Living with a diagnosis of frontotemporal dementia: What helps and hinders?

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Declaration

I declare that the work in this thesis is my own.

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Abstract

Background

Frontotemporal dementia (FTD) is a term used to describe a spectrum of disorders associated with changes to behaviour, affect, speech and physical symptoms. Services have developed based upon the needs of people with Alzheimer's disease, hence, the needs of people with FTD are often unmet. The limited evidence available indicates the views of people with FTD are not heard in research exploring the perspectives of family caregivers and clinicians. Hearing the voices of people with dementia is widely acknowledged as fundamental to providing person-centred care. As such, the absence of the voices of people specifically with FTD is a cause for concern.

Aim

This study aims to explore the lived experience of FTD from the person's perspective and to identify what helps and hinders people in living well with this condition.

Methodology

Interpretative phenomenological analysis (IPA) was selected due to its commitment to exploring how people make sense of life experiences and is a useful approach to deploy in under-researched areas.

Methods

Seven people with FTD took part in individual interviews. Data was collected from a total of thirteen interviews and analysed using IPA guidance. A reflective journal informed and refined the development of themes emerging from the data.

Findings

Four themes emerged from the data: the rocky road through assessment; the changing self; in touch with reality; and keeping going. The four themes and two overarching themes of the need to hear the voices of people with FTD and the importance of them having an element of control throughout their journey

emerged from the study and are represented in the framework entitled ‘the person-led framework for understanding the experience of FTD’.

Conclusion

This study addresses a gap in knowledge about the person’s lived experience of FTD. The study informs clinicians in relation to supporting people with FTD, involves people with FTD in decision-making, and suggests directions for future research.

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This thesis is the result of several years of effort and support from those around me. I am extremely grateful for their contribution.

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Chapter 1 Introduction

1.1 Introduction

This research aimed to explore the lived experience of people with a diagnosis of frontotemporal dementia (FTD). There is a paucity of research surrounding the needs of people with FTD, and in particular, the views and lived experience of people diagnosed with FTD. Currently, research tends to focus upon the pathological disease process, potential pharmacological interventions or the views of other stakeholders rather than understanding the lived experience of FTD. Only one study was found which engaged directly with people with one subtype of FTD to explore their lived experience. Therefore, the lived experience of people diagnosed with other subtypes of FTD requires some investigation.

On one hand, the paucity of research directly exploring the lived experience from the person's perspective is unsurprising given the diagnostic criteria for FTD which includes lack of awareness and insight and the tendency for FTD-specific information to highlight issues regarding personality changes and disinhibited behaviour, thus implying that the person's views may somehow be less valid. However, more surprising is the paucity of research, given people with FTD often require intensive support and pose particular needs that existing services, developed predominantly to meet the needs of people with Alzheimer's type dementia (AD), find challenging to meet.

There is an acknowledgement of the importance of incorporating the subjective views of people with dementia in research (Clark and Keady 2002; Dewing 2007; Nygard 2006; Scottish Dementia Working Group Research Sub-group 2014), yet there is a lack of research incorporating the subjective experiences of people diagnosed with FTD. The involvement of people with dementia in research, policy and clinical service development tends to be represented by people with AD-type dementia, thus the specific needs of people with FTD are under-represented. Understanding the subjective experience of living with FTD

may improve family and staff understanding, lead to the development of appropriate interventions and, in turn, contribute to an under-researched area.

Due to the limited research seeking to understand the lived experience of FTD from the person's perspective, this research aimed to address such a significant gap in the existing knowledge base by focusing on the person's lived experience of FTD and their views regarding what helps and hinders them in living well with the condition.

In this chapter, background context and statistics regarding the prevalence of dementia in the UK will be provided, followed by an overview of the symptoms of FTD and the associated specific needs of people with FTD. The current Scottish Intercollegiate Guidelines Network (SIGN) clinical guidance in Scotland for supporting people with dementia will be discussed and thereafter, my clinical background will be presented. The chapter concludes with a summary and details of how the thesis has been organised.

1.2 Background context of dementia and FTD in the UK

Approximately 885,000 people live with a diagnosis of dementia in the UK. The cost of caring for people with dementia is £34.7 billion annually (Wittenberg et al. 2019), hence, dementia is a national priority (Scottish Government 2010). Alzheimer's Disease (AD) accounts for 60% of all cases of dementia, with frontotemporal dementia (FTD) the second most prevalent cause of dementia in people under the age of 65, having a population prevalence of up to 15 per 100,000 (Graham 2007). However, the prevalence of FTD in people over 65 years is controversial and overall, prevalence is considered to be significantly underestimated (Graham 2007).

1.3 Frontotemporal dementia

In the late 1990s, the term frontotemporal dementia (FTD) was adopted by medical professionals to describe a spectrum of disorders. Despite this attempt to define FTD, to date, a plethora of terms are used to describe FTD disorders.

Some professionals denote the clinical syndrome without histological information such as progressive aphasia, frontal-type dementia or semantic dementia (SD), whereas other researchers include the neuropathological entities such as Pick's disease, ubiquitin-inclusion disease, hybrid clinic-pathological entities (FTD) and more recently, professionals may name specific genetic disorders such as chromosome-17-linked frontotemporal dementia (Hodges 2010). Thus, in defining FTD, one has to understand that the disorders which fall under the term FTD may be grouped differently according to which literature is accessed. For the purposes of this thesis, FTD will be understood as a general label with three main clinical variants: frontal or behavioural variant FTD (bvFTD), semantic dementia (SD), and progressive non-fluent aphasia (PNFA) taken from the work of Hodges (2010). However, there is acknowledgement in this thesis of other disorders which overlap clinically with FTD including FTD with motor neurone disease, corticobasal degeneration (CBD) and progressive supranuclear palsy (PSP) (Alzheimer's Association n.d.).

The prognosis in FTD is poorer in comparison to AD with overall median survival of 6 years (Hodges *et al*. 2003). Although some dementia symptoms are common to all subtypes of dementia, people with FTD experience specific symptoms characteristic of FTD (Diehl et al. 2003; Hodges 2010; Neary 2010). Unlike AD, memory loss is not an early significant feature. The Lund and Manchester Groups (1994) set out clinical diagnostic features of FTD which are widely used today. The core diagnostic features are behavioural, affective, speech and physical disorder. Behavioural disorders include early loss of social and personal awareness, early signs of disinhibition, mental inflexibility, hyperorality, stereotypical behaviour, impulsivity and early loss of insight into a pathological reason for changes to mental state. Affective disorders include emotional indifference or remoteness, somatic preoccupation and aspontaneity. Speech disorders include progressive reduction in speech, repetition of words and phrases and late mutism. Physical signs include early primitive reflexes, incontinence, late akinesia and low blood pressure. Changes in behaviour leading to breakdowns in social situations are common (Neary 2010).

Alzheimer's disease is the most common cause of dementia and accounts for approximately 62% of all cases of dementia. It is unusual for people under the age of 70 years to develop Alzheimer's disease but can affect people under 60 years of age(Alzheimer Scotland 2017). Alzheimer's disease is characterised by a gradual onset of symptoms which include short term memory problems, cognitive decline, problems with language skills, difficulty with daily activities and involves neuropathological changes in the brain such as the development of neurofibrilliary tangles and amyloid plaques (Scheltens et al. 2021).

1.4 Scottish Intercollegiate Guidelines Network (SIGN)

Despite the recognition that people with FTD experience specific symptoms, clinical guidance recommends the use of interventions that were developed to prompt memory or compensate for cognitive changes (SIGN 2006). Therefore, professionals provide support based upon interventions generalised from research from other subtypes for people with FTD. This 'alzheimerisation' of interventions has broader implications for psychosocial research as the guidance is also used to shape every stage of the journey, from the development of support services and care pathways to staff training and future research. This has resulted in people with FTD experiencing difficulty in having their specific needs met (Morhardt 2011; Snowden et al. 2006).

1.5 Clinical background

During my career as a mental health nurse, I have worked with people with dementia in both inpatient and community settings in a variety of organisations ranging from NHS services to social services and the private care home sector, catering for the needs of both younger and older people with dementia. When I decided to undertake the clinical doctorate programme, the most troubling and urgent clinical issue I had faced to date were the problems around effectively and meaningfully supporting people with FTD and improving their psychological well-being and quality of life. Throughout my career supporting people with FTD, the challenges have included difficulty in finding appropriate support due to services being designed to meet the needs of people with AD, predominantly

with short-term memory issues. Where support and services were offered to people with FTD, I found that there was a widely held belief that all people with FTD lacked awareness and insight, which led to the needs of people with FTD being unmet due to the lack of knowledge on the part of health and social care staff regarding the needs of people with FTD. In my experience, people with FTD were often misunderstood by family carers and professional staff, resulting in people with FTD reaching crisis point before people living with other subtypes of dementia and entering hospital or institutionalised care earlier than their counterparts with other subtypes of dementia. There appeared to be a widespread lack of evidence available around appropriate and effective psychosocial interventions for people with FTD.

The Nursing and Midwifery Council (NMC 2018) requires registered nurses to practice from an evidence base. Having experiential knowledge of supporting people with FTD, I had looked for research evidence before about the experiences of people with FTD but found only research from the perspective of family carers or professional staff. However, I had not searched systematically. I could not help but wonder why there was a paucity of evidence of the lived experience of FTD from the person's perspective in comparison to the evidence base of the lived experience of people with AD. My thoughts turned to conversations I had had with professional people whose beliefs about FTD included that the person lacks insight, has no self-awareness and always presents with problematic behavioural changes. Whilst these may be some of the symptoms associated with FTD, they were not an accurate reflection of my experiences of supporting people with FTD. Therefore, I wanted to know what having these symptoms actually 'felt' like. If, as a profession, we are to support people with FTD effectively, it seems fundamental to start with as comprehensive an understanding of the journey from the person's perspective as possible. In doing so it may be possible to develop interventions that meet the needs of people with FTD in a way that is acceptable and useful to them. Although conducting a literature review was a requirement of the taught element of this doctoral study, the literature search helped determine that the topic was worthy of study and the use of literature review methodology enabled

the evidence on the lived experience of FTD to be identified and evaluated systematically (Creswell 2014; Hewitt-Taylor 2017).

In summary, the needs of people with FTD are often unmet due to existing services having been developed predominantly to meet the needs of people with AD. In my clinical experience, the quality of life and health outcomes for people with FTD are often poor and are exacerbated by a lack of knowledge about FTD both in family caregivers and professional staff. There is a paucity of research about FTD from the person's perspective, therefore, I wanted to collate the existing evidence around the lived experience of FTD systematically as a basis for framing the experiences of people living with a diagnosis of FTD and as a starting point for understanding the lived experience of FTD.

1.6 Organisation of the thesis

Chapter Two presents the literature review including the main themes I found from the review. Chapter Three discusses the choice of IPA methodology. Chapter Four presents the methods used. In Chapter Five, the main findings including the themes of the rocky road through assessment, the changing self, in touch with reality and keeping going are presented alongside the 'person-led framework for understanding the experience of FTD'. Chapter Six includes a discussion of the four themes and the thesis concludes with recommendations for clinical practice and future research.

Chapter 2 Literature review

2.1 Introduction

This chapter will discuss how interpretative phenomenological analysis (IPA) methodology influenced how the literature is presented and discussed. Thereafter, the search strategy which was used to identify the literature underpinning the study will be discussed under the themes of the family experience of FTD; understanding and coping with FTD; support, satisfaction and useful approaches; and the impact on self and relationships. The literature has been synthesised and critiqued and gaps in the current knowledge base have been identified providing a rationale for this study. Discussion of the wider literature pertaining to the themes identified in the literature review can be found in Chapter Six.

2.2 Approach to the literature

The clinical doctorate programme requires researchers to be explicit about how they have approached the literature and to provide a rationale regarding how and when literature is accessed. The undertaking of a literature review in qualitative studies requires consideration of when it should be undertaken, how extensive it should be and whether literature should be reviewed (Fry et al. 2017). However, as the literature review in this study formed part of the clinical doctorate programme, the decision was made to include it as a separate chapter in this thesis (Chapter Two).

