people living with dementia this may be particularly important for providing shared frames of reference to anchor dining conversations to. In terms of the social environment, strategies such as using uncertainty frames to support people with tAD to insert their own frames, as used by Tanya, appeared to support the engrossment opportunities for the person with tAD. This relates to findings in the interviews, whereby people discussed supportive social contexts included dining with grandchildren or in places where there were other people with dementia. These environments may be perceived as being less cognitively threatening. Many of these strategies were not reflected upon during the interviews, suggesting subtle aspects of the social and physical environment which people may not be consciously aware of can facilitate dining interactions as they unfold.

7.3 Findings in relation to the literature

7.3.1 Dining experiences among people living with dementia

Overall, this study showed how dining experiences were complex and varied. On the one hand, the findings supported the Life Nourishment Theory developed by Keller and colleagues (e.g. Keller et al., 2010), in terms of dining offering a potential space for positive interaction, promoting connectedness (e.g. Han et al., 2016) and honouring identities (Genoe et al., 2012). In this study, this was understood in terms of Goffman's (1974) concepts around framing conventions and resource continuity, whereby enduring aspects of dining frames and props in the external environment could support people to anchor themselves to experiences of continuity, reality-confirmation and connection, providing a kind of 'safe space' when living with dementia-related changes (e.g. Pearce et al., 2002). This supports the concept of commensality, whereby eating and drinking together is a fundamental social activity, creating and cementing relationships over time (Fiese et al., 2006). However, given these dyads were living with changes, engaging in dining could, at times, promote disconnectedness and confusion in a shared sense of reality and exacerbate experiences of loss associated with living with dementia (e.g. Phinney et al., 1998; Steeman et al., 2006). Furthermore, role changes within the dining space could also relate to loss of sense of self for people with dementia (e.g. Caddell & Clare, 2011) and stress and burden for family members as reported in some of the existing literature (e.g. Papastavrou et al., 2007). Engaging in the shared dining space could also relate to tensions within the social relationship relating to literature on living with dementia overall (e.g. O'Connor, 2007; O'Shaughnessy et al., 2010). Goffman's (1974) Frame Analysis provided an explanatory understanding for these experiences, in terms of engrossment being affected, as well as tensions in identifying cognitive frames in terms of what was going on. Dining could begin to lose meaning when behaviours deviated from people's frames for how dining experiences should be. This related to a deconstruction of meaning and people could begin to anchor frames around eating-related practices as a management task or illness-related experience, losing its meaning as a dining experience. This relates to Keller's (2006) finding that family members of people with dementia could have a 'food as medicine attitude'. Other studies have found that viewing eating-related practices through a task-orientated lens affects mealtime enjoyment for family members of people with dementia (e.g. Sidenvall, 1999; Keller et al., 2006; Aselage & Amella, 2010; Genoe et al., 2012).

Literature on living with dementia reports tensions between continuity and change (Caddell & Clare, 2011), suggesting in some ways dining experiences mirrored the way people were in living with dementia (e.g. Keller et al., 2010). Dining experiences promoted both continuity as well as discontinuity, relating to a state of flux. Given eating-related practices are a particularly well-framed activity, bracketed with various framing conventions, they may more obviously present difficulties for people with dementia when they enter into them, as opposed to more loosely framed activities such as social conversations or interpersonal situations. For example, some therapeutic interventions are being developed around creative and art-based activities for people with dementia (e.g. Beard, 2012) and one reason these may be effective is that they have less expectant frames than activities such as dining which are made up of various framing conventions for behaviour.

This study also addressed how eating out experiences could be affected by dementia-related changes. Reported dining out experiences appeared to have some therapeutic potential, for example, for connecting people with their past, through eating out in familiar restaurants and connecting people with friends and family, as well as relieving family members from cooking-related roles. This relates to the paper by Cassolato et al. (2010) from the Eating Together series on dining out experiences which found this could help people maintain a balanced life, acting as a binding glue for relationships and environmental balance. In this study, this was understood using Goffman’s (1974) Frame Analysis, in terms of the dining out environment providing props to support a social framing for people with dementia and family members. However, it was also found that this activity was perceived as more difficult for many people in this study and many had chosen not to eat out anymore, therefore this activity did not always promote a balanced life but could exacerbate stresses. One suggestion for this was that eating out related to more of an on-stage ‘performance’ (Goffman et al., 1959) whereby people living with dementia may have felt more pressurised to meet societal norms for behaviours within this public setting. Furthermore, many participants discussed how given other diners in restaurants do not have natural frames around dementia to revise their expectations, changes in behaviour may be incorrectly perceived in a socially-guided frame and thus relate to more social judgement of the self by others. This may help to explain why some people in this study reported eating in the corner of restaurants, concealed from the view of others, could be supportive. In the study by Cassolato et al. (2010) it was found eating at ‘off-times’ could be more supportive for people with dementia, i.e. away from judgemental frames from other diners in restaurants.

This study also supported understandings around how individual contexts could shape dining experiences. As outlined in the literature review, other studies found gender-related ideologies with females tending to have a stronger cooking-role identity than men, which influenced the way in which dining experiences and roles became affected when living with dementia (see section 2.3.4). As well as this, factors such as age (e.g. Klinke et al., 2014) and type of relationship also appeared to influence the way changes impacted upon people's dining experiences in this study. For example, people living with older-onset dementias often normalised their situations in relation to their peers. However, this was not a hard-and-fast rule, whereby some older people still struggled to adapt to changes and vice-versa for people with young-onset dementias, as well as gender-related roles having variable influences on the way people appraised their dining experiences. To explain this, this was conceptualised in relation to Scheff, Phillip and Kincaid's (2006) notion of frames as 'defining contexts' using their interpretation of Goffman's (1974) work whereby individuals 'shuffle' through their vocabulary of "words, phrases, propositions and images… so that the situation becomes meaningful for them" (p. 90). 'Age' and 'gender-roles' then may be one 'word' or 'image' but this interacts with other frames and individual contexts to produce meaning. Although it may be important then to identify at-risk groups, i.e. people who may have more difficulties successfully adapting to changes because of various frameworks related to their life contexts, it may also be important to have an in-depth meaningful dialogue with individuals to understand the individual frames of meaning they bring to their dining situations. Many studies on experiences of living with dementia overall also recognise the multidimensional nature of experiences shaped by many factors such as culture, context, relationship dynamic, support structures, personal coping resources and meanings people ascribe to their situations (Hayes, Boylstein, & Zimmerman, 2009; Hibberd et al., 2009; Lin, Macmillan, & Brown, 2012).

A major element of this study, which makes it unique from other studies on dining experiences in dementia is the comparison between dining experiences for people living with different types of dementia. The constant comparison between living with amnestic presentations compared with visual-variations of dementia supported the identification of how specific symptoms could affect dining experiences. Importantly, this highlighted how people with tAD and family members could differ in their perspectives over dining changes, where there appeared to be more frame disputes among people with this diagnosis than for those living with PCA. This is the first study which appeared to differentiate dining experiences, whereby existing studies largely appeared to report on either shared experiences (e.g. Keller et al., 2010; Genoe et al., 2012) or experiences of either people with dementia or family members (e.g. Johansson et al., 2011; 2014). Goffman's (1974) concepts around transforming frameworks provides a language for understanding how people coordinated different perspectives in interaction, supporting understandings of both the complexity of dining experiences when living with tAD and the use of strategies such as benign fabrications to support differential understandings within shared interactions. Koestler (1967) terms this element of Goffman's (1974) theory bisociation whereby he illuminates how people can see phenomena simultaneously from two contradictory viewpoints. These differential perspectives are supported in some ways in the wider literature on living with dementia which suggests people with dementia and family members could work at cross-purposes, relating to tensions when engaging in shared tasks (e.g. Vikström et al., 2008). Using Goffman's (1974) concepts also helped to legitimise perspectives of people with tAD and understand how they often worked to confirm their own reality, for example, engaging in roles related to preparing meals to confirm perspectives they were still able to do this, despite family members often viewing such behaviours in a different frame.

This study also appeared to be the first to examine qualitatively the effects of living with dementia-related visual loss on dining experiences for people with PCA. This related to difficulties with the physical aspects of eating conduct. As found with studies with people who have had a stroke or Parkinson's disease, social embarrassment at not being able to eat 'properly' was reported as a key difficulty for people with PCA in this study (e.g. Carlsson, Ehrenberg & Ehnfors, 2004; Klinke et al., 2014). Similar management strategies were also reported such as eating smaller portions when dining out (Andersson & Sidenvall, 2001), avoiding certain foods, using eating aids (Nyberg et al., 2016), hiding difficulties in the company of others (Klinke et al., 2014) and taking smaller bites and mashing up food (Miller et al., 2006), to maintain social façade and keep symptoms at bay. This study interpreted this in terms of Goffman's (1974) ideas around social embarrassment, as relating to when individuals 'break frame', interrupting the main-frame and "capsizing as an interactant" (p. 349). This understanding helped to conceptualise how family members were also affected by these frame breaks and how an illness framing could come to dominate the main-track of dining experiences. Studies with people with stroke and Parkinson's disease used other theoretical frameworks to explain social embarrassment related to eating conduct difficulties. For example, Merleau-Ponty's (1945) corporeal schema (e.g. Klinke et al., 2014) and Bourdieu's (1977) concept of the habitus (e.g. Gustafsson et al., 2003; Nyberg et al., 2016). These theories generally suggest embodied representations of habit relate to the person not being able to fulfil these 'normal' standards, relating to disorder and embarrassment. These standards are then predicted to 'recalibrate' and new patterns of behaviour become normal and people adapt (Merleau-Ponty, 1945). However, these theoretical explanations largely overlook differences in the way some people adapted whereas others appear not to. They also overlook the effects of the physical and social environments in relating to the way people perceived their dining performance. Furthermore, there appeared to be a cognitive learning aspect to the way people revised their understandings of ‘acceptable’ behaviours within dining situations, for example where people revised their frameworks in interaction with others, as opposed to purely a natural process of recalibration.

7.3.2 Micro-social dining experiences

Another major focus of this study was on micro-social dining experiences among people in this study. This was supported by utilising the sociological lens of Erving Goffman’s (1974) Frame Analysis (1974) which provided a conceptual framework for understanding how people make sense of their everyday life worlds and how they coordinate and manage these understandings when interacting with others. This focus was further supported by the video-based observations, which provided a closer look at how dining interactions could be facilitated as they unfolded when living with dementia. This unique lens provided an understanding of how contextual dining experiences were and how they varied for individuals from moment-to-moment, shaped by the physical and social environments people were engaging in.

Another key element of understanding micro-social experiences was focusing upon how conversations were coordinated within the dining space. It appeared conversations could become disrupted, for example for people with PCA whereby physical difficulties could disrupt conversational frames and for people with tAD, in terms of identifying a shared frame for conversations. The findings with people with tAD compliment the study by Bohling et al. (1991) which also used Goffman’s (1974) Frame Analysis to explain how people living with tAD used benign fabrications and responded flexibly in conversations (see section 4.3). In this study, it was found people often used the physical environment to repair conversations. It appeared the physical environment could support anchoring frames towards a mutual external frame. The physical environment was also used in conversations among people with PCA to distract from eating-related difficulties. The usefulness of the physical environment was further enhanced through video-based observations, whereby it was observed various props within the physical environment supported social conversations when dining. The use of the physical environment has received less emphasis in other studies, in terms of how it can be used to repair conversations when misunderstandings arise. This may be because, as Wohlwill (1973) suggests “the environment is not in the head!” (p. 166) and video-based observations may be more useful for understanding how the environment impacts upon experiences than asking people to reflect upon their experiences. These findings relate to some of the literature in care-homes with people with dementia whereby a more person-centred dining environment, for example including familiarity and home-like environments could support dining experiences (Chaudhury, Hung & Badger, 2013).

7.3.2 Supporting dining experiences

Relating processes to support maintaining meaning in dining experiences from this study to the existing literature, it appeared all the processes which were identified have been reported elsewhere. For example, ‘revising frames’ relates to the normalisation process reported in other studies whereby people may change their attitudes or use humour to accept changes into their dining experiences (e.g. Keller et al., 2006; Hsiao et al., 2013; Papachristou, Giatras & Ussher, 2013; Ball et al., 2015). Furthermore, this study also found that viewing dining in a serious primary framing, related to more changes being perceived as disruptive to experiences, whereas when experiences were transformed in meaning, i.e. in terms of social dining opportunities, this related to more changes being perceived as acceptable. Other studies have found that viewing eating-related practices through a task-orientated lens affect enjoyment for family members of people with dementia (e.g. Sidenvall, 1999; Aselage & Amella, 2010; Keller et al., 2006; Genoe et al., 2012).

The importance of ‘optimising opportunities for continuity’ to support dining experiences has also been identified in existing research. For example, Johansson et al. (2014) found this was useful for family members of people with tAD, describing this as a way of ‘recharging the batteries’ whilst adapting to a new life. This is also reported in the wider coping literature in terms of adapting to dementia overall (e.g. Murray & Livingston, 1998; Pearce, Clare & Pistrang, 2002; Robinson, Clare & Evans, 2005; Caddell & Clare, 2011; Wolverson, Clare & Monz-Cook, 2016). Kullberg et al. (2011) found continuity through dining appeared important for men who had motor impairments, whereby the coping strategies they used appeared to be driven by seeking continuity in their lives, as opposed to adjusting to the disease itself. Kullberg et al. (2011) used continuity theory, which suggests that older adults usually maintain the same activities and behaviours from their earlier years, as an explanation for why consistency in patterns of thinking about dining and cooking roles were important. Another key element identified in this study is in the co-creation of meaning through engaging in situations. This relates to literature which highlights the importance of reciprocacy in supporting each other’s experiences of living with dementia (e.g. Wadham et al., 2016). Atta-Konadu et al. (2011) found the transition in cooking roles among family dyads was supported by ‘reciprocal nurturance’ i.e. promoting one another’s self-worth. Indeed, in this study the social environment appeared to have a key influence on the way other diners framed their dining experiences.

An important finding which extends understanding of dining experiences when living with dementia was how each process was both interconnected as well as limited in its usefulness for maintaining meaning in dining experiences, particularly where they were used in excess or not balanced with other processes (see table 3). For example, too much continuity, i.e. ignoring changes, related to denial and lack of acceptance towards changes and could be maladaptive for coping. Some existing models in dementia research address how processes work together in such an interconnected way. For example, one study by Piiparinen and Whitlatch (2011), applied the Kearney (1996) model to understand coping among family members living with dementia. The researchers used Kearney's distinction between two kinds of mind, suggesting that problem-focused strategies for dealing with changes (i.e. management strategies) occur at the level of the 'surface' mind. However, confronting the losses, in terms of the emotional load, threat, trust and letting go, all occur at the level of the 'deep' mind. They presented the 'ideal' caregiving situation where people are attentive both to the emotional labor involved in care as well as actual tasks and care planning. They suggested that caregivers who have adjusted at the level of the 'deep' mind will not attempt to control or over-manage the situation i.e. using management strategies but will accept certain contingencies and empower the person with dementia, providing a kind of 'innocence of perception' for family members to step-back and stand in when necessary. This relates to some of the findings in this study, whereby family members who revised their frameworks, appeared more likely to use management strategies of empowering the person with dementia to be independent in managing their meal (see section 5.4.6). This may be related to this intersection between the deep mind and surface mind, whereby when family members accept losses at the deep mind level, may be more willing to let dementia-related changes into the main-frame for dining, without wanting to jump in to manage the situation.

7.3.3 Macro-social processes relating to dining experiences

Finally, an important consideration for this study is the philosophical lens which was taken by the researcher in relation to Goffman's (1974) 'structured social psychology' (Verhoeven, 1993, p. 322). This lens recognises both individual agency in framing, as well as framing conventions which exist on more of a societal level which supports individuals in interaction to collectively organise their behaviours (see section 4.2.5). In this study, although the focus was upon the micro-social environment, it was clear wider societal frameworks appeared to influence the frames people both attempted to anchor to and used to structure their experiences. For example, one consideration was that family members often anchored to frames around the caring role being about 'management' and burden and stress. One criticism of work with family members of people with dementia is the suggestion that there has been a preoccupation with the negative or pathological aspects of care, as opposed to focusing on the positive aspects of caring (Twigg & Atkin, 1994; Cohen, Colantonio & Vernich, 2002). If the focus is on the caring role being one of burden and stress and around management of symptoms, this may affect the discourse for family members' meaning-making around their changing eating-related practices. This could further relate to family members disconnecting from a social dining framework and anchoring frames around these wider macro-social discourses. Other macro-social influences such as Western ideologies about the importance of individualism and being responsible for one's own life also appeared to relate to difficulties accepting support and tensions within family dyads in managing changing roles. This was also identified in a study by Fjellström & Synder (2013) with older people and the influence of these ideologies. They found that "there is a dilemma in the dichotomy between encouraging independency and managing food in everyday life when in need of support" (p. 47).

7.4 Evaluation of this research

In section 3.7 the researcher defined and outlined a number of criteria for evaluating this study to ensure rigour. Rigour of this study is addressed and discussed below using these criteria.

7.4.1 Credibility and relevance

Credibility deals with the question "How congruent are the findings with reality" (Merriam, 1998, p. 201) and relevance refers to how relevant the explanatory findings are for meeting the research aims. In this study, the research aimed to address how perceived dining experiences and actual interactions are affected for people living with two types of dementia, tAD and PCA and how people living with these diagnoses support their experiences and interactions. The researcher feels credibility and relevance have been shown in this study in the following ways. Firstly, in utilising standard grounded theory processes for analysis and outlining the exact procedures which were used for analysis in the methods chapter including constant comparison, open coding, focused coding and memoing (see section 3.6). This shows the adoption of well-established research methods which are useful for understanding every day experiences and social processes which can support understanding of behaviours (Glaser & Strauss, 1967). Grounded theory procedures take the researcher from the first stages of data collection, right through to the end stage of writing up (Charmaz et al., 2006) and utilising these procedures throughout the research process was deemed a useful approach, particularly for the researcher as a novice qualitative researcher. It is important to note that the researcher did not apply grounded theory in the 'purest' sense (see section 3.2) and some researchers may suggest this then lacks rigor, however, on balance, the researcher decided to use the tools flexibly for meeting the research aims as opposed to attempting to fit in with a particular ‘school’ of grounded theory. The researcher was mindful of this however and ensured she outlined the exact grounded theory tools which were used for this study as outlined in section 3.6.

Another way a researcher can ensure the findings are credible is ‘prolonged engagement’ between the researcher and participants to form an adequate understanding of the area of interest (Shenton, 2004). This study is advantaged in that the researcher visited family dyads at least twice to collect interview data and four of the families were visited three times to include the dining observations. The interviews were in-depth, with the initial Seeing What They See interviews taking around 3 hours for each visit and dining interviews taking around 1- 1 ½ hours. This provided time for the researcher to develop rapport with participants, which may have supported them to be open about their experiences. As well as this, these procedures supported the researcher to gather rich data and develop an adequate understanding of people’s dining experiences. Prolonged engagement was also supported by data-analysis from the beginning of the data collection process, as recommended by grounded theorists (e.g. Charmaz, 2006), therefore the researcher engaged with the data for over three years, developing a sense of familiarity with the participant’s reported experiences as the analysis and data collection evolved.

Furthermore, in relation to data collection, according to Brewer and Hunter (1989) using different means of data collection supports credibility of the findings as they make up for limitations of other methods. This study utilised vide-based observation methods and individual and dyadic interviews to collect data. These different methods supported understandings from multiple angles. For example, by conducting dyadic interviews this provided some understanding of shared dining experiences. Following this, individual interviews provided space for participants to bring their individual perspectives and differentiate their frameworks from shared perspectives around changes. Although the researcher would have liked to have conducted more video-based observations and have incorporated this earlier in the analysis (see section 7.6), the dining scenarios which were observed also provided rich data in terms of understanding behaviours and interactions during dining. This revealed new data, some of which people did not report in their interviews or which conflicted with responses, providing a more complex understanding of dining experiences. Credibility can also be achieved by including a suitable number of people with which to compare experiences (Shenton, 2004). In this study, 20 family dyads were included in the interviews and four of these participated in the video-based observations. Overall, this provided a wealth of data, including 60 mealtime interviews (two individual and one dyad interview for each family dyad) and rich video data. This provided a substantial data-set with which to compare and identify patterns and themes.

In terms of analysis, to enhance credibility it is recommended that researchers use low-inference descriptions (Ary, Jacobs & Razavieh, 2009, p. 501) staying close to people's accounts. The grounded theory approach of open coding using in-vivo codes, i.e. participant's own words as codes, supported the researcher to stay close to their accounts during the initial stages of analysis. This ensured the themes which developed were grounded in their accounts of their activities, protecting against potential researcher bias. Suitable digital recording equipment (both audio and video) and accurate transcription of interviews and observational data was also important. This included rechecking the digitally recorded data against written transcripts to ensure the wealth of data was captured. The qualitative software, Atlas.ti 5.0, acted as an effective storage system to manage the large amount of data, organise analysis and support the process of constant comparison across the themes and participants. In presenting the findings, thick descriptions of the phenomena under study are thought to enhance credibility, helping to convey the actual situations which have been investigated (Shenton, 2004). In the findings chapters 5 and 6 of this thesis, direct quotations are used to convey people's dining experiences in their own words.

Checking the findings against existing findings and with peers is also suggested to enhance credibility in a qualitative research study (Silverman, 2000; Shenton, 2004). In terms of checking findings against existing literature, this was supported by an 'informed' qualitative methodology which used abductive reasoning (see section 3.6.5), to test the data against the existing literature and theoretical frameworks as the analysis went on. The relationship between this study's findings and existing research is presented in section 7.3, including not only studies on dining experiences in dementia, but also related to the broader literature on experiences of living with dementia overall. The congruence between this study's findings and others enhances the credibility of the findings presented for this study. This congruence also shows how the explanatory understanding using Goffman's (1974) Frame Analysis concepts also has 'grab' (Glaser, 1978) and relevance in relation to experiences of living with dementia overall. Opportunities for scrutiny of this project by colleagues, peers and academics was also welcomed by the researcher. For example, findings were presented at several conferences and seminars and feedback was welcomed by the researcher. Given this study connected with the larger Seeing What They See project (see appendix 1), which included a multi-disciplinary team of researchers, the researcher also utilised opportunities to share findings and gather feedback from colleagues at the multi-disciplinary team meetings.

One suggestion to enhance credibility for qualitative studies which was considered during data collection by the researcher is member checking or sharing transcripts and analysis with participants (Lincoln & Guba, 1985; Page, Samson & Crockett, 2000). Member checking was not done in this study which may limit the credibility of the findings. As outlined in the methods chapter (section 3.3), it was decided member checking was not appropriate for this study, firstly from a confidentiality perspective because individuals often shared perspectives they wished to conceal from their partner in separate interviews and feeding back on these perspectives could have caused tensions and difficulties within the relationship. Secondly, the researcher also understood this data as process, as representing a set of framing patterns people had to understand their dining experiences at one point in time, sharing these transcripts later may not then be relevant at a different time point and may have affected the way families continued to process and shape their dining experiences. The researcher was mindful of doing no harm to participants and taking these factors into account it was deemed inappropriate to share interview transcripts with them, despite the fact this may have enhanced the rigour of this study.

7.4.2 Transferability

Lincoln and Guba (1985) suggest that for a quality study, qualitative researchers should provide a sufficiently thick description of the phenomena under study to allow readers to have a thorough understanding of the boundaries of the study, allowing them to make judgements of how the instances of the phenomenon described may transfer to other situations. This has been provided in the two findings chapters (5 and 6). Furthermore, this is supported by conceptual understanding using Goffman's (1974) Frame Analysis which supported understanding social relationships and contexts which related to various dining situations. This is an important component of providing rich descriptions, in terms of making explicit patterns of cultural and social relationships and context (Holloway, 1997). For example, considerations of how the researchers presence influenced the observations is included in chapter 6 (see section 6.2.4)

In sections 3.4.2 and 5.2 of this thesis, the researcher has also provided a detailed outline of the study sample. This includes details of the recruitment base i.e. the Specialist Cognitive Disorders Clinic at UCLH and restrictions in the type of people who contributed to the data based on this recruitment site. Restrictions include that participants were active volunteers in various research projects and people with PCA had access to specialist support and advice through the clinic. Furthermore, many of the participants were from a White-British, middleclass background. Therefore, there are limitations to the transferability of these findings to other samples and it is important that the researcher is transparent about this.

However, whilst this sample is restricted in some ways, recruitment through the Specialist Cognitive Disorders clinic also afforded access to participants with this rarer-dementia, PCA, which would not have been feasible without access through this recruitment site. This was a key benefit of being attached to the Seeing What They See study. Furthermore, as presented in the results, a diverse range of dining experiences were still reported among this sample, both across and within participants accounts, allowing patterns in psychosocial processes and behaviours to be revealed. Transferability in this study is enhanced by the number of participants who took part, which included 20 family dyads overall (as well as an extra member in the observation with Burt, Denise and her mother). This was a large qualitative sample providing rich information, as well as diverse in terms of including people with two types of dementia and a range of ages, suggesting the findings have some transferability across different contexts.

7.4.3 Dependability

Dependability refers to the consistency of the inquiry processes over time. The researcher has been mindful to document in detail each stage of data collection and analysis in a logical manner in the methods chapter, including details of the decision process which led to the researcher selecting various approaches. Reviewing memos which were written from the beginning of the research process, which included methodological decisions and procedures, helped the researcher to be able to provide a detailed description, including decisions and processes which were used over time for this study. It also supported the researcher to keep track of how the research interests developed over time from a study on eating-related practices to a study on dining (see section 1.4) and the theoretical frameworks which were critically considered in relation to the ongoing data analysis (see section 3.6.5). Furthermore, the codes and groups for codes which developed in the analysis are included in appendix 13 to show how the results relate to the raw data. The quotes used in the results chapters also use codes taken directly from Atlas.ti 5.0 providing an audit trail to the raw data for this study.

7.4.4 Neutrality

Neutrality relates to ensuring that, as far as possible, the works’ findings are the result of the experiences and ideas of participants as opposed to characteristics and preferences of the researcher (Shenton, 2004). Grounded theory emphasises an inductive, data-driven approach, i.e. grounded in peoples' experiences, therefore the use of open and in-vivo coding, as well as transcribing interviews from audio-recording supported the researcher to stay with participants'' accounts of their experiences, supporting neutrality. Abductive reasoning also supported this process of achieving neutrality. Abductive reasoning emphasises being critical and considering various hypotheses from multiple angles along the way, as opposed to adopting a 'pet theory' or idea. In reviewing the memos, which were recorded along the way of this study, at least 14 theories were considered in relation to the emerging data analysis (see section 3.6.5). Following this, Goffman's (1974) Frame Analysis was selected as the most comprehensive and useful sociological approach for helping in the interpretation of themes which were emerging from the analysis in relation to dining. Furthermore, as outlined in chapter four, Goffman is critical of grand theories and suggests sociology should be a classificatory science (Verhoeven, 1993). Therefore, his terms have been used to support the description and classification of changes to dining experiences and how people could maintain meanings, however, given Goffman's (1974) sociological lexicon is flexible, it did not involve forcing data into pre-existing hypothesis or grand theory, which would have affected the confirmability of findings. Using different methods can also reduce the effects of researcher bias, which may have been supported using both interviews and video-based observations.

7.4.5 Work

This refers to how the data can "explain what happened, predict what will happen and interpret what is happening" (Glaser 1978, p. 4). The findings show how certain processes work to support dining experiences, as well as variations in this across participants, relating to individual frame assemblies which governed different dining situations. The findings are the result of careful constant comparison, across and within peoples' experiences. The workability of these findings is also supported by the fact that they also support and help to explain many findings in the existing literature, as discussed in section 7.3.

7.5 Strengths of this study

Many of the strengths and weaknesses of this study have been considered in relation to the evaluative criterion in the previous section. However, here the main strengths which are not covered in these sections are discussed in terms of what this study offers to the existing literature. Firstly, this study contributes to an emerging second-generation of research which distinguishes between different types of dementia, comparing changes and experiences for people living with PCA and tAD. As far as the researcher was aware, this was the only qualitative study to explore dining experiences for people living with PCA. The comparative approach allowed symptom-specific aspects of experiences to be drawn out, in terms of living with an amnestic-led and visual-led dementia. This helped to illuminate specific vulnerabilities to dining experiences, such as for people living with tAD in terms of how different realities were managed in dining interactions. As well as this, comparing between the two diagnoses, helped to draw out similarities in terms of living with a neurodegenerative dementia overall, here this included processes used by people living with tAD and PCA to maintain meaning in dining experiences including revising frames, management strategies and optimising opportunities for continuity.

In terms of the methodological approach, the use of grounded theory procedures and early-engagement with data analysis was a strength for this study. For example, by allowing the research questions to emerge from the main areas of concern among participants, this taught the researcher about how eating-related practices as a dining experiences were important to people living with dementia, as opposed to this activity as a management task (see section 1.4). Listening to participant's accounts and using a data-driven approach, taught the researcher about the importance of personhood (Kitwood, 1997), or seeing the person first and how people could show themselves through engaging in dining-related activities. In this way, it became focused on dementia as a social experience for people with the diagnosis and those around them. The flexible, data-driven approach supported this learning process for the researcher, as opposed to imposing pre-existing hypotheses around aspects of eating-related practices which may not have been important to participants.

Secondly, the use of grounded theory supported a holistic understanding of processes associated with supporting dining experiences, as opposed to viewing different processes in isolation. The constant comparison method as the basic tool of grounded theory was useful for identifying links between the different processes. Furthermore, the constant comparison approach also was useful for comparing and contrasting data from people living with tAD and PCA and the experiences of the person with dementia and their family members. This supported the identification of patterns across the whole sample, as well as identifying specific experiences, for example, differentiating experiences for people with dementia and family members. As outlined in section 3.2 this study was not intended as a 'grounded theory' study i.e. to develop a grounded theory around dining, but rather utilised tools from grounded theory to support an in-depth understanding of people's experiences, grounded in their reports. This supported the identification of different themes and experiences, as opposed to producing a theory which combined experiences which may not capture rich descriptions and variations in the complexity of dining experiences.

In terms of the procedures and data collection approach, this study is advantaged by the amount of data which was collected including video-based observations and individual and dyadic interviews. The procedure of using in-depth interviews and visiting participants on multiple occasions may also have benefited people who took part in this study. For example, people with PCA have largely been excluded from research on their experiences in the past. Therefore, this research offered them the opportunity to have a voice and share their experiences, particularly using a flexible approach to allow space for their concerns to be made central. All people living with dementia who took part in the Seeing What They See study and who were approached and asked to take part in the interviews agreed, suggesting they may have found some benefits from being involved in this kind of research where they are able to reflect in their own words on what was happening in their day-to-day lives. In the words of one participant in the interview:

27:88 Tanya: the biggest help is doing research with you, you would be amazed how much I've learnt this morning just from talking to you, because you think you're on your own… [individual interview, family member, tAD]

It appeared then for Tanya and perhaps others, by talking and engaging in the interviews, they could think through the various changes, helping to continue to organise their frames in a way that supported their changing dining experiences.

Video-based observations also offered an original contribution in understanding dining, in terms of focusing in on the micro-social element of these encounters. This is important as although people with dementia and family members are thought to spend more time together (Evans, 2003), this increased nearness can perpetuate experiences of loneliness and tensions (e.g. Vikström et al., 2008), therefore there is a need to understand what actually is happening when family dyads living with dementia interact together. Observations revealed more about the practice itself, and how it varied in different contexts (Martens, 2012). Observations were also particularly helpful for understanding experiences and strategies for people with tAD, given they did not always verbally report changes or processes they used to support their reality in the interviews. The video-based observations helped to understand how people with tAD appeared to work to support their reality by engaging in familiar frames.

Another strength was the fact observations were conducted after two research visits. The researcher was wary that the presence of a researcher can disturb the scene and affect what is being observed, as well as the use of a video camera causing people to feel on edge (e.g.

Jansson, Nordberg & Grafström, 2001). The fact the researcher had met the participants on two previous occasions, may have supported them to feel more comfortable in being observed. Although the researcher recognised her presence did affect the dining interactions (see section 6.2.4), because the researcher had developed a rapport with participants it may have protected against feelings of being on edge or uncomfortable with being observed.

Possibly the main strength of this study is the use of Goffman's (1974) Frame Analysis to provide a rich, conceptual understanding of dining experiences for people who took part in this study. Few studies have been conducted which apply Goffman's theory to understand illness experiences of living with dementia, therefore this study makes an original contribution to social theory and the field of dementia research, providing an alternative way to conceptualise everyday experiences of living with dementia. A number of aspects of Goffman's (1974) approach provided novel ways to understand how dining experiences could become difficult when living with PCA and tAD. For example, whereby PCA related to vulnerabilities in engrossment and disruptions in the main-track of the dining activity, by contrast tAD appeared to relate to more difficulties identifying the relevant frameworks for dining situations. Another key contribution of his theory, is around natural and social frameworks for judging actions. This helped to explain difficulties with eating out and with social embarrassment in front of strangers which were reported by people living with PCA and tAD in this study. The layering aspect of Goffman's (1974) theory was also novel, whereby he introduced a language for explaining different realms of experiences in interaction and understanding mechanisms which were used by people to manage this such as benign fabrications and concealment during dining interactions.

7.6 Limitations of this study

A number of limitations should also be taken into consideration for this study. Firstly, being situated with the larger Seeing What They See project had both strengths and limitations. In terms of strengths it afforded access to a group of people with a rarer dementia, as well as rich data and a multi-disciplinary team of researchers. However, this study was also confined in some ways by this larger study to a certain group of people with dementia, i.e. volunteers, many long-standing from the Dementia Research Centre and to people who had taken part in the Seeing What They See interviews. This study sample was then 'special' in terms of being engaged in research and perhaps different from experiences of people who may be less engaged in research. As outlined in section 3.4.2 the sample was also restricted in terms of ethnic and racial representation and socio-economic status. Hulko (2009) is critical of studies which include samples largely comprised of mainly white, well-educated, high-class, married professionals in the early-stages of dementia. In Hulko's study she identified that social location (including age, class and geographic location) had a substantial impact on the way people cope with and experience their diagnosis. This is a key consideration for this study and may be bias in its understanding of dining experiences. However, on the other hand, a range of dining experiences were reported by people who took part in this study and this provided some understanding around processes related to varied experiences and strategies to support maintaining meaning in dining. Furthermore, although socio-cultural diversity was an issue, this sample was diverse in other ways, for example, including two different types of dementia and a range of ages.

Another limitation with being attached to this larger study, which has not yet been highlighted was that given these participants had already been visited for the Seeing What They See study, they at times became side-tracked by talking about difficulties and coping overall, i.e. anchoring their frames to the Seeing What They See interviews as opposed to focusing on dining. This meant some of the data was not useful for understanding dining experiences. One way the researcher managed this was by having a focused topic guide to support bringing the focus back to the key areas of interest for this study. However, the researcher was also mindful that the participants should have some control over what they wished to discuss given the researcher was visiting them within their homes and they were volunteering their time. During one visit, with Michael and Claire, Michael was particularly stressed and spent much of the interview discussing his difficulties with living with dementia overall and it was difficult at times to orientate the conversation back to dining given he had other concerns that were more important to him. However, despite this, the researcher still collected rich data on dining experiences overall from family dyads. Furthermore, although in some ways this was a limitation, it also provided a more comprehensive understanding of dining experiences among participants, in terms of not considering dining as an isolated aspect of the day but one which filters into the rest of day-to-day life.