In agreement with Locke et al. (1993), the aim of the IPA literature review is to introduce readers to the field by arguing your proposed study is sound; utilising appropriate inquiry methods; and formulating a research proposal demonstrating how your study can make a useful contribution. As a research gap had been revealed in studies involving the participants' lived experience of frontotemporal dementia, it was not considered useful to expand the review to include research focussing on other sub-types of dementia as this would change the focus from FTD to predominately AD.

Smith et al. (2010) provide a structure for writing up an IPA study that does not include a literature review section, instead they suggest that any previous literature can be drawn upon in the introduction and discussion sections. However, as the clinical doctorate programme required a focussed review, I included a focussed review chapter in order to introduce readers to the current literature around the experience of FTD and which identified a research gap. The widening of the literature review process occurred during the writing up of the thesis and therefore is presented in the discussion section. This also ensures that it does not detract from the importance of the research gap identified in the focussed review presented. I found that as I was writing up the discussion chapter of this IPA inductive study, I was reflecting upon the wider literature around other sub-types of dementia which were not included in the literature review chapter. In order to explore the research gap comprehensively from a broader perspective, it became both relevant and necessary to include this wider literature to provide more background context. This approach fits with the views of Marshall and Rossman (2006) in that within a constructivist orientation, I am required to have a sound understanding of previous FTD specific research. However, there is a need to remain open to emerging hypotheses taking account of the research available involving people with other sub-types of dementia which then required me to explore the wider literature during the writing up of the discussion section. Merton (2010) stated that the act of reviewing the literature is ongoing with results of the review being integrated into the discussion section. Therefore, I made the decision to present the literature review chapter as a standalone review chapter focussing on FTD-specific research and include the wider research involving other sub-types of dementia in the discussion chapter. This decision also accurately reflected when I had accessed wider literature (Corbin and Strauss 2008).

As the aim of a literature review in an IPA study is to introduce readers to the field of interest, to identify key evidence in this field and present an argument as to why the study can contribute to the field (Smith et al. 2010). The literature review has been presented in an evaluative manner consistent with IPA methodology and is used inductively, therefore, did not directly influence the questions explored in the study. Instead, I aimed to use the findings of the

literature review to identify a gap in the evidence upon which to develop my study aim.

Regarding the wider discussion of the literature pertaining to the findings of the literature review, Creswell (1994) states that related literature can be discussed in several parts of a study, therefore, the literature review was updated annually and kept as a separate chapter but used to 'frame' the research. However, discussion of the wider literature is located in Chapter Six with the literature review findings used as an aid for discussion following identification of the themes of this research study found in Chapter Five.

An important aspect of using IPA is the need for researcher reflexivity and to 'bracket' or put to one side preconceived notions (Smith et al. 2010). As a nursing academic with experience working with younger people with dementia, I was aware of literature regarding the specific needs of younger people. However, my clinical experience of working with people with FTD and their family caregivers was based on my experiential learning as opposed to the evidence base. This reflection, alongside a realisation that clinical colleagues were also using mostly experiential knowledge to guide their practice, led me to seek out literature regarding best practice for people with FTD. This required self-awareness of how my clinical experience could influence my understanding of, or participation in, the research process. Therefore, I made a conscious effort to remain focused upon the emerging themes of the literature review, rather than being directed by my own beliefs, experiences and views.

2.3 Search strategy

In order to apply for ethical approval and develop a research proposal, I conducted a systematic search of the literature which was updated annually using the University of Stirling databases listed under the topic search (dementia studies): CINAHL COMPLETE, PsycINFO, SocINDEX with full text, Health Source, Social Care Online, Internurse and Web of Science Core Collection. The search strategy was limited to the English language, peer-reviewed, human, and all adult age groups. Search terms were compiled using

keywords established through mind-mapping (Table 1). A manual check of reference lists of included studies was undertaken to ensure any additional relevant papers were not missed and citation searches were conducted on databases but generated no new papers for inclusion. Finally, a search was undertaken by investigating research by authors of known, relevant papers. This resulted in a request to two authors of one included paper requesting any relevant unpublished work; however, no further research was included. The initial search was undertaken in 2014 and updated annually up to and including February 2021.

Table 1: Search terms

Search 1: dementia OR frontotemporal dementia OR frontotemporal lobar dementia OR BvFTD OR behavioural variant frontotemporal dementia OR semantic dementia OR Pick* disease OR progressive aphasia OR progressive non-fluent aphasia OR hybridclinico-pathological entities OR ubiquitin-inclusion disease OR familial tauopathy OR frontolobar dementia OR frontotemporal degeneration OR frontolobar degeneration
Search 2: people OR person* OR patient* OR client* OR service user* OR participant* OR individual*
Search 3: family OR families OR spous* OR child* OR daughter* OR son* OR wife OR wive* OR husband* OR partner* OR life partner* OR family carer* OR unpaid carer* OR informal carer*
Search 4: paid carer* OR staff OR therapist* OR allied health professional* OR formal carer* OR paid carer* OR professional* OR Nurs* OR multidisciplinary team* OR assistant* OR worker* OR support OR team* OR healthcare personnel OR social care staff OR housing staff OR support staff
Search 5: experience* OR patient* experience* OR life experience* OR work experience* OR volunteer experience* OR perception* OR practice* OR observation* OR view* OR reflection* OR belief* OR subjective OR experiential
Search 6: living with OR life OR diagnosis OR life experiences OR coping OR coping

with OR understand of OR suffering OR bear OR tolerat* OR recognis* OR endure OR life style OR daily activit* OR attitude* Search 7: qualitative OR interview* OR (mh “Grounded Theory”) OR (mh “Phenomenology”) OR phenomenology*” OR (MH "Ethnological Research") OR (MH "Ethnology") OR "ethnograph*" OR MH "Case Studies") OR (MH "Nursing Care Studies") OR (MH "Field Studies") OR "case stud*" OR (MH "Action Research") OR (MH "Exploratory Research") OR (MH "Focus Groups") OR (MH "Interviews+") Search 8: s1 AND s2 AND s3 AND s4 AND s5 AND s6 combined Search 9: s2 AND s3 AND s4 combined Search 10: s1 AND s9 AND s5 and s6 Search 11: s1 AND s5

The database searches (Table 1) were combined with ‘and’ resulting in 795 articles being identified. Following the removal of duplicates, a manual check of titles and abstracts was undertaken which resulted in 57 articles being reviewed in accordance with the inclusion and exclusion criteria (Table 2) which resulted in 42 full-text articles being excluded. The remaining 15 studies were critically appraised for quality and specific relevance to the lived experience of FTD using the Critical Appraisal Skills Programme (CASP no date) Checklists and Strengthening the Reporting of Observational Studies in Epidemiology (STROBE no date).

Table 2 : Literature review inclusion and exclusion criteria

Inclusion Criteria	Exclusion Criteria
• Adults (16+ years) • Research includes the direct experiences and/or views of stakeholders (person, family caregiver, professional staff) of frontotemporal dementia • Article/research available in English • No more than 10 years old	• Studies focusing on diagnosis • Studies focusing on the efficacy of tools • Studies focusing on aspects of treatment rather than the experience of living with frontotemporal dementia • Studies focusing on the pathology of the disease • Studies focusing on pharmacology

The literature review revealed a paucity of research regarding the lived experience of FTD from the person's perspective. The existing research was mostly of quantitative design and concerned with neuropathology associated with searching for medical cures and pharmacological treatments. In order to find research regarding the lived experience of FTD, the search was broadened out from my initial focus upon the experiences of people diagnosed with FTD to include the experiences of family caregivers and clinicians. I discovered the literature available was concerned with family and staff caregiving roles; the symptoms of FTD and how to cope with symptoms; family and staff caregivers' views on the support they require and receive; and the impact of FTD upon carers' sense of self and relationships.

In summary, the literature review identified 15 papers that explored the concept of the lived experience of FTD (Appendix 1). Synthesis of the 15 papers resulted in four main themes (Table 3), which will be discussed in turn in this chapter.

Table 3: Emergent themes

1	Family caregiver experience of FTD
2	Understanding and coping with FTD
3	Support, satisfaction and useful approaches
4	The impact of FTD on the sense of self and interpersonal relationships

2.4 Family caregiver experiences of FTD

Six papers considered the experiences of family caregiving and the impact upon their mental health and well-being. Nicolaou et al. (2010) investigated the extent of depression and anxiety in family carers of people with FTD compared to AD. The results revealed no significant differences between the mental health of the two groups. Similarly, a study by Riedijk *et al*. (2008) recruited 63 familial *c*aregivers of people with FTD to examine changes in caregiver burden and family relationships over two years. There were no statistically significant changes in psychological status with caregiver burden decreasing and psychological well-being remaining stable over 24 months. Riedijk et al. (2008)

found that whilst relationship closeness and getting along were preserved, communication and sharing views on life between the person and their family caregivers reduced alongside negative changes to social support. These findings concur with those of Johannessen et al. (2017) who found that family caregivers of younger people with FTD described an increasing dependence upon the family for care.

In conclusion, the mental health status of family caregivers of people with FTD and AD were similar with caregiver burden decreasing and psychological well-being increasing over two years. However, deterioration in communication and sharing life views was experienced by family caregivers of FTD which led to a reduction in social support and an increased dependence upon family to provide caregiving. The deterioration in social support and increasing caring responsibilities experienced by family caregivers of people with FTD highlights potential additional support needs to maintain mental well-being.

2.4.1 The impact of neuropsychiatric symptoms on family caregivers

The deterioration discussed in section 2.4 regarding communicating and sharing life views, as described by family caregivers, was found to be compounded by the neuropsychiatric symptoms of FTD. Eight papers examined how neuropsychiatric symptoms impacted upon the caregiver experience. Rasmussen et al. (2019) identified that neuropsychiatric symptomatology was described as a gradual process whereby changes become more noticeable over time and caregivers found changes in their family member annoying, strange and worrying. Despite their gradual identification of changes, caregivers were reluctant to seek advice from professionals or friends due to a combination of embarrassment regarding behaviours, difficulties in pinpointing specific changes and remaining in a state of denial. However, the study does not explicitly explore whether the caregiver burden and experience increased during the journey of FTD. Rather, they identified themes that occurred at particular times along the journey such as moving from ‘becoming distant’ to ‘becoming insecure’ to ‘becoming devastated’ to ‘becoming a stranger’, all of which suggest a sense of caregiver isolation.

The isolation experienced by family caregivers of people with FTD was also identified by Massimo et al. (2013), who interviewed two wives of people with FTD in the USA and Oyebode et al. (2013) who interviewed six relatives in the UK. Both studies concur with Riedijk et al. (2008) and Rasmussen *et al.* (2019) by identifying that family caregivers experience distress and isolation due to behavioural changes; social isolation; loss of shared understanding; disinhibited behaviour; lack of empathy; changing future plans; and blunted emotions.

In regard to coping with neuropsychiatric symptoms, caregivers expressed issues as reported by Pozzebon et al. *(*2018) who interviewed 13 spouses of people with PPA (primary progressive aphasia). Caregivers described feeling uncertain regarding how best to manage unpredictable situations. In particular, caregiver burden was associated with symptoms of FTD including anger and emotional detachment (Massimo et al. 2013). Pozzebon et al. (2017) also identified issues regarding one spouse of a person living with semantic variant PPA (svPPA) in terms of managing anger. Particular issues surrounding unsafe driving were highlighted by Johannessen *et al*. (2017) who interviewed 16 family caregivers of younger people with frontotemporal lobar degeneration (FTLD), and Rasmussen et al. (2019) who interviewed 14 family caregivers of people with FTD. These findings highlight some different issues experienced by caregivers of people with FTD as compared to AD.