A key limitation of this study was the fact that only four observations were carried out, which were conducted over a year after the last interviews with these participants. Given the interests of this study developed over time with on-going analysis, the potential usefulness of observations was not identified until initial stages of data analysis. Ideally, observations would have been conducted on a wider scale and in conjunction with the interviews, to understand more about how participant's frameworks translated to dining interactions in-situ, however this was not practically possible, partly given the researcher needed to gain ethical permission to conduct these observations. Given dementia is neurodegenerative, some of the participants functioning had declined since the interviews and therefore their difficulties differed from when the interviews were conducted. It was therefore important to have an initial debrief on changes since the last visit and these were noted in the field notes from these visits. Despite these limitations, the video-based observations were identified as a useful methodology which enhanced and refined understanding of the themes which had emerged from analysis of the interview data, as well as providing unique understandings around how people could support their dining experiences as they unfolded. Some could also argue that the presence of the researcher meant that dining experiences were not reflective of people's typical dining experiences. However, this became part of the analysis and the presence of the researcher supported understanding around how having a 'guest' could influence the dining interactions which were observed. As well as this, the researcher was a novice in using video-based observations and on reflection the research may have benefited from video-cameras being left with participants to record their dining scenarios in a more naturalistic situation or a smaller less intrusive device. Furthermore, the analysis process was identified to be fairly difficult given little research identified on how to describe details in video-based data (see section 3.5.4). However, the researcher followed recommendations from Knoblauch (2012) whereby actions and interactions were sequentially transcribed and returned to including as much talk and visual conduct as possible. However, it is important to consider the transcripts of video data are a version of events by the viewer, open to researcher bias, as with other sources of data (Gibson et al, 2005).

Another consideration was that the interview data relied on retrospective knowledge of day-to-day dining situations. Given people with tAD have short-term memory impairments, these understandings were affected. Distinguishing the present from how things used to be is often a primary difficulty for people with tAD (Graneheim & Jansson 2006, Edvardsson & Nordvall 2008), therefore accessing their experiences was difficult at times. For example, people with tAD appeared to talk less in the interviews than people with PCA and may ask the researcher to consult their family members when they were not always sure of exact changes or experiences. To understand what these types of appraisals meant, this relied on the researcher interpreting these reports in relation to reports from family members. For example, management strategies such as repeatedly going to prepare meals or helping themselves to easy access foods were reported by family members as opposed to the person with tAD themselves. Therefore, it was difficult to confirm if this was a coping strategy to support their frame realities as interpreted in this study. it is important to emphasise these are interpretations, compared with the conscious reporting of processes reported by people with PCA. However, observing individuals with tAD and reporting on family members' observations supported understanding of experiences associated with living with tAD. Furthermore, people with tAD did not always have impaired insight and some consciously reported difficulties with identifying relevant cognitive frames to inform their actions and relying on familiar frames. Using Goffman's (1974) Frame Analysis also helped to legitimise the person with tAD's perspective of little changes to mealtimes as their reality and this being as important for understanding dining experiences as family members' reports of changes. This meant that their experiences were valued and seen as being purposeful and having meaning (Dewing, 2002) in this study.

The final limitation which will be discussed here is the fact that this study only collected data at one point in time, as opposed to taking a longitudinal perspective, as in the Eating Together study which explored experiences over 6 years (e.g. Keller et al., 2010; Genoe et al., 2012). Dementia is a neuro-degenerative condition, therefore understanding dining activities over-time would have been more representative of this progression, understanding how people with tAD and PCA continue to adapt and process changes. Given the constraints of the time-frame for the Seeing What They See study, as well as the practical fact this thesis study was funded for a total of three years, it was not feasible to conduct a longitudinal study on dining experiences within the remit of this study. However, data was analysed using gerund '-ing' words to emphasise this data as process and this helped to understand experiences in flux as opposed to viewing the data as having static meaning.

7.7 Implications for practice

This section considers how the findings are suggestive that the following may be useful for supporting people to maintain meaning in dining experiences and interactions when living with dementia. These suggestions may be useful for health and social care professionals working with people living with dementia in the community. The results are encouraging in suggesting people living with dementia can and often do continue to create a 'new normal' for dining alongside their changing situations.

Firstly, as suggested by Keller et al. (2010), encouraging families to engage in eating-related experiences as dining activities, and exploring the role dining can play in helping people maintain their sense of self and social connections may be useful. This could help people connect to frames related to social dining experiences and supporting wellbeing, as opposed to taking a food-as-fuel or management-based approach. This may support people living with dementia to question the social meanings management strategies such as eating aids may carry for individuals as opposed to just introducing them to facilitate the management of eating. Raising awareness that opportunities to engage in activities to confirm sense of self and foster social connections can become more limited for people with dementia (Steeman et al., 2007), may help encourage families to maximise dining as an event to offset these difficulties. This also has important implications for care homes where time restrictions may relate to an over-focus on ‘getting things done’ in a primary framework among staff which impact residents and their own opportunities for dining experiences together with residents (Hung & Chaudhury, 2011; Henkusens et al, 2014). Previous studies have reported that nursing staff in care facilities tend to focus on the mechanical task of feeding but overlook the individual needs and psychosocial aspects of residents' mealtime experiences (Pearson, FitzGerald & Nay, 2003; Gibbs-Ward & Keller, 2005). Bringing dining to the forefront or main-frame, for example, by introducing environmental cues which are meaningful to people for ‘dining’ such as a radio, candles or magazines which may help people anchor to frames around dining. In the study by Keller et al. (2015) they identified a strategy whereby family members had a bowl in the centre of the table with pieces of paper with different conversation ideas on them such as reminiscing about past holidays which may support this focus upon dining.

Secondly, the study suggests that it is important for professionals to have a ‘meaningful dialogue’ with families living with dementia (Zarit & Leitsch, 2001) to understand frame assemblies for how dining situations *should* be to them and the way dementia-related changes interfere with or complement these assemblies. Some people may then need more support with adjusting their understandings or behaviours, and it may be useful to target at-risk groups, such as men new to cooking roles, people living with early-onset dementias and perhaps certain personality-types e.g. people who value individualism and with more rigid thinking styles or conservative expectations for dining where these individuals may have more difficulty revising frames around changing behaviours. It may be important to recognise individuals who are stuck in certain framing patterns or a state of helplessness and target interventions for these individuals.

Furthermore, as some researchers suggest there may be an over-emphasis upon functional ‘problems’ and problem-focused strategies in dementia care which may lead to ideas that management or fixing situations is what ‘being a carer’ is about (e.g. Klinke et al., 2013). However, this study suggests that it is important to use a balanced, interconnected system of various strategies. From the findings in this study over-use of management strategies could be detrimental to dining experiences, for example, where this can relate to hypervigilance, control and attempts to ‘fix’ situations, relating to a lack of enjoyment and people with dementia perhaps hiding their difficulties and being disempowered. However, in the words of one family member in this study (Denise) dementia cannot be fixed. There may be a need to raise awareness of coping as an interacting system, and the importance of a balanced approach to care. For example, employing management strategies whilst accepting certain contingencies and empowering the person with dementia at the ‘deep mind’ level (Piiparinen & Whitlatch, 2011). This may involve emotional work in supporting people to accept losses into their everyday dining interactions as opposed to trying to cover up or fix these behaviours.

It may also be useful to support families living with dementia to employ an ‘innocence of perception’ (Koestler, 1959) in relation to dining frameworks, liberating themselves from various framing conventions which do not serve the actual situation. This relates to the therapeutic use of arts-based initiatives with people with dementia which are free of rigid framing standards and thus more varied behaviours may be accepted into these interactions (Beard, 2012). Challenging personal frames and changing narratives, e.g. from certain dining behaviours being framed as ‘wrong’ to being framed as new and different and related to dementia, i.e. within a natural framework may be helpful. However, this is complicated by the paradoxical finding that enduring frames people had for dining also supported them to anchor themselves to a ‘normal’ aspect of the day and experience a sense of continuity through change (Caddell & Clare, 2011). It may be that oscillating between continuity and change helps people to gradually reframe and support their dining experiences, without feeling overwhelmed with such changes (Atta-Konadu et al., 2011).

Many of the problems reported in this study relate to dining out and targeting this may also be useful for supporting people living with dementia to relate to their wider communities (Sørensen et al., 2008). For example, it may be useful for dining out establishments to be trained in becoming more understanding of diverse dining behaviours and create dementia-friendly environments. This relates to other changes where in the UK, for example they have introduced ‘relaxed checkout lanes’ in supermarkets for people with dementia (Lay, 2018). As identified in this study physical and social environments impact upon the frame assemblies people use to make sense of their experiences. Work could be done with people with dementia to support revising their frames around eating out and planning management strategies to help them maintain social façade, reducing the risk of retreating from these environments and social isolation (Steeman et al., 2007). It may be important for family members to exercise tact in dining out environments, supporting people with dementia to maintain social façade and using the concealment track where appropriate. This relates to the moral debate around whether reality orientation or validation therapy may be more useful. It may be appropriate for family members to question whether orientating the person to ‘their reality’ would be detrimental to their sense of self and social self when engaging in activities such as dining and respond accordingly. For example, benign fabrications may be more suitable in formal dining situations whereas reality orientation may help individuals revise their frames when they are more relaxed, such as when eating at home.

Overall, the different strategies outlined in table 3 may be useful to support families living with PCA and tAD to continue to find meaning in their dining experiences. Raising awareness of strategies which participants did not consciously report in the interviews but which were observed in the dining scenarios may also be helpful. For example, strategies such as uncertainty frames which are less ‘cognitively’ threatening, using eating aids which everyone uses (not just the person with dementia) and props in the physical environment to support conversation appeared to be helpful for dining interactions but were not overtly discussed in the interviews. Further work using video-based observations may further elucidate other types of subtle behaviours which facilitate dining interactions for people living with dementia.

7.8 Future directions for research

There are many areas in which research could develop in terms of understanding dining with dementia. As suggested above, further work using video-based observations with people living with dementia could help develop understanding around subtle strategies which may facilitate dining interactions. Furthermore, studies could also continue to differentiate experiences of living with various dementia-related symptoms. This study supported understandings around how dining experiences could be affected when living with two types of dementia, however there are over 100 types of dementia as researchers and practitioners continue to distinguish between the many subtypes of this condition (e.g. Karantzoulis & Galvin, 2011). There is a need for more second-generation research which distinguishes experiences of living with these differential diagnoses and studying experiences in terms of dining, may support understandings of how these diagnoses affect social experiences. For example, as outlined in section 2.2.4, qualitative studies on dementias such as behavioural-variant frontotemporal dementia highlight unique changes to eating-related practices including behaviours such as cramming food into the mouth and uncooperativeness (Kumamoto et al., 2004). How these types of behaviours are coordinated and affect the meaning of mealtimes as a dining opportunity could be addressed in future investigations. This type of work could provide a more thorough understanding of how the ‘many faces of dementia’ may affect dining which could help to provide more specialist information and support for people.

Understanding more about how different contexts shape the way dining is affected by dementia could also be investigated in future. For example, understanding the impact of pre-dementia selves, personalities and pre-dementia relationships, would support further understandings around how the person’s dining experience comes to be affected by dementia, further emphasising personhood (Kitwood, 1997) as opposed to focusing on symptoms. As outlined in section 2.2.3 some research suggests family members who experience less satisfaction in caring reported previous difficulties in their relationship before dementia and were more likely to report caring without enjoyment (Ribeiro & Paúl, 2008; Shim et al., 2013). These past situations, i.e. about the person, are important to consider. The findings in this study suggest personality and the way people perceived themselves, affected the way changes in functioning were framed in terms of how they could show themselves through dining interactions by engaging in various roles. Other contexts, such as different relationships, could also further be explored. For example, this study included one mother-daughter relationship, whereby changes in roles threatened their sense of who they were in relation to one another (see section 5.3.1) and further research could help to establish the way different relationship types can be affected by dementia-related changes.

Another area of dining which could be further addressed is eating out and eating with different social groups. Many people in this study discussed both highs and lows in relation to dining with groups of people when living with dementia, therefore future studies could look further at dining at a broader level with family and friends, perhaps utilising video-based observations. Grandchildren were reported to be particularly supportive in the interviews for helping to create enjoyable dining experiences, therefore further work could look at this in more detail, including how wider social networks frame changes and how interactions are coordinated in groups of people to support inclusion of the person with dementia. From the observations in this study, just dining with two or more people began to show the complexity of how frames could be layered with different understandings, for example, whereby family members engaged in collusive communication with the researcher. Further research could look at how frames are managed in wider social groups. Furthermore, there is a need for more naturalistic work of dining observations which do not include the researcher. For example, leaving video-cameras with people living with dementia and recording multiple dining experiences, to continue to understand how dining interactions unfold and can be supported.

Research with community-dwelling dyads could also look at how dining experiences are supported for people as they move into the more advanced stages of dementia. PCA is known to develop into a more generalised dementia over time (Shakespeare et al., 2015) and people in the advanced stages of tAD also often experience dementia-related visual loss (e.g. APA, 1994) therefore, understanding how symptoms of both dementia-related visual loss and memory difficulties affect dining experiences could further be addressed. One may expect dining experiences to become more problematic within these situations, as both pathways towards vulnerable social experiences which Goffman (1974) describes may then be affected (see diagram 1, section 7.2). It may be that families continue to work using different processes to help maintain meaning within their dining interactions.

Finally, in terms of broader research into experiences of living with dementia, further research could continue to develop using Goffman's Frame Analysis to study daily experiences of living with dementia, perhaps in other areas aside from dining, such as informal interactions as in the study by Bohling (1991). One area which Goffman (1974) highlights as important is also macro-structural frames which inform the types of framing conventions which people attempt to anchor their behaviour to. Future work in critical gerontology could extend understandings of the way dementia is framed and positioned, for example in the media and how this may inform the way individuals make meaning in their everyday encounters. Zeilig (2015) presents how dementia is framed in the media as a "vast, natural or monstrous force that we must fight" (p. 261). Similarly, quoting the words of Terry Pratchett who had a diagnosis of PCA: "People seem to think of Alzheimer's as something rather terrible and dreadful, almost as if witchcraft is involved" (see Borland, 2012). These types of macro-frameworks may influence the way people are able to cope with dementia-related changes in daily life. it may also be important to consider the macro-social frameworks there are available around dining and what are deemed 'appropriate' dining behaviours for older adults. To provide an example, one may be accustomed with perceiving a child spilling or dropping food in media-based discourses, such as on a TV advert for a cleaning product. However, it would be surprising to perceive an adult spilling or dropping food, suggesting perhaps macro-social perspectives have an important role filtering into people's interpretations of their dining experiences. Cross-cultural studies and further work in critical gerontology could provide a further understanding of how people 'assemble' the frameworks that they bring to current, everyday dining experiences.

7.9 Conclusions

Dementia currently affects around 850,000 people in the UK and these numbers are projected to rise, and whilst there is no cure for this condition, understanding how to support people diagnosed with dementia to 'live well' is important. Many people with dementia live at home, and this condition can largely be viewed as a socio-relational experience which also affects family members who may provide increasing amounts of informal support and spend more time together with the person with the diagnosis. Supporting dining experiences may help to maximise opportunities to 'live well' with dementia. Returning to Kitwood's (1997) model of psychological needs as presented in the introduction (see section 1.2), eating-related practices as a social interaction could nurture the essential needs of inclusion, occupation and identity for people with the diagnosis and family members.

This study has shown how dining experiences and interactions could become problematic for people living with dementia. Experiences were complex and largely situational depending upon the physical and social environments people engaged in. It also highlights the capacity and work many of the people living with dementia put in to maintain meaning in their dining experiences. Many participants revised their frames to assemble new narratives which suited changes in behaviours, as opposed to being bound by pre-dementia frames which did not suit their dining interactions. Dining with dementia appeared to support family dyads to develop complex problem-solving skills, to learn management strategies and become flexible in their expectations, as well as to coordinate their coping processes with other diners to facilitate a smooth flow of activity. Overall, supporting family dyads to anchor their frames around eating-related practices as a dining opportunity may help to promote the psychological needs of individuals living with dementia. This could include introducing props in the environment, whether it be a candle at the table or listening to a radio programme together, whereby these props may help to anchor frames around eating-related practices as a social interaction. This could support people to continue to see themselves as a family who dine together, as opposed to moving towards perspectives of being ‘patient’ or ‘carer’, preventing eating-related practices becoming a functional care task.

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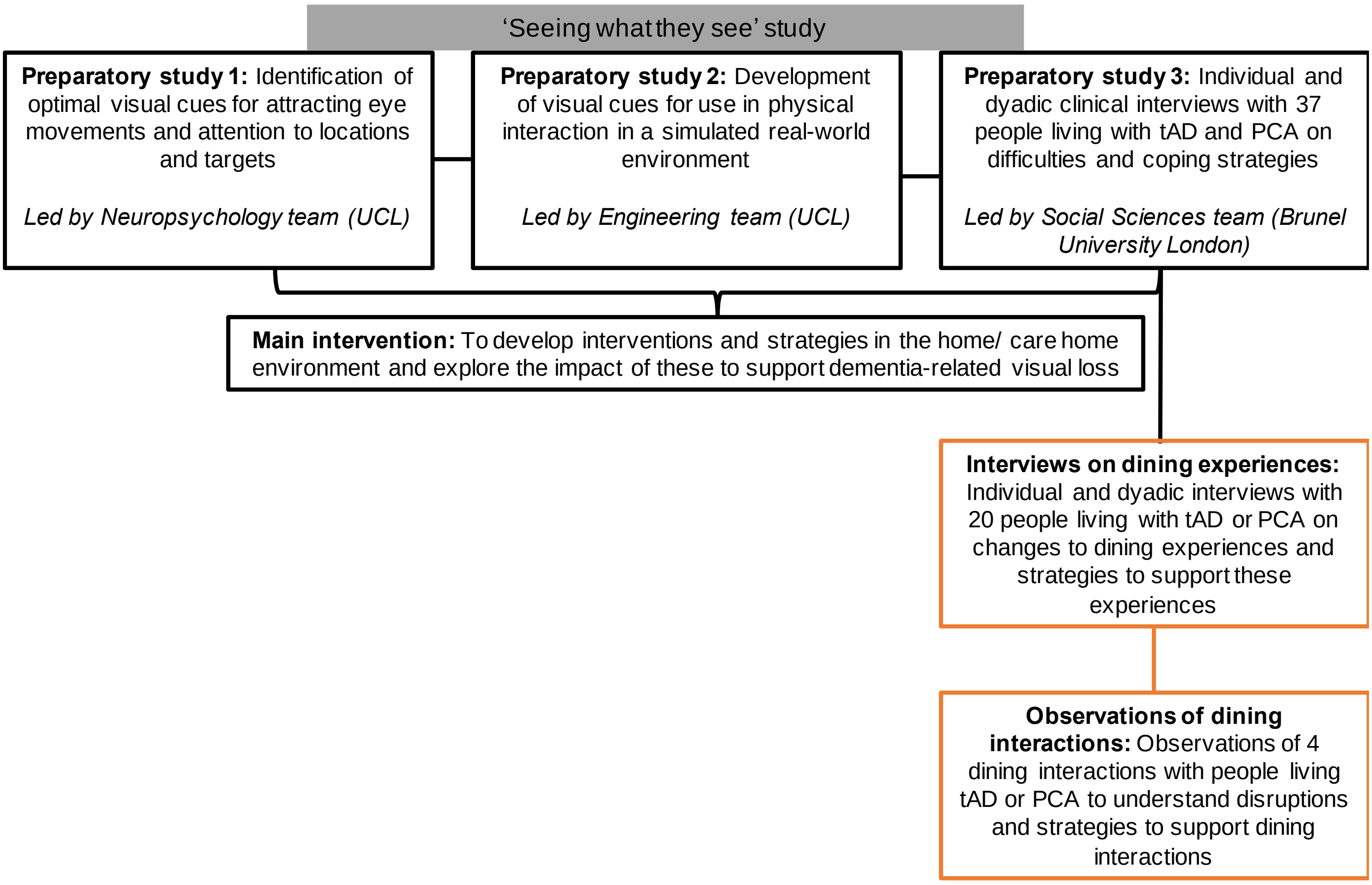
Appendices

Appendix 1: Diagram of the different study strands and aims



‘Seeing what they see’ study

Preparatory study 1: Identification of optimal visual cues for attracting eye movements and attention to locations and targets

Led by Neuropsychology team (UCL)

Preparatory study 2: Development of visual cues for use in physical interaction in a simulated real-world environment

Led by Engineering team (UCL)

Preparatory study 3: Individual and dyadic clinical interviews with 37 people living with tAD and PCA on difficulties and coping strategies

Led by Social Sciences team (Brunel University London)

Main intervention: To develop interventions and strategies in the home/ care home environment and explore the impact of these to support dementia-related visual loss

Interviews on dining experiences: Individual and dyadic interviews with 20 people living with tAD or PCA on changes to dining experiences and strategies to support these experiences

Observations of dining interactions: Observations of 4 dining interactions with people living tAD or PCA to understand disruptions and strategies to support dining interactions

Appendix 2: Studies on experiences of eating-related practices

Topic area	Study	Aims/Objectives	Sample/ Setting	Methods	Results
Overall experiences of eating-related practices	Ball et al., 2015	Perceptions of family members of mealtimes	14 family members of people with dementia/ Australia	Telephone-based qualitative interviews	Nutrition-related care was reported as challenging and frustrating. Strategies included supervising meals and providing snacks/finger foods. Strategies could contribute to further caregiver burden/ stress.
	Brijnath, 2011	Links between food and caregiving	20 family members of people with dementia/ India	Ethnographic study, lived experience of caregiving, semi-structured interviews and observations of eating	Eating sweets fosters pleasure, enabling couples to hold onto relationships in a time of change. Anxieties when people with dementia stop eating.
	Carlsson, Ehrenberg & Ehnfors, 2004	How people affected by stroke experience living with eating difficulties	3 people who had a stroke/ Sweden	Exploratory study, observational combined with interviews	Overarching theme of ‘striving to live a normal life’, subthemes ‘abandoned to learn on one’s own’, ‘experiences of losses’ and ‘feeling dependent’.
	Chen et al., 2016	Perceptions of low-literate older adults with heart disease about their eating experiences	13 low-literate older adults with heart disease/ Taiwan	Descriptive study, semi-structured interviews	(1) Eating-related hardships because of low literacy; (2) eating adjustments due to low literacy; and (3) misinformation about

					dietary modifications for heart disease.
	Hsaio et al., 2013	Experiences of ‘problematic’ eating behaviours	13 family members of people with dementia/ Taiwan	Descriptive study, qualitative interviews	Family members tended to have negative attitudes and behaviours regarding changes to the person with dementia’s eating conduct.
	Johansson & Johansson, 2009	Family members’ experiences of their next of kin's eating and swallowing disorders.	9 family members of people who had a stroke/ Sweden	Constant comparative approach, qualitative interviews	(1) Family member becoming provider for health and wellbeing, (2) sensitive attitudes about the next of kin's changed appearance, (3) adaptation to the new situation.
	Johansson et al., 2011	Managing mealtime tasks such as cooking and food shopping among people with dementia.	15 people with dementia (9 living alone)/ Sweden	Ethnographic, qualitative interviews	Meals as normal. Preserving the self through engaging in mealtime roles. Interviews not always consistent with observations.
	Johansson et al., 2013	To explore and describe spouses’ experiences of food activities and meals in couples with dementia	10 family dyads of people with dementia / Sweden	Ethnographic, thematic analysis and qualitative content analysis	Foodwork and meals sometimes changed; shopping, preparing food, eating, social interaction become complicated, which seemed to lead to transitions in roles, routines and relations.

	Jones & Nasr, 2017	Eating difficulties after stroke	8 people who had a stroke / UK	Participatory study. Focus group and visual photography	Identified barriers to managing eating including physical, social, environmental and emotional issues. Participants recognised that sustaining eating activities regardless of their disabilities was important for their wellbeing.
	Keller et al., 2006	Eating conduct changes and strategies	23 family members of people with dementia, including probable Alzheimer's (14), senile dementia (2), mixed dementia (2), frontal temporal lobe (3) and Parkinson's related dementia (2)/ Canada	Thematic analysis, qualitative interviews	Changes reported which made eating-related practices more difficult. Some families adapted by employing strategies whereas others did not resolve their mealtime problems. Mealtimes as a social activity could be neglected where a 'food as medicine' attitude could be adopted.
	Klinke et al., 2013	Experiences of eating and eating-related difficulties	7 younger- stroke survivors (<65 years)/ Iceland	Descriptive phenomenology, observation combined with interviews	Social embarrassment, main theme. difficulties and concerns when eating in the company of other people, and may 'escape' from this and chose to eat at home where it was 'safe'.

	Medin et al., 2010	Experience and management of eating situations among persons affected by stroke	13 people who had had a stroke/ Sweden	Constant comparison, qualitative interviews	Experiences and desire to master eating situations varied, and was related to values and previous habits. Eating difficulties were experienced as disgusting, uncomfortable, strenuous, or unproblematic and not implying shame. Getting help from others could be experienced as embarrassing and undesirable.
	Miller et al., 2006	Feelings and attitudes towards living with changes in swallowing	14 people with Parkinson's disease and their family members/ UK	Qualitative interviews	Different coping strategies within dyads could cause tensions and difficulties, affecting the other person. Family members often felt guilty with seeing their partner struggling and worrying about them choking. Psychosocial impact, with subthemes of alterations to eating habits, feelings of stigma, need for social adjustment and carers' issues. Presence of significant impact was not necessarily associated with abnormal range

					scores on objective swallowing assessments. Some succeeded in adjusting how, what and when they ate and drank, meaning they could maintain mealtime enjoyment. Psychosocial experiences concerned people most.
	Moloney & Walshe, 2018	To use autobiographical accounts to explore the experiences of those living with swallowing problems following stroke.	10 autobiographies available in English/ country not specified	All references to eating, drinking and swallowing were extracted. Interpretive phenomenological analysis	Six key themes: “physical consequences of dysphagia”; “process of recovery”; “coping and adjusting”; “changed relationships”; “society” and “control”
	Nyberg et al., 2016	How elderly persons with motoric eating difficulties perceive and perform their food and meal practices in everyday life	3 people who had Parkinson’s disease, 2 who had a stroke, 5 with tremors but no diagnosis/ Sweden	Semi-structured interviews and observation, content analysis	The meal as a performance. All adjustments were used to demonstrate proper food and meal behaviour, to maintain social façade and to act according to perceived norms.
	Odencrants, Ehnfors & Grobe, 2005	To describe experiences of meal-related situations	13 people with COPD/ Sweden	Qualitative interviews and diaries, content analysis	Feelings of dependence, level of activity, transport of food, having company or being alone, appetite, hunger and need of time. The categories showed

					factors common to all people, such as a desire of having company, but also findings associated with the ageing process, such as altered intake of food and decreased activity level. Some findings indicating a more disease-specific nature (e.g. breathing, positive and negative feelings and the need of time).
	Papachristou, Giatras & Usshet, 2013	The impact of dementia progression on "food-related processes" shopping, preparation and eating	20 family members of people with dementia/ UK	Semi-structured interviews, thematic analysis	Set pattern of decline in functioning as dementia progressed and family members using strategies such as food shopping alone and taking over meal preparation. Eating out was described as a problematic yet enjoyable experience.
	Perry & McLaren, 2003	Perceptions and responses to eating difficulties	113 people who had a stroke/ UK	Semi-structured interviews, thematic analysis	Level of impairment did not translate to how much this impairment was a handicap or perceived as a problem in relation to mealtime experiences. Two major themes: "getting back to normal" and "getting by".

	Wallin et al., 2013	Partners' experiences of everyday life in caring for a dying person with eating deficiencies at home.	9 people interviewed 3-6 months after the death of their partner/ Sweden	Interpretative descriptive study, semi-structured interviews	Described experiences of how eating deficiencies brought about changes in the participants' everyday lives. Two patterns of experiences were identified: the challenge of doing the best for their dying partner around matters involving food and mealtimes, and experiences of striving to maintain ordinariness, including holding on to social values around food, despite experiences of unfamiliarity when the dying partners' habits were changed.
	Westergren et al., 2016	Used the biopsychosocial framework, the international classification of functioning and health system (ICF) to conceptualise an understanding of mealtime experiences.	19 people with Parkinson's disease/ Sweden	Semi-structured interviews, content analysis	Overwhelming challenges and helplessness that participants who had Parkinson's disease reported in relation to losing control over the mealtime situation, facing deteriorating function and not being able to participate socially. Eating difficulties affected their self-esteem, enjoyment, family

					dynamics, and social life.
Eating Together series: Six-year longitudinal study with people with dementia and family members at home on the meaning and experience of mealtimes in families living with dementia in	a) Keller et al., 2010 b) Genoe et al., 2010 c) Genoe et al., 2012 d) Keller et al., 2015 e) Cassolato et al., 2010 f) Lam & Keller, 2015 g) Wong et al., 2015	Meaning of mealtimes for families living with dementia	26 family dyads living with dementia/ Canada (a-e) f) sub-set of 6 Chinese Canadian families living with dementia g) Case of 1 mother/ daughter dyad from the eating together study chosen on the basis of their resilience and ability to adapt	Constructivist grounded theory, semi-structured interviews	The life nourishment theory (LNT) (a, b, c) a) Theme 1: Being connected at mealtimes: including being face to face, participating psychologically and getting support. Used attachment theory (Bowlby, 1979) and personhood (Kitwood, 1991). b) Theme 2: “Families deliberately worked at supporting identity” (p. 191) through having meaningful roles, protecting dignity and

the community.					being accepted for who the person is and reaffirming self in the world. c) Theme 3: Dynamic process of becoming aware of change, attaching meaning to change, and responding to change. d) Strategies of how to support mealtimes and adapt to evolving life e.g. living in the movement, maintaining social engagement and continuity. e) Eating out as balancing life. Two types of balance were identified: (1) environmental balance through spicing up life and minimising demands and (2) social balance through binding glue and being part of a peer group. f) Life Nourishment Theory and some culturally-specific

					themes: taking on the role of the elder, transferring culture across the generations, and keeping culture. g) The dyad focused on positive gains and personal growth, and balanced past pleasures whilst adapting to a new normal.
	Papachristou, Hickeys & Iliffe, 2016	To develop and evaluate the content, format, and usefulness of two separate booklets (one newly developed and one existing) on food-related processes.	20 dementia family members/ UK	Think-Aloud method was used to gather information about their views on the two booklets in focus groups	Tailored information may enhance caregivers' confidence and support them in making decisions to help them adapt to food-related changes.
	Johansson et al., 2015	To explore and describe staff views on how to improve mealtimes for persons with dementia who are still living at home	22 staff working with people with dementia in the community/ Sweden	Inductive content analysis, Four focus groups	Proposed actions were enabling meals at home, taking over, and moving meals outside of the home. In addition, it was found that, the types of meals served to these persons should be as familiar to the individual as possible. Meals should be prepared in the home and, as much as possible, by the person

					him/herself, to preserve and maintain abilities and independence. A suggested way to maintain independence was the use of technical devices, such as timers and talking watches.
Food-related roles	Anderson & Sidenvall, 2001	impact of Parkinson's disease on managing food shopping, cooking and carrying out meals among women who held these roles previously	10 women with Parkinsons/ Sweden	Qualitative narrative interviews	Specific difficulties in relation to Parkinson's symptoms, such as difficulty transporting food to mouth due to tremors and weakness. Related coping strategies such as taking smaller bites, eating slowly and mashing up food. Eating with others was embarrassing and stressful and related to coping strategies such as withdrawing from social occasions or eating smaller portions.
	Atta-Konadu et al., 2011	*From the eating together series*: Food-related role change experiences of	Subset of 9 family dyads from the eating together study/ Canada	Constructivist grounded theory	Sliding into food-related roles. driven by a gradual process of moving back and forth through steps

		spousal male care partners and their wives with dementia			and strategies to retain meaning as food roles shifted.
	Boyle, 2014	Whether men are willing to cook when their wives develop dementia	21 married couples living with dementia/ UK	Ethnographic and creative methods using participant observation and interviews	Men are often unable or unwilling to cook when their wives develop dementia or, alternatively, they take over cooking altogether, thereby excluding their wives from a task they enjoy. Gendered patterns of authority or control were apparent in the couples' decision-making dynamics, indicating that gender inequality in relationships persists even when women develop dementia.
	Fjellström et al., 2010	Examine how people living with persons with Alzheimer's disease (AD) perceived everyday life aspects of food choices, cooking, and food-related work	17 family members of people with dementia/ Sweden	Descriptive, Focus groups	Cooking and preparing meals were particularly challenging for male family members who took on this role, given they were not necessarily familiar or skilled in food preparation compared to female family members who typically had these roles previously.

	Gustaffson et al., 2003	The cultural meaning of accomplishing food-related work by older women, when disease has diminished their abilities and threatens to make them dependent	72 women: 18 who had a stroke, 18 who had rheumatoid arthritis, 18 who had Parkinson's disease and a control group. Excluded dementia/ Sweden.	Ethnographic analysis, Semi-structured interviews	Across all the women, they appeared to value independence and feared dependence at mealtimes, given these women had previously been independent and responsible for food-related tasks. They also identified differences in experiences, whereby people who were not disabled highly valued dependence, people with rheumatoid arthritis tried to live a normal life and ignore their disease, people with Parkinson's disease wanted to cook their own food for as long as they could and people who had experienced a stroke engaged in food-related training and worked at becoming their own masters again.
	Kullberg et al., 2011	how older men with somatic diseases living in ordinary housing approach the question of food-related activities	18 men diagnosed with Parkinson's disease, rheumatoid arthritis, or stroke. Excluded dementia/ Sweden	Thematic analysis, Semi-structured interviews	They found that some men appeared to have no interest in food-related activities and expressed a lack of concern, whereas for others who had had

					this role previously, the non-cooking situation was a disappointment and frustration for these men. For those who were cooking as a ‘need’ they used strategies such as cooking convenience foods and ready-made meals, whereas for those co-habiting, they often helped with mealtime tasks, and interaction with others could be an adaptive strategy for men who had activity limitations but wished to continue performing food-related tasks. activity limitations, personal interests, and a wish to maintain continuity and independence, affected the men's approaches to these activities. Used continuity theory to explain why consistency in patterns of thinking about mealtimes and cooking roles were

					important for participants in their study.
	Russell, 2007	Meal preparation and personal care of elderly men caregivers who care for wives with cognitive impairment related to Alzheimer's type dementia, stroke, brain injury, or other causes.	30 elderly men/ USA	Qualitative open-ended interviews	Many men struggled with the demands of care work, especially within entrenched gender norms and masculine scripting. Data also demonstrates, however, that men are less avoidant of hands-on, personal care than has been reported in the past. Among the multiple tasks and task areas of care work, cooking and meal preparation presented a particularly unique and precarious challenge for many men in the study. Complexity was a hallmark of meal preparation, as many men discovered first-hand that food management is a series of unacknowledged, unseen tasks that involve strategic planning, coordination, and time juggling.
	Majlesi & Ekström, 2016	Interaction and collaboration between	One family dyad living with dementia/ Sweden	Video recording, Analysed the sequential	Analyses highlight how the person with dementia can actively

		people with dementia and their spouses in relation to the performance of household chores with the focus on instruction as an interactional context to engage the person with dementia in collaboration to accomplish joint activities		orgnaisation of actions orientated towards the accomplishment of a joint multi-task activity of baking.	use the material environment—including collaborating partners—to compensate for challenges and difficulties encountered in achieving everyday tasks.

Appendix 3: Interview schedule for Seeing What They See study

Patient and Carer Interview Schedule

Using a narrative approach, the semi-structured interviews will take place, as much as possible, in the patient's home environment. The visits will be conducted by two researchers to enable the patient and the carer interview to be conducted concurrently following the dyad interview:

1. Introduction and consent (15 minutes)
   - re-consent patient participant into PCA longitudinal study
   - consent carer participant into prep study 3
2. Walk through the home (30 minutes)
   - to be completed virtually or through real tour of home
3. Short break
4. Dyad interview (60 minutes)
5. Short break
6. Patient interview and carer interview (60 minutes)
   - complete and discuss questionnaires
   - break after 60 minutes so re-coordinate timing of individual interviewers
7. Debrief, invitation for Rachel's study and thank you (10 minutes)

Walk Through

1. Talk me through a typical day together from when you get up to going to bed at night.
   Probe: daily activities, problems faced (and feelings about them), coping strategies, mealtimes

2. Thinking about your home environment and the rooms in the house do they support your daily lives?
   Probe: changes since diagnosis, future changes, belonging and attachment to home, potential future and existing interventions

3. Have you modified your home in any way since [individual with dementia] got diagnosed?
   Probe: at what point was this needed/why did you implement it? Perceived success and 'lifespan' of intervention, future interventions and needs

Dyad Interview

1. Shared and personal narrative.

   Probe: tell me about yourself /ves (where brought up, school, work, employment/retirement, hobbies), shared history (marriage, children etc.), recent history (diagnosis, diagnosis journey - e.g. why did they seek help? What help have they had since?)

2. Has this routine changed since [individual with dementia] got diagnosed?
   Probe: impact of visual/cognitive impairments, daily activities, problems faced, coping strategies, relationship

3. How do you perceive your daily lives in the future?
   Probe: short and long term coping strategies, relationship, problems

Patient Interview

1. Earlier you and [IWD/carer] talked about [situation] can you talk to me a bit more about this?
   Probe: coping, changes since diagnosis and future changes

Interview is then facilitated by using the following scales:

2. The Activities of Daily Living Questionnaire
   Probe: challenges, coping mechanisms, impact on daily life

3. Assessing quality of life in older adults with cognitive impairment
   Probe: changes over time and impact (e.g. job, social interests), strategies to mediate problems/stresses/losses, anticipated problems/stresses/losses, positive views of situation/plans/future, meanings associated with situation overall

4. Dyadic Relationship Scale
   Probe: impact of illness on relationships, quality of relationships now versus in the past, new relationships, strategies to maintain relationships

Carer Interview

1. Earlier you and [IWD/carer] talked about [situation] can you talk to me a bit more about this?
   Probe: coping, changes since diagnosis and future changes

Interview is then facilitated by using the following scales:

2. The Activities of Daily Living Questionnaire
   Completed by carer
   Probe: challenges, coping mechanisms, impact on daily life

3. Assessing quality of life in older adults with cognitive impairment
   Completed by carer
   Probe: changes over time and impact (e.g. job, social interests), strategies to mediate problems/stresses/losses, anticipated problems/stresses/losses, positive views of situation/plans/future, meanings associated with situation overall

4. Dyadic Relationship Scale
   Probe: impact of illness on relationships, quality of relationships now versus in the past, new relationships, strategies to maintain relationships

5. Relatives of the impaired elderly: correlates of feelings of burden

Probe: Thoughts on caring, commitment, stresses, coping, anticipated future, meanings associated with caring role and situation overall

Appendix 4: List of grounded theory studies in dementia research

Author, date	**Topic**	**‘Type’ of GT used**	**Approach**	**Research ‘product’**
Studies into experiences of living and coping with changes related to dementia				
Allen, Oyebode & Allen, 2009	Experiences of having a father with early-onset dementia	Data analysis using grounded theory, mixed Straussian analysis methods, adopted constructivist grounded theory worldview	-Reading theories that were relevant during the process of analysis -Theoretical sampling, revision of interview guide -Theoretical saturation -Coding following line-by-line coding, focused coding, categorising and model building	Integrated model with overarching theme ‘one day at a time’ and five major themes: (1) damage of dementia (2) reconfiguration of relationships (3) caring (4) strain (5) coping
Beard, Fetterman, Wu & Bryant, 2009	Perceptions of ‘aging well’ by individuals with dementia and family members	Data analysis using constant comparison and coding paradigm of classic grounded theory	-No theoretical sampling -Open coding, core category -Thematic categories -Constant comparison	No integrated theory, themes of physical and mental health, social activity, independence and happiness related to ageing well
Beard, Knauss & Moyer, 2009	Open ended questions about the experience of living with dementia, web-based survey	Data analysis using constant comparison and coding paradigm of classic grounded theory	-No theoretical sampling, analysis following data collection -Open coding -Constant comparison -Themes generated	3 themes, said to be interacting and overlapping, no core category, descriptive presentation of results -Causes of rough spots and getting through them

				-Working around problems and related obstacles -Enriching our lives and how further to enrich them
Brown & Alligood, 2004	Experience of help seeking by older wives caring for husband with dementia	Straussian grounded theory	-Newman's (1986) theory of health as expanding consciousness was used as theoretical framework to interpret the findings -Constant comparison -Theoretical sampling -no mention of coding procedure	Substantive theory of 'help seeking choices: taking one day at a time': The antecedent category of realising wrongness, with subthemes of recognizing a problem, accepting direction from others and recognizing help needs,
Brown et al., 2007	Experience of help seeking by older husbands caring for wives with dementia	Straussian grounded theory	-Newman's (1986) theory of health as expanding consciousness was used to interpret the findings -Constant comparison -Core category	Core category of 'doing the best I can', preceded by 'changing patterns'. Choices to use interaction strategies of 'relinquishing', 'reaching out' and 'shouldering' which were influenced by many intervening conditions. Consequence of help-seeking process was 'continuing on'.
Chung, 2000	Family knowledge of dementia and how they made sense of the disease	Data analysis using Straussian grounded theory	-No theoretical sampling -Constant comparison -Open coding, axial coding, selective coding -Core category	Two central categories were identified: (a) lay interpretation of dementia is associated with family carers' limited understanding of dementia, (b) a process of searching for a subjective understanding of dementia is a means of gaining control of dementia.

a) Chung, Ellis-Hill & Coleman, 2008 b) Chung, Ellis-Hill & Coleman, 2017	Caregiver's experiences of involving the person with dementia in activity Discussing key theme: to show how family carers recognised the continuing needs of their relatives and so enhanced their relatives agency and autonomy	Data analysis using Straussian grounded theory	-Does not specify exact coding procedures, states transcripts were read, re-read and coded to develop concepts further until all core concepts were identified. Concepts were developed by constant comparison until no new categories emerged. -memoing	-5 different themes of emotions related to different types of experiences: from the usual pattern through a recognisable, then illogical, then irresponsible through to a dispossessed pattern -recognising and supporting relatives agency to enhance personhood
Daly et al., 2013	Experiences of family members managing alterations to relationships within their social worlds	Classic grounded theory	-Concurrent methods of theoretical sampling, constant comparative analysis, memo writing and theoretical sensitivity -No mention of when the literature was approached	Theory of 'sustaining place': Informal carers' main concern was identified as 'Living on the fringes', which was stimulated by dementia-related stigma and living a different life
a) Derksen et al., 2005 b) Vernooij-Dassen et al., 2006	a) Impact of disclosure of the diagnosis of dementia on the person with dementia and spouse b) Changes from 2 weeks to 12 weeks	Constant comparative analysis using Straussian grounded theory	-Constant comparative analysis -Iterative process of constant comparison -Theoretical saturation	Three key themes of changes in awareness, partnership and social relationships

Duggleby et al., 2009	Experience of hope for family members caring for a person with dementia	Constructivist grounded theory	-Theoretical sampling to reach theoretical completeness or ‘saturation’ -Initial, focused and theoretical coding -Integrated into emerging theory	The main concern of the study participants was “fading hope,” which they dealt with by “renewing every day hope” through (a) coming to terms, (b) finding positivesand (c) seeing possibilities
Harris & Keady, 2009	Meaning and construction of selfhood and identity among people with dementia	Classic grounded theory	-Purposive sampling -Analytic strategy of GT following data collection -Themes as opposed to integrated theory	Emergence of five themes: (1) identity as a worker; (2) identity of abandoned individual; (3) sexual identity; (4) family identity; and (5) identity as an individual engaged in living
a) Hellström, Nolan & Lundh, 2007; b) Hellström, Nolan & Lundh, 2005; c) Hellström, Nolan & Lundh, 2005	Main aim of study: to explore the ways people with dementia and spouses experience dementia overtime a) Strategies that spouses use to live	Constructivist grounded theory	-Constant comparison and theoretical sampling, altering questions as went along -Unspecified data analysis process	Integrated theory on ‘the dynamics of couplehood in dementia’ including three aspects in iterative process: ‘sustaining couplehood’, ‘maintaining involvement’ and ‘moving on’

	positively when one partner has dementia b) Case study of one participant from the study c) ‘Emergent fit’ of results with other existing theories			
Hulko, 2009	The relationships between the experiences of people with dementia and the intersections of race, ethnicity, class and gender	Mixed version of classic, Straussian and constructivist grounded theory Informed by feminist perspectives on research (e.g. Brown et al., 2005)	-Theoretical concept of intersectionality and interlocking oppressions underpinned the investigation -Theoretical sampling -Data collection and analysis simulataneous -Theoretical saturation	Experiences of dementia are shaped by the complex interaction of identity constructs such as race, class, gender and ethnicity; hence, views on life with dementia, responses of others and meaning making will vary based on the social location of the person with dementia
Johannessen & Möller, 2013	Experiences of living with early-onset dementia	Straussian grounded theory	-Theoretical sampling, adapting questions in interviews throughout data collection -Open, axial and selective coding -Two core categories identified	One category, the process *toward a dementia diagnosis*, covered two subcategories; describing *changes* and *being diagnosed.* Another category *fighting for dignity* describes how the informants try to maintain their quality of life, covering two subcategories; *intrapsychic challenges* and *social challenges*.

Johannessen, Engedal & Thorsen, 2016	How adult children experienced the influence of their parents' dementia on their own development during adolescence	Analysis utilising modified version of Straussian grounded theory without intention of formulating a theory but to give insight into a unknown field	-Analysis following data collection -open coding, axial coding, constant comparison	Concept of detachment: moving apart, greater personal distance and calmer emotional reactions, resilience and need for social support
Keady, 1999	Longitudinal experience of dementia among family members and people with dementia	Modified version of classic grounded theory	-Theoretical sampling in advance of interviews (structured sample recruitment) -Reviewed literature throughout and related findings to existing theory (Wilson, 1989) -Identifying temporal stages likely to affect the experience of dementia before data collection	Integrated theory of 'working' including working apart, together and alone and linking scheme of 'maintaining involvement' for families living with dementia
Lewis, 2015	The problem that caregivers of individuals with dementia face at the end of life and how they attempt to resolve that problem	Classic grounded theory	-Theoretical sampling -Constant comparative analysis -Memos -Theoretical saturation -Exploring existing theories in final stages	Basic social psychological problem of role entrapment. Resolving problem through 5-stage process of missing the past, sacrificing self, yearning for escape, reclaiming identity and finding joy

Lin, Macmillian & Brown, 2012	Changes in the family member's experiences of looking after a relative living with dementia	Straussian grounded theory	-Followed process of open, selective and axial coding as recommended by Strauss and Corbin (1998) -No mention of theoretical sampling -No mention of when the literature was approached	Core category 'my life changed' with sub-categories of commitment, responsibility and duty and support. Not fully integrated 'what changes were experienced did not appear to conform to any fixed pattern'
Molyneaux et al., 2012	The impact of dementia on a couple's relationship and how couples co-create their account of couplehood in dementia	Constructivist grounded theory	-Theoretical sampling and saturation -Line by line coding, memo writing, associated themes -Reflective journal to monitor judgements and decisions	Five themes that represents the co-construction of couplehood in dementia (1) shifting identities within couplehood, (2) maintaining the relationship despite dementia, (3) the good old days (4) technically being a carer (5) sharing experiences of dementia Not integrated.
Nay et al., 2015	Experiences and meaning of social participation for family carers of people living with dementia	Classic grounded theory	-Theoretical saturation (no mention of theoretical sampling) -Constant comparison -Line by line coding, abstraction of themes	Core category of 'adaptation' which involved four themes: autonomy to choose, the impact of caregiving, employing strategies and establishing meaningful connections.

Netto, Jenny & Philip, 2009	Investigating the gains experienced by family caregivers of people with dementia	Analysis guided by grounded theory (unspecified type)	-Theoretical sampling -Data selectively transcribed (focusing on research questions) -Literature helped to shape the interview guide -A coding paradigm and comparisons: open, axial and selective	Three themes relating to caregiver gains: (1) Personal growth (2) Gains in relationships (3) Higher level gains Theory not integrated.
Perry, 2002	Experiences of wives giving care to people with dementia	Analysis guided by Straussian grounded theory	-Guided by symbolic interactionism -Theoretical sampling -Line-by-line, axial coding, identification of the core concept -Memoing	Process of recognising changes in their husband's work, phase of drawing inferences about what they observed, rewrite identities for their husbands that incorporate dementia, constructing a new life to sustain both partners.
Pesonen, Remes & Isola, 2013	Experience of receiving a diagnosis of dementia from family members and people with dementia, shared meanings	Analysis guided by Straussian grounded theory	-Theoretical sampling -Theoretical saturation -Open, axial and selective coding and linking of categories	Core category 'shared processes in the family', couples built a shared understanding of challenges, suggesting it was an individual and shared experience.

Read, Toye & Wynaden, 2016	Experiences of people diagnosed with dementia and their expectations of their support needs and how they wished to live their lives	Classic grounded theory	-Constant comparison -Theoretical sampling of participants and saturation -Open coding, theoretical coding and selective coding	Core problem of 'losing control'. This concept encompassed loss of role function and independence, uncertainty about the future and fear of being a burden. To manage the problem of losing control, participants engaged in a process of finding meaning where they sought answers to address their concerns and implemented strategies to assist them to maintain connectedness to their pre-diagnosis life for as long as possible.
Sherman & Boss, 2007	Experiences of spousal caregiving in the late-life remarried context	Informed by classic grounded theory for analysis	-Family systems theory (Constantine, 1986) provided a theoretical framework for this study -Initial line-by-line coding -Constant comparison -Not developing grounded theory	Themes of later life remarriage as a complex family context, rejection of parental remarriage by adult children, meanings of family and stepfamily, desertion in the caregiving role, conflict in caregiving, proactive caregiving and opportunities for rapprochement
Sørensen, Waldorff & Waldemar, 2008	How patients with mild Alzheimer's disease cope with the changes they face concerning everyday life and social relations	Straussian grounded theory	-Theoretical sampling, adapting the interviews -Theoretical saturation -Conceptual category and subcategories -Axial coding -Selective coding	Awareness of decline in personal dignity and value. Coping strategies were adaptations to the altered situation to maintain a feeling of wellbeing. The spouse appeared to be the most important social relation.

(a) Steeman et al., 2007; (b) Steeman et al., 2013	(a) Living with early stage dementia (b) follow up from previous study	Mixed classic grounded theory and constructivist grounded theory Included 'narrative analysis'	-Theoretical sampling and loose structure of interviews, becoming more in-depth over time -Open coding, focused, theoretical and emergence of core category	(a) Balancing feelings of value and worthlessness. Narrative as an expression of one's attempt to counterbalance devaluation. Integrated model displaying this 'struggle'. (b) Major theme- a struggle to be valued, was clearly present in follow-up interviews, also a shift in the concept of 'being valued' from being valued for what you do towards being valued for who you are
a) Strang & Haughey, 1998 b) Szabo & Strang, 2007	a) Experiential understanding of respite care for caregivers of people with dementia b) Experience of control as perceived by family caregivers who care for relatives with dementia	Narrative inquiry for data-collection, used classic grounded theory and secondary analysis of data for analysis (Glaser & Strauss, 1967)	-Theoretical saturation -Theoretical sampling -Methodological and theoretical memos	a) Factors influencing the caregivers' abilities to experience this respite include the nature of the pre-illness relationship between the caregivers and their dependent family members, role expectations, the attributes of the available respite services and time. b) The experience of control was related to how caregivers managed or coped with their caregiving situations. The dimensions of control were characterised as either "maintaining control" or as "lacking control" with each dimension relating to caregivers' beliefs about caregiving

Wang et al., 2017	Experiences of spousal caregivers caring for people with dementia	Classic grounded theory	-Theoretical sampling for data collection until saturation -Glaser's original approach using constant comparison, open coding, memo writing, theoretical coding	Core category of 'progressive compensatory symbiosis', integrated theory with three components: making a commitment, awareness of unbalanced intimacy and implementing a compensatory scheme
Weaks, Wilkinson & McLeod, 2015	Exeriences of people with dementia and family members of telling others about their diagnosis	Ethnographic study, analysis informed by Straussian grounded theory methods	-Open coding -Grouping codes -Constant comparison -Iterative process -No mention of coding types or memoing	No theory outlined, participants recognised the need to tell others about their diagnosis but these conversations were difficult to initiate and manage and hindered the processing of emotions
Werezak & Stewart, 2002	Experiences of learning to live with early-stage dementia	Qualitative approach and using Straussian grounded theory analysis	-Theoretical sampling to identify the participants, used a semi-structured interview format based on previous research (Keady & Nolan, 1995) -Followed process of open, selective and axial coding	Continuous process of adjusting to early-stage dementia' that begins with various antecedents and proceeds through the stages of anticipation, appearance, assimilation and acceptance. This process evolved as participants' awareness of themselves and their outer world changed
Wilson, 1989	Experience of family members of people with dementia	Classic grounded theory for analysis	-Analysis following data collection therefore did not use theoretical sampling -open coding, coding for categories, theoretical coding, identifying the	Substantive, integrated theory of family cargiving: 'coping with negative choices': with three stages (1) taking it on, (2) going through it (3) turning it over

			core variable and theoretical saturation	
Wuest, Ericson & Stern, 1994	The reciprocal process of becoming strangers for caregivers and people with dementia	Data analysis following approach of classic grounded theory	-Convenience sample -Constant comparison -Selective sampling -Comparison to the literature	Becoming strangers: interact on a continuum from intimacy to alienation through dimensions of dawning, holding on and letting go.
Studies into experiences of dementia within a daily activity				
Brorsson et al., 2016	Problematic situations in using zebra crossings for people with dementia	Data analysis using Straussian grounded theory	-Coding and analysis following data collection -Open, axial and selective coding -Memos to capture emerging categories which were compared across data sets	Core category of ‘the hazard of meeting unfolding problematic traffic situations when only one layer at a time can be kept in focus’, Presents different layers of problematic situations.

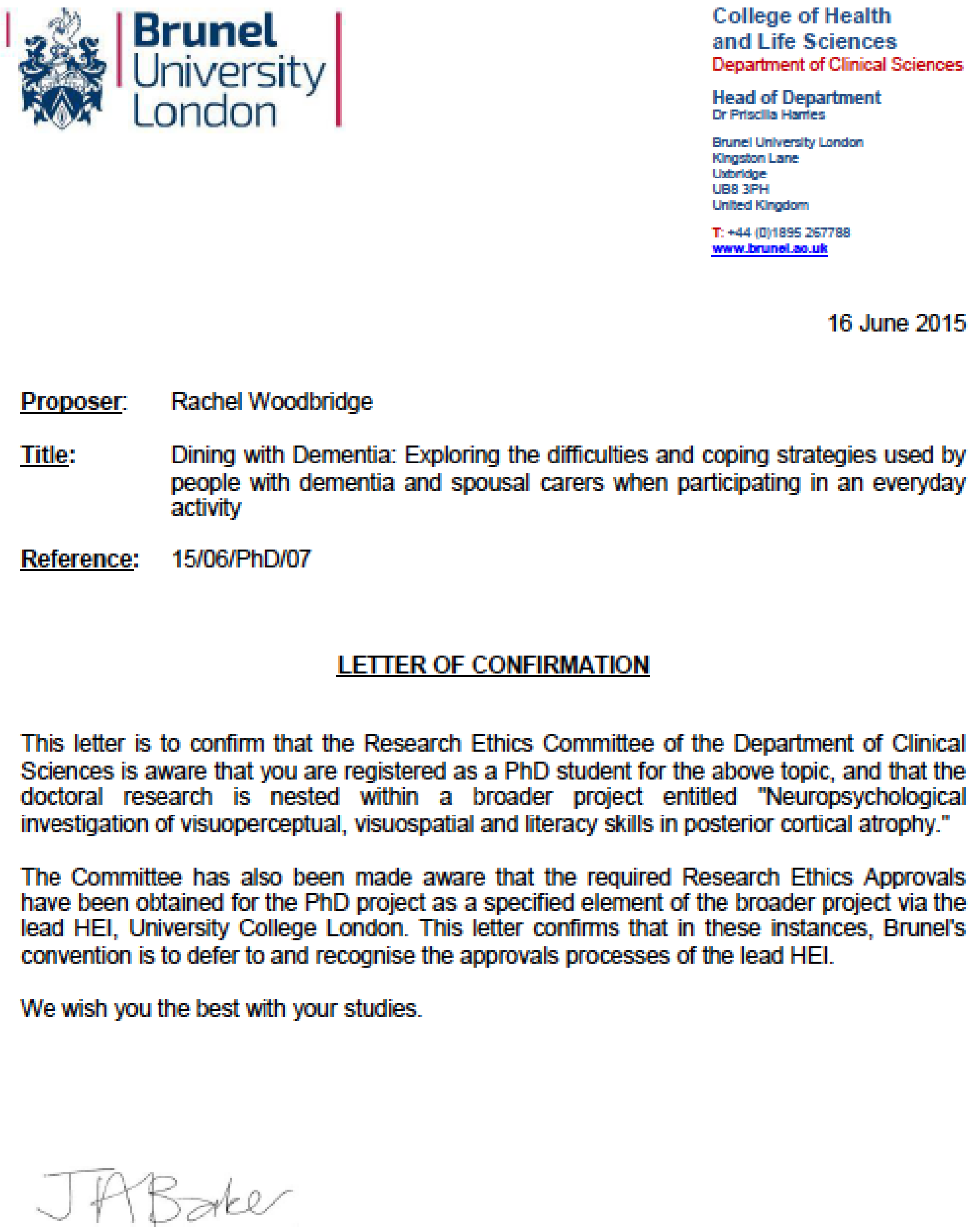
Brorsson et al., 2013	To discover and describe problematic situations and critical incidents during grocery shopping	Data analysis using Straussian grounded theory	-Analysis following data collection -Open coding -axial coding, combining codes -Constant comparison -Core category	Core category ‘a challenging and unstable process of meeting critical incidents in grocery shopping’, with six categories describing critical incidents and actions used to meet them
Burnside et al., 2017	Perceptions of taking part in an art engagement programme among people with dementia and family members	Data analysis using Straussian grounded theory	-Telephone qualitative interviews, -data analysis conducted after data collection -Open, axial and selective coding, no mention of memoing	Conceptual model including antecedents, structure, process and outcomes of the art based programme ‘here: now conceptual model’
Camic, Baker & Tischler, 2016	Experiences of art based programmes at art galleries among people with dementia	Data analysis using Straussian grounded theory	-Open sampling -Relational and variational sampling -Theoretical sampling -Open, axial and selective coding	The emerging theory has four primary components: the art gallery is seen as being a physically-valued place that provides intellectual stimulation and offers opportunities for social inclusion that can change how dementia is perceived. These components coalesced to create positive emotional and relational effects for those with dementia and caregivers.

a) Keller et al., 2010 b) Keller et al., 2016 c) Genoe et al., 2010 d) Atta-Konadu, 2011 e) Cassolato et al., (2010)	'Eating together study', Longitudinal study on the meaning and experience of mealtimes in families living with dementia in the community	Constructivist grounded theory	-Two theories used as guiding frameworks for this study: attachment theory (Bowlby, 1979), personhood (Kitwood, 1997) -Selective and theoretical sampling -Initial, focused, axial and theoretical coding -Memoing -Conceptual maps	a) -Doesn't show how themes are interrelated, descriptive presentation, but suggests they are -Mealtimes relate how families were being connected, honouring identity and adapting to an evolving life b) Strategies of how to support mealtimes and adapt to evolving life e.g. living in the movement, maintaining social engagement and continuity of mealtime activities c) Dynamic process of becoming aware of change, attaching meaning to change and responding to change d) Sliding into food-related roles. e) Eating out as a way of balancing life, Two types of balance were identified: (1) environmental balance through spicing up life and minimizing demands and (2) social balance through binding glue and being part of a peer group
Mahoney et al., 2015	Family caregivers perspectives about issues that arise when their family members lose the ability to dress independently	No mention of which type of grounded theory informed by followed Sarantakos (1993) qualitative analytic procedures	-Purposive sampling -Constant comparison -Line by line coding -Patterns/ variations to develop the major category	Preservation of self model: 'care recipient to care giver' that portrays the caregiving trajectory. Process of preserving dignity, dressing 'battles', discomfort and then preservation of self and health.

			-Analysis until saturation (no mention of theoretical sampling)	
Unadkat et al., 2016	How group singing activities benefits people with dementia and their partners	Qualitative design in accordance with classic grounded theory	-Theoretical sampling -Open coding -Selective coding -Theoretical coding -Theoretical sufficiency as opposed to theoretical saturation	‘Group singing model’, group singing was experienced as joyful and accessible. Accessibility of singing combined with effective facilitation, created an environment for active participation and enjoyment. Joint benefits in terms of participation in new experiences.
Studies into experiences of dementia across and within specific cultures				
Borrayo et al., 2007	Explore Latino caregivers’ cultural explanatory models of caring for an older adult with dementia	Analysis using Straussian grounded theory techniques, not aiming to develop theory	-Analysis following data collection -Open coding -Axial coding using coding paradigm	Qualitative rich descriptive information answering the research questions about the meanings of caregiving, overall experiences and caregivers’ understandings of dementia

Botsford, Clarke & Gibb, 2012	Experiences of partners of people with dementia in two minority ethnic communities	Constructivist grounded theory approach	-Constant comparison -Theoretical saturation -Open coding, Memo writing, focused coding, core concepts	'Redefining relationships'. Greek Cypriot partners tended to emphasise family relationships whereas African Caribbean partners tended to view themselves primarily as an individual or as part of a couple.
Lawrence et al., 2008	Exploring caregiving experiences of people with dementia from the three largest ethnic groups in the UK	Qualitative methodology drawing on the classic grounded theory approach	-Theoretical sampling, different perspectives purposefully sought to test and refine the emergent theory -Literature informed the interview questions -Constant comparison -Theoretical memos -similarities and differences	Theory not integrated around a core concept: Carers were identified as holding a 'traditional' or ' non-traditional' caregiver ideology, according to whether they conceptualised caregiving as natural, expected and virtuous. This informed feelings of fulfilment, strain, carers' fears and attitudes towards formal services. The majority of the south Asian, half of the Black Caribbean and a minority of the White British participants were found to possess a traditional ideology.
Lawrence et al., 2011	Exploring the subjective reality of living with dementia from the perspective of people with dementia from the three largest ethic groups in the UK	Classic grounded theory	-Theoretical sampling and saturation -Open coding -Constant comparison -Identification of core category and focused coding	Main theme: threat to valued elements of life. Process of appraisal in which they assessed the degree their condition and support needs interfered with valued elements of life, culturally informed process

Appendix 5: Brunel University ethics approval letter



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16 June 2015

Proposer: Rachel Woodbridge

Title: Dining with Dementia: Exploring the difficulties and coping strategies used by people with dementia and spousal carers when participating in an everyday activity

Reference: 15/06/PhD/07

LETTER OF CONFIRMATION

This letter is to confirm that the Research Ethics Committee of the Department of Clinical Sciences is aware that you are registered as a PhD student for the above topic, and that the doctoral research is nested within a broader project entitled "Neuropsychological investigation of visuoperceptual, visuospatial and literacy skills in posterior cortical atrophy."

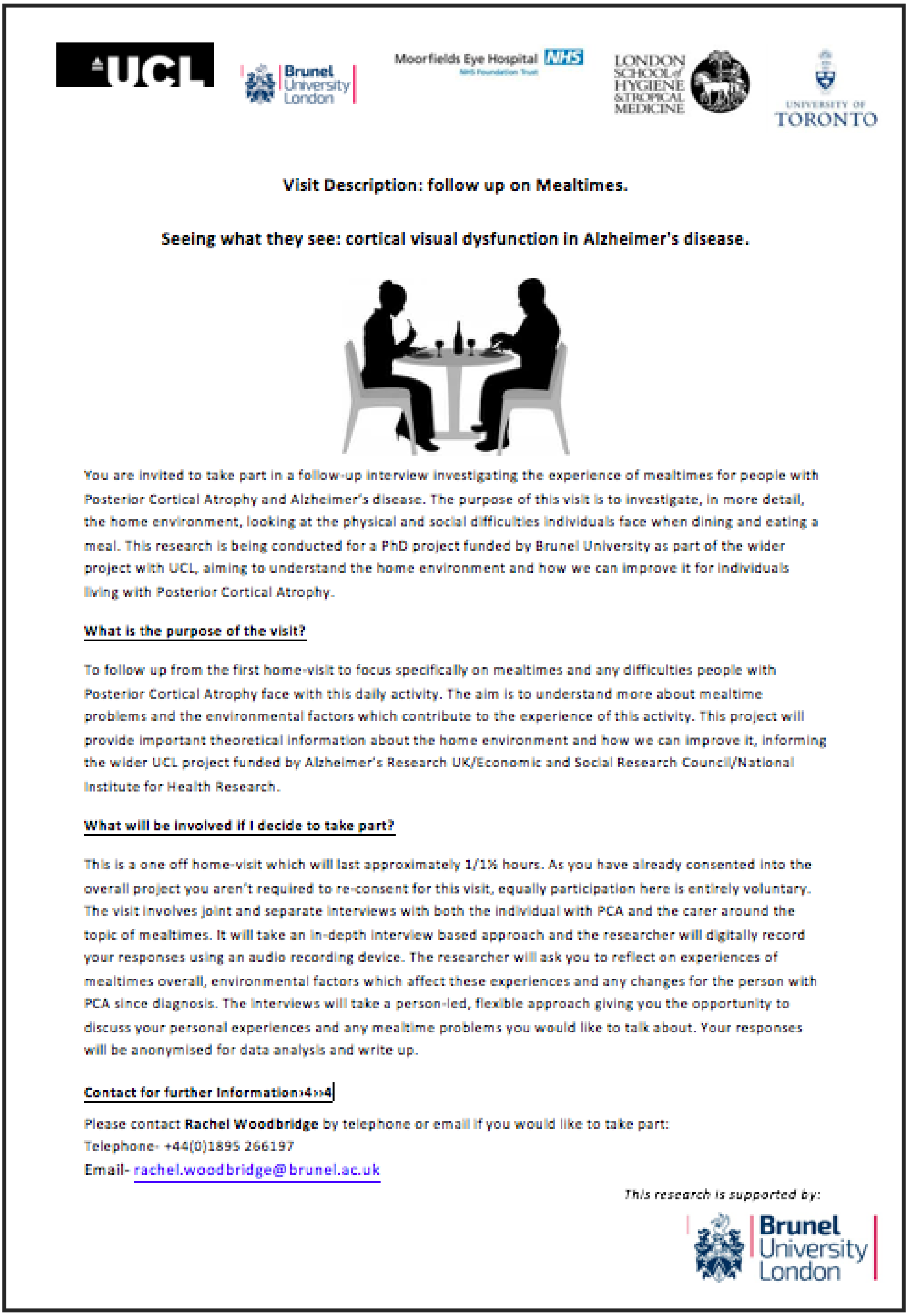
The Committee has also been made aware that the required Research Ethics Approvals have been obtained for the PhD project as a specified element of the broader project via the lead HEI, University College London. This letter confirms that in these instances, Brunel's convention is to defer to and recognise the approvals processes of the lead HEI.

We wish you the best with your studies.

J A Barker

Dr John Barker
Chair, Research Ethics Committee of the Department of Clinical Sciences

Appendix 6: Information sheet on dining with dementia



UCL Brunel University London Moorfields Eye Hospital NHS NHS Foundation Trust LONDON SCHOOL of HYGIENE &TROPICAL MEDICINE UNIVERSITY OF TORONTO

Visit Description: follow up on Mealtimes.

Seeing what they see: cortical visual dysfunction in Alzheimer's disease.

You are invited to take part in a follow-up interview investigating the experience of mealtimes for people with Posterior Cortical Atrophy and Alzheimer's disease. The purpose of this visit is to investigate, in more detail, the home environment, looking at the physical and social difficulties individuals face when dining and eating a meal. This research is being conducted for a PhD project funded by Brunel University as part of the wider project with UCL, aiming to understand the home environment and how we can improve it for individuals living with Posterior Cortical Atrophy.

What is the purpose of the visit?

To follow up from the first home-visit to focus specifically on mealtimes and any difficulties people with Posterior Cortical Atrophy face with this daily activity. The aim is to understand more about mealtime problems and the environmental factors which contribute to the experience of this activity. This project will provide important theoretical information about the home environment and how we can improve it, informing the wider UCL project funded by Alzheimer's Research UK/Economic and Social Research Council/National Institute for Health Research.

What will be involved if I decide to take part?

This is a one off home-visit which will last approximately 1/1½ hours. As you have already consented into the overall project you aren't required to re-consent for this visit, equally participation here is entirely voluntary. The visit involves joint and separate interviews with both the individual with PCA and the carer around the topic of mealtimes. It will take an in-depth interview based approach and the researcher will digitally record your responses using an audio recording device. The researcher will ask you to reflect on experiences of mealtimes overall, environmental factors which affect these experiences and any changes for the person with PCA since diagnosis. The interviews will take a person-led, flexible approach giving you the opportunity to discuss your personal experiences and any mealtime problems you would like to talk about. Your responses will be anonymised for data analysis and write up.

Contact for further Information›4››4

Please contact **Rachel Woodbridge** by telephone or email if you would like to take part:
Telephone- +44(0)1895 266197
Email- rachel.woodbridge@brunel.ac.uk

This research is supported by:

Brunel University London

Appendix 7: Topic guide for the interviews

Introduction- I'm here to understand more specifically about the mealtime experience and the kind of issues that might be affecting this experience for my PhD. By the mealtime experience I mean the activity of sitting down with [caregiver] eating and having a conversation.

Dyad: Contextual Questions

1. Describe the typical mealtime activity overall at home:
   Probe: Where do you usually eat your meals (breakfast, lunch, dinner)? Who do you sit with? What do you usually eat? Who cooks? Who initiates eating? Changes since diagnosis-why? What did mealtimes mean to you as a couple in the past? Future of mealtimes? How does it compare to other ADLs (dressing/toileting etc.)

2. What is your eating environment like at home and does it support your needs?
   Probe: interventions in physical environment, future, lighting, type of food eaten, utensils used, number of people eat with, carer support

3. How do you find the dining environment when eating out?
   Probe: restaurants/cafes/friend's house, changes since diagnosis (eat out more or less at home)/the environment- e.g. noise/lighting/barriers/dealing socially with staff/people who don't know the individual, enjoyment of food

4. What about the different people you eat with. How is your experience of eating with friends/family/people you don't know so well?
   Probe: larger vs. smaller groups, familiarity, social context? Keeping up with conversations? Amount of input to conversations? Social coping with problems

5. What do mealtimes mean to you as a couple?
   An 'event'- think about them and prepare for them before hand, passing time of day, stressful vs. enjoyable, motivated by food

Carer: Focus on mealtimes at home

-Administer perceived experiences scale
Discuss: reasons why gave rating, changes in physical and social environment, atmosphere, changes in conversation as well as any difficulties in act of eating, experience of texture/taste/smells of different foods, changes in type of food preference, familiar vs. unfamiliar foods

-Now let's try and think about to a mealtime experience that didn't go so well for [individual] that they didn't enjoy?
Probe: Reasons didn't enjoy (physical/social), type of meal eaten, people attended, conversation

-Over the last week can you think back to a mealtime experience that went particularly well for [individual], that they really enjoyed?