In comparing the experiences of family caregivers of people with FTD and AD, Nicolaou et al. (2010) concluded that family caregivers of people with FTD have greater levels of distress associated with meeting needs such as activities of daily living, behavioural and psychological symptoms, and socio-economic difficulties. In addition, Nicolaou et al. (2010) found families of people with FTD experienced a greater risk of threatening behaviours. Such findings concur with Rasmussen et al. (2019) who found family caregivers reduced their working hours because of caregiving responsibilities and Johannessen et al. (2017) who found that people with FTD were reluctant to apply for benefits which increased the financial impact of FTD upon family caregivers. Again, these findings may indicate additional needs of caregivers of people with FTD.

Although there is a consensus in the literature as to neuropsychiatric symptoms causing caregiver burden and changes to mental health, there are differences as to the degree to which caregivers experience burden and mental distress along the caregiving continuum. The differing results may be accounted for by different study design and recruitment processes. In the study by Riedijk et al. (2008), 32 participants dropped out who had been identified as having higher levels of behavioural symptoms and emotional caregiver burden. This study does not seek to understand the reasons for the high drop-out rate or explore the experiences of the participants who dropped out. Massimo et al. (2013) and Oyebode et al. (2013) recommended that future research raise awareness of the symptomatology and improve understanding around the causes of behaviour.

The recruitment of participants of the above studies examining caregiving experiences and burden may also have influenced the findings. Riedijk *et al*. (2008) and Nicolaou et al. (2010) recruited participants via support services, therefore, family caregivers were already in receipt of support. Recruitment criteria excluded people with a recent diagnosis. Hodges (2010) reports that receiving a diagnosis of FTD can take years, leaving family caregivers unsupported, therefore, a recommendation for future research is to recruit carers of people newly diagnosed with FTD. Riedijk et al. (2008) reported incongruence between caregiver presentation at interviews and questionnaire results. This suggests that study design has an impact on findings, and caregiver burden scores may have been affected by carers adjusting to burden over time. They recommend that future studies should be methodologically designed to take response shifting into account.

In summary, there is a need for more qualitative research which seeks to understand and build meaning around the subjective experience of FTD in order to increase knowledge about the condition and the impact upon family caregivers. Key issues for future research include the distress experienced by caregivers of people with FTD due to the neuropsychiatric symptoms associated with FTD. However, the literature to date focuses upon the experience of burden associated with caregiving as a prominent theme, yet

there are methodological issues that require attention, which could cause under-reporting of difficulties and consequently an issue of families being insufficiently supported if the true picture of burden is not represented. The literature included in this theme represents the experience of family caregivers. In order to build a comprehensive understanding of the lived experience of FTD, there is also a need for future research to explore the lived experience of FTD from the person's perspective.

2.5 Theme 2: Understanding and coping with FTD

Eleven studies related to how family caregivers and staff made sense of the symptoms of FTD, examining how they reacted to the symptoms and exploring the coping strategies employed to manage caregiving. Nicolaou et al. (2010) found that the length of time to receive a diagnosis of people with FTD and AD was similar, however, Rasmussen et al. (2019) found that there was a significantly longer timescale for people receiving a diagnosis of FTD. The longer waiting time may be explained by clinicians not recognising or understanding family members' concerns regarding relatives' personality changes, behavioural issues and loss of function.

Rasmussen et al. (2019) explored the difficulties FTD caregivers had in understanding symptoms of FTD prior to their family members receiving a diagnosis. Johannessen et al. (2017) described the onset of symptoms as sneaking and incomprehensible early signs of dementia. The changes noted in the person by family caregivers were not obvious and could be attributed to other mental health conditions and not always picked up by healthcare professionals (Rasmussen et al. 2019). One paper sought to understand the lived experience of the behavioural variant (bvFTD) from the person's perspective. Griffin et al. (2016) interviewed five people with a diagnosis of bvFTD in the UK. All participants were bewildered about the difficulties associated with FTD, had problems in understanding the extent of their difficulty, and the impact upon themselves and their caregivers. Participants had difficulty in identifying the changes they were experiencing. In order to

understand the symptomatology, the provision of FTD-specific information is recommended by Massimo et al. (2013) and Oyebode et al. (2013). Kindell et al. (2014) interviewed the wife and son of a person living with SD to understand the causes of behavioural symptoms and identified that early interventions should take account of the structural stigma caregivers face through professionals' lack of knowledge of FTD.

Particular changes in behaviour and habits of people with fvFTD were identified by Oyebode et al. (2013) which included loss of drive and motivation and excesses of behaviour such as changes in eating and walking. The study identified loss of inhibition with occurrences of risky and embarrassing behaviour. Risky and embarrassing behaviour was also identified by Kindell et al. (2014) in a person with SD. Oyebode et al. (2013) and Kindell et al. (2014) identified changes in communication as a key issue in caregivers' difficulties in making sense of the behaviour. Not understanding behavioural changes were linked to communication issues identified by Massimo et al. (2013) who found caregivers of people with FTD attributed family members' lack of empathy as an indication of not caring about them rather than understanding emotional changes as a symptom of FTD.

As well as family caregivers having difficulty understanding the symptoms of FTD, staff were found to be unaware of the diagnosis of frontal lobar degeneration (FLD) and associated behavioural symptoms. Edberg and Edfors (2008) interviewed 10 health care staff supporting people with frontal-type symptoms in a special housing unit and Rasmussen and Hellzen (2013) interviewed 10 staff working with people with FLD in a nursing home in Norway. Staff described difficulties related to resident behaviour associated with lack of inhibition, poor judgement, emotional reactions such as anger and anxiety, problems with hyperactivity and diminishing physical ability in self-care activities. Both Edberg and Edfors (2008) and Rasmussen and Hellzen (2013) identified that the relationship between the staff and the person required getting to know the person as an individual but at the same time staff experienced fear of deteriorating behaviour and felt uncertain about how to continue to care for the person well.

From the family caregiver's perspective, caring for the person well meant there was a need to find coping strategies that helped them to manage negative emotions associated with caregiving. Caregivers found themselves working around their family member's lack of awareness and taking on more caring tasks and roles (Oyebode et al. 2013; Riedijk et al. 2008). Increasingly, caregivers found themselves having to police and protect their family members in social situations and explain and defend their family member (Kindell et al. 2014). In employing such coping strategies, Pozzebon et al. (2018) identified that family caregivers described a need to 'get on with life', which included building caring capacity by regulating internal dialogue. This self-grounding technique was discovered to be essential in helping spouses explore and accept support in order to reconnect with their partner and other social networks. Self-grounding could include keeping calm and reassuring oneself. However, as caregivers strived to promote the quality of life for their family member, they came to rely upon adhering to the family member's imposed routines and compensating for their relative's lack of planning.

Similar strategies were identified by staff caregivers of people with FTD who emphasised the need to create a calm and positive atmosphere (Edberg and Edfors 2008; Rasmussen and Hellzen 2013). To create a positive atmosphere, there was a need to build up a trusting relationship with the person by doing things together whilst at the same being flexible and adaptable to the situation. Edberg and Edfors (2008) and Rasmussen and Hellzen (2013) emphasised the need for staff to pick up on non-verbal cues and to be 'one step ahead' of the person to pre-empt difficult situations and to make the most of momentary opportunities to build the therapeutic relationship. Both studies highlight that the positive experiences of staff can be translated into action such as the need to be clear and consistent when supporting people with FTD, the need for staff to work together and planning ahead with flexibility.

In summary, the papers revealed that making sense of the symptoms of FTD can be difficult for family caregivers to understand and are difficult to identify clearly. This feeling of bewilderment is also experienced by the person. Delays in receiving a diagnosis may be explained through symptoms being unlike

those experienced by people with AD and FTD symptoms being unfamiliar to professional staff.

The emotional and behavioural symptoms experienced by family caregivers of people with FTD lead to family caregivers having to 'get on with life' by employing a range of coping strategies. Strategies such as planning ahead and getting to know the person were found to be helpful in supporting the person to live well with FTD. However, it is notable that only one paper sought the views of the person with a diagnosis of FTD directly. Therefore, further research is required which takes account of the views of people with FTD.

Additionally, there are some methodological considerations that require to be explored in the studies included in this section. The recruitment process by Rasmussen and Hellzen (2013) may be biased due to participants being recruited in conjunction with the unit leader. No details are provided regarding selection criteria. Two participants withdrew and were replaced (reason/s unknown). The Edberg and Edfors (2008) study was not exclusive to people with FTD, therefore, it is unclear how much data relates to people with FTD. This may indicate a cultural influence in how symptoms and people are viewed, supported and organised in Sweden. The studies by Edberg and Edfors (2008) and Rasmussen and Hellzen (2013) were carried out in Scandinavia. Culturally, the organisation and provision of care are different from those of the UK, therefore, the findings must be considered in terms of cultural appropriateness to other environments.

Griffin et al. (2016) acknowledged that bias may have occurred as a result of adjustments made during the interview process to increase communication, however, without additional support to enhance communication, the views of the persons with bvFTD would have been reduced. Due to communication problems, the synthesis of the data may be biased despite the researchers' attempts to minimise bias. However, despite small participant numbers, the findings represent the views of people with bvFTD and demonstrate that direct engagement with people with bvFTD is possible and recommend further

research exploring how people with a diagnosis of FTD make meaning of their situation.

2.6 Theme 3: Support, satisfaction and useful approaches

Fourteen papers relate to theme three regarding the support received by people with FTD, the satisfaction with the support received from family caregivers' perspectives and the identification of useful approaches that help people live well with FTD.

The difficulties in receiving a diagnosis of FTD have been identified in Chapter Five, however, Oyebode et al. (2013) emphasise the need for appropriate sources of support, solace and hope for family caregivers at the time of diagnosis. The need for appropriate and FTD-specific support concurs with the findings of Riedijk et al. (2008) who identified that family caregivers of people with FTD need ongoing support to cope with the neurodegenerative nature of FTD and concurs with Kindell et al. *(*2014) who found that family caregivers need particular support in managing the emotional challenges associated with caring for people with FTD. Pozzebon *et al*. (2017, 2018), Johannessen et al. (2017) and Kindell et al. (2014) all identified a need for early intervention in terms of FTD-specific information and the need for person-centred and family-centred support throughout all stages of the journey to promote quality of life.

Furthermore, the need for FTD-specific support leading to appropriate interventions is identified by Nicolauo et al. (2010) where FTD carers reported at least 12 needs with a minimum of six unmet needs (greater than the AD group); and that FTD carers received greater informal support and required significantly more help. Formal help required for the two groups of carers was similar. This study found similarities concerning the behavioural and psychological symptoms of dementia (BPSD), but that FTD carers had particular needs that differed from those of AD carers, such as the younger age of onset, FTD characteristics, and access to appropriate services, information

and support. The study concluded by highlighting a need for tailor-made support for FTD, clear differentiation of dementia subtypes, and development of FTD-specific interventions. The need for specific FTD interventions was also highlighted by Sagbakken et al. *(*2017), who interviewed 11 relatives of people with FTD regarding the delivery of dignified care, and in studies by Pozzebon et al. (2018) and Kindell *et al*. (2017). The three studies highlighted the need for family carers to retain an element of control over the support being provided. It was found that person-centred interventions created a positive identity for the person and ensured remaining skills were utilised. The need for FTD-specific interventions is further highlighted in the findings of Rosness et al. (2008) who explored the experiences of 60 dyads of family caregivers and care recipients to identify the provision of support and satisfaction with support and found that people with FTD were admitted more frequently to day care and respite care, thus identifying the particular needs of people with FTD.

However, despite the need for FTD-specific support being identified in the literature, Kindell et al. (2014) and Johannessen et al. (2017) both found that the support received by FTD caregivers was based upon the needs of AD caregivers. This left FTD caregivers in receipt of information about other subtypes of dementia suggesting interventions such as reminiscence therapy which were not always considered positive interventions for people with FTD. Griffin et al. (2016), Kindell et al. (2017) and Nicolauo *et al*. (2010) all call for the development of interventions and provision of FTD-specific support based upon the particular needs of people with FTD. As well as FTD-specific support, Sagbakken et al. (2017) identified the need for the person to influence their own care in order to ensure delivery of dignified care in which the person has autonomy in care decisions, thus maintaining their integrity. Massimo et al. (2013) concluded by identifying the need for further research on the effectiveness of interventions for people with FTD.