Probe: Reasons for enjoyment (physical/social), type of food eaten etc., people attended, conversation

-How do mealtimes compare to other daily activities such as dressing, showering, travelling?
Probe: similarities/differences, reasons, social/physical coping more broadly

Individual: Focus on mealtimes at home

-Administer perceived experiences scale
Discuss: reasons why gave rating, changes in physical and social environment, atmosphere, changes in conversation as well as any difficulties in act of eating, experience of texture/taste of different foods, changes in type of meal preference

-Now let's try and think about to a mealtime experience that didn't go so well and you didn't enjoy?
Probe: Reasons didn't enjoy (physical/social), type of meal eaten, people attended, conversation, atmosphere

-Now, over the last week can you think back to a mealtime experience that went particularly well and that you really enjoyed?
Probe: Reasons for enjoyment (physical/social), type of food eaten, people attended, conversation, atmosphere

-How does the experience of mealtimes compare to other daily activities such as dressing, showering, travelling?
Probe: similarities/differences, reasons, social/physical coping more broadly

Walk through (dyad @ the end)

Finally, anything you really would like to add about mealtimes? And would you mind if I had a look at the dining space where you typically eat your meals.
Probe: Discuss suitability- changes, future changes, environmental barriers (clutter, lighting, noise, objects). Ask them to demonstrate any difficulties, show dining equipment and utensils they use etc.

Appendix 8: Example of a transcribed interview

PS3788C PhD Interview

46:18

RW: So if you could both start by describing typical mealtimes at home and how they go

Dawn: well normally, some time ago I was the cooker, but somehow, Alesha has taken over and thank god she does cook good food so I just shut my mouth [laughs]

RW: so you're the cooker now Alesha is that right?

Alesha: yes I do cook… yeah so I cook, erm, more or less everyday, so yeah

RW: Was that a recent thing or?

Dawn: some time ago…

Alesha: no it's not recent

Dawn: a couple of years,

Alesha: yeah it's been a couple of years where I cook regularly so we take it in turns to help mum get ready in the mornings so whoever's helping Mum get ready, they get breakfast, lunch mum will probably grab something at the day centre at St Mark's and then when I come in from work then I cook something and we'll eat

RW: yeah do you go to the day centre everyday?

Alesha: apart from Tuesdays, do you know the Alzheimer's society, they have singing for the brain on a Tuesday apart from that Monday to Friday, Saturday, so they pick her up at 10 o clock

RW: so you're doing most of the cooking, how was that process was it a gradual thing?

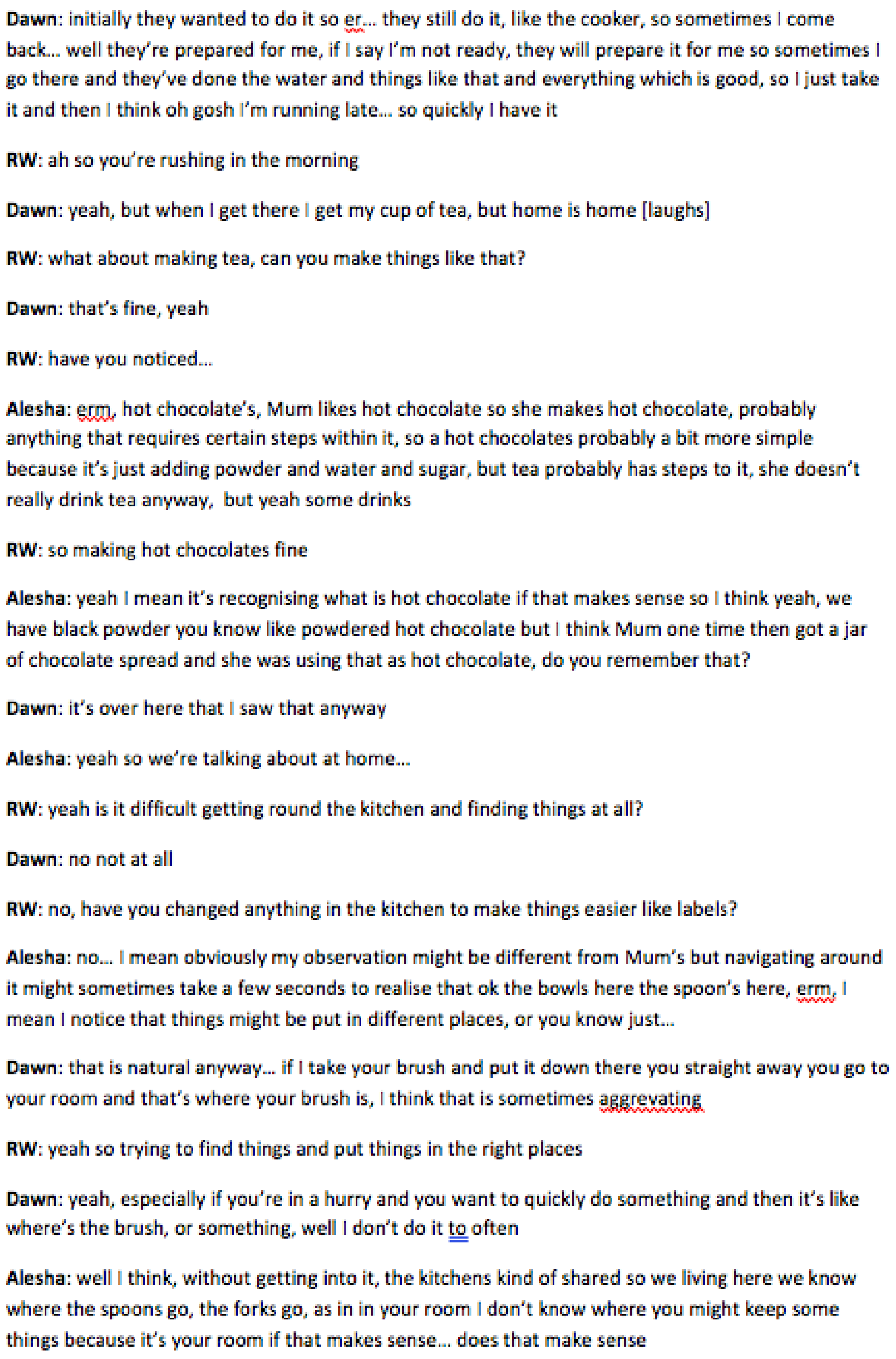
Dawn: it all depend upon what she's cooking because I'm, you don't need to… bread or something like that

Alesha: I think she's just asking about the preparation of food, so yeah, probably about a, yeah so a couple of years ago I think it's just if Mum's making something and there's other difficulties putting it together or some ingredients forgot… but even before I used to cook anyway, cook my own thing and then Mum used to cook probably more African dishes that I don't know how to cook, and then I was probably making my things there… when I come home from work, I think how it started was if Mum hadn't cooked then I'd just cook, gradually there wasn't anything there, if that makes sense, not saying that you didn't… and now it is kind of like I kind of have to too make sure that we're having a proper meal

RW: a proper meal in the evenings

Alesha: yeah so I try and put something together

RW: and what about making breakfast, are you making your own breakfast in the morning or is that something that



Dawn: initially they wanted to do it so er… they still do it, like the cooker, so sometimes I come back… well they're prepared for me, if I say I'm not ready, they will prepare it for me so sometimes I go there and they've done the water and things like that and everything which is good, so I just take it and then I think oh gosh I'm running late… so quickly I have it

RW: ah so you're rushing in the morning

Dawn: yeah, but when I get there I get my cup of tea, but home is home [laughs]

RW: what about making tea, can you make things like that?

Dawn: that's fine, yeah

RW: have you noticed…

Alesha: erm, hot chocolate's, Mum likes hot chocolate so she makes hot chocolate, probably anything that requires certain steps within it, so a hot chocolates probably a bit more simple because it's just adding powder and water and sugar, but tea probably has steps to it, she doesn't really drink tea anyway, but yeah some drinks

RW: so making hot chocolates fine

Alesha: yeah I mean it's recognising what is hot chocolate if that makes sense so I think yeah, we have black powder you know like powdered hot chocolate but I think Mum one time then got a jar of chocolate spread and she was using that as hot chocolate, do you remember that?

Dawn: it's over here that I saw that anyway

Alesha: yeah so we're talking about at home…

RW: yeah is it difficult getting round the kitchen and finding things at all?

Dawn: no not at all

RW: no, have you changed anything in the kitchen to make things easier like labels?

Alesha: no… I mean obviously my observation might be different from Mum's but navigating around it might sometimes take a few seconds to realise that ok the bowls here the spoon's here, erm, I mean I notice that things might be put in different places, or you know just…

Dawn: that is natural anyway… if I take your brush and put it down there you straight away you go to your room and that's where your brush is, I think that is sometimes aggrevating

RW: yeah so trying to find things and put things in the right places

Dawn: yeah, especially if you're in a hurry and you want to quickly do something and then it's like where's the brush, or something, well I don't do it to often

Alesha: well I think, without getting into it, the kitchens kind of shared so we living here we know where the spoons go, the forks go, as in in your room I don't know where you might keep some things because it's your room if that makes sense… does that make sense

Dawn: I don't like putting things in my bedroom…. If it's just clothes and stuff like that but not saucepans

Alesha: yeah in the kitchen where we both go on a daily basis, I'm just saying to Rachel that sometimes maybe not, and it happens to all of us, a plate might be put in the wrong place, or a spoon might be put in the wrong place that can happen, but there's no labels because I think in the beginning we kind of went label crazy we had a label maker, but what tends to happen is that first bit might be read like 'plates' 'cups' or whatever and then it's not read it just becomes part of the… it's not read

RW: ah ok so you get so used to it being there

Alesha: yeah so it's, and I mean, I think some cupboards are more noticeable than others so there's a cupboard here and everything gets put in there… not everything but theres a cupboard there for plates and bowls and a cupboard over here for cups but that cupboard for some reason doesn't get noticed

RW: so there's one place where quite a lot of things tend to go back in

Alesha: yeah it's just easier for me to just put them back because then I can't really see a way of making it clearer for wherever things should go if that makes sense

RW: yeah it does, do you miss cooking at all?

Dawn: infact yeah I miss cooking because er,

Alesha: I miss your cooking as well

RW: aw,

Alesha: especially things that I can't make you know like…

RW: did you have some good dishes that you used to make

Dawn: no, no, before I thought I was a good cook until I met their cooking and I thought… you don't have a chance [whispers] they've got it, they cook better than me, it's the spices, I think the trick in this is the spices… they know where to get a good spice…

Alesha: Sainsbury's mum

Dawn:… sometimes I look at it and think where did they get this

Alesha: oh that's when we're trying to drug you yeah we just put a little bit of something on it [laughs]… yeah but no African dishes because we're from Nigeria there's a few dishes that mum used to that if I attempt it I might put someone in hospital [laughs]

Dawn: [laughs]

Alesha: I leave those ones out

RW: aww so you miss some of your mum's cooking that she used to do?

Alesha: yeah we get by and by so

RW: and where are you eating, where are you having your meals?

Alesha: mainly in here

RW: in here

Dawn: yeah we'll come here

RW: and do you have the TV on or are you chatting?

Alesha: tv's on and…

Dawn: chatting some chatting

Alesha: not every day we eat together but the majority of the time we eat together

Dawn: especially weekends

RW: yeah how are weekends working are they a bit different or? Cos you're not at work then are you

Alesha: we… erm, we've got a thing now… between me my brother and my sister, like a rota system in place, so we alternate who will be with Mum on Saturday and who will be with Mum on Sunday, it's not a rule but if your with her on that Saturday then you take care of the meal… and do it that way, but I mean on the weekend I probably have a little bit more time to cook or make something a little bit nicer erm so I'd leave that and then that person can warm it up for Mum

RW: oh ok so you might prepare something and then leave it?

Alesha: yeah but somebody has to be there to, if that makes sense, so yeah…. Otherwise it gets left

RW: and what about eating out do you eat out at all in restaurants and things?

Dawn: sometimes, sometimes not always because ehh, what is it with Vince, I don't know whether he thought I was hungry or whatever so he said lets go for a walk, and we were in the…. I've forgotten what it's called, is it Chinese, Chinese or something and then but we didn't have it there we brought it home

RW: ah ok so you might get a takeaway and bring it back and have it here?

Dawn: yeah

RW: do you enjoy eating out?

Dawn: it depends… if the food is nice, I'll be attracted to it

RW: yeah and what about snacking and things… are you a snacker?

Alesha: yeah

Dawn: I am but I'm cutting it down

RW: ah ok… have you noticed that, snacking and things?

Alesha: erm, from what I've noticed is that… maybe if it's hard to prepare something, like if there's bread, bread gets eaten a lot and erm yeah, that's mainly the snacking

RW: ah ok, just plain bread on it's own

Alesha: plain bread on it's own… with hot chocolate… I watch you [laughs]… that look was like how did you know?!

RW: yeah… where's all the bread gone!

Dawn: yeah and she buys nice bread to

Alesha: I've been trying not to buy bread anymore because I've been reading this book which says that bread can increase the severity of Alzheimer's

RW: oh really

Alesha: yeah like basically they're doing like research on what, there's something in wheat and what it can do to the brain so erm, I'm a bit paranoid, because obviously with everything going on I tend to research and stuff because obviously I might have the gene or something like that… so just been reading

Dawn: so many people have got it… my colleagues some of them are driving me mad… I take my bag, I mean especially when it's time for us to sit down and the driver to bring us here, by and by, I don't know how that happens, I don't know if it's my luck, by and by I forget something and so… this woman come and talk to me as if I am [sighs]…

Alesha: who was it?

Dawn: I don't know, I don't know, it was today, I think probably she thinks probably I'm some little girl that she can talk to…

Alesha: but who is she… is she the east African one?

Dawn: no, no I'm talking about…

Alesha: but I've seen her before… is she dropping you off in the van?

Dawn: no,no

Alesha: she works there?

Dawn: I don't know if she works there or she's just like me…. I haven't got any relationship with her

RW: yeah, how many people go over all?

Alesha: it's a community centre but I think they have different groups in there

RW: yeah cos it looks kind of small and then I saw loads of people outside

Dawn: mm

RW: and what's the food like there is it nice

Dawn: it is nice, it is nice, today what did we have… oh I forget [laughs] yeah the food is good, the food is good

RW: what kind of food do they give you?

Dawn: most of the time it's fish and chips… is probably top

RW: ahh ok, that's quite a big lunch isn't it

Dawn: oh and then they will cut it for you, so you don't need to bite the whole thing

RW: oh that's good… are you doing that with some meals, cutting it up before hand and making it easier to eat?

Alesha: no, I mean thinking about it maybe I should… but I don't think it's hard to eat… just the use of cutelry, holding cutlery

RW: is that fine do you think?

Alesha: erm I don't think…

[phone rings]… but yeah, err, so like sometimes eating with hands so yeah

RW: ok so that's changed a bit… have you noticed that it's difficult to use cutlery?

Dawn: oh no not at all, not at all, not at all

RW: yeah

Dawn: I'm just thinking with the cutlery it depends what kind of food you're eating or cutting, obviously it will be different from… say if I'm cutting bread because I've done that for many years you don't even think you just go… whereas another meal comes and you think I haven't seen this food before… you take your time and decide what to… but that doesn't mean it's affecting the… [cutlery use] well I don't know I don't think so

Alesha: yeah unless I put the cutlery on the food then I've noticed she's started eating with hands… it's just a reminder that that's obviously the tool that, you know how we're kind of without thinking you know your fork goes in your left hand, so just yeah sometimes I can see it's a bit of a difficulty

Dawn: it's not a problem, it's not a problem, because there's so many left handed people in the world you see

RW: yeah, are you left handed?

Dawn: no

RW: but you've started putting the fork in your right hand sometimes?

Dawn: it depends, it depends, so even then it's not now I think right from the day I was born I think I was doing that

RW: ahh ok, yeah

Dawn: cos if I'm cutting bread it's quicker, and if it's going there then I will turn it

RW: yeah do you eat with a tray

Dawn: yeah we've got trays

Alesha: and that table, mainly mum would eat off that table

RW: yeah and who's initiating mealtimes?

Alesha: it would be me… there is, I find some difficulty around mealtime, just mum saying whether she's hungry or not, it's not, I don't always find it that straight forward in terms of are you hungry, yes or no

Dawn: ok

Alesha: sometimes it has to take like, I don't know I find most frustration… maybe that's my perspective but I find most frustration is around mealtime because you want to make sure that, say someone's hungry… that you want to make sure that, she doesn't really say yeah I'm hungry, it's not a criticism, I just… I think I just need to appreciate you know that sometimes your not sure if your hungry so you think oh am I peckish or am I actually hungry so there's a bit of erm… yeah, but it like takes, because I come in from work and I might have had a late lunch whereas mum might have eaten before that so it wouldn't be a straight forward thing of oh I'm hungry can we eat… it would be kind of questions like oh what do you think we should have tonight? Should I go to the shop? Are you hungry? Are you hungry? Or like… sort of, not a direct thing, so I get a bit worried if I'm missing or not that she's hungry to cook, yeah

RW: mmm, so it's not like every night you get in from work and it's like right 6.30 lets have dinner

Alesha: no it's not set times, it's not set times, because I don't want to make food if erm, if it's not going to be eaten, but it might be a thing where she says she's not hungry and then later on she's snacking on something… so, yeah I can't always… it's not always set times that I will be hungry or Mum will be hungry so we just have to kind of, either make food for myself and just hope that if I make food for myself it can then bring up ok I'm hungry I can smell the food, I can bring up the food, or showing the food sometimes describing what I'm going to cook might not be what she thinks she wants to eat but seeing it cooked and prepared is… ok…

RW: it's like a trigger

Alesha: yeah so I say like ok I'm going to have chicken, I don't eat meat, but I say to her we're going to have chicken and she says oh we have chicken everyday which we don't, because I don't eat chicken, but once it's prepared and she can see ok this is the meal, it's time to eat… so sometimes it is a bit like…

RW: so sometimes before the meal you might not feel hungry necessarily?

Dawn: oh no it's not like that it could be we had a meal say 2 o clock or something and by 4.30 or even 5 she'll say are you hungry and I feel like, how do I say, because I'm not hungry now but it looks as if it won't be long before I'm hungry… that kind of feeling in my tummy

RW: yeah

Dawn: and I say to myself… look you do what you want to do if you want to cook, cook, because I can sit down and watch television and she's doing something but if she needs me, but sometimes she'll say do you want this or do you want that and sometimes it's difficult

RW: it's difficult to know when you'll be hungry

Dawn: mm

RW: does it happen in the evening sometimes that then you just won't cook

Alesha: yeah I think the other day what happened… erm, so like a situation like that… erm, I think obviously because I can't read your mind and I know it doesn't always happen but you don't know what answer to give you know, but it's one of those things where I come in from work, I don't know maybe it might sound a bit selfish, but I just want to know am I cooking now or I'm not, so I can sit down… or do I know I need to cook later and then what happens… what I think happened the other day was, so I asked mum if she was hungry, she said no, but then she started making her own food, and I could just hear the struggle, I was in my room but I could hear the struggle of the process and I'm kind of like [sighs], you know

Dawn: I'm not saying nothing [laughs]

Alesha: so you know it's just kind of a bit… and all in all it took just over three hours where I could have just done it, so yeah, I think it happens sometimes like that but you just have to

RW: do you think it's because you want to cook and you want to make food in your own time?

Dawn: no, no

Alesha: I don't know Mum maybe I'm wrong but if she sees me come in from work and I might be tired I think she's just trying to be mindful of ok look I don't want you to cook

Dawn: she has read my mind… because I'm at home, ok I don't like being alone at home but err, I don't mind… no, no, no… but there's times that I feel lonely, so when I sit there like that I feel happy… I've got a good, but if I knew, this particular day, later on I said to myself … we were talking and then the food came in, because much as I am hungry, and I wasn't hungry, it's not like, oh I haven't eaten the whole day… [starving] it's not like that… and I thought she was going to say ok if you don't want to eat rice I'm going to give you like tea or hot chocolate or whatever… so I would have had to be the one to get it rather than me getting it from her

RW: yeah so it's more you initiating the meal then

Dawn: yeah I mean it helps if I'm kind of told I'm hungry, because I never mind getting up and making something to eat because I know that does create some difficult… but it's more frustrating when she could be hungry, she's snacking which snacking is whatever, but she's hungry and I know

that there's food that could be cooked, nothing is said until it's a point that... and then she doesn't really eat properly, so I just think well you know, it can be a bit thingy, you feel a bit guilty because I could have cooked you know so it's quite difficult to force someone to eat when you don't know if they're hungry or not, it's not always clear, it's not always clear, so I'm just like ok if your not hungry I'm literally taking it as in your not hungry and I'm going to make myself something to eat you know

RW: yeah, how many times would you say that happens in a week?

Dawn: oh no, in a week

Alesha: I'd say at least once or twice... it will happen at least once or twice

Dawn: not much at all

RW: yeah, what were meals like in the past?

Alesha: when Mum was cooking... there was always food made and if it wasn't cooked on that day there'd be some from the day before, so there'd be sauce and rice, like something that you can put together... so there was always, now that I remember if I'd come home and smell food I know that I don't need to go back to the shops and get something to eat, because mum had made something because when my step dad was alive my mum used to... he basically was a caretaker in central London so he used to have to stay there when he was working so mum cooked food for us and then she'd take some food for my step dad and give him food so that was happening, we were going back and forth and then that gradually stopped so...

RW: so you wouldn't all necessarily be together at a mealtime, it might be a time that... oh there's food in the kitchen and you can help yourself after work

Alesha: yeah we'd eat together at the weekend but rarely on a weekday so yeah, that's the thing that, and I mean I was more or less just thinking about myself so... if there was no food and I couldn't be bothered to cook, I'd know it was just me not eating, as in now it's different in that way, if there's no food I have to think, so I'm always thinking about food and what to cook and what to eat and stuff like that and what needs to be bought... yeah so it's more... I think before I did kind of take it over thinking ok yeah I'll do this but I think now it is I need to make something to eat so

RW: yeah thinking about it and preparing meals

Dawn: you've been a mum for how many months now

Alesha: months.. years

Dawn: it is a lot

Alesha: yeah

Dawn: yeah I appreciate that... and when I say ohh, thank you, what have I done, she hasn't done anything for me, that's what she's saying, not that she hasn't done anything but it's like don't mention it... something like that, but yeah I'm very very grateful

RW: ah yeah well you used to do all the cooking when the kids were growing up so it's your turn now

Dawn: well they were babies so no question, no answer

Alesha: so when I go to my Dads… my Dad lives in north London when I go to his house I literally get him to cook for me, because you know sometimes you want someone to cook for you so sometimes I just say to him before can you start cooking [laughs]… just to have that, but otherwise it's fine

RW: yeah, is it strange kind of cos obviously you're the mum and you're the daughter and roles have changed a little bit in terms of taking over the household stuff is that difficult or is it… you know has it changed your relationship dynamic or not really?

Dawn: yeah a bit… but it's just because of err

Alesha: the situation

Dawn: the situation… it's the situation that's all

Alesha: yeah I think probably if I wasn't working full time it probably, I mean on a day to day basis it's not every day that… but even today I'm conscious of the fact that ok this is fine, but just say I'm going to yoga, if I made it to yoga, I need to go and get something to make before I go to yoga so that I know that I can go… I know that Mum has eaten something, so sometimes it is a bit, I don't know, like a bit of pressure on that side, cos I don't know I see myself as thart… if I don't eat anything I'm fine, and if I'm hungry, I'm hungry you know whatever but if someone else is relying on that food then it's kind of a bit of an

Dawn: well that's natural isn't it

Alesha: mm, but yeah I think it has changed… I think it being food, it's kind of more central to like the roles of a mother and the roles of a child, so not to say ok I'm older now you know I'm not like, I'm in my 20s but the mother that's part of a nurturing role for the mother to cook the food and as much as I like cooking and I probably would still be cooking then that makes the roles change a bit in that sense

Dawn: yeah but what your saying is it's the norm for some homes or some, err, cultures, but at the end of the day, it's the same thing, it's the same thing, cos wherever you go there's people there, everybody they just want to make their homes happy… so definitely it's things like this, it will be everywhere… I'm not saying that err, ask her she said oh no, but similar things are happening…I haven't been to anybodies house, but I can imagine, because what I… I'll be reading a book and I'll feel like wow, but it's something that most people do… I was trying to remember what the book was… so sometimes we think that, I'm one of them, I'm the only one that is doing it and they say that and then they say that but then when you meet other people, that's why it's good to have friends and things like that cos it's not only the book that gives us wisdom… sometimes true friends, sometimes people will say things to you and I think I will never forget this, dwell on it, if it's good for you you take it, if it's not you throw it away… so sometimes we wait to long to go to school and come back, and everythings gone… [talks about something she's read]… at the end of the day we can't change things, so when we do things this way it's beneficial

RW: yeah so the way you do it now, it works, and there's other people that may be in a situation like that

Dawn: it's up to the individual homes… individual homes

RW: yeah homes are different and work differently

Dawn: yeah cos sometimes if I hear something or see something good I copy it, I copy it,

RW: so the way you've got it now kind of works for you guys

Dawn: yeah especially now that she's come out with what's bothering her, not bothering her but by and by she was waiting for us to say something… you want to tell us how you want to

Alesha: no I think it could be better in terms of there's a gap between when my Mum comes home and I come home, or say… erm, you know if I'm after work I want to go out somewhere

Dawn: fine!

Alesha: I know… I'm not… I'm just saying in terms of like, I don't know, sometimes I've not been able to do that if no-ones here

RW: yeah so just a bit of a back-up just in case

Alesha: exactly, if there's anything left it has to be warmed and that's another process in itself that like…

RW: and that's not been able to be done

Alesha: no, so and I don't know about my sister but my brother doesn't really cook so it's kind of like I don't know like no one else cooks if that makes sense, you know sometimes things become erm kind of expected, not that I have to but I'm just the one who cooks so… you know, it's like even when my brother was here at the weekend, so you know we take turns to, so I ended up cooking… I was going to detach myself from and thought ok it's not my weekend so I'm not going to cook but I ended up cooking because my brother doesn't cook

RW: yeah, so you're thinking about it and preparing in advance

Alesha: yeah, yeah, so I think, but I think the way it is now it works as well as it can do

Dawn: because it's good to talk… so if we don't talk about

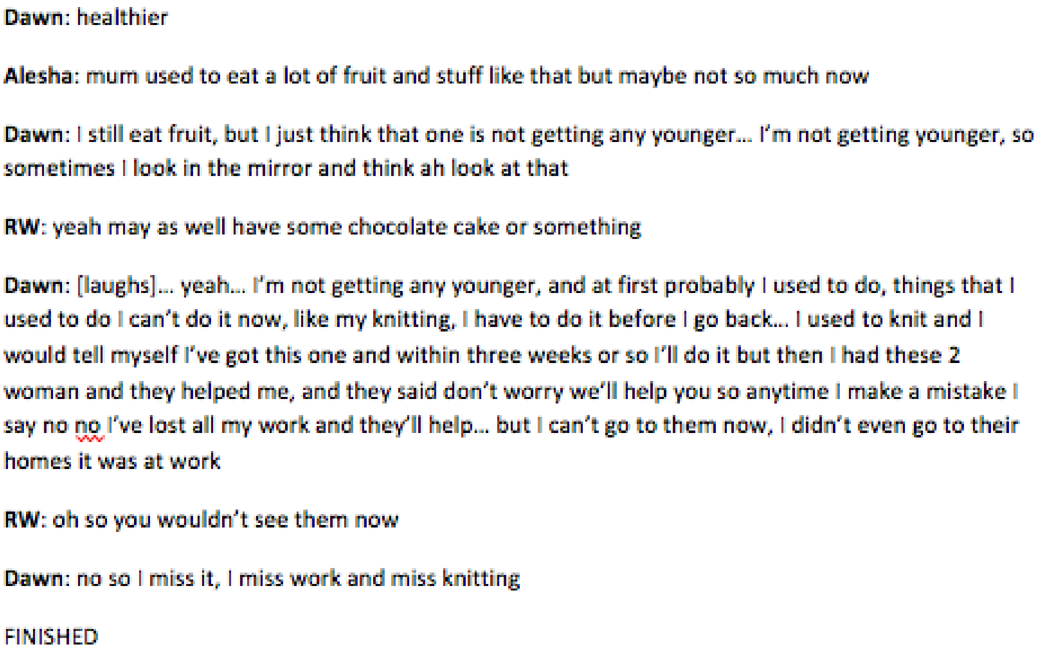
Alesha: yeah it's not something that… I'd probably say it to you if needs be but I think just as we're talking about it yeah it's mentioning it, but it's not something I'm losing sleep over

RW: yeah it's just one of those things

Alesha: it's just one of those things yeah but erm yeah it works for the situation at the moment

RW: yeah have you noticed any taste changes or anything like that, or foods that you've gone off that you used to like?

Alesha: probably like sweet stuff more, I don't know and correct me if I'm wrong mum I don't mean to be a snob but I think mum used to be healthier before but maybe not so much now



Dawn: healthier

Alesha: mum used to eat a lot of fruit and stuff like that but maybe not so much now

Dawn: I still eat fruit, but I just think that one is not getting any younger… I'm not getting younger, so sometimes I look in the mirror and think ah look at that

RW: yeah may as well have some chocolate cake or something

Dawn: [laughs]… yeah… I'm not getting any younger, and at first probably I used to do, things that I used to do I can't do it now, like my knitting, I have to do it before I go back… I used to knit and I would tell myself I've got this one and within three weeks or so I'll do it but then I had these 2 woman and they helped me, and they said don't worry we'll help you so anytime I make a mistake I say no no I've lost all my work and they'll help… but I can't go to them now, I didn't even go to their homes it was at work

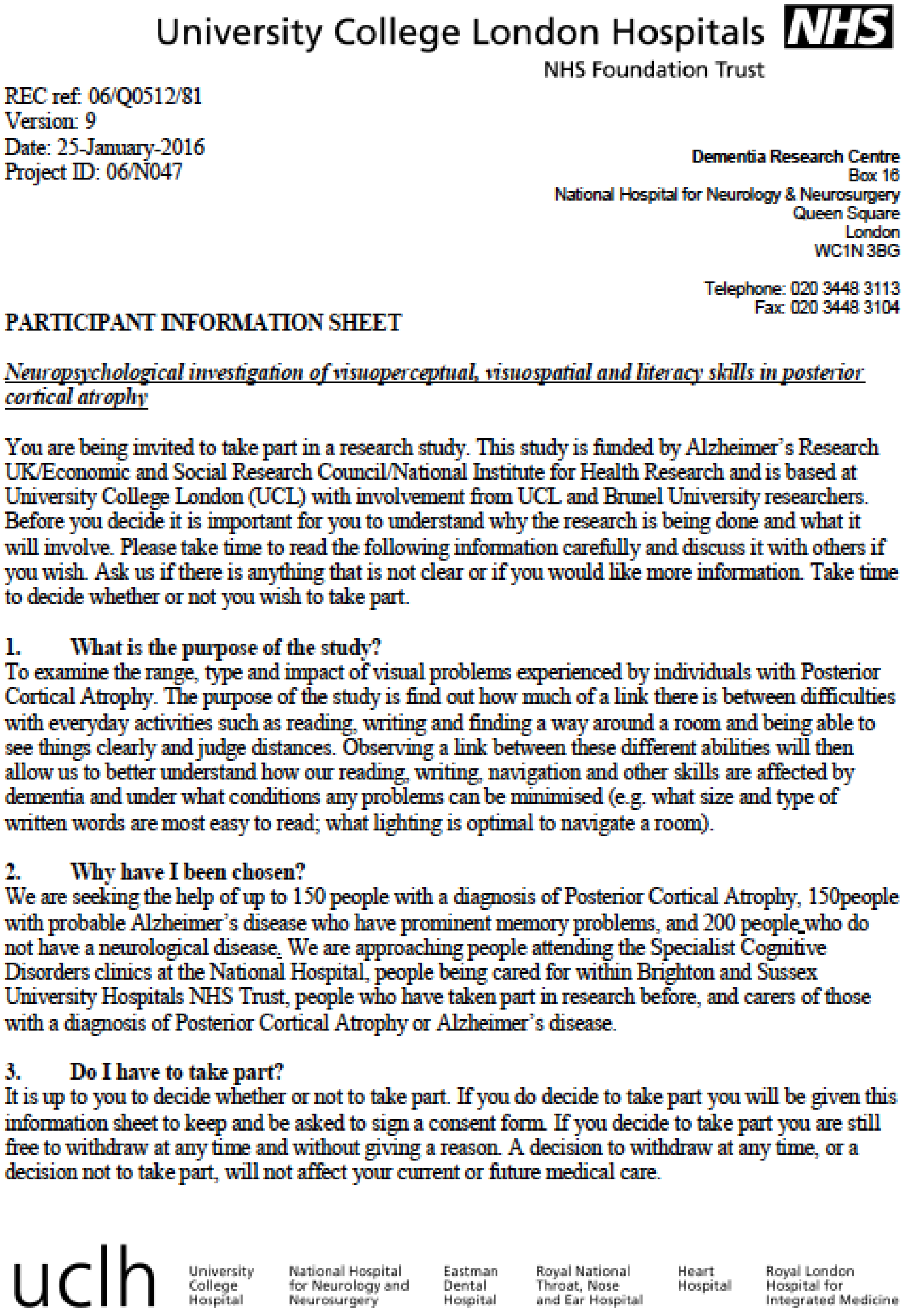
RW: oh so you wouldn't see them now

Dawn: no so I miss it, I miss work and miss knitting

FINISHED

Appendix 9: Information sheets, consent forms and ethical approval for video-based observation

Information sheet person with dementia:



University College London Hospitals NHS
NHS Foundation Trust

REC ref: 06/Q0512/81
Version: 9
Date: 25-January-2016
Project ID: 06/N047

Dementia Research Centre
Box 16
National Hospital for Neurology & Neurosurgery
Queen Square
London
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Telephone: 020 3448 3113
Fax: 020 3448 3104

PARTICIPANT INFORMATION SHEET

Neuropsychological investigation of visuoperceptual, visuospatial and literacy skills in posterior cortical atrophy

You are being invited to take part in a research study. This study is funded by Alzheimer's Research UK/Economic and Social Research Council/National Institute for Health Research and is based at University College London (UCL) with involvement from UCL and Brunel University researchers. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

1. What is the purpose of the study?

To examine the range, type and impact of visual problems experienced by individuals with Posterior Cortical Atrophy. The purpose of the study is find out how much of a link there is between difficulties with everyday activities such as reading, writing and finding a way around a room and being able to see things clearly and judge distances. Observing a link between these different abilities will then allow us to better understand how our reading, writing, navigation and other skills are affected by dementia and under what conditions any problems can be minimised (e.g. what size and type of written words are most easy to read; what lighting is optimal to navigate a room).

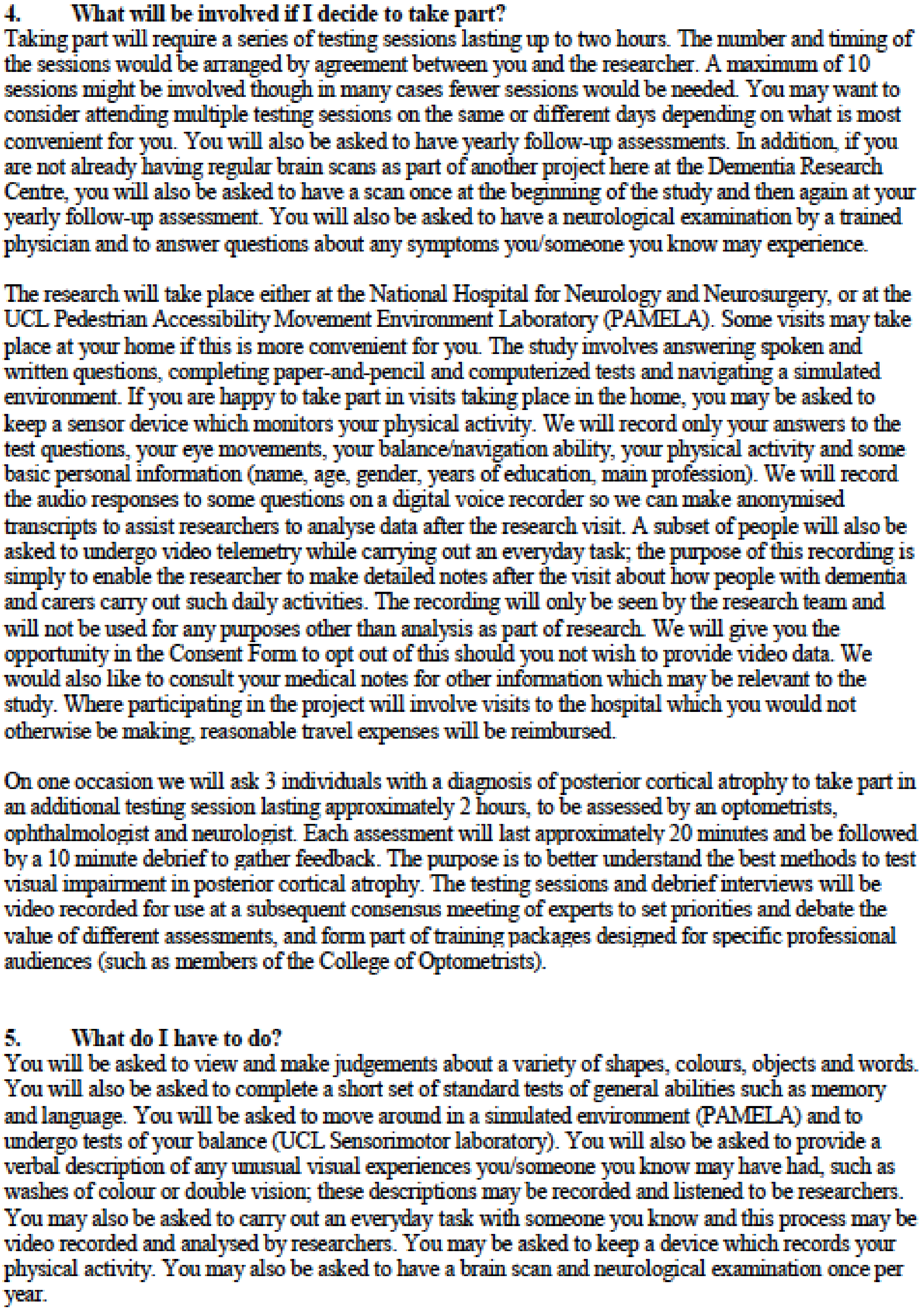
2. Why have I been chosen?

We are seeking the help of up to 150 people with a diagnosis of Posterior Cortical Atrophy, 150people with probable Alzheimer's disease who have prominent memory problems, and 200 people who do not have a neurological disease. We are approaching people attending the Specialist Cognitive Disorders clinics at the National Hospital, people being cared for within Brighton and Sussex University Hospitals NHS Trust, people who have taken part in research before, and carers of those with a diagnosis of Posterior Cortical Atrophy or Alzheimer's disease.

3. Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect your current or future medical care.

uclh University College Hospital · National Hospital for Neurology and Neurosurgery · Eastman Dental Hospital · Royal National Throat, Nose and Ear Hospital · Heart Hospital · Royal London Hospital for Integrated Medicine



4. What will be involved if I decide to take part?

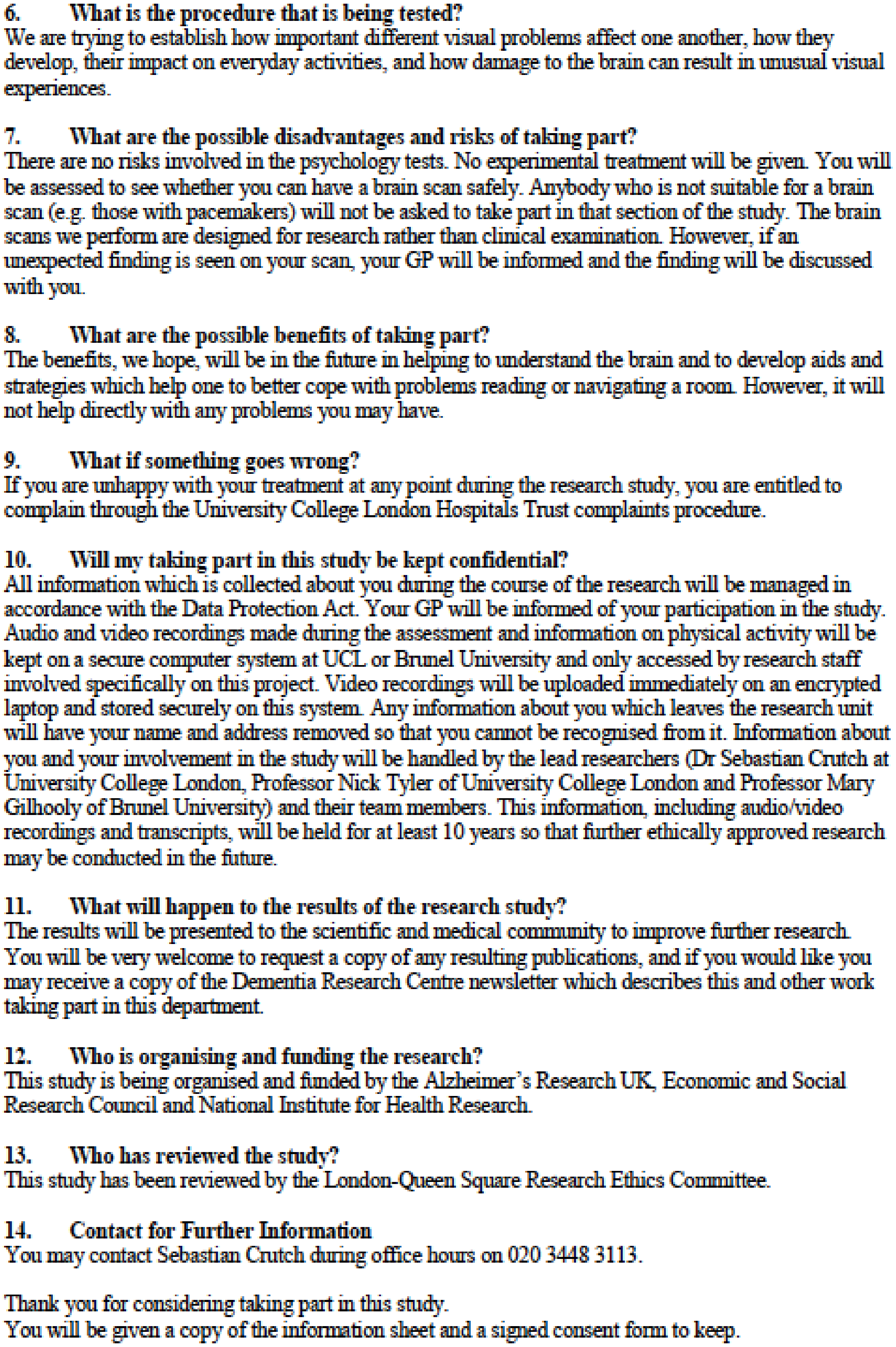
Taking part will require a series of testing sessions lasting up to two hours. The number and timing of the sessions would be arranged by agreement between you and the researcher. A maximum of 10 sessions might be involved though in many cases fewer sessions would be needed. You may want to consider attending multiple testing sessions on the same or different days depending on what is most convenient for you. You will also be asked to have yearly follow-up assessments. In addition, if you are not already having regular brain scans as part of another project here at the Dementia Research Centre, you will also be asked to have a scan once at the beginning of the study and then again at your yearly follow-up assessment. You will also be asked to have a neurological examination by a trained physician and to answer questions about any symptoms you/someone you know may experience.

The research will take place either at the National Hospital for Neurology and Neurosurgery, or at the UCL Pedestrian Accessibility Movement Environment Laboratory (PAMELA). Some visits may take place at your home if this is more convenient for you. The study involves answering spoken and written questions, completing paper-and-pencil and computerized tests and navigating a simulated environment. If you are happy to take part in visits taking place in the home, you may be asked to keep a sensor device which monitors your physical activity. We will record only your answers to the test questions, your eye movements, your balance/navigation ability, your physical activity and some basic personal information (name, age, gender, years of education, main profession). We will record the audio responses to some questions on a digital voice recorder so we can make anonymised transcripts to assist researchers to analyse data after the research visit. A subset of people will also be asked to undergo video telemetry while carrying out an everyday task; the purpose of this recording is simply to enable the researcher to make detailed notes after the visit about how people with dementia and carers carry out such daily activities. The recording will only be seen by the research team and will not be used for any purposes other than analysis as part of research. We will give you the opportunity in the Consent Form to opt out of this should you not wish to provide video data. We would also like to consult your medical notes for other information which may be relevant to the study. Where participating in the project will involve visits to the hospital which you would not otherwise be making, reasonable travel expenses will be reimbursed.

On one occasion we will ask 3 individuals with a diagnosis of posterior cortical atrophy to take part in an additional testing session lasting approximately 2 hours, to be assessed by an optometrists, ophthalmologist and neurologist. Each assessment will last approximately 20 minutes and be followed by a 10 minute debrief to gather feedback. The purpose is to better understand the best methods to test visual impairment in posterior cortical atrophy. The testing sessions and debrief interviews will be video recorded for use at a subsequent consensus meeting of experts to set priorities and debate the value of different assessments, and form part of training packages designed for specific professional audiences (such as members of the College of Optometrists).

5. What do I have to do?

You will be asked to view and make judgements about a variety of shapes, colours, objects and words. You will also be asked to complete a short set of standard tests of general abilities such as memory and language. You will be asked to move around in a simulated environment (PAMELA) and to undergo tests of your balance (UCL Sensorimotor laboratory). You will also be asked to provide a verbal description of any unusual visual experiences you/someone you know may have had, such as washes of colour or double vision; these descriptions may be recorded and listened to be researchers. You may also be asked to carry out an everyday task with someone you know and this process may be video recorded and analysed by researchers. You may be asked to keep a device which records your physical activity. You may also be asked to have a brain scan and neurological examination once per year.



6. What is the procedure that is being tested?

We are trying to establish how important different visual problems affect one another, how they develop, their impact on everyday activities, and how damage to the brain can result in unusual visual experiences.

7. What are the possible disadvantages and risks of taking part?

There are no risks involved in the psychology tests. No experimental treatment will be given. You will be assessed to see whether you can have a brain scan safely. Anybody who is not suitable for a brain scan (e.g. those with pacemakers) will not be asked to take part in that section of the study. The brain scans we perform are designed for research rather than clinical examination. However, if an unexpected finding is seen on your scan, your GP will be informed and the finding will be discussed with you.

8. What are the possible benefits of taking part?

The benefits, we hope, will be in the future in helping to understand the brain and to develop aids and strategies which help one to better cope with problems reading or navigating a room. However, it will not help directly with any problems you may have.

9. What if something goes wrong?

If you are unhappy with your treatment at any point during the research study, you are entitled to complain through the University College London Hospitals Trust complaints procedure.

10. Will my taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be managed in accordance with the Data Protection Act. Your GP will be informed of your participation in the study. Audio and video recordings made during the assessment and information on physical activity will be kept on a secure computer system at UCL or Brunel University and only accessed by research staff involved specifically on this project. Video recordings will be uploaded immediately on an encrypted laptop and stored securely on this system. Any information about you which leaves the research unit will have your name and address removed so that you cannot be recognised from it. Information about you and your involvement in the study will be handled by the lead researchers (Dr Sebastian Crutch at University College London, Professor Nick Tyler of University College London and Professor Mary Gilhooly of Brunel University) and their team members. This information, including audio/video recordings and transcripts, will be held for at least 10 years so that further ethically approved research may be conducted in the future.

11. What will happen to the results of the research study?

The results will be presented to the scientific and medical community to improve further research. You will be very welcome to request a copy of any resulting publications, and if you would like you may receive a copy of the Dementia Research Centre newsletter which describes this and other work taking part in this department.

12. Who is organising and funding the research?

This study is being organised and funded by the Alzheimer's Research UK, Economic and Social Research Council and National Institute for Health Research.

13. Who has reviewed the study?

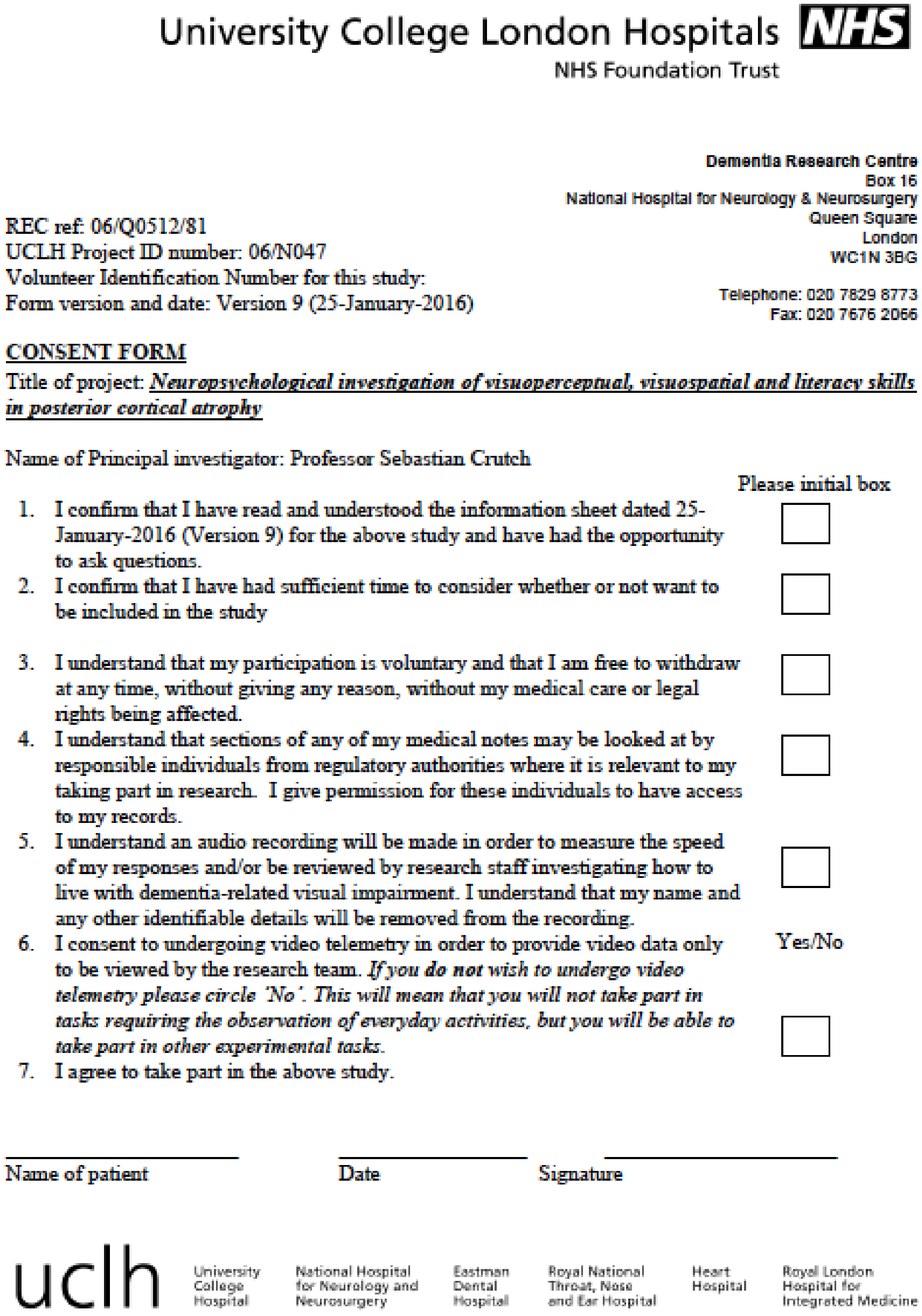
This study has been reviewed by the London-Queen Square Research Ethics Committee.

14. Contact for Further Information

You may contact Sebastian Crutch during office hours on 020 3448 3113.

Thank you for considering taking part in this study.
You will be given a copy of the information sheet and a signed consent form to keep.

Consent form person with dementia:



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NHS Foundation Trust

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National Hospital for Neurology & Neurosurgery
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WC1N 3BG

Telephone: 020 7829 8773
Fax: 020 7676 2066

REC ref: 06/Q0512/81
UCLH Project ID number: 06/N047
Volunteer Identification Number for this study:
Form version and date: Version 9 (25-January-2016)

CONSENT FORM

Title of project: ***Neuropsychological investigation of visuoperceptual, visuospatial and literacy skills in posterior cortical atrophy***

Name of Principal investigator: Professor Sebastian Crutch

Please initial box

1. I confirm that I have read and understood the information sheet dated 25-January-2016 (Version 9) for the above study and have had the opportunity to ask questions. ☐
2. I confirm that I have had sufficient time to consider whether or not want to be included in the study ☐
3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐
4. I understand that sections of any of my medical notes may be looked at by responsible individuals from regulatory authorities where it is relevant to my taking part in research. I give permission for these individuals to have access to my records. ☐
5. I understand an audio recording will be made in order to measure the speed of my responses and/or be reviewed by research staff investigating how to live with dementia-related visual impairment. I understand that my name and any other identifiable details will be removed from the recording. ☐
6. I consent to undergoing video telemetry in order to provide video data only to be viewed by the research team. *If you **do not** wish to undergo video telemetry please circle 'No'. This will mean that you will not take part in tasks requiring the observation of everyday activities, but you will be able to take part in other experimental tasks.* Yes/No
7. I agree to take part in the above study. ☐

Name of patient ________________ Date ________________ Signature ________________

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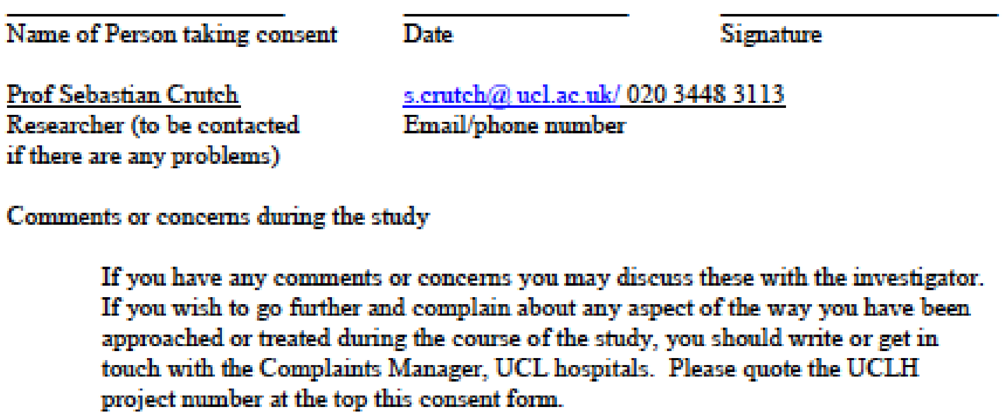


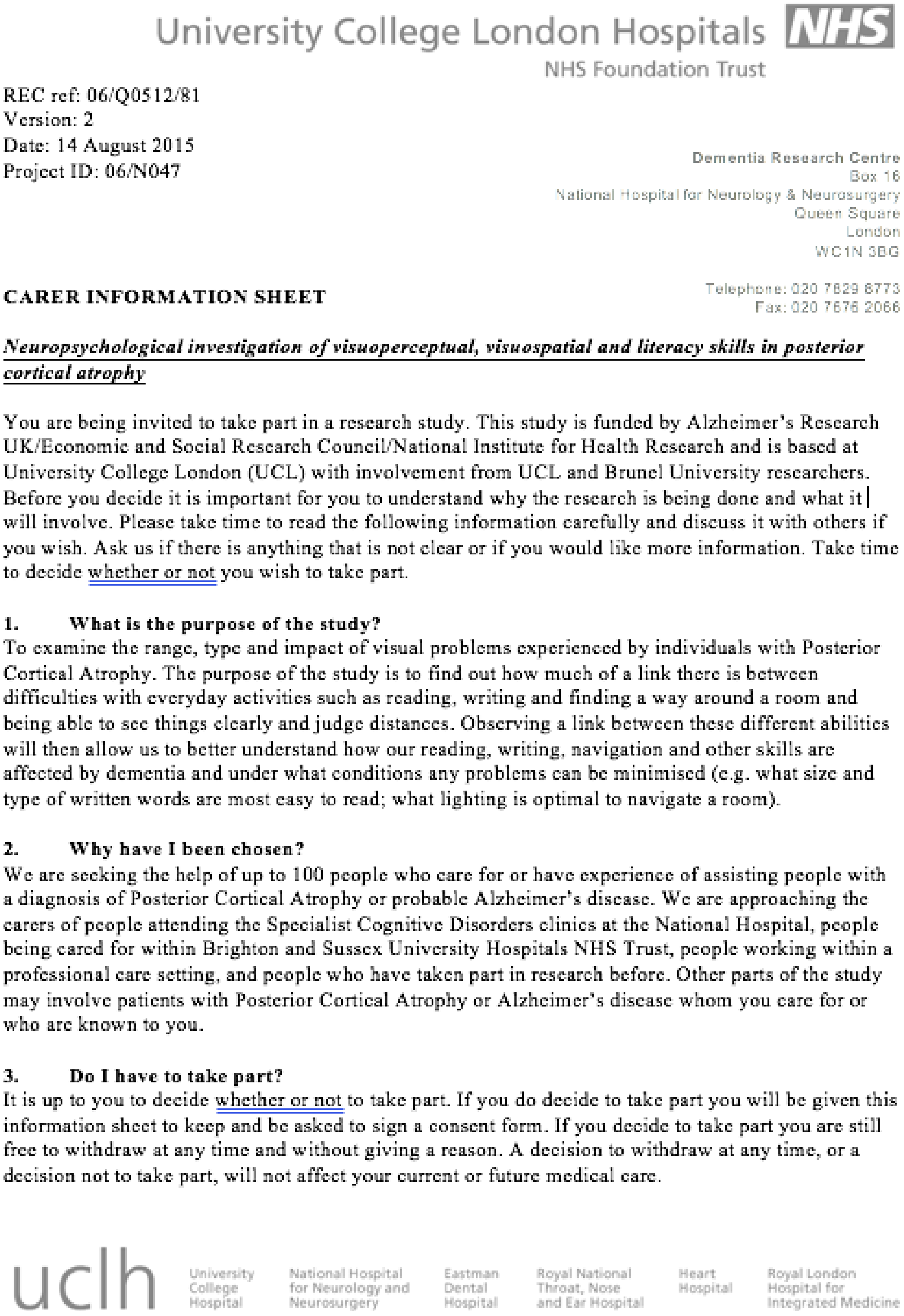
Name of Person taking consent	Date	Signature

Prof Sebastian Crutch Researcher (to be contacted if there are any problems)	s.crutch@ ucl.ac.uk/ 020 3448 3113 Email/phone number

Comments or concerns during the study

If you have any comments or concerns you may discuss these with the investigator. If you wish to go further and complain about any aspect of the way you have been approached or treated during the course of the study, you should write or get in touch with the Complaints Manager, UCL hospitals. Please quote the UCLH project number at the top this consent form.

Information sheet family member:



University College London Hospitals NHS
NHS Foundation Trust

REC ref: 06/Q0512/81
Version: 2
Date: 14 August 2015
Project ID: 06/N047

Dementia Research Centre
Box 16
National Hospital for Neurology & Neurosurgery
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CARER INFORMATION SHEET

Neuropsychological investigation of visuoperceptual, visuospatial and literacy skills in posterior cortical atrophy

You are being invited to take part in a research study. This study is funded by Alzheimer's Research UK/Economic and Social Research Council/National Institute for Health Research and is based at University College London (UCL) with involvement from UCL and Brunel University researchers. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

1. What is the purpose of the study?

To examine the range, type and impact of visual problems experienced by individuals with Posterior Cortical Atrophy. The purpose of the study is to find out how much of a link there is between difficulties with everyday activities such as reading, writing and finding a way around a room and being able to see things clearly and judge distances. Observing a link between these different abilities will then allow us to better understand how our reading, writing, navigation and other skills are affected by dementia and under what conditions any problems can be minimised (e.g. what size and type of written words are most easy to read; what lighting is optimal to navigate a room).

2. Why have I been chosen?

We are seeking the help of up to 100 people who care for or have experience of assisting people with a diagnosis of Posterior Cortical Atrophy or probable Alzheimer's disease. We are approaching the carers of people attending the Specialist Cognitive Disorders clinics at the National Hospital, people being cared for within Brighton and Sussex University Hospitals NHS Trust, people working within a professional care setting, and people who have taken part in research before. Other parts of the study may involve patients with Posterior Cortical Atrophy or Alzheimer's disease whom you care for or who are known to you.

3. Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect your current or future medical care.

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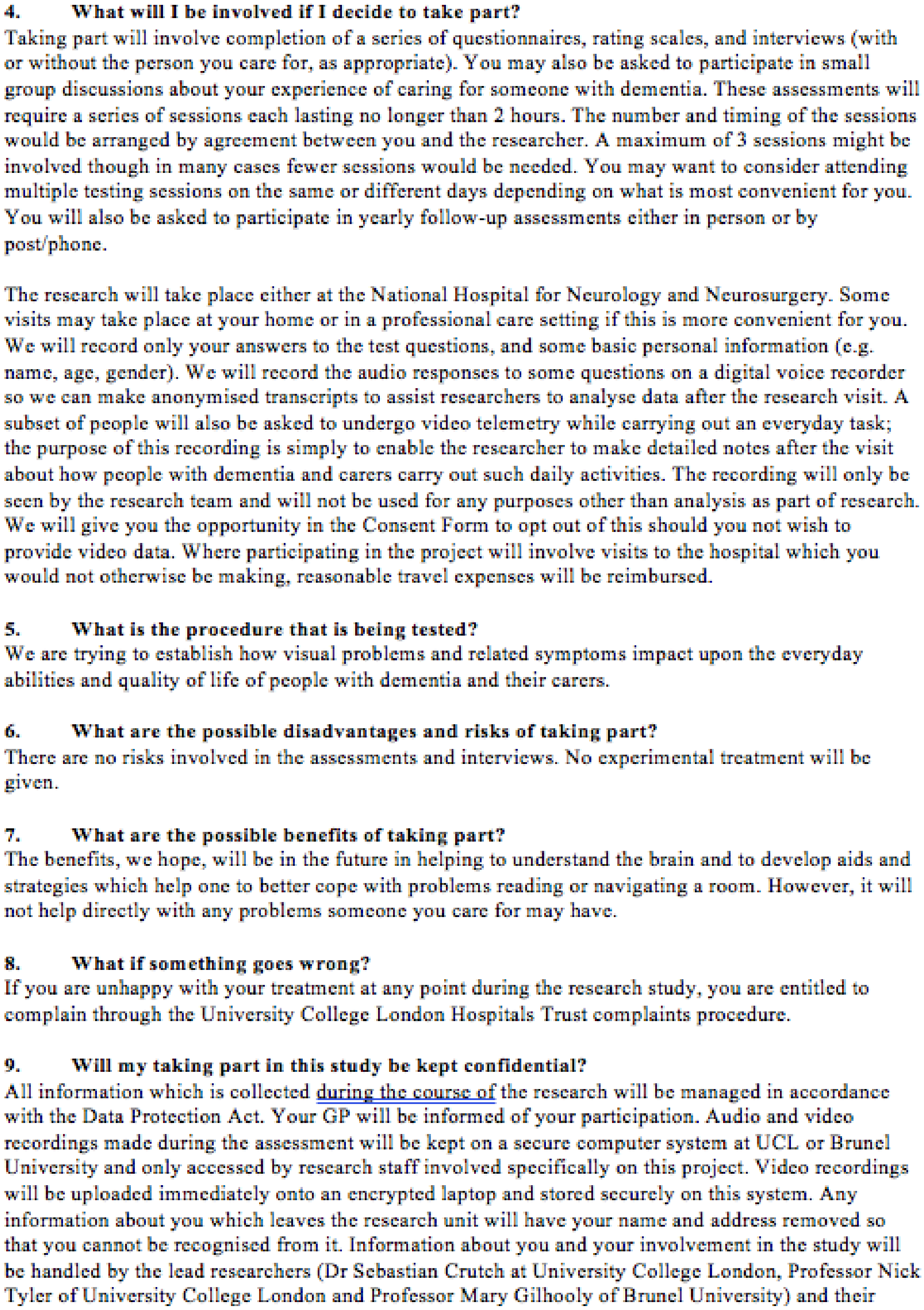

4. What will I be involved if I decide to take part?

Taking part will involve completion of a series of questionnaires, rating scales, and interviews (with or without the person you care for, as appropriate). You may also be asked to participate in small group discussions about your experience of caring for someone with dementia. These assessments will require a series of sessions each lasting no longer than 2 hours. The number and timing of the sessions would be arranged by agreement between you and the researcher. A maximum of 3 sessions might be involved though in many cases fewer sessions would be needed. You may want to consider attending multiple testing sessions on the same or different days depending on what is most convenient for you. You will also be asked to participate in yearly follow-up assessments either in person or by post/phone.

The research will take place either at the National Hospital for Neurology and Neurosurgery. Some visits may take place at your home or in a professional care setting if this is more convenient for you. We will record only your answers to the test questions, and some basic personal information (e.g. name, age, gender). We will record the audio responses to some questions on a digital voice recorder so we can make anonymised transcripts to assist researchers to analyse data after the research visit. A subset of people will also be asked to undergo video telemetry while carrying out an everyday task; the purpose of this recording is simply to enable the researcher to make detailed notes after the visit about how people with dementia and carers carry out such daily activities. The recording will only be seen by the research team and will not be used for any purposes other than analysis as part of research. We will give you the opportunity in the Consent Form to opt out of this should you not wish to provide video data. Where participating in the project will involve visits to the hospital which you would not otherwise be making, reasonable travel expenses will be reimbursed.

5. What is the procedure that is being tested?

We are trying to establish how visual problems and related symptoms impact upon the everyday abilities and quality of life of people with dementia and their carers.

6. What are the possible disadvantages and risks of taking part?

There are no risks involved in the assessments and interviews. No experimental treatment will be given.

7. What are the possible benefits of taking part?

The benefits, we hope, will be in the future in helping to understand the brain and to develop aids and strategies which help one to better cope with problems reading or navigating a room. However, it will not help directly with any problems someone you care for may have.

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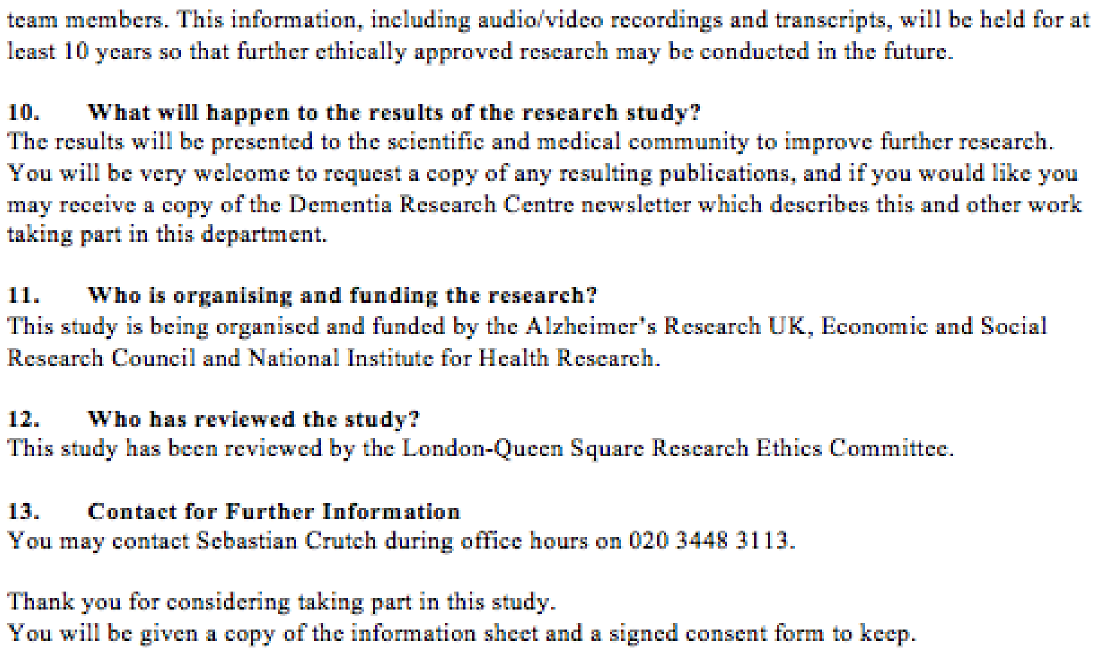

team members. This information, including audio/video recordings and transcripts, will be held for at least 10 years so that further ethically approved research may be conducted in the future.