In order to ensure the delivery of dignified care, it is necessary to explore the satisfaction of people receiving care. Rosness et al. (2008) conducted research using a structured questionnaire during interviews to ask about the care provided and satisfaction. They compared the provision of support to patients

and family caregivers of patients with FTD and AD. Findings suggested that FTD family carers were significantly less satisfied with the counselling and follow-up care provided by specialist health services and the information provided. This concurs with the findings of Johannessen et al. (2017) who identified that FTD caregivers preferred to receive support from specialist younger-onset services as opposed to older adult dementia services as they considered staff supporting younger people with dementia to have more knowledge about FTD.

As well as preferring to access support from specialist services for younger people, Sagbaaken *et al*. (2017) found that there is a need for FTD-specific nursing home provision. Sagbaaken et al. (2017) interviewed nine relatives of people with FTD living in care homes and two relatives of people with FTD accessing day care. The rationale for FTD-specific nursing home care included the younger age of people with FTD, their higher levels of physical health compared to older people, particular symptoms of FTD such as disinhibition and a need to raise awareness of FTD.

There is a consensus in the literature regarding raising awareness of FTD and its subtypes in both the wider community and among professional staff (Kindell et al. 2014). Johannessen et al. (2017), Rasmussen et al. (2019) and Sagbaaken et al. (2017) call for an increase in staff competence about FTD and found that GPs and specialists had a lack of knowledge of FTD. In order for FTD-specific interventions to be provided, there is a need to support staff delivering interventions in terms of increasing knowledge and managing the increased emotional demands and ethical issues that arise as a result of supporting people with FTD (Edberg and Edfors 2008).

Pozzebon et al. (2017) found that as well as increasing knowledge and awareness of FTD in staff, there is a need to tailor interventions to account for ongoing changes in presentation and recognise the importance of declining language for people with FTD. Johannessen et al. (2017) concurred and identified a need for interdisciplinary support throughout the journey with particular emphasis placed upon the need for assistance with finances and

benefits for people with FTD. Rosness et al. (2008) also called for awareness-raising activities such as education for police services regarding the symptoms of people with FTD.

In summary, family caregivers of people with FTD have been found to require more and different support compared to family caregivers of people with other subtypes of dementia. The need for increased support continues throughout the journey with FTD. Family caregivers require FTD-specific information which places the person at the centre of support provided.

With regard to the satisfaction expressed with current support, FTD family caregivers were found to be less satisfied with the support they received as compared to caregivers of people with other subtypes of dementia and requested FTD-specific services that would allow them and their family members some control over their journey.

Useful approaches such as the need to raise awareness in the public, health care professionals and wider support services have been identified alongside the need to support staff and caregivers of people with FTD given the particular needs associated with a diagnosis of FTD. More research is necessary to explore appropriate and effective therapeutic interventions for people living with FTD.

2.7 Theme 4: The impact of FTD on the sense of self and interpersonal relationships

Five papers relate to theme four which identified the impact of FTD upon the caregivers' sense of self and changes in interpersonal relationships. Kindell et al. (2014) interviewed the wife and son of a person with SD. They describe the impact of FTD on their family member as being akin to losing their family member. Pozzebon et al. (2017) interviewed one spouse of a man with svPPA who describes having to readjust her own sense of self as her spouse changed. According to Rasmussen et al. (2019) family caregivers of people with FTD describe feeling insecure which concurs with the findings of Massimo et al.

(2013) and Pozzebon et al. (2017) who describe caregivers as living a decline in terms of their sense of self, changed spousal relationship, reduced social world and loss of a shared meaningful future. Rasmussen et al. (2019) described this as ‘becoming devastated’.

One study considered changes to self and relationships from the perspective of the person. Griffin et al. (2016) identified that people with bvFTD recognised changes in their self which they considered a threat to their identity. Participants coped with the threat to self by blaming others or avoiding potentially stressful situations.

Given the significant changes in self which family caregivers experience and the threats to self, as described by people with FTD, the preservation of roles and activities and maintenance of links to the outside world are important in terms of preserving a positive sense of self (Massimo et al. 2013; Sagbaaken et al. 2017). A fundamental part of retaining a positive sense of self in caregivers of people with FTD was linked to the quality of spousal and family relationships. Pozzebon et al. (2017) identified that the most enduring caregiving challenge was coping with the relational disconnect and concurs with the studies by Kindell et al. (2014), Oyebode et al. (2013), and Pozzebon et al. (2018).

Relational disconnect featured in the studies of Massimo et al. (2013) and Oyebode et al. (2013) who reported that participants felt their family member was no longer the same person and their relationship had changed. Findings demonstrated that caring for a person with FTD and AD are different in that FTD caregivers face changes to emotional capacity and relationships earlier in the journey. More research is required into understanding causes of symptoms, early intervention and effectiveness of interventions in order to inform service provision for caregivers of people with FTD and support them to experience positive relationships with their family member.

Conversely, Riedijk et al. (2008) found no significant changes in the quality of the pre-morbid relationship between carer and care recipient, the current relationship and the relationship at 24 months. They used a visual analogue

scale to rate responses of relational closeness, communication, vision and getting along. Caregivers rated the quality of their pre-morbid relationship as being significantly better than baseline. The quality of the relationship from baseline to 24 months was unchanged. Closeness and getting along were unaffected, but communication and sharing views were reduced. In order for the caregiver to experience closeness and getting along with their family member, there is no need for verbal communication. However, to be able to communicate and share views, the person requires to participate verbally. People with FTD can experience language difficulties which may impair their ability to verbalise their feelings, which can result in the caregiver feeling verbal communication has deteriorated and results in a lack of opportunity to share views. This is an important differentiation to make which is not explored explicitly in the studies by Massimo et al. (2013) or Oyebode et al. (2013). The IPA approach in Massimo et al. (2013) and Oyebode et al. (2013) generated themes that may not be included in the measures utilised by Riedijk et al. (2008), therefore, this finding is not fully understood. Changes in relationships may involve other factors that require further exploration and provide opportunities for staff to support family caregivers to reframe their relationships and develop interventions aimed at sustaining emotional and relational connections (Pozzebon *et al*. 2017).

Changes in relationships from the person's perspective were explored by Griffin *et al.* (2015) who found that people with bvFTD were concerned about social relationships. Participants did not perceive a change in relationships but were aware they may have done something wrong. This led to threats to self which resulted in the person blaming others or avoiding particular situations. Further research is required to build upon the findings of Griffin et al. (2016) to include the views of people with other subtypes of FTD given their significance in relation to understanding the lived experience of FTD and interventions and approaches that help or hinder living well with the condition.

In summary, family caregivers of people with FTD were found to encounter difficulties and changes in their relationships earlier in the journey as compared to caregivers of people with AD. People with FTD were aware that changes to

the self had occurred, which impacted upon their relationships. The difficulties in communicating and sharing views in family relationships affect interpersonal relationships, therefore, further research is required to explore the impact of FTD upon social identities, sense of self and interpersonal relationships from the perspectives of family caregivers as well as the person diagnosed with FTD.

2.8 Summary of findings from the literature review

This review of the literature builds a picture around the lived experience of FTD from the perspectives of family caregivers, staff and persons with a diagnosis of FTD. The findings tell us family FTD caregivers face particular challenges specific to caring for people with FTD. Challenges include seeking assessment and diagnosis of FTD, understanding the symptoms particular to FTD, coming to terms with changes to sense of self, roles and relationships and finding approaches and coping strategies that facilitate living well with FTD. This literature review has highlighted the need for FTD-specific interventions and professional support that takes account of individual needs and development of support to meet the needs of caregivers and professional staff, whilst at the same time hearing the voice of the person living with a diagnosis of FTD.

This research study will add to the existing literature by exploring the experience of FTD from the person's perspective. The experiences of people living with bvFTD were explored in one study (Griffin et al. 2015), thus, there is a need to research the experiences of people with all subtypes of FTD. Taking a collaborative approach that places the perspectives and experiences of people with FTD at the centre could raise understanding of the lived experience of the condition, and lead to enhancements to existing support and future development of FTD-specific interventions that address the needs of people with FTD, and in doing so, benefit their family caregivers and staff by improving health and social outcomes.

2.9 The aim of the study and the research questions

The literature synthesis has identified that the experience of living with FTD is an under-researched area. The perspective of the family caregiver dominates, with two studies exploring professional staff experiences and only one paper found that sought the views of people with FTD. The paper by Griffin et al. (2016) demonstrates that it is possible to engage with people with FTD directly. What remain unclear are the views of people with a diagnosis of all subtypes of FTD. This gap in the evidence base underpins the study aim to explore the lived experience and views of people with a diagnosis of FTD.

In order to explore the experiences of people living with a diagnosis of FTD, the following questions are posed:

- How do people with frontotemporal dementia (FTD) describe their daily experience of living with FTD?
- What do people with frontotemporal dementia (FTD) feel helps and hinders them in living well with FTD?

This chapter has identified the approach taken in the literature review, provided details of the search strategy and identified four emergent themes which informed the study aim and research questions in relation to understanding more fully the lived experience of FTD from the perspectives of people living with the condition. Discussion of the themes identified in the literature review in the broader literature can be found in Chapter Six. The following chapter will discuss the study methodology.

Chapter 3 Methodology

3.1 Introduction

This chapter presents the process undertaken to arrive at a choice of study methodology. First, there is consideration of both quantitative and qualitative approaches and how the research aim of understanding the lived experience of people with a diagnosis of FTD may be best achieved. My own ontological and epistemological positions are explored taking into consideration the clinical relevance of the study. An overview of the qualitative research methodologies and their usefulness and appropriateness in terms of meeting the research aim is considered and the rationale for the selection of an IPA methodology is discussed. The chapter concludes with a description of how quality was ensured by following the guidance of Yardley (2000, 2008).

3.2 Consideration of quantitative and qualitative approaches

Chapter Two highlighted the paucity of qualitative research regarding the lived experience of FTD from the persons' perspective. The majority of quantitative studies were concerned with measuring family caregiver burden (Guevara et al. 2015; Nicolaou et al. 2010; Riedijk et al. 2008; Shuling et al. 2017; Torrisi et al. 2017; Uflacker et al. 2015). The literature search revealed a dominance of quantitative research with the main aims being the generation of data which enhanced understanding of the pathology of FTD, the development of medical interventions and finding a cure (Armstrong and Cairns 2011; Cerami and Cappa 2013; Li et al. 2016; Meijboom et al. 2017).

Quantitative approaches involve the development of a numerical description of a phenomenon and methods can include questionnaires and structured interviews. Whilst acknowledging the importance of understanding pathology, developing medical interventions and seeking a cure, such research aims require a research design that tests theories, identifies variables to research,

utilises standards of reliability and validity, and involves statistics (Bowling 2010; Creswell 2014; Gray 2011; Tilling et al. 2010). The methods employed in quantitative research such as questionnaires and structured interviews limit the depth of understanding of a phenomenon and distance the researcher from the participants (Gilbert 2011). A quantitative research design does not seek to understand the lived experience of people with FTD.

The quantitative researcher must use unbiased approaches which lead to the production of precise and unambiguous data (Gilbert 2011), whereas in aiming to understand the lived experience of FTD, the generation of rich, individualised data is necessary (Creswell 2014). Although numerical data are viewed positively within a post-positivist worldview, the failure of the researcher to immerse themself in the social and cultural construction of reality does not fit with the proposed research aims of understanding how people experience living with FTD and how they make sense of FTD (Guba and Lincoln 1994; Silverman 2000). In taking a qualitative approach the researcher can explore the individual's experiences in depth (Creswell 2014; Gilbert 2011).

In order to develop a rich understanding of how people experience FTD, a qualitative approach is useful in exploring and understanding the meaning of experiences. Creswell (2014) described the qualitative approach as flexible and incorporating an inductive style, having a focus upon individual meaning, and allowing the researcher to build a complex picture of a situation. The inductive nature of the process allows questions and themes to emerge. Data is usually collected in the participant's own environment to take account of the social and cultural context. Data analysis builds intuitively with meanings and themes emerging which the researcher then interprets (Creswell 2013; Gilbert 2011; Robson 2011).

3.3 Understanding the lived experience

Worldviews or paradigms (Lincoln *et al*. 2011), are *"a basic set of beliefs that guide action"* (Guba 1990 p.17). Ontology is concerned with the study of the

nature of being or reality (Creswell 2014), whereas epistemology tries to understand the meaning of knowing (Gray 2011).

The literature review identified that research concerning the experiences of people living with FTD has been dominated by experiences of people supporting people with FTD rather than the person themself. With the exception of one study by Griffin et al. (2016), the assumptions held about the ontology or reality of FTD are derived from the observations and experiences of family carers or professionals (Caceres et al. 2016; Dinand et al. 2016; Guevara et al. 2015; Johannessen et al. 2017; Kindell et al. 2014; Kindell et al. 2017; Massimo et al. 2013; Nicolaou et al. 2010; Oyebode *et* al. 2013; Pozzebon et al. 2017; Pozzebon et al. 2018; Rasmussen and Hellzen 2013; Riedijk et al. 2009; Rosness et al. 2008; Rutherford 2014; Sagbakken et al. 2017; Shuling et al. 2017; Torrisi et al. 2017; Uflacker et al. 2016) or professional carers (Edberg and Edfors 2008; Rasmussen et al. 2019). The paucity of studies that approach people with FTD for their views may be accounted for by the diagnostic criterion for FTD which includes lack of insight and the practice guidance developed upon such a diagnostic criterion (Banks and Weintraub 2008; Mendez and Shapira 2005; Neary et al. 1998; O'Keefe et al. 2007; Rankin *et al*. 2005; SIGN 2006; Lund and Manchester Groups 1994; Williamson et al. 2009).

However, research exists that makes recommendations for changes to the diagnostic criterion regarding lack of insight for FTD. The study of Evers et al. (2007) recommended that loss of insight should not be included as a core diagnostic criterion for FTD but be included as a supportive criterion as loss of insight was found to be a heterogeneous concept. Despite the challenge to the current diagnostic criteria, most studies around the experience of FTD and loss of insight and awareness are researched from the perspectives of families and professionals; consequently, the reality presented is not representative of the experience of the person who has FTD but represents family caregivers' and professionals' experiences.

Griffin et al. (2016) researched the subjective experience of people diagnosed with bvFTD. They suggest there is a common perception that people with

bvFTD lack insight, therefore, would not be able to provide a valid or reliable account of their experience. This view reflects my own experiences of clinical practice whereby family carers and professionals discount the person's account because it is different from their own. Whilst FTD can cause decreased insight (Hodges 2007), it has been my experience that people with FTD in the earlier stages of the disease are able to voice their views, and high degrees of insight are intact. With regard to reliability and validity, in taking an IPA approach to research, the 'truth' of the experience is a truth unique to that individual and forms a fundamental part of the idiographic element of IPA.

Griffin et al. (2016) went on to state that despite participants having a range of levels of insight and awareness, people with a diagnosis of bvFTD were able to participate in the interview process. Again, this reflects my clinical experience of being able to involve the person in decision-making to varying degrees dependent upon their cognitive ability and communication skills. Griffin et al. (2016) acknowledged that recruiting people with bvFTD who still retain capacity to consent to studies is difficult and may explain the lack of research involving the person with the diagnosis. The difficulties surrounding recruitment in this study are discussed in section 4.6.

However, in order to develop understanding and knowledge about the experience of FTD, I believe that exploring the experience of the person from their perspective is a fundamental requirement in generating knowledge. My worldview is that it is important, as far as possible, to understand how the person experiences FTD rather than the accuracy or truth being told from another person's perspective (Smith et al. 2010). Therefore, as this reality from the person's perspective has only been qualitatively explored in one study by Griffin et al. (2016), this is an area of research that requires further exploration to generate more in-depth and representative knowledge. Furthermore, the participants in the study by Griffin et al. (2016) all had a diagnosis of bvFTD. My study included people with any subtype of FTD and sought to ascertain their views on what helps and hinders them in living well with FTD, thereby generating evidence that will support professionals to have an increased awareness of the needs of people with any subtype of FTD.

A qualitative approach to research contains underlying philosophical assumptions, methods and procedures. Social constructivists believe individuals seek to understand the world within which they live and develop subjective meanings (Robson 2011). As meanings are variable and individual, the researcher seeks the complexity of the meanings rather than narrowing ideas into themes. The researcher's role is to make sense of the meanings that others have of the world. Rather than beginning with a theory, the researcher develops a theory or pattern of meaning inductively. In immersing oneself in the rich data generated, it is important to acknowledge that researchers (as individuals too) will interpret the data through the lens of their own experiences and interactions. The researcher must position themself clearly by acknowledging that the interpretation of data will be influenced by their own personal, cultural and historical experiences (Creswell 2014). My own biases, views and experiences are discussed in Chapters Three and Six.

The primary aim of this study concerns exploring the lived experience of FTD from the participants' perspective. The secondary aims are concerned with the views of people with FTD around the support they access, the usefulness of the support and the strategies employed to live well. The qualitative approach selected fits with the research aims as the underlying philosophical assumption is one of social constructivism which lends itself to a phenomenological strategy of inquiry. A qualitative approach employs the methods best suited to elicit the experiences and views of people with FTD. Therefore, due to the exploratory nature of my research aim, a qualitative approach has been selected which aims to gather an in-depth understanding of the lived experience of FTD and the reasons underpinning the phenomenon (Gray 2011).

In contemplating my own epistemological beliefs, I consider worldviews a general philosophical way of seeing the world and the type of research that you use in a study. Creswell (2014) explains that worldviews can often be based upon professional discipline orientation (Creswell 2014). The concept of person-centredness was developed from the work of Rogers (1951), which involves having a non-judgmental attitude towards those you support and having unconditional positive regard for that person, their wishes and beliefs.

This concept of person-centredness was first introduced as personhood to the field of dementia care by Kitwood (1997). Kitwood (1997, p.8) defined personhood as “a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being”. As a mental health nurse trained to strive for person-centredness (Blake et al. 2020; Brooker and Latham 2016; Colomer and de Vries 2014; Kitwood 1997; Middleton-Green et al. 2017), I believe that trying to interpret and understand the individual’s experience of FTD is at the centre of understanding the symptoms and behaviour observed by caregivers and enhanced understanding can improve the provision of effective and acceptable support.

My own worldview has undoubtedly been constructed around years of clinical experience supporting people with FTD and their caregivers. However, for Husserl (1982), in taking a phenomenological approach, the researcher must disengage from the assumptions made about any given experience. In order to disengage, he developed a phenomenological method that researchers could utilise to identify the fundamentals of the human experience. He described a need to ‘bracket’ the assumptions we have to be able to focus upon our perception of the world. Thereafter, the researcher undertakes a series of ‘reductions’ which provides an alternative way of considering the experience. Through these ‘reductions’ the researcher is able to minimise their own beliefs or views around the experience and seek the essence of the experience being told. Husserl (1982) suggested that undertaking this process of reductions was essential before any other research takes place. In adopting a phenomenological approach and becoming aware of my own influences and beliefs, I tried to bracket off my influences and beliefs and sought to understand, as far as possible, the experience of FTD from the person’s perspective (Gray 2011).

The term ‘bracketing’ has different roles in descriptive and interpretative phenomenological approaches from the methods utilised by researcher to disclose their past or to decide to use their background in the study (Kiikkala and Asted-Kurki 2015); the need to see the data from the participants’ perspectives (Husserl 1970); to the researcher interpreting the data (Heiddeger

1962). However, as an experienced mental health nurse I was keen to utilise the data from both the participants' and my own interpretations whilst at the same time trying not to be influenced by my own preconceived ideas. Dorfler and Stierand (2020) describe the use of transpersonal reflexivity used during bracketing in order to identify presumptions, previous knowledge and beliefs of which the person is not already aware. Transpersonal reflexivity involves a deeper process than reflexivity and goes beyond subject reflection to include slef-reflection and the notion of personal knowledge where personal boundaries between my supervisors and myself analysing data resulted in a coming together of analysis and thinking.Therefore, my bracketing activity consisted of moving between openness to the participants way of thinking and understanding my supervisor's interpretations of the data. I became more critical in my interpretation of the interview content given my professional knowledge of supporting people with FTD, analysing data alongside my supervisors and seeking clarification from participants during interviews. My reflections were kept in the form of a journal.

Thus the bracketing process was of a personal nature in that I reflected upon my own values, beliefs and self-knowledge and those of my supervisors (Chan et al. 2013), but at the same time influenced how I used IPA theory in the study as it dictated the way in which the literature was used in the study aligned to my epistemological position and ontological perspective (Gearing 2004). Further reflection on 'bracketing' can be found in section 6.8.

3.4 Clinical relevance and epistemology

The rationale for studying the lived experience of people with a diagnosis of FTD developed from recognition in my previous clinical practice that the support provided by professionals required more research and from a professional desire to improve my understanding of FTD. In ensuring that the views of the person are placed at the centre of support, the development of interventions, policies and clinical guidance can be enhanced, making them acceptable and useful for the person.

The drivers for hearing the voice of the person are embedded in best practice literature, policies and strategies (Alzheimer Europe 2017; Scottish Dementia Working Group Research Sub-group 2013; Scottish Government 2011a; Scottish Government 2011b; Scottish Government 2017). There is broad acknowledgement in healthcare quality improvement literature that hearing the voice of the person will contribute to effective and meaningful clinical change (Lindenmeyer et al. 2007). The aim of quality improvement approaches involving the person is to improve health literacy, promote decision-making, increase self-management of conditions, improve the safety of interventions, improve access to health care advice, enhance the quality of care received, improve processes and develop services and educational resources (Coulter and Ellins 2016; Gleeson et al. 2016). However, Sacristan et al. (2016) reported in the research world that people are regarded as data sources rather than proponents of developing clinical interventions. People living with long term conditions should be involved in research and be proponents of developing the research questions to explore and the outcomes to be assessed (Coulter and Ellins 2006; Gleeson et al. 2016; Lindenmeyer et al. 2007; Sacristan *et al*. 2016; Tinetti and Basch 2013; NHS Institute for Innovation and Improvement 2013). There is now a strong argument in the literature around the need to involve people with dementia and/or AD and their carers in research activity and design (Bartlett 2012; Gove et al. 2017; Lindenmeyer et al. 2007; Moniz-Cook et al. 2008; Øksnebjerg. et al. 2018; Testadl et al. 2014; Woods 2017). In my study, people with dementia were consulted in the design of participant information sheets, consent forms and the interview schedule which are detailed in section 4.7.1 and Appendices Four, Five, Six, Seven and Eight.

3.5 Selection of qualitative research methodology

Qualitative research involves many strategies of enquiry including narrative research such as grounded theory (Charmaz 2006; Corbin and Strauss 2007; Strauss and Corbin 1990, 1998; ethnography (Fetterman 2010; Wolcott 2008); case study research (Stake 1995; Yin 2009, 2012); participatory action research (Kemmis and McTaggart 2000); discourse analysis (Cheek 2004), and

phenomenology (Moustakas 1994); amongst several other qualitative designs. In considering which approach to take, I explored the aforementioned approaches and considered the advantages and limitations of each design in terms of how well they might achieve my research aims. I will outline the major disadvantages of the identified methods for my approach when the rationale for IPA is discussed.

Phenomenological research focuses on the need to understand how individuals view themselves and their world. The approach seeks to create rich understanding and insights into the meaning of everyday life experiences (Creswell 2014; Patton 2002; Robson 2011; Starks and Trinidad 2007). The phenomenological approach contains no explicit theoretical orientation. Instead, studies begin by gathering information from participants to gain a sense of their experience leading to rich, detailed descriptions of the central phenomenon (Pringle *et al*. 2011). In contrast, grounded theory (Glaser and Strauss 1967), aims to generate theories regarding process, action or interaction grounded in the views of the participants (Creswell 2014). Although grounded theory is a strategy that is used in under-researched areas and could generate a theory accounting for people's experiences, this approach would not address the aim of understanding or making sense of the individual experience.