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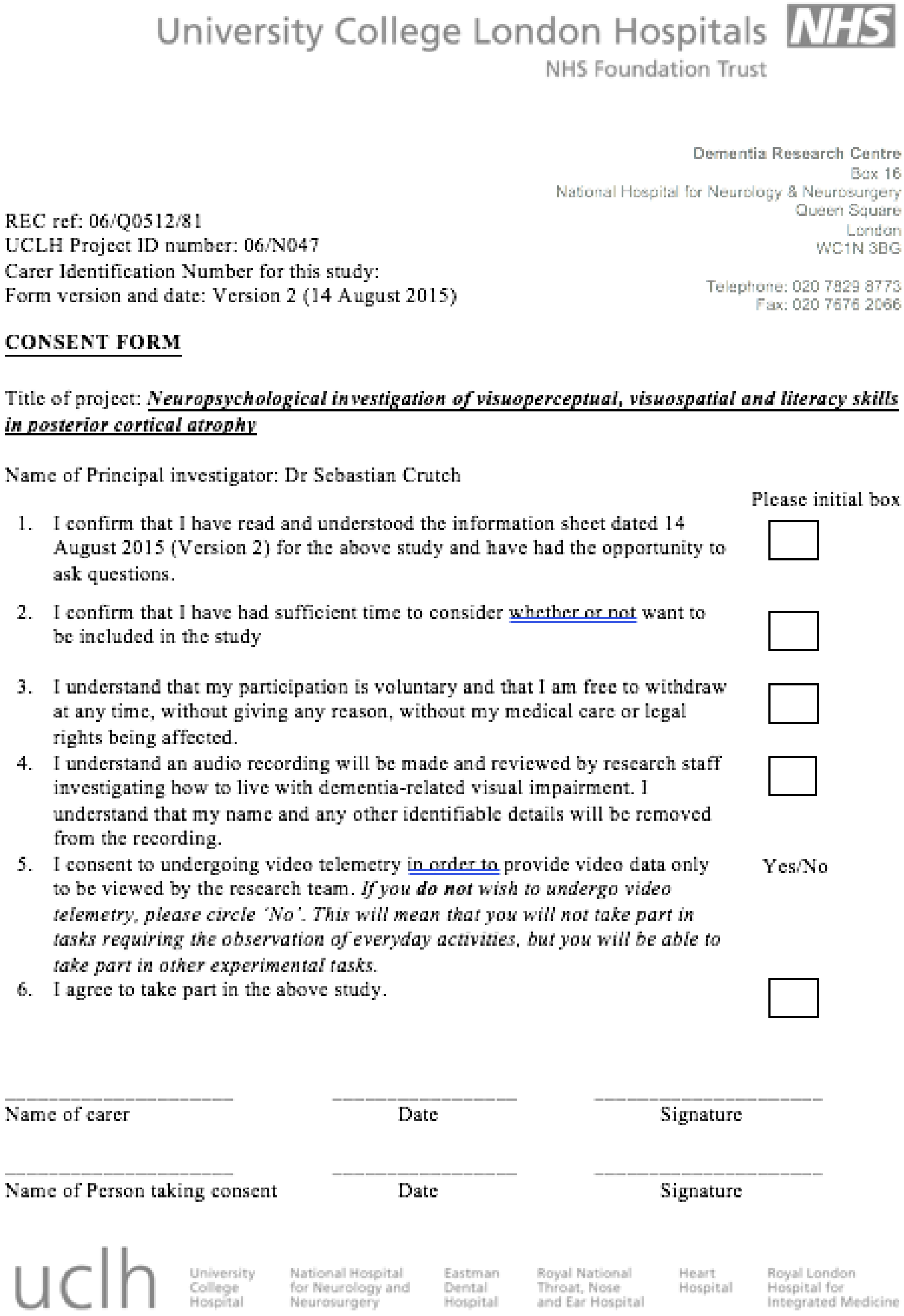

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Telephone: 020 7829 8773
Fax: 020 7676 2066

REC ref: 06/Q0512/81
UCLH Project ID number: 06/N047
Carer Identification Number for this study:
Form version and date: Version 2 (14 August 2015)

CONSENT FORM

Title of project: ***Neuropsychological investigation of visuoperceptual, visuospatial and literacy skills in posterior cortical atrophy***

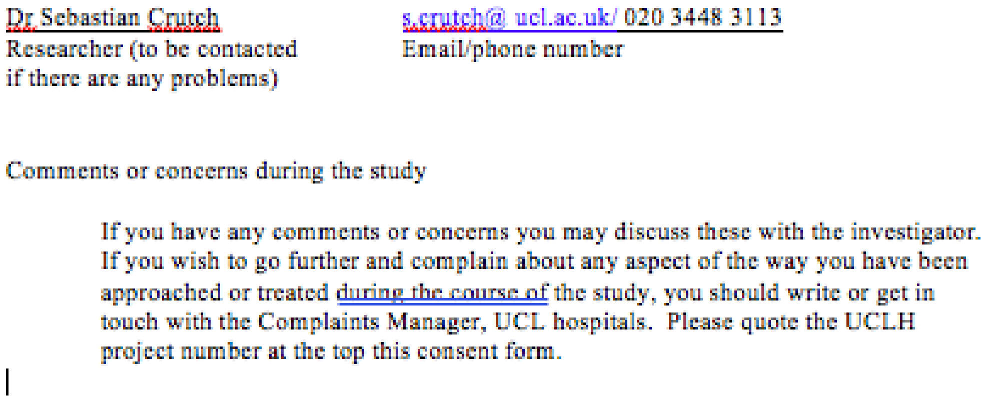
Name of Principal investigator: Dr Sebastian Crutch

Please initial box

1. I confirm that I have read and understood the information sheet dated 14 August 2015 (Version 2) for the above study and have had the opportunity to ask questions. ☐
2. I confirm that I have had sufficient time to consider whether or not want to be included in the study ☐
3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐
4. I understand an audio recording will be made and reviewed by research staff investigating how to live with dementia-related visual impairment. I understand that my name and any other identifiable details will be removed from the recording. ☐
5. I consent to undergoing video telemetry in order to provide video data only to be viewed by the research team. *If you **do not** wish to undergo video telemetry, please circle 'No'. This will mean that you will not take part in tasks requiring the observation of everyday activities, but you will be able to take part in other experimental tasks.* Yes/No
6. I agree to take part in the above study. ☐

____________________	________________	____________________
Name of carer	Date	Signature
____________________	________________	____________________
Name of Person taking consent	Date	Signature

uclh University College Hospital · National Hospital for Neurology and Neurosurgery · Eastman Dental Hospital · Royal National Throat, Nose and Ear Hospital · Heart Hospital · Royal London Hospital for Integrated Medicine

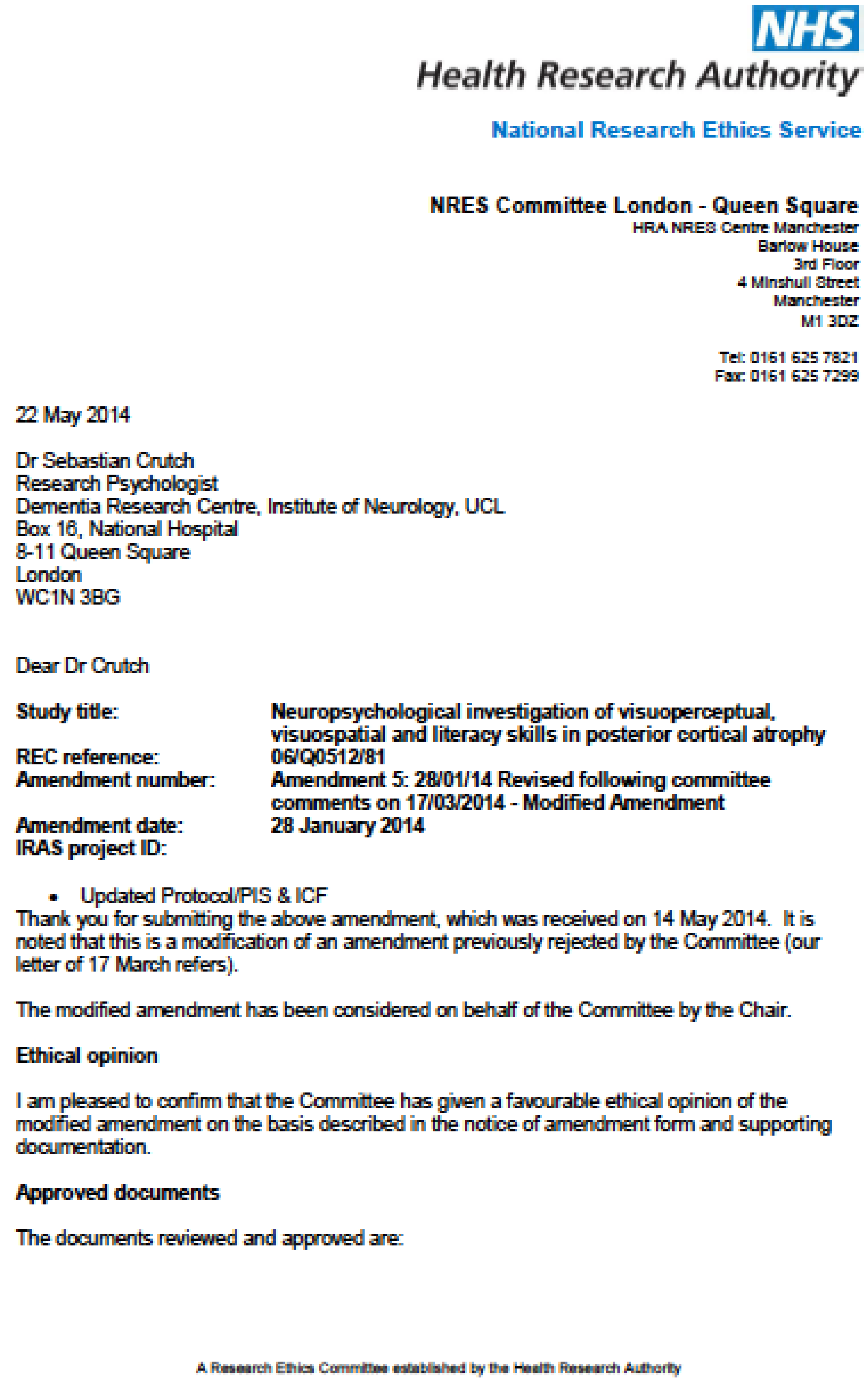


Dr Sebastian Crutch	s.crutch@ ucl.ac.uk/ 020 3448 3113
Researcher (to be contacted if there are any problems)	Email/phone number

Comments or concerns during the study

If you have any comments or concerns you may discuss these with the investigator. If you wish to go further and complain about any aspect of the way you have been approached or treated during the course of the study, you should write or get in touch with the Complaints Manager, UCL hospitals. Please quote the UCLH project number at the top this consent form.

Ethics amendment approval letter



NHS
Health Research Authority
National Research Ethics Service

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M1 3DZ

Tel: 0161 625 7821
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22 May 2014

Dr Sebastian Crutch
Research Psychologist
Dementia Research Centre, Institute of Neurology, UCL
Box 16, National Hospital
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Dear Dr Crutch

Study title: **Neuropsychological investigation of visuoperceptual, visuospatial and literacy skills in posterior cortical atrophy**
REC reference: **06/Q0512/81**
Amendment number: **Amendment 5: 28/01/14 Revised following committee comments on 17/03/2014 - Modified Amendment**
Amendment date: **28 January 2014**
IRAS project ID:

- Updated Protocol/PIS & ICF

Thank you for submitting the above amendment, which was received on 14 May 2014. It is noted that this is a modification of an amendment previously rejected by the Committee (our letter of 17 March refers).

The modified amendment has been considered on behalf of the Committee by the Chair.

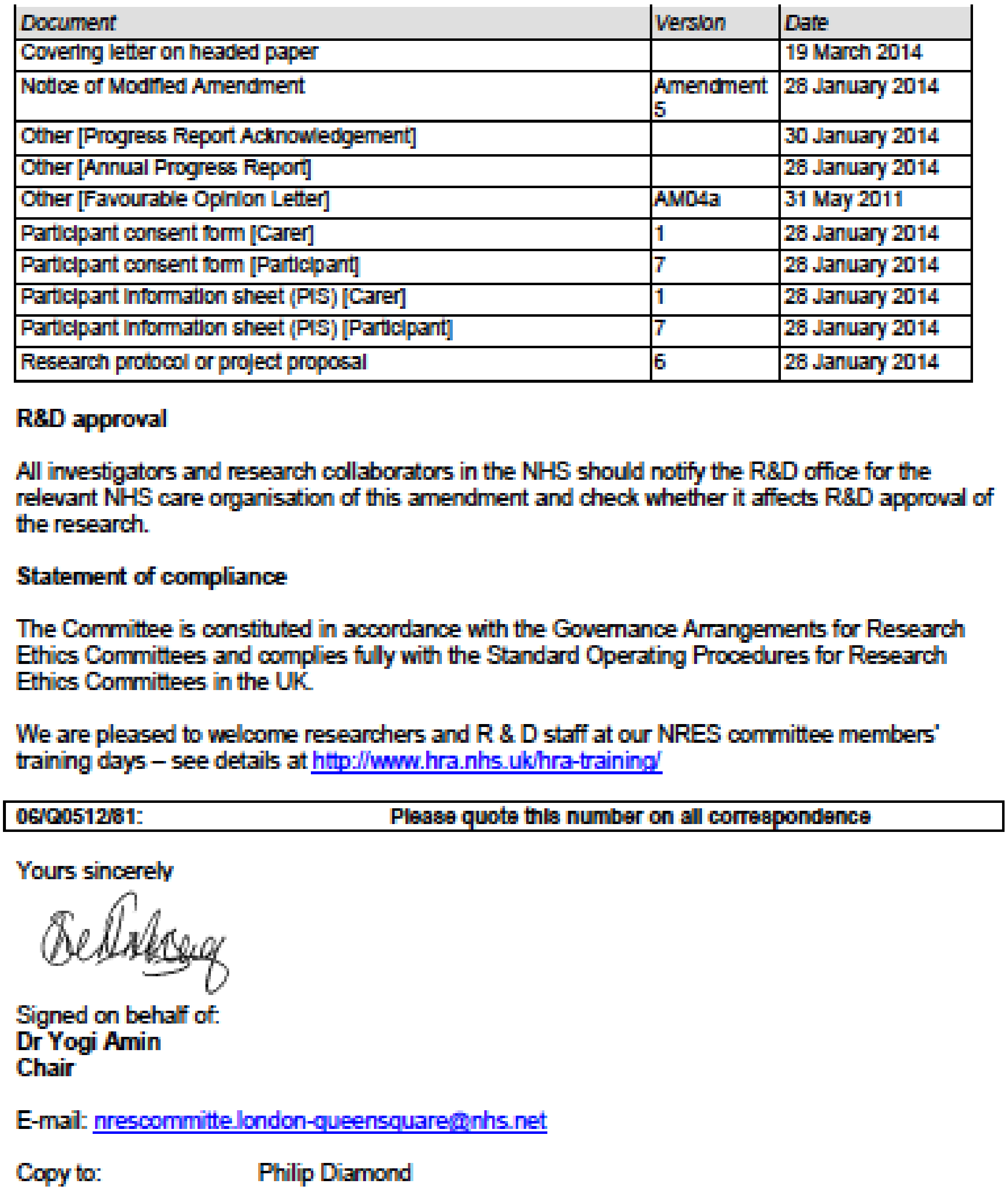
Ethical opinion

I am pleased to confirm that the Committee has given a favourable ethical opinion of the modified amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved are:

A Research Ethics Committee established by the Health Research Authority



Document	*Version*	*Date*
Covering letter on headed paper		19 March 2014
Notice of Modified Amendment	Amendment 5	28 January 2014
Other [Progress Report Acknowledgement]		30 January 2014
Other [Annual Progress Report]		28 January 2014
Other [Favourable Opinion Letter]	AM04a	31 May 2011
Participant consent form [Carer]	1	28 January 2014
Participant consent form [Participant]	7	28 January 2014
Participant information sheet (PIS) [Carer]	1	28 January 2014
Participant information sheet (PIS) [Participant]	7	28 January 2014
Research protocol or project proposal	6	28 January 2014

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

06/Q0512/81: Please quote this number on all correspondence

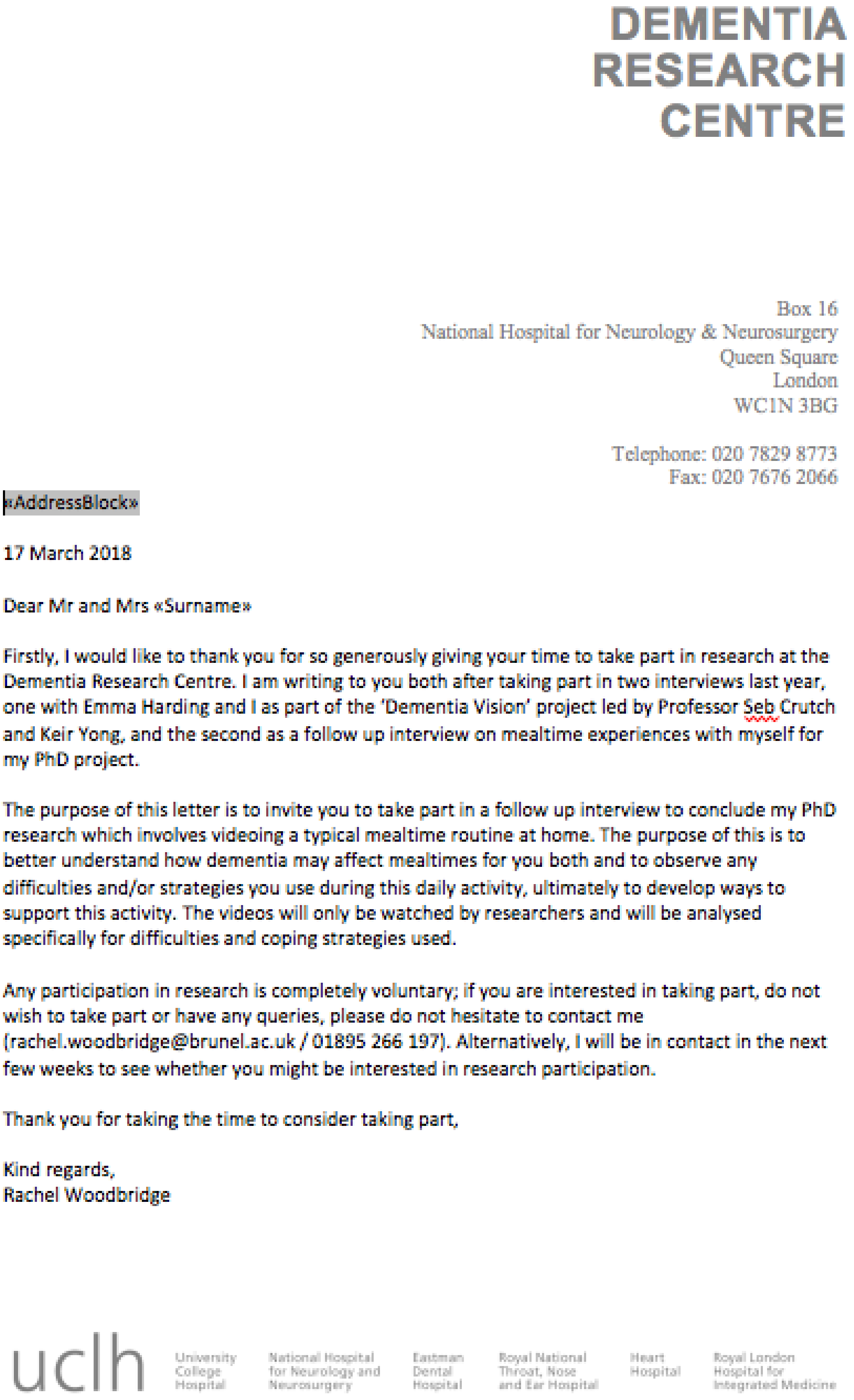
Yours sincerely

Signed on behalf of:
Dr Yogi Amin
Chair

E-mail: nrescommitte.london-queensquare@nhs.net

Copy to: Philip Diamond

Appendix 10: Letter of invitation for observations



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17 March 2018

Dear Mr and Mrs «Surname»

Firstly, I would like to thank you for so generously giving your time to take part in research at the Dementia Research Centre. I am writing to you both after taking part in two interviews last year, one with Emma Harding and I as part of the 'Dementia Vision' project led by Professor Seb Crutch and Keir Yong, and the second as a follow up interview on mealtime experiences with myself for my PhD project.

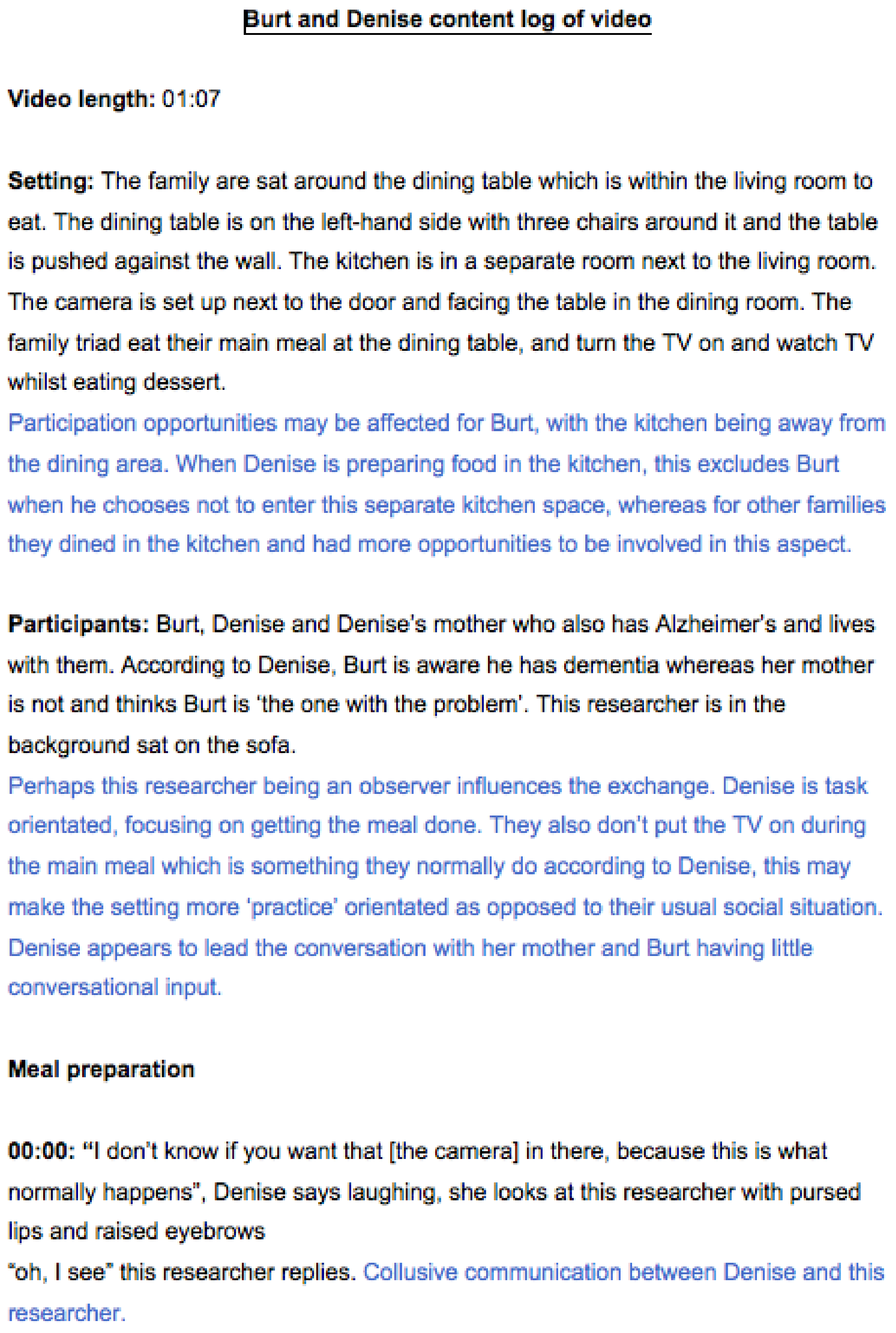
The purpose of this letter is to invite you to take part in a follow up interview to conclude my PhD research which involves videoing a typical mealtime routine at home. The purpose of this is to better understand how dementia may affect mealtimes for you both and to observe any difficulties and/or strategies you use during this daily activity, ultimately to develop ways to support this activity. The videos will only be watched by researchers and will be analysed specifically for difficulties and coping strategies used.

Any participation in research is completely voluntary; if you are interested in taking part, do not wish to take part or have any queries, please do not hesitate to contact me (rachel.woodbridge@brunel.ac.uk / 01895 266 197). Alternatively, I will be in contact in the next few weeks to see whether you might be interested in research participation.

Thank you for taking the time to consider taking part,

Kind regards,
Rachel Woodbridge

Appendix 11: Example of a transcribed observation



Burt and Denise content log of video

Video length: 01:07

Setting: The family are sat around the dining table which is within the living room to eat. The dining table is on the left-hand side with three chairs around it and the table is pushed against the wall. The kitchen is in a separate room next to the living room. The camera is set up next to the door and facing the table in the dining room. The family triad eat their main meal at the dining table, and turn the TV on and watch TV whilst eating dessert.

Participation opportunities may be affected for Burt, with the kitchen being away from the dining area. When Denise is preparing food in the kitchen, this excludes Burt when he chooses not to enter this separate kitchen space, whereas for other families they dined in the kitchen and had more opportunities to be involved in this aspect.

Participants: Burt, Denise and Denise's mother who also has Alzheimer's and lives with them. According to Denise, Burt is aware he has dementia whereas her mother is not and thinks Burt is 'the one with the problem'. This researcher is in the background sat on the sofa.

Perhaps this researcher being an observer influences the exchange. Denise is task orientated, focusing on getting the meal done. They also don't put the TV on during the main meal which is something they normally do according to Denise, this may make the setting more 'practice' orientated as opposed to their usual social situation. Denise appears to lead the conversation with her mother and Burt having little conversational input.

Meal preparation

00:00: "I don't know if you want that [the camera] in there, because this is what normally happens", Denise says laughing, she looks at this researcher with pursed lips and raised eyebrows

"oh, I see" this researcher replies. Collusive communication between Denise and this researcher.

"Yeah it's all, it all gravitates to there", Denise says, pointing to the kitchen area. Denise discusses separately that Burt and Denise often 'hover' in the kitchen whilst she is preparing the meal

Burt is smiling behind her, chuckles. Appears Burt is not quite sure what is going on and yet laughs along, perhaps recognising this change in his behaviour.

Denise goes off to the kitchen and Burt stays in the living room and starts humming.

You then hear Denise's mother come down from upstairs into the kitchen area, "do you want me to do anything" she says to Denise in the kitchen. Burt then leaves the living room and goes into the kitchen. Perhaps both Burt and Denise's mother have the relevant frameworks that it is meal preparation time and so head to the kitchen area.

The camera follows them into the kitchen area and you can see Burt and Denise's mother standing behind Denise whilst she is preparing the meal.

The kitchen is the area for engrossment in meal preparation, by Burt and Denise's mother entering this space they are both including themselves in the preparation aspect. Denise's framing of this (see field notes) is that they are unable to help her and she finds this both amusing and difficult at times when they are standing behind her whilst she is trying to prepare the meal.

Denise's mother comes into the living room and engages in social conversation with this researcher whilst Burt and Denise are still in the kitchen. This researcher tells Denise's mother her name and the two discuss a friend she has with a daughter with the same name. She tells this researcher she went to their wedding. You can also hear Denise and Burt communicating in the kitchen (01:35).
Burt spending time in the kitchen provides an opportunity for him socially to connect with Denise.

03:05: Burt comes into the living room, Denise's mother is still conversing with this researcher, she says "Rachel" to Burt and he doesn't respond and goes to look out the window "he doesn't remember" Denise's mother says laughing. "Right lets go and see 'do you want the table [Denise's mother shouting through to kitchen]… No she said not didn't she" she says as she walks into the kitchen. "Alright" she walks through to kitchen.

Denise's mother wants to help but then sees no opportunity for engrossment given Denise has stated she doesn't want help. When Burt enters the room, Denise's mother decides to leave and try and engross herself with the tasks. According to Denise (see field notes), her Mother believes she doesn't have Alzheimer's and Burt is the 'one with Alzheimer's'. As well as this, I am there to observe Burt in his normal mealtime routines and so she might see this as her being outside of the Alzheimer's framing. She confirms this when she says 'Rachel' and he doesn't remember, excluding herself from this framing. By going to the kitchen and looking busy this might help her confirm this framing whilst Burt is not engaged in the preparation roles.

Laughing Burt says to this researcher "it's a mad house". He starts plumping the cushions on the sofa.

This is a framing that Denise used when this researcher walked in the door at the start of the visit. Burt could be referring to the fact they operate in a chaotic but open framing in daily life, aligning himself with Denise's framing to show he understands life has changed.

By plumping the cushions this also affords Burt the opportunity to be engrossed and have a role whilst Denise is preparing the meal.

This researcher repeats, "it's a mad house?"

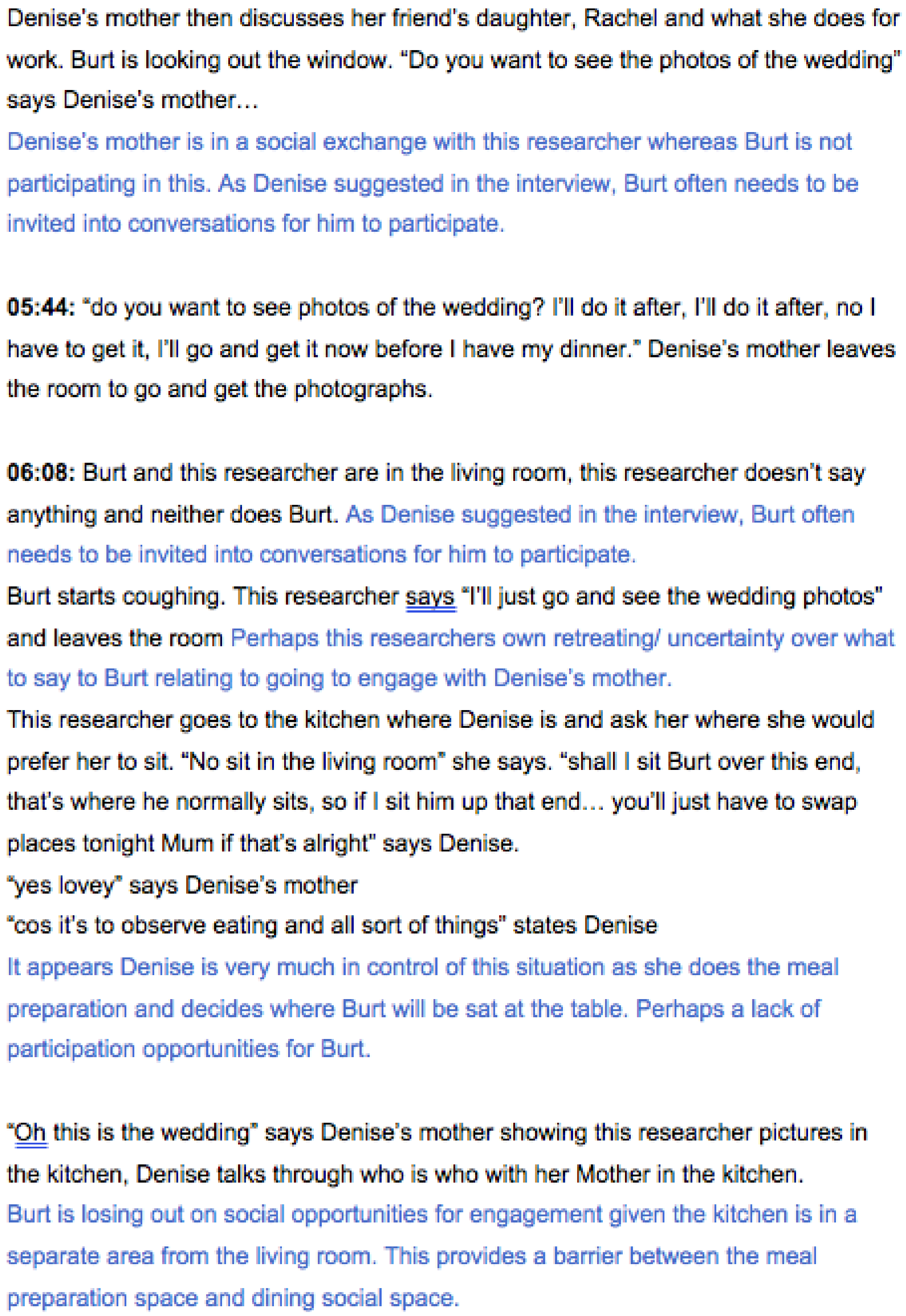
"good though" Burt says

"good, that's the most important thing" this researcher says.

Burt may be showing he understands there is confusion during meal preparation and shows his acceptance framing of this as he is able to laugh about it and says it's 'good though'.

04:40: Denise's mother walks back into the living room and calls this researcher by the wrong name. "Rita!" you hear Denise calling from the kitchen, all share in laughing in open framing of this mistake.

Humour shows acceptance process of this mistake.

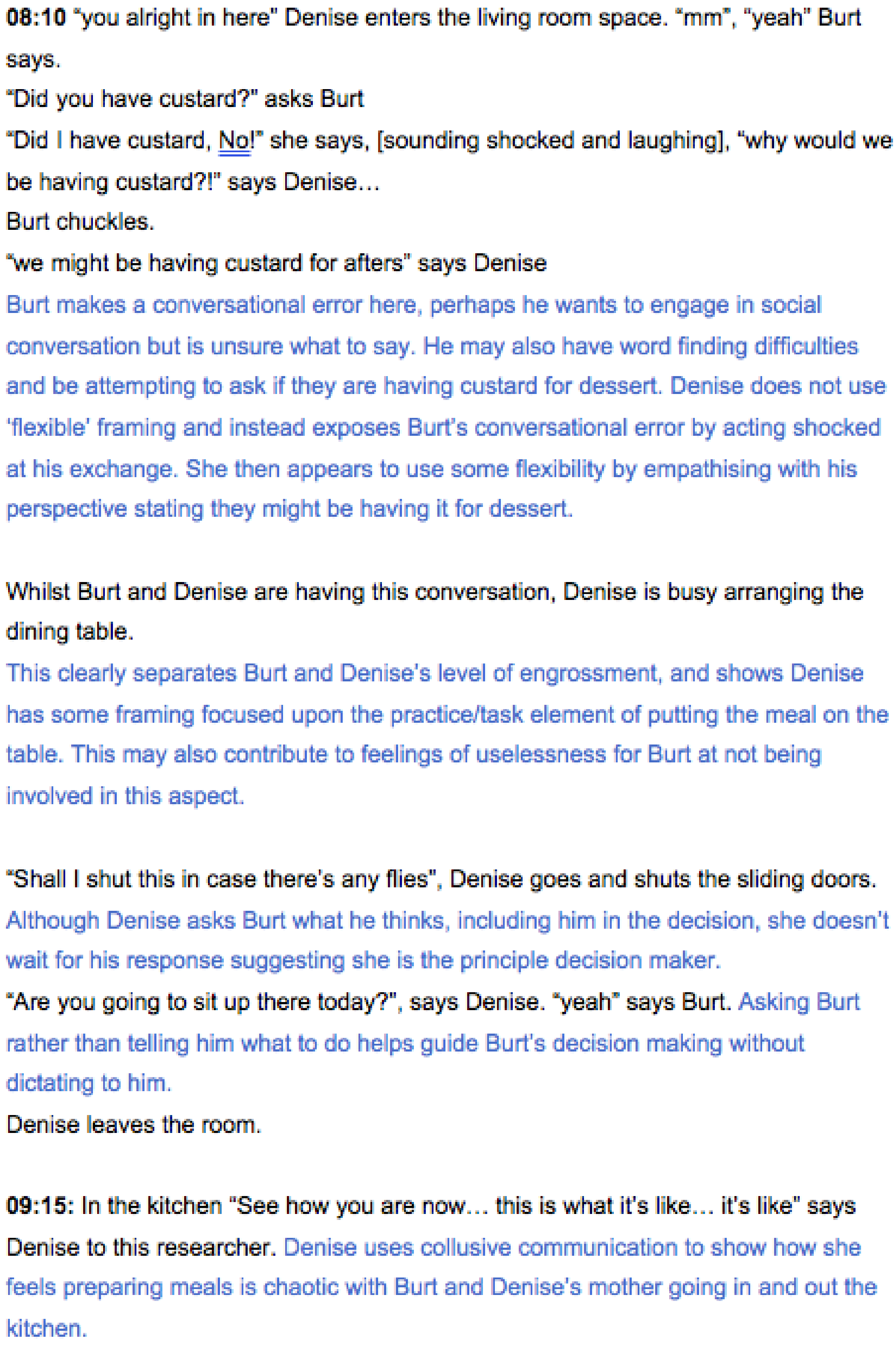


Denise's mother then discusses her friend's daughter, Rachel and what she does for work. Burt is looking out the window. "Do you want to see the photos of the wedding" says Denise's mother…
Denise's mother is in a social exchange with this researcher whereas Burt is not participating in this. As Denise suggested in the interview, Burt often needs to be invited into conversations for him to participate.

05:44: "do you want to see photos of the wedding? I'll do it after, I'll do it after, no I have to get it, I'll go and get it now before I have my dinner." Denise's mother leaves the room to go and get the photographs.