Initially, phenomenology focuses on the subject matter to try to understand the individual's experience. The researcher must methodically experience the phenomenon as fully as possible and 'bracket' off their current understandings and preconceived ideas. The result should be renewed or expanded meaning and picking up on significant findings that may not have been part of the original research focus (Gray 2011). The phenomenological approach assumes there is an essence to shared experience by acknowledging the importance of knowing what people experience and how they interpret the world (Gray 2011).

Chapter Two identified the focus of the study as understanding the lived experience of FTD. Interpretative phenomenological analysis is a qualitative research methodology that focuses on exploring how people make sense of major life experiences (Smith et al. 2010). Interpretative phenomenological

analysis considers people to be sense-making creatures, therefore, their personal accounts will contain each individual's understanding and making sense of living with FTD, and their awareness of threats to the sense of self (Smith *et al*. 2010). Other approaches explore the person in terms of their cultural, social and political environments such as ethnography (Robson 2011), case studies (Gray 2011), participatory action research (Lewin (1946), and discourse analysis (Creswell 2014), however it was felt that the focus on cultural and casual relationships, group dynamics, political contexts, and how the story is constructed linguistically in such approaches, were different from the focus of this study of understanding how individuals make sense of their lived experiences.

Initially a concept introduced by Husserl in the 1990s, Husserl's phenomenological stance was developed into an interpretative form by Heiddeger and Gadamer (Koch 1999). Interpretative phenomenological analysis draws on the Heideggerian tradition and offers an analysis that brings together various strands of phenomenology and goes beyond description. Interpretative phenomenological analysis acknowledges that lived experience has significance in individuals' lives and relates to important past events, impacts on present life experience and has future ramifications (Smith et al. 2010). Furthermore, IPA acknowledges that the researcher's understanding and interpretation of the experience is filtered through what the individual chooses to reveal. Although observing participants may have been a method whereby interpretation of participants is possible, in considering an ethnographic approach where participants are observed in their natural setting (Gilbert 2011), it was felt this approach did not fit with the aim of this study in seeking to understand how a person with a diagnosis of FTD makes sense of their lived experience.

A major theoretical underpinning of IPA is hermeneutics, which is the theory of interpretation and is concerned with the dynamism of the relationship between the whole and its parts. Hermeneutics takes into account the social and psychological aspects of experience. The central concept of 'being in the world' illustrates the connection between mind and body, the lived experience and

society. Heidegger (1962) believed that how we interpret the world arises from our past experiences and that understanding between people occurs as a result of living in relation to others in a hermeneutic circle of interpretation. The hermeneutic circle is concerned with the dynamic relationship between part of a story and the whole story at various levels, i.e. a single word only becomes understandable when read as part of a sentence, but the sentence is understandable because of the words it contains. Therefore, the analyst moves back and forth between the meaning of the word and the sentence (Smith et al. 2010). Discourse analysis involves the analysis of a story with particular emphasis on how the story is constructed and how people use language to create and enact identities (Creswell 2014). Although the linguistic way in which the experience is expressed will form part of a deep analysis of the data, it is not the focus (Robson 2011; Smith et al. 2010; Starks and Trinidad 2007).

A hermeneutic approach allows the researcher to propose meaningful insights into the data which may not have been explicitly expressed by the participant. The hermeneutic approach can be seen in the interpretative comments made on the interview transcripts (Appendix 12), which aim to explore how and why participants have discussed their experience, thinking about the context from all interviews and identifying more abstract concepts (Smith et al. 2010). The hermeneutic circle involves going to and fro in the data rather than in a linear process (Smith et al. 2010). Therefore, retaining flexibility such as considering different interpretations of the meanings in the data and constant refining of themes throughout data gathering and analysis is a core requirement and strength of phenomenology (Campbell and Scott 2011). The researcher must be able to analyse the data in a way that acknowledges the parts of data that are influenced by their relationship to the other parts and then to the whole which means multiple perspectives and meanings may be generated and changed as data analysis is performed (Smith et al. 2010).

The researcher engages in the double hermeneutic approach to interpret the account from the individual’s perspective and to understand the experience as accurately as possible in an idiographic way. In order to embed themselves in the hermeneutic circle of interpretation, researchers must gain access to

participants' thinking to interpret and understand their actions. This can only occur if the researcher 'brackets out' their own preconceptions (Gray 2011). Heidegger (1962) talked about the dangers of fore-structures and how our preconceptions can inhibit interpretation. He stressed the importance of being aware of our own fore-structures when analysing data but also that in analysing the data, the researcher can become more aware of their fore-structures and, therefore, more effectively 'bracket' off their fore-structures. More reflection around the need to 'bracket' oneself off can be found in section 6.8.

3.6 Quality in qualitative research

The diversity of views and inconsistent use of terminology surrounding how to demonstrate or measure quality in qualitative research has contributed to the difficulty in demonstrating "rigor" (Morse et al. 2008), therefore the quality criteria of Yardley (2000, 2008) has been used throughout this study. Lincoln and Guba (1986, 2011) proposed that research based upon a constructivist standpoint required different criteria from traditional social sciences. They acknowledged that using quality criteria designed for quantitative research in qualitative studies were incompatible and suggested that as opposed to internal validity, qualitative studies should strive to be credible; that an alternative to external validity was transferability; that reliability could be demonstrated in achieving dependability; and that confirmability, as opposed to objectivity, were more achievable and realistic in qualitative research. The quality criteria set out by Yardley (2000, 2008) incorporates four principles that address the requirements of Lincoln and Guba (1986, 2011) which are sensitivity to context; commitment and rigour; transparency and coherence; and impact and importance.

Creswell (2014) concurred with Lincoln and Guba (1986; 2011) and provided an explanation of how validity and reliability could be achieved in qualitative research. Creswell (2014) describes qualitative validity as a process whereby the researcher checks the accuracy of their findings by employing certain procedures such as ensuring findings are accurate, reflect the participants'

viewpoints and make sense to the reader. Creswell (2014) states that trustworthiness, authenticity and credibility are all elements that can demonstrate validity in qualitative research. Creswell (2014) continued by defining qualitative reliability as the requirement that the researcher's approach is consistent. Consistency is achieved by documenting all steps and procedures in a transparent manner (Gibbs 2007). Therefore, Creswell (2014), Lincoln and Guba (1986, 2011), and Gibbs (2007) suggest that achieving quality in qualitative research is possible, but in a different way from that of quantitative research, and requires alternative terminology and processes such as the quality criteria of Yardley (2000, 2008) which will be discussed later in section 3.6.

Smith et al. (2010) agreed that within IPA studies, there is a requirement to demonstrate quality. Smith et al. (2010) suggest demonstrating the thoroughness of the study; the appropriateness of the sample chosen in relation to the research question; the quality of interviews; and the comprehensiveness of analysis. Smith et al. (2010) wrote that guidance, to achieve validity and reliability, should be incorporated at every stage of the research process. Therefore, I decided to follow the guidance of Smith et al. (2013) from the outset of my study. It was fundamentally important to me that I demonstrated sensitivity to context; commitment and rigour; transparency and coherence; and trustworthiness as far as possible not only in the findings but also the process of analysis and writing up, so that the study would be of a quality that could impact upon and influence clinical practice (Donovan and Sanders 2010).

The quality criteria of Yardley (2000, 2008) contains four principles that address the concerns of demonstrating quality in qualitative studies. The principles are sensitivity to context; commitment and rigour; transparency and coherence; and impact and importance of research. The principle of sensitivity to context requires the researcher to be sensitive to the socio-cultural milieu in which the study is situated (Yardley 2000, 2008). Choosing an IPA approach demonstrated the desire to focus upon the individual and engage closely using semi-structured interviews. The sensitivity to context continued in the way in

which analysis was conducted including the use of verbatim excerpts that clearly illustrated and supported the argument presented. Each claim can be located in the interpretative notes on the individual's transcripts. Furthermore, sensitivity to context was demonstrated in the literature review annual updates to keep myself up to date with the latest research pertaining to this study.

The principle of commitment and rigour incorporates several elements including the degree of attentiveness given to the participant during data collection. Sensitivity and consideration towards participants was a fundamental principle of the study and was incorporated throughout. Rigour was demonstrated through the inclusion of a consultative group of people with early-stage dementia who co-produced information leaflets, consent forms and the interview schedule. In addition, the selection process led by gatekeepers already known to participants ensured only people who met the study criteria were included. The quality of the interviews can be examined as each interview is transcribed verbatim and reflects an interviewing style where care was taken to ensure the participant did not become distressed and had the opportunity to talk and to be listened to carefully.

Regarding the rigour of data analysis, the analysis follows the guidance of Smith et al. (2010) and incorporates coding, descriptive comments, interpretative comments, linguistic comments and identification of emergent themes, which are clearly identifiable on all transcripts. The annotated comments include important information about individual participants and the excerpts from transcripts included in the thesis represent all participants. The checking and re-checking of my understanding and interpretation of participants' understanding were demonstrated through re-checking of information and interpretation in second interviews with participants, through samples of transcripts being interpreted by my supervisory team to ensure similar conclusions were being drawn, and through the guidance of an IPA expert. This is discussed in more detail in section 4.8

The third principle of transparency and coherence is reflected throughout the study. Transparency refers to how clearly the stages of the research process

are described. Details of the research process stages are discussed in section 4.5 onwards.The details include how participants were selected and the use of gatekeepers; how the interview schedule was co-produced; how interviews were conducted; and the steps followed in analysis. The thesis includes tables and appendices which are transparent and demonstrate a coherent approach in terms of initial coding, development of descriptive comments, linguistic comments and conceptual comments leading to the generation of emergent themes. In addition, drafts of the thesis were read by people with no knowledge of FTD to ensure the thesis was coherent and understandable. An IPA expert was consulted regularly to provide feedback regarding the production of clear themes and the development of a framework for understanding the experience of FTD from the person's perspective. Transparency is further demonstrated in excerpts from my reflective journal which can be found later in Chapter Three.

The commitment to being transparent has ensured the study is coherent. Coherence refers to the fit between existing research and the underlying theoretical assumptions of the approach being implemented. This study adheres to the principles of IPA (Smith et al. 2010) in taking a phenomenological approach focusing upon the experience of each individual, the attention to the hermeneutic process and the comprehensive level of interpretation.

The fourth principle refers to the impact and importance of the research (Yardley 2000, 2008). The study highlights and discusses themes that are valid to the individual and this group of people living with FTD. The findings identify new information that has not been reported on previously and will be of interest to people with FTD, family caregivers and professionals. The findings have the potential to make a significant contribution to current understandings of FTD and could be used in developing new interventions and revising current clinical guidance.

3.7 Reflexivity

Interpretative phenomenological analysis emphasises that engaging in research is a dynamic process where the researcher takes an active role (Smith and Eatough 2006). The aim is to try to reach an understanding and interpretation of the 'insider perspective'. There is a need for qualitative researchers to take a reflexive approach regarding their impact upon the research process in order to enhance the trustworthiness and credibility of their findings by taking account of the researcher's values, beliefs, knowledge and biases (Cutcliffe 2003). Mental health nurses who become researchers have to shift between existing clinical knowledge and skills and research knowledge and skills and can do this safely by ensuring they use a reflective approach and develop reflexive strategies. In using reflection to develop reflexive strategies, the researcher can develop an enhanced professional and ethical perspective (Brunero et al. 2015). Therefore, throughout the study, I maintained a reflexive journal that contained my personal reflections and decisions made during the research process (Lincoln and Guba 1986). In taking a reflexive approach I discovered two significant issues upon which I had reflected throughout the study. The first issue is my ongoing concern and worries about participants' welfare, and the second, identifying a theme during the study which I had not been previously aware of and thus had not considered whilst working in previous clinical roles with people with FTD.

Watmough *et al*. (2010) discussed the issue of role identity and maintaining boundaries when the research methods utilised involve direct contact with participants. They identified and discussed issues surrounding maintaining the integrity of the research whilst at the same time adhering to the professional responsibilities of being a registered nurse. Hay-Smith *et al*. (2016) identified that the researcher's role can encompass similar skills to those required in a clinical role such as engaging with participants and developing relationships.

This notion of a developing relationship was particularly evident in the participants whom I interviewed twice who 'opened up' more during the second

interview. In the following excerpt, George's wife (Susan) is not present during the second interview.

> *George: Susan doesn't know she's doing it but I've no control over my own life. Susan's controlling my life, if you understand what I mean (George, Interview 2, page 12).*

Below is an excerpt from my journal where I have reflected upon the content of the second interview with George and it illustrates the concern I have around whether a third interview might be necessary or compound the concerns I already have.

> *"there is still a need to be mindful of being relaxed and friendly enough to ensure someone feels safe to be interviewed, but at the same time, maintaining a professional boundary. I really think that if I had offered a 3rd interview, this would have not yielded more information but may have been detrimental in that it could have created a dependence upon my visits as George seemed to enjoy being able to talk about his experiences very much (especially on the 2nd interview). Therefore, I think the decision not to offer a 3rd interview was correct".*

Hay-Smith et al. (2016) identified the theme of incidental clinical findings in research. This is when, during an interview, you discover an issue surrounding the support or care the participant receives. In this case, Mary revealed she felt her support required to be more proactive.

> *Mary: for all they know I might not be as good as they might think I am ... and... and I am [crying] I'm not always like this. Em, I am generally fine em, but if they think I should be going there and I'm not ... you'd have thought somebody they would have been in touch. (Mary, Interview 2, page 41).*

The following is an excerpt taken from my journal reflecting on Mary's concern about her current support network. The excerpt illustrates the similarities and

differences between the clinical role and researcher role but also takes account of the Declaration of Helsinki (World Medical Association 2016) which places an ethical responsibility on researchers to place participant welfare first and foremost.

> *"Should I have told the service manager how Mary is feeling? I'm feeling torn between the content of the interview being highly personalised and confidentiality being important. She is the only participant in the study using that particular service, therefore she would be immediately recognisable."*

Crucially, I did not ask Mary whether she would like me to inform the service manager of her views as I felt that was not the role of the researcher. I continued with the interview and did not explore this issue. However, I became concerned that Mary felt unsupported and also unsafe. It was clear she thought that something could happen to her and the service would not notice and thus not respond. There could be an issue around Mary's understanding of the purpose and remit of the drop in service. After the interview ended, I explained the remit of support provided to her and encouraged her to discuss her concerns with her keyworker. As a result of Mary's concerns around her support, in future interviews, I ensured I knew more about the support being accessed by participants and the purpose and remit of the support services.

I also need to try to keep a sense of perspective in that my main role is one of researcher and not nurse. It proved difficult to keep them separate, but I did ponder over whether separating the two roles was the right thing to do. The skills I have learnt in engaging with people as a nurse have been crucial in the interviewing process. What I do need to try to do is manage my concerns around the well-being of participants. It feels natural to care and be concerned as participants are living with a neurodegenerative condition, but at the same time, they all have support networks and families who can advocate on their behalf if required. Perhaps this is more about me missing my clinical role where I had the opportunity to build up a solid therapeutic relationship over months

and/or years. The following quote is an excerpt from my journal in July 2020 after writing up results.

> *"This reflection has taken me almost full circle. It's because of my skills and experience as a clinician that I've been able to interview participants and elicit in-depth personal information about their experience. However, at the same time, this has made the establishment of a therapeutic relationship with participants happen quickly, particularly over the 2 interviews, which in turn has increased the sense of loss of relationship I now experience as I will never see or speak to the participants again. The finality of the situation is difficult to contend with as I would like to know they are receiving the best support possible and living well with FTD. Knowing participants are safe and well is only possible in my previous clinical role—not in my current role as researcher."*

Hay-Smith et al. (2016) went on to identify the theme of over-identification with the patient and/or participant. All participants became emotional at points during the interviews and this was managed sensitively by me using my clinical skills. However, I felt emotional after interviews were completed as I found myself thinking and wondering how participants were coping with living with the degenerative aspects of FTD. I was aware I could not extend timeframes or boundaries but significant parts of my reflections/journal are taken up with thinking about participants. This over-identification with participants accords with the findings of Arber (2006) who discussed the issues surrounding closeness and distance between participant and researcher and extols the importance of taking a reflective approach. Goldspink and Engward (2019) spoke about identifying reflexive 'echoes' which are a mixture of the participant's and researcher's words and experiences that resonate with each other. They proposed that reflecting on and recognising such 'echoes' can add depth to the understanding and subsequent analysis necessary when using IPA methodology. Thus, I am left considering that identifying with participants (which caused me some emotional discomfort) has led me to reflect at a deeper level than I had done previously and whilst considered by me to be a negative experience (due to the ongoing concern regarding participants' welfare), I have

now been able to draw upon the findings of Goldspink and Engward (2019) to reframe the ongoing concern as a positive experience, in that this may have enhanced analysis of data and helped illuminate the experiences of participants in a more comprehensive way.

Additionally, Hay-Smith et al. *(*2016) identified a theme entitled the 'uninvited clinical expert', which is when researchers find themselves in a situation where they have 'automatically' used their clinical knowledge to identify concerns. However, my reflection went beyond the findings of Hay-Smith et al. (2016) in that discovering the importance of the theme of physical changes for all participants, I was aware that the issue of physical symptoms had not been adequately assessed or discussed in my previous clinical practice.

> *"Perhaps the starkest finding which has affected me personally and professionally is the extent to which participants have experienced physical changes as a result of having FTD. Throughout my nursing career I have been taught about, and researched, the psychological and behavioural aspects of FTD. Perhaps this is because these are the symptoms which cause people to have been referred to me as a clinician and services find most challenging. However, now I have discovered that for all seven participants the symptoms that affect their quality of life most are physical. I feel very upset that I did not pick up on this and although I know I did my best for patients at the time, finding out that I have missed asking about such a fundamental issue for people living with FTD in my clinical practice makes me feel I have missed important opportunities to have improved their quality of life."*

However, in taking on board the 'echoes' identified by Goldspink and Engward (2019) rather than focus on the aspects of my previous clinical roles which I now believe were left unexplored, I am able to take the findings of physical symptoms and potentially use these findings to improve current clinical support for people with FTD.

3.8 Conclusion

After consideration of a range of relevant qualitative research approaches, the idiographic nature of this study fitted well with the aim of exploring in detail the lived experience of each research participant using IPA (Smith et al. 2010; Smith and Osborn 2003). Therefore, IPA was selected due to its connection with the research aims of the proposed study, its compatibility with my worldviews and the approach influences how the findings are presented, explored and concluded.

This chapter has discussed how consideration was given to the study design and the relationship between ontology, epistemology and methodology. This chapter has also included a discussion on the importance of taking a reflective approach and developing reflexive strategies throughout the study. The study methods are discussed in Chapter Four.

Chapter 4 Study methods

4.1 Introduction

The previous chapter provided the rationale for a qualitative approach to understanding the lived experience of FTD and why IPA was an appropriate methodology for the study. This chapter will present the aim of the study; the process used to select the data collection method; issues around safeguarding and details of the data collection method; consideration of ethical issues and ethical approvals; access to potential participants and recruitment; participant demographics; the methods used to establish and gain consent; data analysis; and writing up of the thesis.

4.2 Study aim

This study aimed to explore and understand the experience of living with a diagnosis of FTD. To address the study aim, the following research questions were developed:

- How do people with frontotemporal dementia (FTD) describe their daily experience of living with FTD?
- What do people with frontotemporal dementia (FTD) feel helps and hinders them in living well with FTD?

I anticipated that the first research question would address the aim of the study by identifying the lived experiences of people with a diagnosis of FTD. The second question would help me understand the experience in the context of that individual's life and their ways of coping positively with FTD.

4.3 Method selection

Crotty (1998) emphasised the importance of the relationship between epistemology, theoretical perspective, methodology and methods when

designing a research study, which was discussed in Chapter Three. Although the IPA research process is iterative and inductive, the stages of the research process have been presented here in a more linear way to provide a clear understanding of the stages involved in the study from the selection of the data collection method, the participants involved in the study, the structure of interviews, transcription of interviews, data analysis process, to the writing of the first draft of the thesis.

4.4 Safeguarding and data collection method

Given the needs and potential vulnerability of participants, I agreed with the findings of Webb et al. (2020) who emphasised that the selection of data collection method should be flexible and safeguard the wellbeing of participants as far as possible. Therefore, a range of data collection methods was considered which have been used in previous IPA studies and included interviews (Clare 2002: Merrick et al. 2016; O'Shaughnessy et al. 2010; Van Dijkhuizen et al. 2006; Wawrziczny et al. 2016); focus groups (Phillips et al. 2016: Tomkins and Eatough 2010) and diary-keeping (Morrell-Scott, 2018).

Webb et al. (2020) recommended that research processes must not become disabling to people with dementia, therefore, the selection and application of data collection method need to be flexible to adapt to the needs of people with dementia. In this study, the decision to undertake individual interviews with participants as a data collection method as opposed to diary-keeping or focus groups was based on research evidence (Digby et al. 2016; Kendall et al. 2010; Novek and Wilkinson 2019; Pesonen et al. 2011; Pratt 2002; Webb et al. 2020) and also on my experience of supporting people with FTD. I had found that people with FTD could have difficulties coping with noisy environments and experience deficits in attention and concentration which would have made alternative methods such as focus groups or diary-keeping less suitable. However, being flexible to the wishes of individual participants within the IPA approach was felt to be important, therefore, it was acknowledged that participants may wish a carer or gatekeeper to be present during interviews, so

the decision was made to invite participants with FTD to individualised interviews with a carer or gatekeeper supporting them if they so wished. In aligning researcher needs with participants' needs, Smith et al. (2010) wrote that this adds to the robustness of the study and adheres to the principles of IPA. Individual interviews were felt to most likely meet the aims of the study in terms of entering the participants' worlds, but also safeguarded the participants as far as possible. By being flexible during interviewing, as well as fitting with the research aim, the interview data collection method facilitated close monitoring of the participant by the interviewer for any signs of distress and as an experienced nurse, I was able to respond immediately and effectively to such signs (Hellström et al. 2007).

4.5 Ethical issues and approval

A key consideration from the beginning of the proposal had been the possible impact of the research on participants and how to minimise the likelihood of creating distress. Having followed the criteria of several bodies to gain the research approval consideration was given to sensitive development of research questions; how to ensure the anonymity of participants; ways of ensuring ongoing consent processes; how to be open and honest regarding research goals; the need to be sensitive towards participants before, during and after interviews; and how to offer appropriate and sensitive debriefing (Hellström et al. 2007). All considerations were detailed in the ethical approval applications.

The study received University of Stirling General University Ethics Panel (GUEP) approval on 19th April 2017 (Reference: GUEP100) to recruit participants exclusively from the third sector. In the following 11 months, only two recruits were identified, therefore, I applied for ethical approval through the National Health Service (NHS). This involved me seeking ethical approval from the University of Stirling NHS, Invasive or Clinical Research (NICR) Committee (Reference: NICR 16/17–Paper No. 77). Full Integrated Research Application System (IRAS) ethical approval by NICR and the Research and Development

(R&D) Management was granted on 4th May 2018 (Reference: LR/AG18/ES/0003).

4.5.1 Ethical processes and consideration

Of fundamental importance to gaining ethical approval for the study was demonstrating clear procedures around the issue of establishing and gaining consent. Scottish law presumes that adults have capacity to make decisions for themselves and the Adults with Incapacity (Scotland) Act (2000) aims to protect people who lack capacity to make particular decisions. The process for establishing, gaining and reviewing consent throughout the study followed the guidance for social work and health care staff (Scottish Government 2008), the principles of the Adults with Incapacity (Scotland) Act (2000) and the process consent method for people who have dementia (Dewing 2007), which was developed in acknowledgement of the importance of empowering people with fluctuating capacity to participate in research whilst at the same time ensuring that safeguards are in place that are neither over nor under-protective. The process consent method was adhered to throughout the study and involves five elements.