06:08: Burt and this researcher are in the living room, this researcher doesn't say anything and neither does Burt. As Denise suggested in the interview, Burt often needs to be invited into conversations for him to participate.
Burt starts coughing. This researcher says "I'll just go and see the wedding photos" and leaves the room Perhaps this researchers own retreating/ uncertainty over what to say to Burt relating to going to engage with Denise's mother.
This researcher goes to the kitchen where Denise is and ask her where she would prefer her to sit. "No sit in the living room" she says. "shall I sit Burt over this end, that's where he normally sits, so if I sit him up that end… you'll just have to swap places tonight Mum if that's alright" says Denise.
"yes lovey" says Denise's mother
"cos it's to observe eating and all sort of things" states Denise
It appears Denise is very much in control of this situation as she does the meal preparation and decides where Burt will be sat at the table. Perhaps a lack of participation opportunities for Burt.

"Oh this is the wedding" says Denise's mother showing this researcher pictures in the kitchen, Denise talks through who is who with her Mother in the kitchen.
Burt is losing out on social opportunities for engagement given the kitchen is in a separate area from the living room. This provides a barrier between the meal preparation space and dining social space.



08:10 "you alright in here" Denise enters the living room space. "mm", "yeah" Burt says.
"Did you have custard?" asks Burt
"Did I have custard, No!" she says, [sounding shocked and laughing], "why would we be having custard?!" says Denise…
Burt chuckles.
"we might be having custard for afters" says Denise
Burt makes a conversational error here, perhaps he wants to engage in social conversation but is unsure what to say. He may also have word finding difficulties and be attempting to ask if they are having custard for dessert. Denise does not use 'flexible' framing and instead exposes Burt's conversational error by acting shocked at his exchange. She then appears to use some flexibility by empathising with his perspective stating they might be having it for dessert.

Whilst Burt and Denise are having this conversation, Denise is busy arranging the dining table.
This clearly separates Burt and Denise's level of engrossment, and shows Denise has some framing focused upon the practice/task element of putting the meal on the table. This may also contribute to feelings of uselessness for Burt at not being involved in this aspect.

"Shall I shut this in case there's any flies", Denise goes and shuts the sliding doors.
Although Denise asks Burt what he thinks, including him in the decision, she doesn't wait for his response suggesting she is the principle decision maker.
"Are you going to sit up there today?", says Denise. "yeah" says Burt. Asking Burt rather than telling him what to do helps guide Burt's decision making without dictating to him.
Denise leaves the room.

09:15: In the kitchen "See how you are now… this is what it's like… it's like" says Denise to this researcher. Denise uses collusive communication to show how she feels preparing meals is chaotic with Burt and Denise's mother going in and out the kitchen.

Denise starts dishing up the meal, Denise's mother has photo album and is going through the pictures with this researcher. Denise starts talking about the wedding whilst dishing up the food, can hear the conversation going on from the living room where Burt is.

Again, Burt loses out on social connection opportunities given the other participants are in a separate room.

10:57: Burt comes into the camera view, he is plumping pillows on the sofa continuously. You can hear laughing and plates clattering in kitchen from the video.

By plumping the cushions continuously this may provide Burt with a sense that he is participating in a useful task whilst Denise is preparing the meal.

"Go and put knives and forks on the table Mum" says Denise,

"Ok" says Denise's mother,

Denise's mother walks into the living room and lays out knives and forks on the table.

Denise's mother is smiling. "that's right what do we want for… we've got salt and pepper, what we got to eat we've got meat and…"

Denise's mother appears to enjoy having a useful role in meal preparation. Burt is sitting down in the living room whilst Denise's mother is doing this.

Denise's mother goes over to where Burt is sat near window, "skies a bit blue now" she says to him…

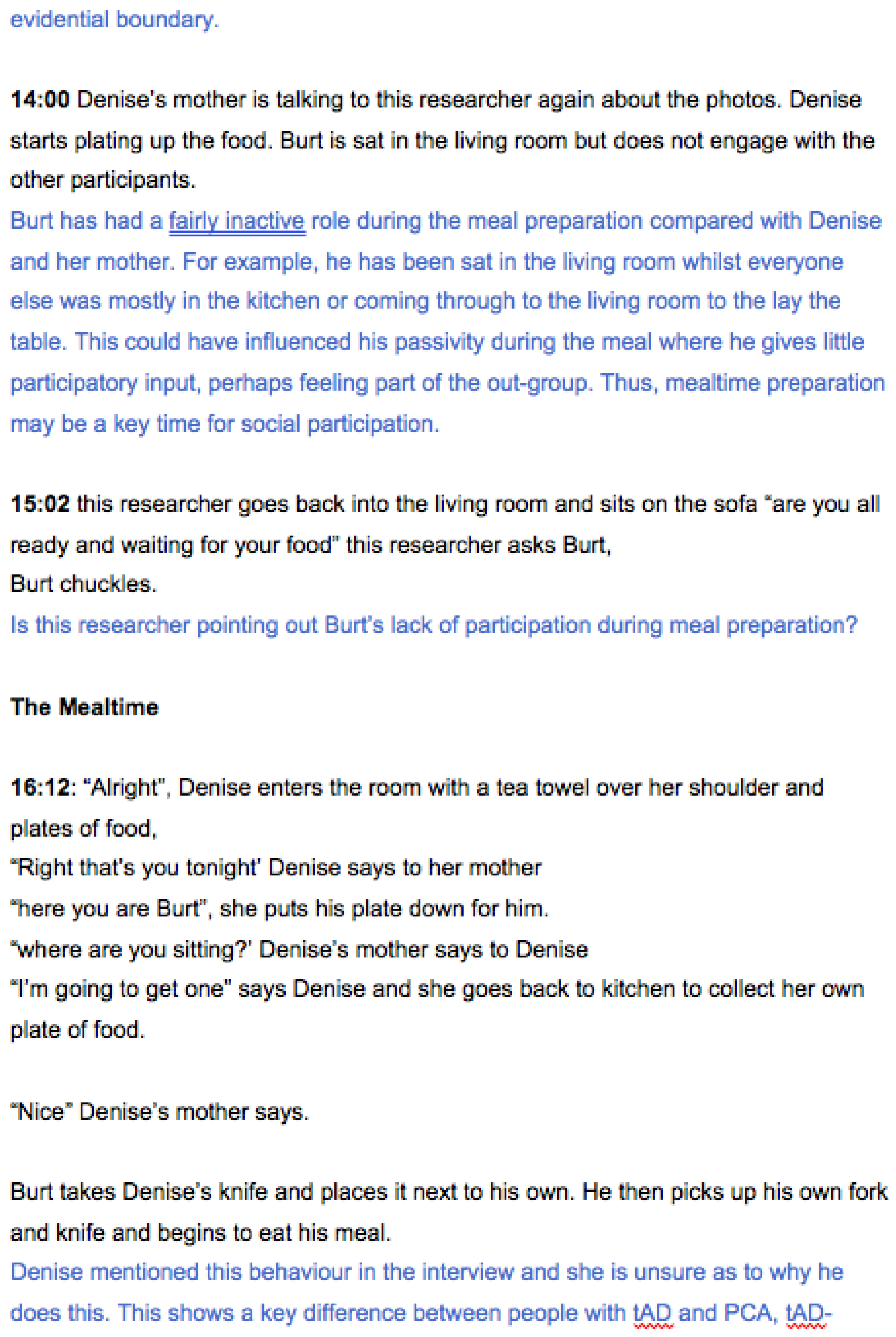
"mm" says Burt. Denise's mother then leaves the room and goes back into the kitchen.

13:30: "Rachel… the fun could start now, or it could just go swimmingly" says Denise

Denise frames the changes as 'fun' in a humorous tone, showing a sense of acceptance towards the new normal for this mealtime. This also shows the uncertainty she feels towards how the mealtime will go.

Denise's mother is laughing "yes".

It is unclear if Burt hears this from the dining area however you can hear it from the video suggesting he may be in ears length of this exchange. This may make the evidential boundary clear to Burt i.e. that others 'know something' beyond his own



evidential boundary.

14:00 Denise's mother is talking to this researcher again about the photos. Denise starts plating up the food. Burt is sat in the living room but does not engage with the other participants.

Burt has had a fairly inactive role during the meal preparation compared with Denise and her mother. For example, he has been sat in the living room whilst everyone else was mostly in the kitchen or coming through to the living room to the lay the table. This could have influenced his passivity during the meal where he gives little participatory input, perhaps feeling part of the out-group. Thus, mealtime preparation may be a key time for social participation.

15:02 this researcher goes back into the living room and sits on the sofa "are you all ready and waiting for your food" this researcher asks Burt,

Burt chuckles.

Is this researcher pointing out Burt's lack of participation during meal preparation?

The Mealtime

16:12: "Alright", Denise enters the room with a tea towel over her shoulder and plates of food,

"Right that's you tonight' Denise says to her mother

"here you are Burt", she puts his plate down for him.

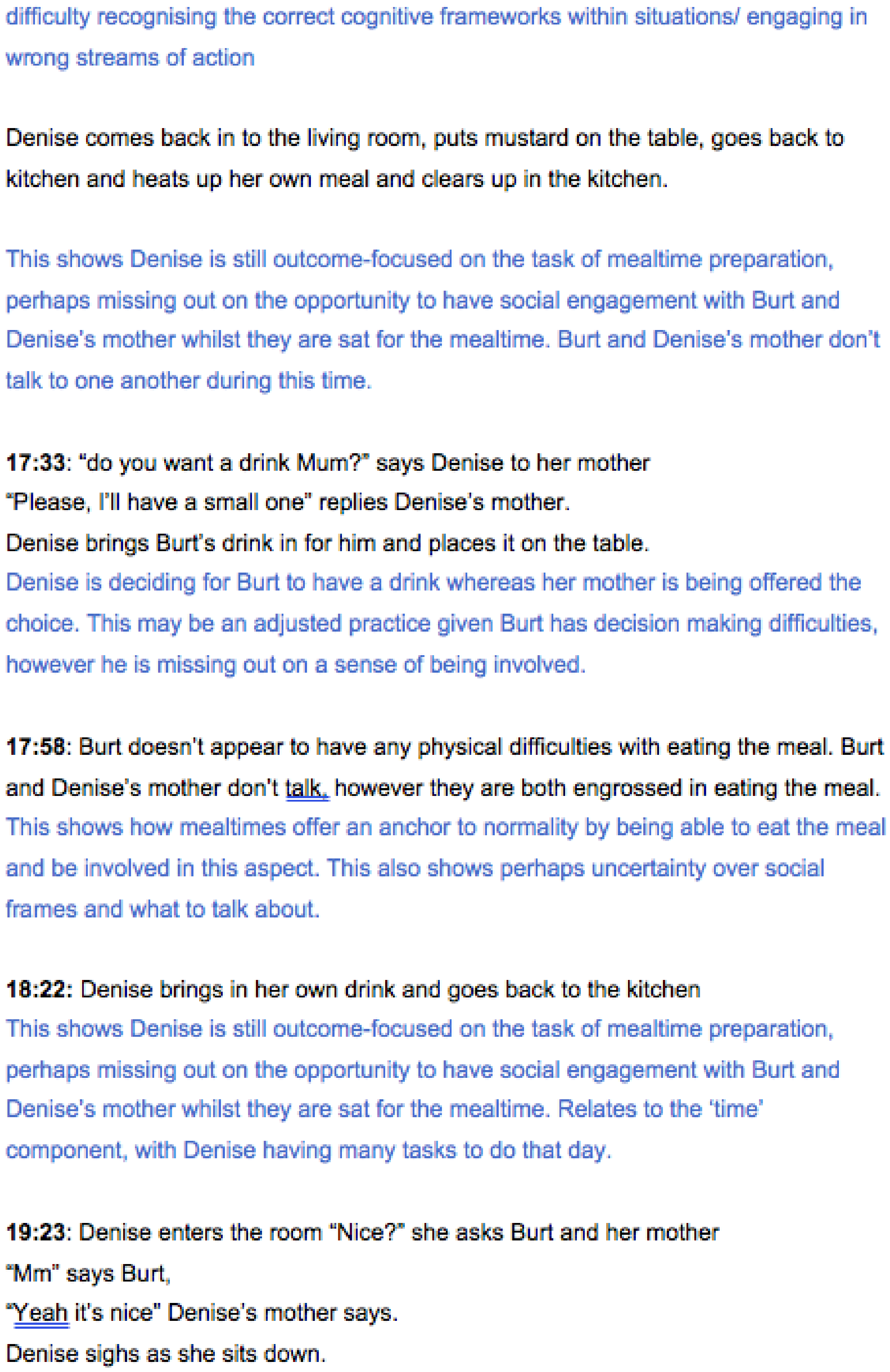
"where are you sitting?' Denise's mother says to Denise

"I'm going to get one" says Denise and she goes back to kitchen to collect her own plate of food.

"Nice" Denise's mother says.

Burt takes Denise's knife and places it next to his own. He then picks up his own fork and knife and begins to eat his meal.

Denise mentioned this behaviour in the interview and she is unsure as to why he does this. This shows a key difference between people with tAD and PCA, tAD-



difficulty recognising the correct cognitive frameworks within situations/ engaging in wrong streams of action

Denise comes back in to the living room, puts mustard on the table, goes back to kitchen and heats up her own meal and clears up in the kitchen.

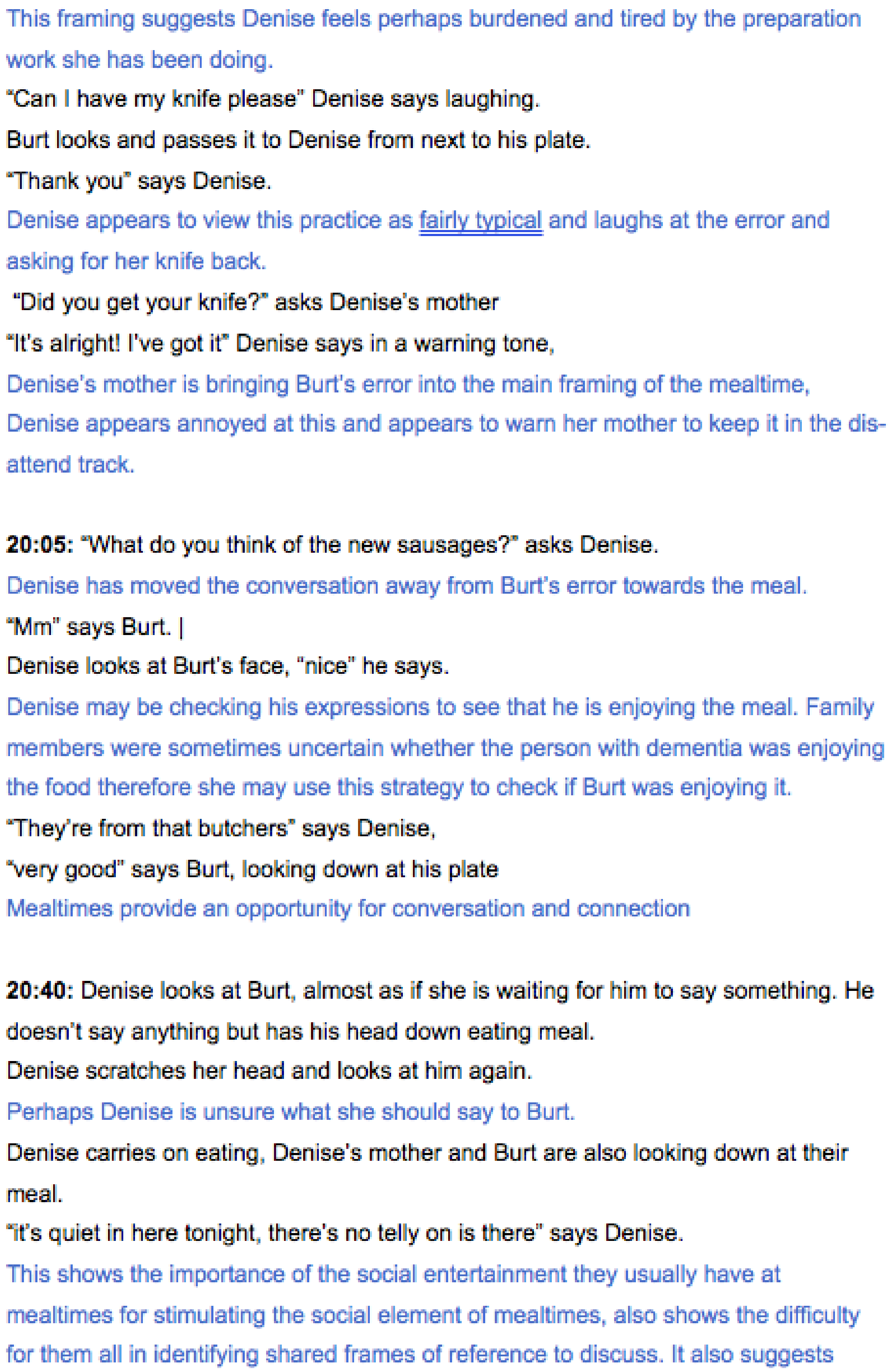
This shows Denise is still outcome-focused on the task of mealtime preparation, perhaps missing out on the opportunity to have social engagement with Burt and Denise's mother whilst they are sat for the mealtime. Burt and Denise's mother don't talk to one another during this time.

17:33: "do you want a drink Mum?" says Denise to her mother
"Please, I'll have a small one" replies Denise's mother.
Denise brings Burt's drink in for him and places it on the table.
Denise is deciding for Burt to have a drink whereas her mother is being offered the choice. This may be an adjusted practice given Burt has decision making difficulties, however he is missing out on a sense of being involved.

17:58: Burt doesn't appear to have any physical difficulties with eating the meal. Burt and Denise's mother don't talk, however they are both engrossed in eating the meal.
This shows how mealtimes offer an anchor to normality by being able to eat the meal and be involved in this aspect. This also shows perhaps uncertainty over social frames and what to talk about.

18:22: Denise brings in her own drink and goes back to the kitchen
This shows Denise is still outcome-focused on the task of mealtime preparation, perhaps missing out on the opportunity to have social engagement with Burt and Denise's mother whilst they are sat for the mealtime. Relates to the 'time' component, with Denise having many tasks to do that day.

19:23: Denise enters the room "Nice?" she asks Burt and her mother
"Mm" says Burt,
"Yeah it's nice" Denise's mother says.
Denise sighs as she sits down.



This framing suggests Denise feels perhaps burdened and tired by the preparation work she has been doing.

"Can I have my knife please" Denise says laughing.

Burt looks and passes it to Denise from next to his plate.

"Thank you" says Denise.

Denise appears to view this practice as fairly typical and laughs at the error and asking for her knife back.

"Did you get your knife?" asks Denise's mother

"It's alright! I've got it" Denise says in a warning tone,

Denise's mother is bringing Burt's error into the main framing of the mealtime, Denise appears annoyed at this and appears to warn her mother to keep it in the dis-attend track.

20:05: "What do you think of the new sausages?" asks Denise.

Denise has moved the conversation away from Burt's error towards the meal.

"Mm" says Burt. |

Denise looks at Burt's face, "nice" he says.

Denise may be checking his expressions to see that he is enjoying the meal. Family members were sometimes uncertain whether the person with dementia was enjoying the food therefore she may use this strategy to check if Burt was enjoying it.

"They're from that butchers" says Denise,

"very good" says Burt, looking down at his plate

Mealtimes provide an opportunity for conversation and connection

20:40: Denise looks at Burt, almost as if she is waiting for him to say something. He doesn't say anything but has his head down eating meal.

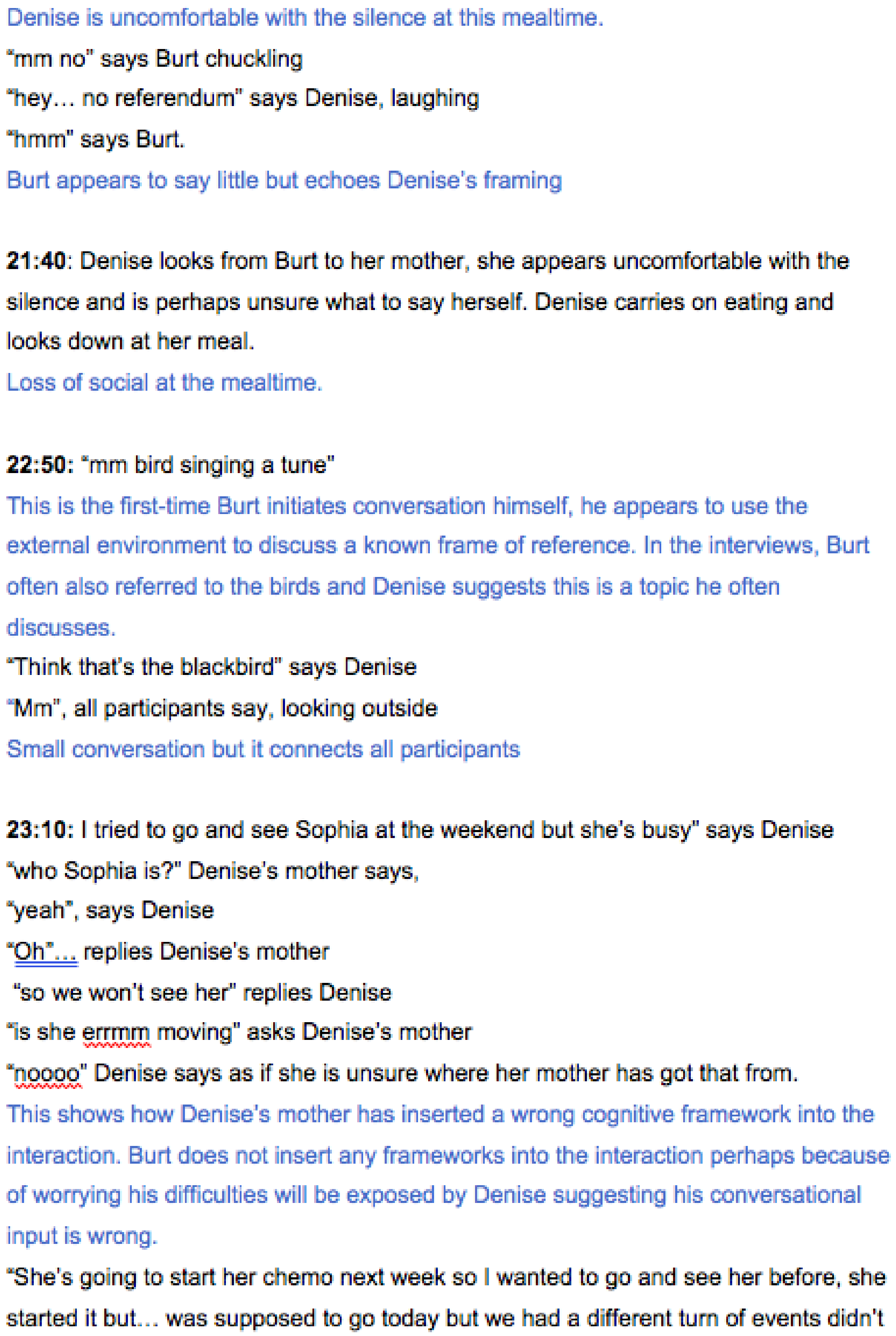
Denise scratches her head and looks at him again.

Perhaps Denise is unsure what she should say to Burt.

Denise carries on eating, Denise's mother and Burt are also looking down at their meal.

"it's quiet in here tonight, there's no telly on is there" says Denise.

This shows the importance of the social entertainment they usually have at mealtimes for stimulating the social element of mealtimes, also shows the difficulty for them all in identifying shared frames of reference to discuss. It also suggests



Denise is uncomfortable with the silence at this mealtime.

"mm no" says Burt chuckling

"hey… no referendum" says Denise, laughing

"hmm" says Burt.

Burt appears to say little but echoes Denise's framing

21:40: Denise looks from Burt to her mother, she appears uncomfortable with the silence and is perhaps unsure what to say herself. Denise carries on eating and looks down at her meal.

Loss of social at the mealtime.

22:50: "mm bird singing a tune"

This is the first-time Burt initiates conversation himself, he appears to use the external environment to discuss a known frame of reference. In the interviews, Burt often also referred to the birds and Denise suggests this is a topic he often discusses.

"Think that's the blackbird" says Denise

"Mm", all participants say, looking outside

Small conversation but it connects all participants

23:10: I tried to go and see Sophia at the weekend but she's busy" says Denise

"who Sophia is?" Denise's mother says,

"yeah", says Denise

"Oh"… replies Denise's mother

"so we won't see her" replies Denise

"is she errmm moving" asks Denise's mother

"noooo" Denise says as if she is unsure where her mother has got that from.

This shows how Denise's mother has inserted a wrong cognitive framework into the interaction. Burt does not insert any frameworks into the interaction perhaps because of worrying his difficulties will be exposed by Denise suggesting his conversational input is wrong.

"She's going to start her chemo next week so I wanted to go and see her before, she started it but… was supposed to go today but we had a different turn of events didn't we. So we'll have to find something else to do won't we". Denise is looking at Burt even though talking to her mother.

Perhaps Denise is trying to bring Burt into the conversation but he doesn't have the cognitive frameworks relevant for this conversation.

24:50: Burt's nearly finished the meal and Denise has just started, she looks at her mother and then at Burt.

It appears Denise wants some social contact with Burt and her mother, however is having difficulty identifying relevant cognitive frameworks.

"It's quite nice isn't it, do you like them sausages?" asks Denise

"mm", "very nice" says Denise's mother

Mealtime as a connection point, commensensality between them.

"We found a market where they deliver it" says Denise

"What's that" says Burt

"the butchers… this new butchers that we found"…

"oh righty!" replies Burt

"on the corner, I shouldn't say we found them, Claire found them"

Denise provides social conversation and memory for the other participants to discuss

26:22: "Were you hungry?" asks Denise,

"Mm, hmm, very good"… replies Burt

"you was!" says Denise.

Burt has finished his meal whilst Denise and her mother still have some left. Burt's holding the cutlery in his hands, he appears unsure what to do now.

Eating the meal as an anchor to normality.

26:42: "This time last Wednesday it was really cold" says Denise, …

"it was very cold" replies Burt

"it was horrible wasn't it" says Denise laughing… "we had a stew because it was so cold",

Food and mealtimes connecting the social conversation, orientate to shared reality.

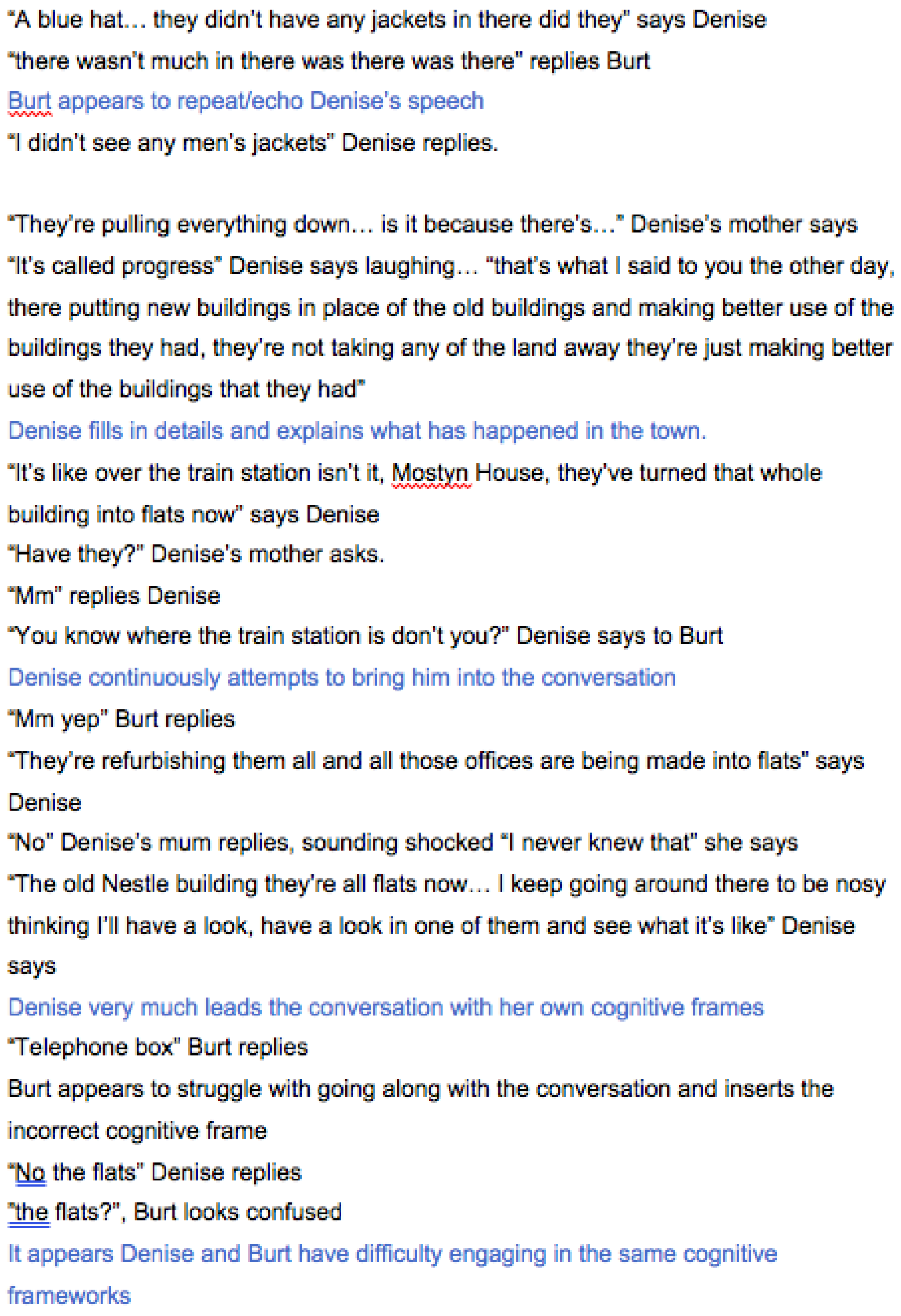
"it wasn't nice at all" says Denise's mother,

"no it was horrible" replies Denise

27:10: Burt is holding his knife and fork up whilst everyone else is eating, he twists them around in his hands. He looks around as if unsure what to do. He then takes a sip of his drink. Burt then looks at his drink and puts it back down. He takes hold of knife and fork again. He looks down and starts moving his plate, cutlery and cup around. He then rubs his hands together and looks up.
Denise asks "was it nice",
"mm" Burt replies, "it was very nice", he puts his head down and looks distant.
Engaging in the mealtime may provide a meaningful opportunity for engrossment for Burt, however when he is finished he now appears unsure of what cognitive frameworks apply and starts fidgeting with the cutlery and plate as if unsure of what to do.

28:35: "I'll have to phone Harry later cos he said he was going to come and do the ceiling" says Denise,
Denise's mother replies "oh good",
Denise looks at Burt, "what did you say?" he asks
Sense that he is disengaged from the social conversation
"Well I text him a few days ago and he text when we were in hospital and he said can I come tomorrow so I text him back, yes, cos obviously we couldn't do very much in hospital…so I'll try and phone him now and make sure he's coming… and then we'll only have one loft hatch"
Burt doesn't reply and starts twisting his knife around,
"won't we!" Denise says
"mm" replies Burt
Difficulty for Denise in terms of engaging Burt in conversation, appears he is unsure of what to say in relation to her conversational input.

30:00: "What was the dress I bought?" asks Denise's mother
"The top, white with blue stripes… white… well brown stripes",
"oh" Denise's mother says,
"you got a hat didn't you" Denise says to Burt,
"hmm" Burt says. "Hm?" He burps.



"A blue hat… they didn't have any jackets in there did they" says Denise
"there wasn't much in there was there was there" replies Burt
Burt appears to repeat/echo Denise's speech
"I didn't see any men's jackets" Denise replies.

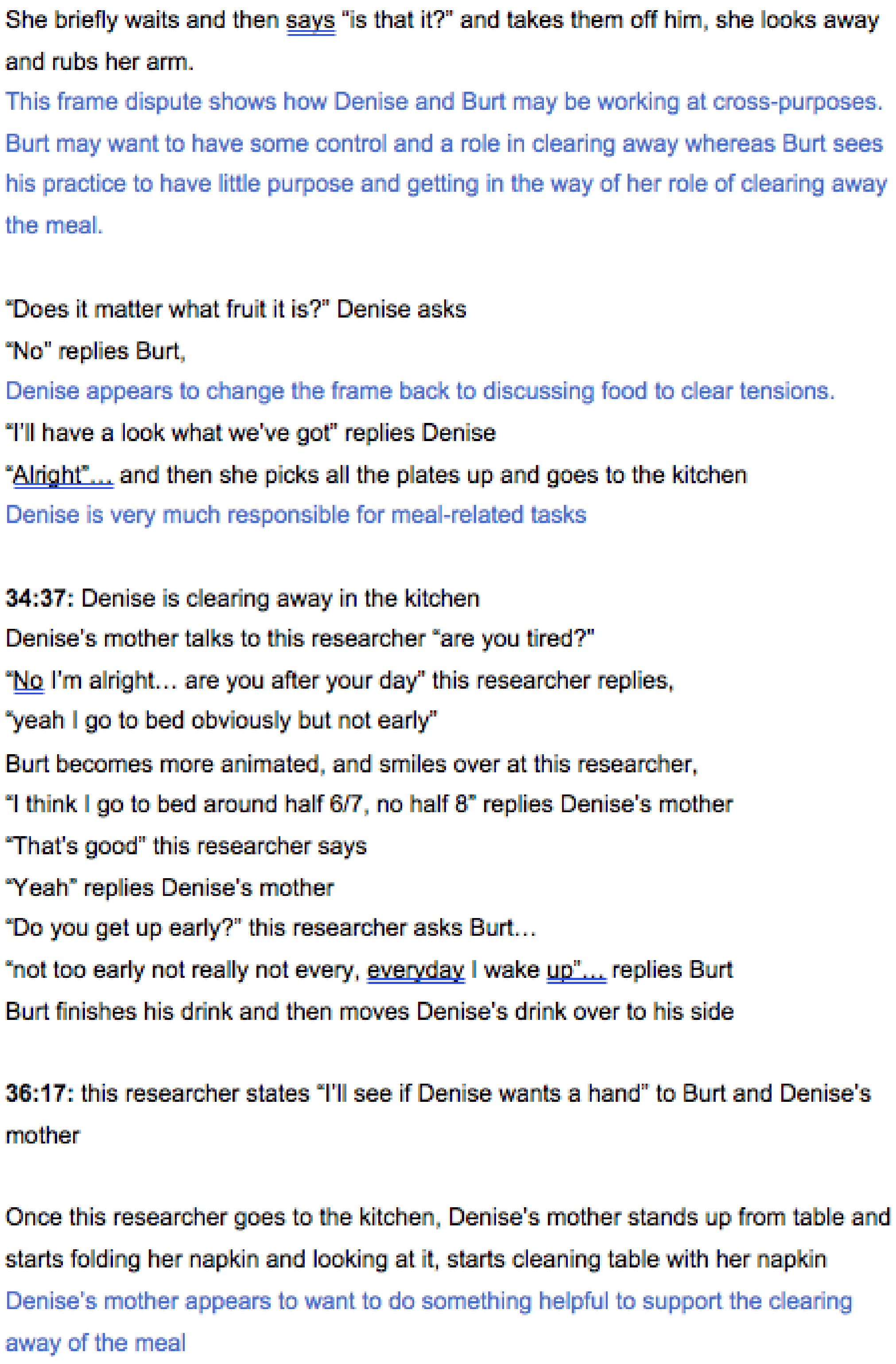
"They're pulling everything down… is it because there's…" Denise's mother says
"It's called progress" Denise says laughing… "that's what I said to you the other day, there putting new buildings in place of the old buildings and making better use of the buildings they had, they're not taking any of the land away they're just making better use of the buildings that they had"
Denise fills in details and explains what has happened in the town.
"It's like over the train station isn't it, Mostyn House, they've turned that whole building into flats now" says Denise
"Have they?" Denise's mother asks.
"Mm" replies Denise
"You know where the train station is don't you?" Denise says to Burt
Denise continuously attempts to bring him into the conversation
"Mm yep" Burt replies
"They're refurbishing them all and all those offices are being made into flats" says Denise
"No" Denise's mum replies, sounding shocked "I never knew that" she says
"The old Nestle building they're all flats now… I keep going around there to be nosy thinking I'll have a look, have a look in one of them and see what it's like" Denise says
Denise very much leads the conversation with her own cognitive frames
"Telephone box" Burt replies
Burt appears to struggle with going along with the conversation and inserts the incorrect cognitive frame
"No the flats" Denise replies
"the flats?", Burt looks confused
It appears Denise and Burt have difficulty engaging in the same cognitive frameworks

"You know where the train station is" says Denise, "you know the flats, yeah, well that was all offices wasn't it, there was no one in them, Nestle had left it years ago… so over the last few years they've turned them all into flats … but it took longer because they had loads of asbestos in there and they had to strip it all out"
Denise explains her own perspective to support Burt and her mother to understand her perspective.
"Mm" replies Burt
"So instead of pulling it all down, they've refurbished them all, I don't know what sort of flats, one bedroom or studio I don't know but I keep wanting to be nosy, I keep wanting to be nosy and have a look in the show flat" says Denise
"Go and have a look then" replies Burt
"Go and have a nosy, I don't want to live there but…" Denise says
"That was very, very nice, I can't eat any more" says Denise's mother
Both Burt and Denise's mother appear disinterests in discussing changes in the town, perhaps due to having a lack of cognitive frameworks for this and therefore this conversation lacks meaning for them

Clearing away

"What do you want for dessert… do you want some dessert? Denise asks,
"Mm yeah good" replies Burt
"What would you like? What do you want for dessert" Denise asks
"What is there?" replies Burt
There's fruit and yoghurt or ice cream" Denise asks
"fruit and ice cream" replies Burt
"You did say custard but it's a bit warm for custard, or rhubarb, Do you want rhubarb and custard or fruit and ice cream?" asks Denise
"I'll go for the fruit and ice cream" replies Burt
"Do you want fruit and ice cream?" Denise asks her mother
"Yes please" she replies.

34:02: "have you finished?" Burt hands Denise his plate and then he starts moving the cutlery round as if putting them in order.
"are you going to give them to me?" asks Denise, appearing frustrated.



She briefly waits and then says "is that it?" and takes them off him, she looks away and rubs her arm.

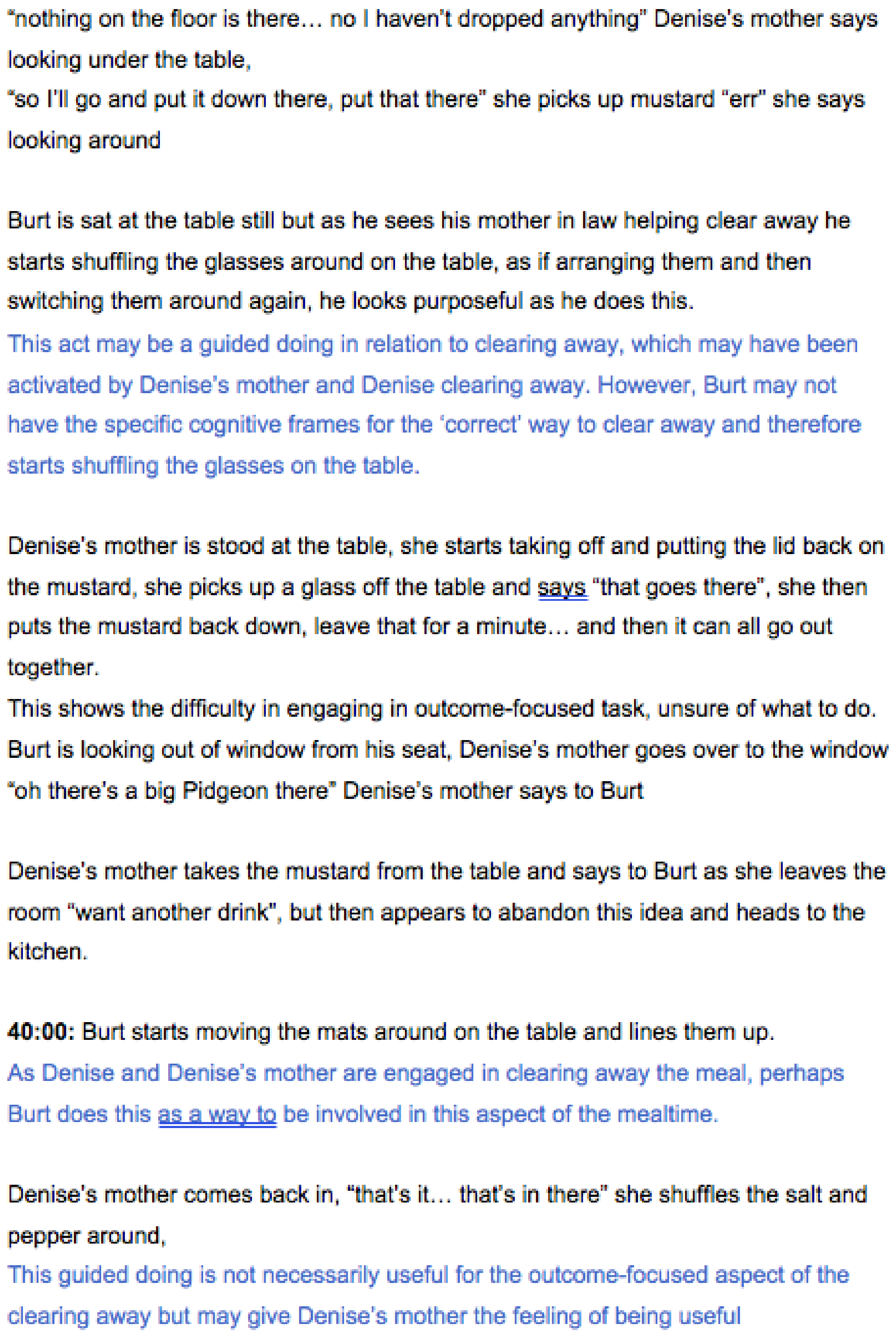
This frame dispute shows how Denise and Burt may be working at cross-purposes. Burt may want to have some control and a role in clearing away whereas Burt sees his practice to have little purpose and getting in the way of her role of clearing away the meal.

"Does it matter what fruit it is?" Denise asks
"No" replies Burt,
Denise appears to change the frame back to discussing food to clear tensions.
"I'll have a look what we've got" replies Denise
"Alright"... and then she picks all the plates up and goes to the kitchen
Denise is very much responsible for meal-related tasks

34:37: Denise is clearing away in the kitchen
Denise's mother talks to this researcher "are you tired?"
"No I'm alright... are you after your day" this researcher replies,
"yeah I go to bed obviously but not early"
Burt becomes more animated, and smiles over at this researcher,
"I think I go to bed around half 6/7, no half 8" replies Denise's mother
"That's good" this researcher says
"Yeah" replies Denise's mother
"Do you get up early?" this researcher asks Burt...
"not too early not really not every, everyday I wake up"... replies Burt
Burt finishes his drink and then moves Denise's drink over to his side

36:17: this researcher states "I'll see if Denise wants a hand" to Burt and Denise's mother

Once this researcher goes to the kitchen, Denise's mother stands up from table and starts folding her napkin and looking at it, starts cleaning table with her napkin
Denise's mother appears to want to do something helpful to support the clearing away of the meal



"nothing on the floor is there… no I haven't dropped anything" Denise's mother says looking under the table,
"so I'll go and put it down there, put that there" she picks up mustard "err" she says looking around

Burt is sat at the table still but as he sees his mother in law helping clear away he starts shuffling the glasses around on the table, as if arranging them and then switching them around again, he looks purposeful as he does this.
This act may be a guided doing in relation to clearing away, which may have been activated by Denise's mother and Denise clearing away. However, Burt may not have the specific cognitive frames for the 'correct' way to clear away and therefore starts shuffling the glasses on the table.

Denise's mother is stood at the table, she starts taking off and putting the lid back on the mustard, she picks up a glass off the table and says "that goes there", she then puts the mustard back down, leave that for a minute… and then it can all go out together.
This shows the difficulty in engaging in outcome-focused task, unsure of what to do.
Burt is looking out of window from his seat, Denise's mother goes over to the window "oh there's a big Pidgeon there" Denise's mother says to Burt

Denise's mother takes the mustard from the table and says to Burt as she leaves the room "want another drink", but then appears to abandon this idea and heads to the kitchen.

40:00: Burt starts moving the mats around on the table and lines them up.
As Denise and Denise's mother are engaged in clearing away the meal, perhaps Burt does this as a way to be involved in this aspect of the mealtime.

Denise's mother comes back in, "that's it… that's in there" she shuffles the salt and pepper around,
This guided doing is not necessarily useful for the outcome-focused aspect of the clearing away but may give Denise's mother the feeling of being useful

"You've got that one there, that drink that drinks yours yeah" Denise's mother says to Burt
"yep that one's there and that one's there" he replies and points carefully to the two glasses next to each other
This shows how Burt feels that his shuffling of the glasses on the table is purposeful and his role in relation to the clearing away of the meal

40:46: "where shall we put the…" Denise's mother asks Burt, as she starts moving the chairs around the dining table
"just put it in the place we usually put it," replies Burt
Denise's mother starts moving chair lining up next to the sofa
This shows a purposeful act for both Burt and Denise's mother which on a pragmatic level is not useful but may support their feelings of being useful
Burt starts moving the glasses around on the table as Denise's mother starts moving the chairs.

"Do you want?... OH!... That's normally Burt's job" says Denise as she walks into the room,
"what are you doing with the chairs" says Denise laughing
"erm…" replies Denise's mother looking embarrassed
This shows how Denise holds the 'power of beliefs' and Denises mother is exposed for her difficulty/ embarrassed

"Do you want Emmerdale on", Denise asks her mother and Burt
"yeah" they both say
"put the chair back then" Denise says laughing…
"no put the chair….[appears to become slightly frustrated] that's normally Burt's job isn't it shifting the furniture"
Denise uses humour to accept the changes, fluctuating with frustration with the fact this activity is not particularly useful

"That's it"… says Burt,
"that's it" Denise replies as she puts the chair back where it was before

41:50: Denise turns the TV on
"ohhhh that's that guy isn't it" Burt says [he appears interested and moves closer to the TV]
"Oh is this that man" Denise's mother says excitedly
"Yeah" replies Denise
"He's the one that errmm… actually got. What's he got?" asks Burt
Denise says "I don't know what he's got, something motor neuron… he's a scientist isn't he"
"Yeah, He's a scientist guy" replies Burt
Denise leaves the room
this shows how social entertainment can be a source of connection and identifying shared cognitive frameworks

Burt looks animated at the TV, he drinks his drink and puts it back down, and then drinks Denise's drink and puts it back down, he appears more engaged as his movements have quickened.

Denise's mother leaves the room

42:00: Burt now has three glasses in front of him and starts lining up the glasses in a straight line, he then looks over at the TV and watches an advert. Burt then goes back to switching the glasses around in different orders. He does this repeatedly.

46:14: Denise's mother comes back into the room. "that goes there" she says moving a glass on the table. She takes two full glasses back to the kitchen and leaves the empty one on the table.

Burt then starts shuffling the salt and pepper on the table and moving the mats around. He shakes his empty glass.
Although Burt's movements aren't purposeful from an outcome-focused perspective, they are relevant to 'clearing away' and thus may be motivated by this framework.

48:04: Denise's mother comes back in, "err", she walks around the table, looks at the TV and goes back to kitchen.

Again Burt is excluded from clearing away as Denise and Denise's mother are in the kitchen. However, he appears engrossed and pre-occupied with his own activity of shuffling items on the table and watching the TV. This suggests Burt has found a task which is purposeful for him.

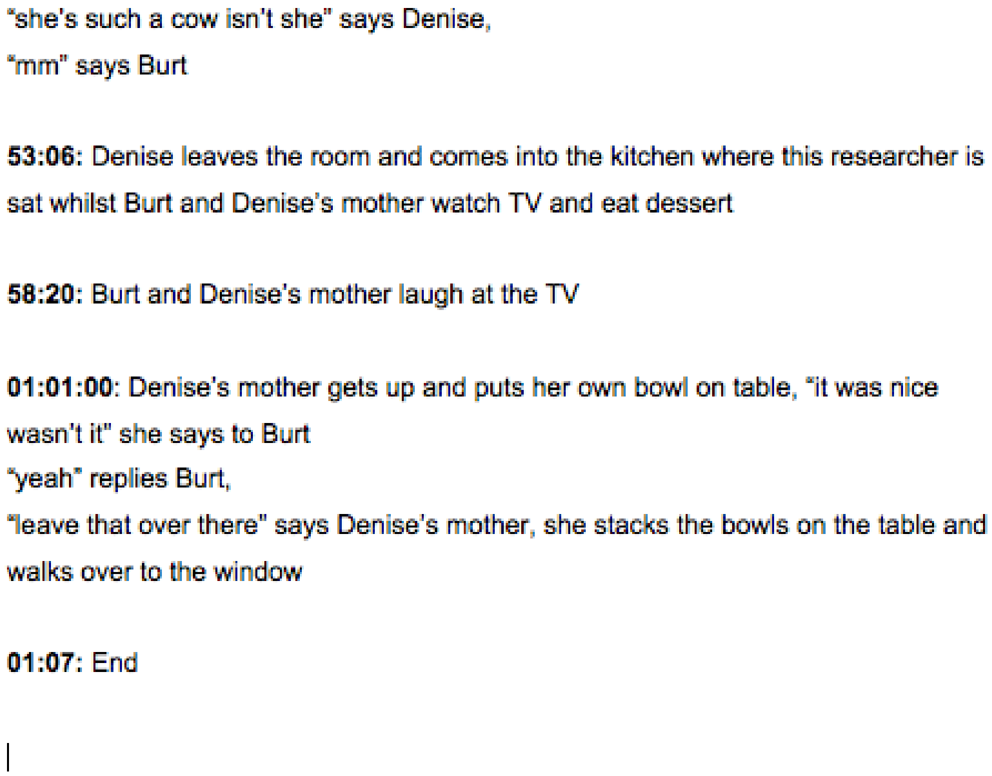
49:00: "Burt!" Denise calls from the kitchen,
Burt jumps up, "ah ah", he goes into kitchen,
"here you go, here's your dessert" says Denise…
"hmm"
"That's yours" from kitchen, "alright" Denise says,
"mmhmm" replies Burt
Burt does not thank Denise which may relate to her feelings of cooking being a burden

Denise's mother enters room with dessert, followed by Burt. They sit down on the sofa instead of at the table to watch the TV.
"oh what they done" says Denise's mother
The TV appears to provide them with some shared cognitive frameworks

49:35: Denise clears up in the kitchen, Burt and Denise's mother stay sat on the sofa.
"are you done sitting at the table" asks Denise
"we're watching Emmerdale" replies Denise's mother
this shows the shared engrossment Burt and Denise's mother have in watching TV together

Both Denise's mother and Burt laugh at the TV, they make a few sounds whilst watching but don't talk to one another.

51:00: "is it alright?" asks Denise,
"Yes it's lovely" Denise's mother replies
Denise comes sits down with them "mmm" oh she's a bad one" says Denise's mother



"she's such a cow isn't she" says Denise,
"mm" says Burt

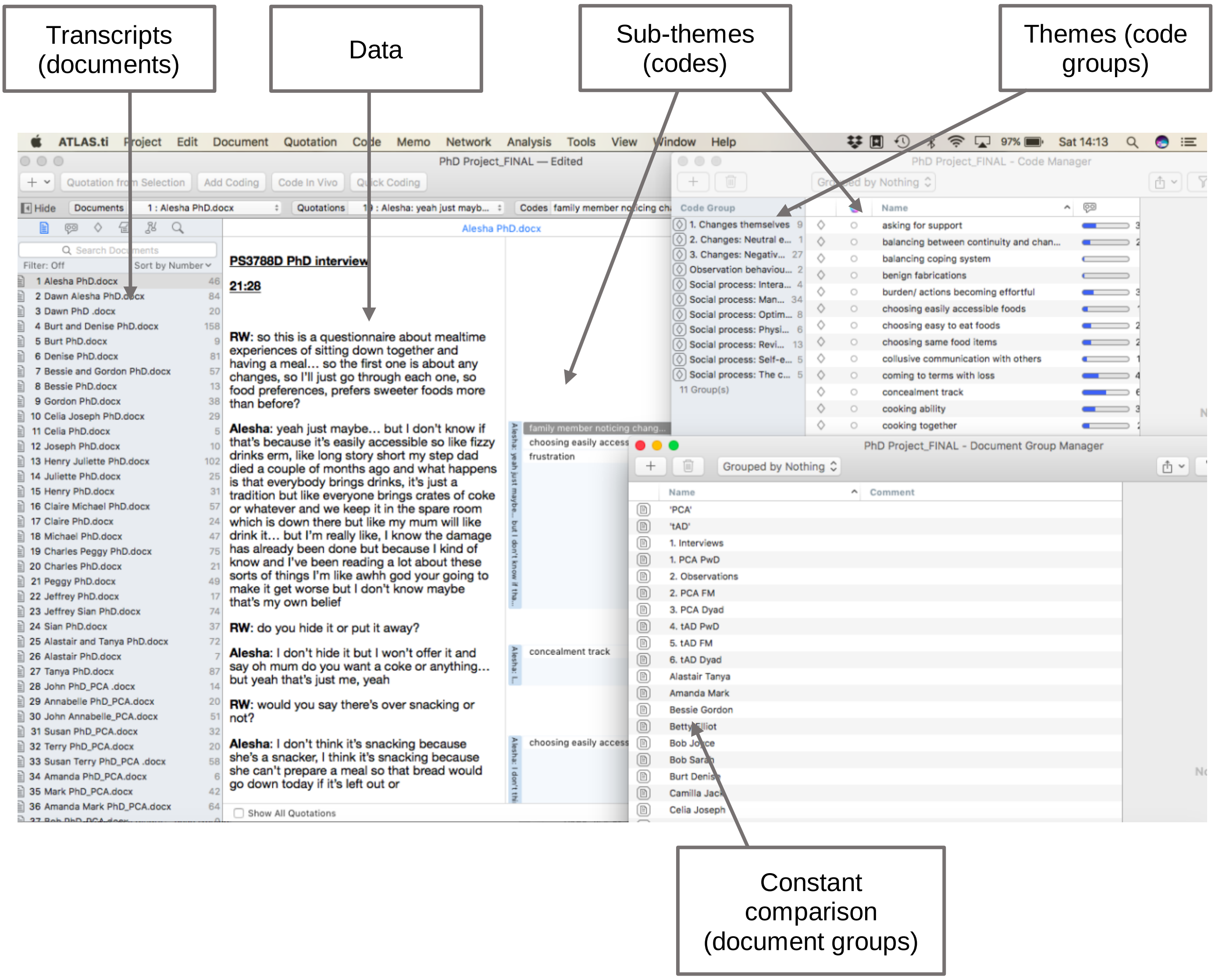
53:06: Denise leaves the room and comes into the kitchen where this researcher is sat whilst Burt and Denise's mother watch TV and eat dessert

58:20: Burt and Denise's mother laugh at the TV

01:01:00: Denise's mother gets up and puts her own bowl on table, "it was nice wasn't it" she says to Burt
"yeah" replies Burt,
"leave that over there" says Denise's mother, she stacks the bowls on the table and walks over to the window

01:07: End

Appendix 12: Screenshot of Atlas.ti software and the functions used for this study



Transcripts (documents)

Data

Sub-themes (codes)

Themes (code groups)

Constant comparison (document groups)

1 Alesha PhD.docx	46
2 Dawn Alesha PhD.docx	84
3 Dawn PhD .docx	20
4 Burt and Denise PhD.docx	158
5 Burt PhD.docx	9
6 Denise PhD.docx	81
7 Bessie and Gordon PhD.docx	57
8 Bessie PhD.docx	13
9 Gordon PhD.docx	38
10 Celia Joseph PhD.docx	29
11 Celia PhD.docx	5
12 Joseph PhD.docx	10
13 Henry Juliette PhD.docx	102
14 Juliette PhD.docx	25
15 Henry PhD.docx	31
16 Claire Michael PhD.docx	57
17 Claire PhD.docx	24
18 Michael PhD.docx	47
19 Charles Peggy PhD.docx	75
20 Charles PhD.docx	21
21 Peggy PhD.docx	49
22 Jeffrey PhD.docx	17
23 Jeffrey Sian PhD.docx	74
24 Sian PhD.docx	37
25 Alastair and Tanya PhD.docx	72
26 Alastair PhD.docx	7
27 Tanya PhD.docx	87
28 John PhD_PCA .docx	14
29 Annabelle PhD_PCA.docx	20
30 John Annabelle_PCA.docx	51
31 Susan PhD_PCA.docx	32
32 Terry PhD_PCA.docx	20
33 Susan Terry PhD_PCA .docx	58
34 Amanda PhD_PCA.docx	6
35 Mark PhD_PCA.docx	42
36 Amanda Mark PhD_PCA.docx	64

PS3788D PhD interview

21:28

RW: so this is a questionnaire about mealtime experiences of sitting down together and having a meal… so the first one is about any changes, so I'll just go through each one, so food preferences, prefers sweeter foods more than before?

Alesha: yeah just maybe… but I don't know if that's because it's easily accessible so like fizzy drinks erm, like long story short my step dad died a couple of months ago and what happens is that everybody brings drinks, it's just a tradition but like everyone brings crates of coke or whatever and we keep it in the spare room which is down there but like my mum will like drink it… but I'm really like, I know the damage has already been done but because I kind of know and I've been reading a lot about these sorts of things I'm like awhh god your going to make it get worse but I don't know maybe that's my own belief

RW: do you hide it or put it away?

Alesha: I don't hide it but I won't offer it and say oh mum do you want a coke or anything… but yeah that's just me, yeah

RW: would you say there's over snacking or not?

Alesha: I don't think it's snacking because she's a snacker, I think it's snacking because she can't prepare a meal so that bread would go down today if it's left out or

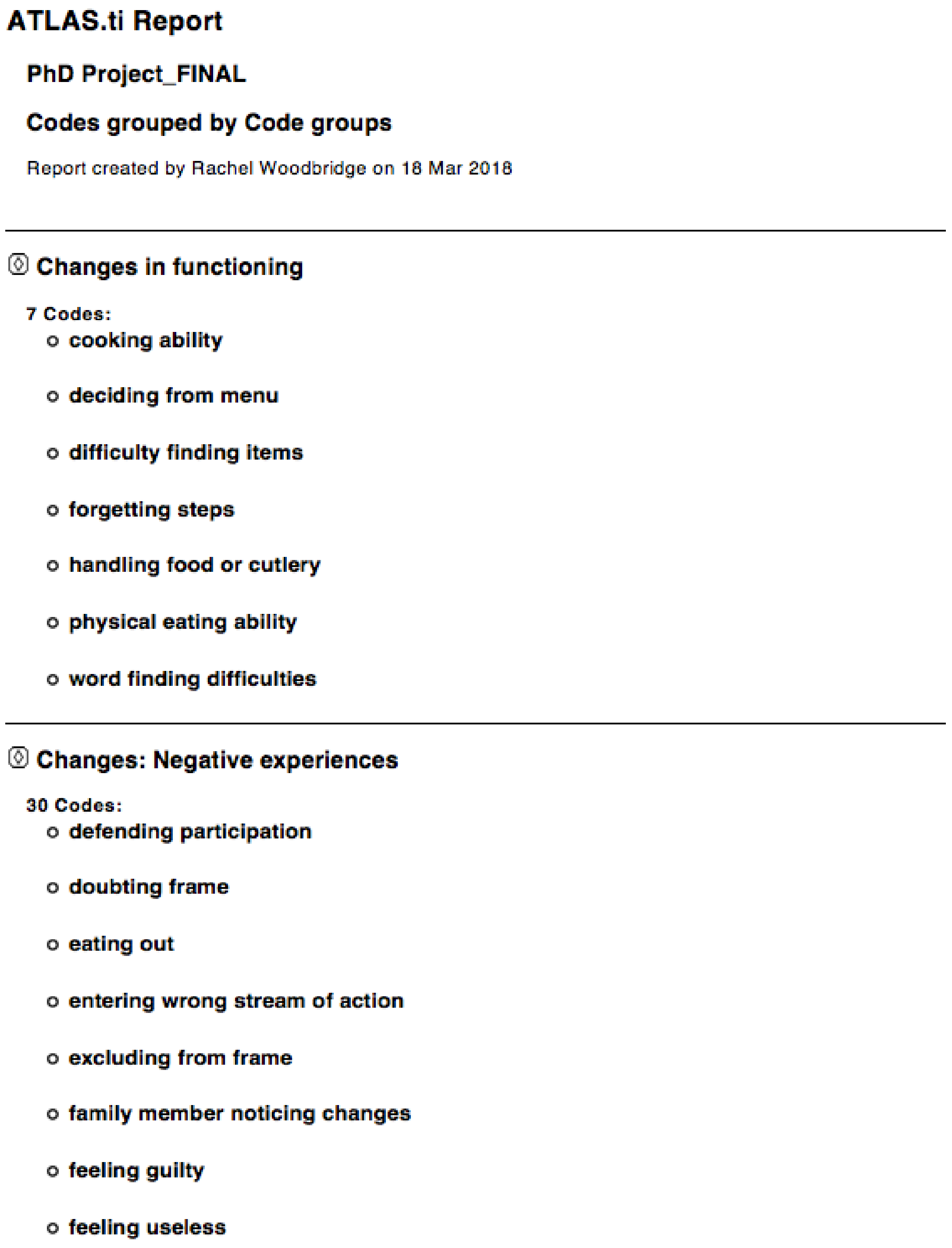
Code Group	
1. Changes themselves	9
2. Changes: Neutral e…	1
3. Changes: Negativ…	27
Observation behaviou…	2
Social process: Intera…	4
Social process: Man…	34
Social process: Optim…	8
Social process: Physi…	6
Social process: Revi…	13
Social process: Self-e…	5
Social process: The c…	5

11 Group(s)

Name
asking for support
balancing between continuity and chan…
balancing coping system
benign fabrications
burden/ actions becoming effortful
choosing easily accessible foods
choosing easy to eat foods
choosing same food items
collusive communication with others
coming to terms with loss
concealment track
cooking ability
cooking together

Name	Comment
'PCA'	
'tAD'	
1. Interviews	
1. PCA PwD	
2. Observations	
2. PCA FM	
3. PCA Dyad	
4. tAD PwD	
5. tAD FM	
6. tAD Dyad	
Alastair Tanya	
Amanda Mark	
Bessie Gordon	
Betty Elliot	
Bob Joyce	
Bob Sarah	
Burt Denise	
Camilla Jack	
Celia Joseph	

Appendix 13: List of data codes and associated groups



ATLAS.ti Report

PhD Project_FINAL

Codes grouped by Code groups

Report created by Rachel Woodbridge on 18 Mar 2018

Changes in functioning

7 Codes:

- cooking ability
- deciding from menu
- difficulty finding items
- forgetting steps
- handling food or cutlery
- physical eating ability
- word finding difficulties

Changes: Negative experiences

30 Codes:

- defending participation
- doubting frame
- eating out
- entering wrong stream of action
- excluding from frame
- family member noticing changes
- feeling guilty
- feeling useless

- frame disputes
- frustration
- helplessness
- interacting factor: individual contexts
- lack of meaning
- lacking 'proper' mealtime etiquette
- lacking interest in food
- losing independence
- losing social connection
- losing the person they were
- loss of previous roles
- low self-esteem
- mealtimes becoming a practical 'care task'
- observation: frame breaks
- over-engrossment
- social embarrassment
- social enjoyment vs. food-related task
- uncertainty over frames for situations
- uncertainty over the others perspective
- uneven distribution of roles
- working at cross-purposes
- worrying can't meet frame expectations

Changes: Neutral experience

2 Codes:

- neutral perspective of changes
- positive appraisal of changes

Maintaining meaning: Interconnected system

5 Codes:

- balancing between continuity and change
- multiple processes to maintain meaning
- revising frames influencing continuity
- revising frames influencing management
- seeing value in maintaining meaning

Maintaining meaning: Management strategies

31 Codes:

- asking for support
- benign fabrications
- choosing easily accessible foods
- choosing easy to eat foods
- choosing same food items
- collusive communication with others
- concealment track
- cooking together
- deciding for
- defending participation
- different roles
- discussing known frames of reference

- **eating aids**
- **eating out**
- **eating/drinking less**
- **following others framework**
- **hypervigilance/control**
- **management causing negative experiences**
- **physical support**
- **providing memory**
- **pwd wanting to be helpful**
- **respite from situation**
- **retreating from environments**
- **simplifying eating practice**
- **simplifying steps**
- **slowing practice**
- **social entertainment**
- **taking over cooking/prep roles**
- **talking less**
- **using other senses**
- **verbal prompting**

Maintaining meaning: Optimising continuity

10 Codes:

- **defending participation**
- **discussing known frames of reference**

- **interacting factor: perceived extent of the change**
- **maintaining facade**
- **normalising**
- **pre-dementia dining traditions**
- **resilience in environments**
- **retained abilities/ roles**
- **self-induced misalignment**
- **social enjoyment vs. food-related task**

Maintaining meaning: Physical dining contexts

8 Codes:

- **eating out**
- **exaggerating physical environment**
- **noisy environments**
- **observations: novel context**
- **props in physical environment**
- **spending time with other people with dementia**
- **supportive physical contexts**
- **unfamiliar food presentations**

Maintaining meaning: Revising frames

12 Codes:

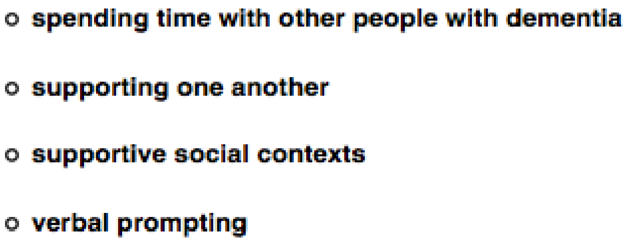
- **coming to terms with changes**
- **downward comparison**
- **flexible conversations**
- **humour**

- interacting factor: perceived extent of the change
- interacting factor: threat to self-concept
- interacting factor: time
- normalising
- positive appraisal of changes
- rationalising around diagnosis
- resilience in environments
- social enjoyment vs. food-related task

Maintaining meaning: Supportive social contexts

17 Codes:

- asking for support
- concealment track
- cooking together
- cues in social environment
- different roles
- empowering other to join frame
- flexible conversations
- following others framework
- observation: conversation relying on pre-existing frames
- observation: family member filling in convo
- pwd wanting to be helpful
- self-efficacy for maintaining meaning
- social entertainment



- spending time with other people with dementia
- supporting one another
- supportive social contexts
- verbal prompting

Appendix 14: Examples of memos

Date: 11/12/2014
Type: Data collection
First mealtimes study (fieldnotes)

First mealtime study with Terry and Susan (PCA), she did not enjoy mealtimes, felt trapped, tried to escape them, he had a very matter-of-fact approach

Date: 12/01/2015
Type: first 3 themes
Early analysis

Mealtimes presented issues for all
CAREL- friends/ family older age, done everything want to do in life/ not seeing as a problem, related to individual context

Date: 14/01/2015
Type: Methods
Early interests

Focusing the research on social mealtimes, working on interview schedule,
What are the difficulties and coping strategies with mealtime experiences?

‘dining with dementia’

Physical vs. social environment

Acceptability of certain behaviours in different contets e.g. formal/social/functional

Date: 15/01/2015
Type: abductive reasoning, theoretical developments
Concept of schemas

Mealtimes are a well-developed schema so complex representations of it, organization is richer and these schemas are more resistant to change (Fiske and Taylor, 1984)

Date: 15/01/2015
Type: questions in next interviews

-Try new foods? Interest in new foods?
What about special occasions? Dining out
What do you talk about at mealtimes? Different from the past?

Appendix 15: Glossary of terms from Goffman’s (1974) Frame Analysis

Anchoring: frames are anchored towards a familiar frame through several devices including bracketing, unconnectedness and resource continuity

Benign fabrications: deceptive frames which are perceived to be in the best interests of the person ‘contained’ within them (pg. 87)

Bracketing: particularly relevant for organised social activities such as mealtimes, where the activity is marked off from the ongoing flow of surrounding events by a special set of boundary markers, such as setting the table and clearing away the meal

Clearing the frame: revealing the true framework to someone who is contained within a fabricated framework

Concealment track: where two or more people can conceal the true framing of a situation from another person e.g. operating in collusive communication with one another

Dis-attended track: where other frameworks which may threaten the main-track are covered up and dis-attended to, to prevent disruption of the activity

Evidential boundary: the boundary between different frames of understanding among people in interaction. For example, Goffman suggests people are often aware of the evidential boundary between themselves and others. This relates to self-induced perception, whereby people may choose to focus upon frames which confirm their sense of reality, whilst acknowledging they do not hold the power of beliefs

Fabrications: the intentional effort of one or more individuals to manage activity so that a party of one or more others will be induced to have a false belief about what it is that is going on

Flooding out: when an individual fails to sustain the frame in which it finds itself, they may ‘flood out’ of the frame, for example, by laughing or covering up their face with their hands

Frames/frameworks: the cognitive meaning contexts that individuals bring to everyday situations such as mealtimes, providing a dimension of meaning.

Frame breaks: disruptions to the main-track framework, affecting the typical ‘smooth flow of activity’

Frame disputes: disagreements over the correct cognitive framework which apply in a situation

Frame transformation: a primary framework can be keyed or fabricated to mean something different from the original interpretation

Frame trap: trapped within a fabricated frame by others, whereby others contain the person within a fabricated framework

Framing conventions: the ‘ideal’ framework for situations, often based on structural and societal frameworks

Keying: transforming the meaning of an activity from what it literally appears to be, i.e. the primary framework, to something else

Main-track: dominant storyline or main framework which defines a situation

Muffings: “when a person who does not sustain in every way an image of human guidedness we often find these situations amusing” (pg 39, Goffman).

Natural frameworks: unguided actions which occur beyond human consciousness through natural forces. An example of this may be interpreting a person with dementia’s actions in relation to the pathology or disease as opposed to being an intentional act by the person with dementia

Negative experiences: those in which an individual does not have a viable response or frame for the activity, or they cannot engross themselves within the frame that apparently does apply in the social situation (pg. 379).

Normal deviants: someone who does not meet the expectations for ‘normal’ behaviour within a situation, this often relates to negative judgements being made about them and can result in being stigmatised

Normality/normal: subjective representation of the typical expectations a person has for behaviour and situations, depending upon their individual frameworks

Out-of-frame acts: when an actor fails to contain themselves during a performance and act outside the main-track. Fellow performers may attempt to co-operate for this, by adjusting their own lines and actions to contain the event naturally, or it can disrupt the activity and relate to negative experiences

Person-role formula: the connection between the person and the role that they play, giving out certain impressions of the person to others within social situations

Primary frameworks: the actions which are said to be “real or actual, to be really or actually or literally occurring” (Goffman, 1974: 47)

Resource continuity: material traces left behind anchor activity to the external world

Social frameworks: involving human guided-ness which are considered and intentional, related to the will and effort of the individual. Actions which are interpreted in a ‘social framework’ are subject to social appraisal and judgement from others given they are perceived to be motivated and intentional by the individual.

Unconnectedness: ignoring aspects of the situation which are not relevant to the ongoing frame