The first element of the process consent method (Dewing 2007) considers background and preparation. Alzheimer Europe (2009) produced a report that highlighted the importance of providing appropriate and relevant information in written form to ensure as fully as possible that potential participants understood the information provided. The information sheets were developed following this guidance and took account of dementia-friendly principles (Appendices Four, Five and Ten).

Potential gatekeepers were identified by third sector managers. I ensured that information sheets, consent forms and the interview schedule were available to potential gatekeepers in advance of meeting them to give them time to read the material and consider participating. Thereafter, I met potential gatekeepers to ensure they understood the aim of the study; inclusion and exclusion criteria for potential participants; and their role in the study regarding recruitment and in

supporting clients during and after the study. I met with gatekeepers on more than one occasion. Only people who were considered by gatekeepers to be able to provide informed consent were approached. While working on the basis of presumed capacity, people who were known to lack capacity (where this had been assessed and documented), were not approached to participate in the research.

Furthermore, the Alzheimer Europe (2009) report explored issues involved in assessing a person's capacity to understand the information provided. Several studies have highlighted that people with dementia do not always fulfil the criteria for informed consent due to not understanding the information provided, forgetting the information, and poor ongoing understanding (Agarwal et al. 1996; Buckles et al. 2003; Cacchione 2011; West *et al*. 2017). However, each aforementioned study emphasised the importance of people with dementia being included in research and the need to employ strategies that maximised participation as a vulnerable group in an under-researched area. Potential participants were informed as to how to approach gatekeepers or me to ask questions before they decided whether to take part in the study. All interested potential participants gave their consent to gatekeepers to forward their contact details to me.

The second element of the consent process (Dewing 2007) is concerned with establishing the basis for consent. The method requires the researcher to consider in detail the person's usual self-presentation; their usual level of ill-/well-being; how a decrease in well-being may be triggered; how any decrease in well-being can be recognised; any significant conversation or behaviour that may indicate a need for psychotherapeutic intervention; and how the person usually consents to other activities. All the aforementioned elements were taken into account by gatekeepers before approaching potential participants.

Although several tools have been developed to assess capacity (Appelbaum and Grisso 2001; Dunn et al. 2006; Jeste et al. 2007; Kim *et al*. 2001), formal assessment of capacity was outwith the remit of the gatekeepers and researcher. However, as a researcher, I adhered to the principles of capacity

assessment to identify and prevent stress and distress in participants. Gatekeepers were able to provide information as to how best to recognise any aspects of an individual's verbal or non-verbal communication that may indicate distress. Throughout the interviews, I monitored participants for signs of fluctuating capacity and distress.

The third element of the process consent method (Dewing 2007) considers initial consent. Before interviews commenced, I explained the study to potential participants and answered any questions. As an experienced clinician, I was able to gauge the participant's ability to understand the information and whether they met the inclusion criteria. One potential participant was referred whom I considered lacked capacity to understand the process and was deemed ineligible for inclusion in the study. As for the participants who were able to provide informed consent, I asked them to read the consent form and sign and date the form (Appendices Seven and Eight). I then explained that, should they change their mind about being involved in the study at any point, they were able to leave with no changes to the support they received.

The fourth element ensures that the focus given to initial consent was maintained throughout the study. Capacity can fluctuate and someone who may have been considered able to consent at the start of the study may become less able during the interview process. If at any point, the participant demonstrated any signs of confusion, the interview would be stopped and I would seek to ensure that the participant still met the inclusion criteria. As a registered mental nurse, I used my communication and assessment skills to pick up on changes in capacity or distress based upon the guidance from the Scottish Government (2000) and the guide for social work and health care staff (Scottish Government 2008).

Three participants became upset during the interviews. I asked whether the participants wanted a break and assessed whether they still met the inclusion criteria. No participants were found to lack capacity to consent at any time and the three participants who became upset all stated they wished to continue with

the interview. They were offered follow-up support from managers of services they accessed.

Should it have become apparent during interviews that a participant who had given informed consent appeared to lose capacity to consent, I would have withdrawn the participant from the study. Any non-identifiable data already collected with consent would be retained and used in the study but no further data would be collected. This process follows the guidance from the Scottish Government (2000) and the guide for social work and health care staff (Scottish Government 2008) which both acknowledge that capacity to consent may fluctuate.

The fifth element involved feedback and support. Feedback was provided to participants twice, after the transcription of interviews and one year later, via letters summarising the progress of the study (Appendix Nine). Participants and gatekeepers had my contact details and could contact me at any time. One participant telephoned asking for an update which I provided.

I discovered that support immediately following interviews was required. Once the interviews finished, participants would often continue to talk about living with FTD and begin to ask questions about the condition. I answered the questions to the best of my ability and signposted participants to relevant sources of information and support. I reflect upon this in Chapters Three and Six.

4.6 Participant access and recruitment

Recruitment involved contacting third sector organisations directly and adhering to their processes. Following all necessary ethical approvals being granted, the third sector research managers approved the study and I made contact with two branches of one organisation on the suggestion of the research manager who provided specialist support to carers of people with FTD or services for younger people with dementia. I also contacted one branch with whom I had worked collaboratively in a previous clinical role (Polit and Beck 2013).

The third sector organisation research manager identified three staff as appropriate gatekeepers. I contacted them, arranged to meet, and provided information about the study (Appendix Ten). As the service managers were known to service users with a diagnosis of FTD, managers agreed to make initial contact with potential participants. I provided managers with information and inclusion and exclusion criteria for the study and asked them to identify potential participants (Table 4). To ensure that managers were aware of their role, I provided them with an information sheet and answered their questions about the study (Appendices Four, Five and Ten). The managers were provided with participant information sheets to disseminate to potential participants (Appendices Four and Five). Managers distributed the information sheets (Appendices Four, Five and Ten) to potential participants who met the inclusion criteria.

Table 4: Participant inclusion and exclusion criteria

Participant inclusion criteria	**Participant exclusion criteria**
• People with a diagnosis of Frontotemporal Dementia or a subtype of Frontotemporal dementia provided by a consultant psychiatrist, consultant neurologist or consultant psychologist	• People who have not received a diagnosis of Frontotemporal Dementia or a subtype of Frontotemporal dementia provided by a consultant psychiatrist, consultant neurologist or consultant psychologist
• People who can communicate verbally and are able to discuss their thoughts	• People who cannot communicate verbally and are not able to discuss their thoughts
• People who can speak English	• People who cannot speak English
• People who are able to provide informed consent	• People who cannot provide informed consent

People consenting to share contact details with me were given two weeks to consider the implications of taking part. They were able to ask managers questions and reflect on whether to take part or not. Potential participants who

indicated an interest in taking part were contacted by me and an initial meeting arranged to discuss involvement in the study. Interested individuals were aware that I was available to speak to or meet with family members or unpaid carers to discuss any issues or questions.

During interviews, family members, staff or another person were present if requested by the participant. The role of the family members, staff or another person was as a supportive observer. However, as it was anticipated they may contribute to the discussion, a consent form was developed for supportive observers (Appendix 11). One participant was interviewed twice with their support worker present and one participant was interviewed once with his wife present. Having a support worker present was found to be reassuring for the participant as they stated they were slightly anxious about being interviewed by a stranger and wanted someone who knew them well to be present. Although one advantage of having the support worker present was that the support worker was able to prompt the person about particular events pertaining to the topic being discussed, I did feel that on one occasion the presence of the support worker and their recollection of events may have inhibited the person from discussing their deeper feelings. However, participants needed to be able to have someone supporting them if they felt that was desirable and helped them to be more at ease during the interview process.

Two potential participants indicated that they would like to participate and were interviewed in June/July 2017. In the following five-month period I telephoned and e-mailed the services I had permission to contact in the third sector and attended meetings with managers and one FTD carers' support group in Greater Glasgow and Clyde to try to recruit more participants. Although the carers of people with FTD were enthusiastic about the study, their family members could not consent to be interviewed. However, I maintained regular contact with the staff member facilitating the group and one further recruit was identified and interviewed in January/February 2018.

Following receipt of full ethical approval from the East of Scotland Research Ethics Service (Eo*SRES*) on 26th January 2018, I tried to recruit via the NHS.

Recruiting from the NHS was problematic in that, as a non-NHS employee, I had to complete a research passport document asking me to specify a manager within the NHS sites from which I wanted to recruit who was willing to oversee the study. The sites identified were NHS Fife, NHS Tayside and NHS Greater Glasgow and Clyde. The rationale for selecting NHS Fife and NHS Tayside was pragmatic in that I had contacts in both sites who were willing to be the named manager on the research passport and sites were within travelling distance. The rationale for including NHS Greater Glasgow and Clyde was that it had the largest population from which to recruit. After months of liaising with NHS Greater Glasgow and Clyde Research and Development Department and specialist older adult psychiatric clinic staff, I was unable to identify anyone to name on the research passport, therefore, recruitment in NHS Greater Glasgow and Clyde was not possible. This was unfortunate as I was contacted by a person with a diagnosis of FTD who wished to be interviewed, was not known to the third sector organisations, but lived within the NHS Greater Glasgow and Clyde area, and who I was unable to recruit to the study.

Consultant psychiatrists of old age in NHS Fife and NHS Tayside were provided with information sheets to distribute to potential recruits but no participants were identified. In January 2018, one person was successfully recruited from the third sector. I contacted another third sector organisation again and asked for permission to contact a service in the Forth Valley area with whom I had collaborated previously. This resulted in one more person being recruited. Due to the problems in recruitment, I contacted another dementia specialist project in Forth Valley that had helped with the consultation and development of the interview schedule and participant information sheets. This service was managed by Social Services who required evidence of the University and NHS ethical approvals to approach service users regarding the study. The service re-introduced me to two people with a diagnosis of FTD who took part in the consultation group who were then recruited to the study and interviewed in March 2018. One further person was recruited through the third sector who was interviewed in September 2018. By September 2018, seven participants had been recruited to the study through the third sector and Social

Services culminating in a total of 13 interviews. Although the NHS REC ethical approval had been necessary in order to recruit from Social Services, no participants were recruited directly from NHS Scotland. The difficulties in recruitment significantly extended the timeframe for data collection.

4.7 Data collection

As identified in section 3.2, a qualitative study design was selected. Due to the sensitivity of the study aim and research questions, I wanted to include people with dementia in the design of the information sheets, consent forms and interview schedule, with the aim that all information would be developed collaboratively; be understandable for people with dementia; ask relevant questions, and as far as possible not lead to any distress for participants (Scottish Dementia Working Group Research Sub-group 2014). However, finding an established group of people with FTD in Scotland was not possible, therefore, I contacted a service for people with early-stage dementia, with whom I had previously collaborated, to ask if they would be interested in co-designing and reviewing the interview schedule, consent forms and participant information leaflet (Gove et al. 2017; Walsh and Griffiths 2020; Wang et al. 2019). Changes implemented after consultation included the alternative ordering of questions on the interview schedule and ensuring adherence to dementia-friendly principles regarding written information (DEEP 2013; Gove et al. 2017; Waite et al. 2018; Walsh and Griffiths 2020; Wang et al. 2019).

4.7.1 Establishing an interview process

In addition to the consultative group co-producing the information sheets, consent forms and interview schedule, in the second meeting I sought the views of the group regarding the number of interviews per participant. Four of the six members felt that multiple, shorter interviews were preferable to one longer interview due to the issues they had personally experienced with reduced attention, concentration and short-term memory problems (Calman et al. 2013; Flowers 2008; Kipps et al. 2010: Snelgrove 2014). At this point, the two other members of the consultative group disclosed that they had a

diagnosis of FTD and that, unlike the other four members, short-term memory loss was not a big issue for them. However, they both felt strongly that multiple shorter interviews would be preferable to one longer interview. Their preference for shorter interviews was based upon their own experiences of having difficulties with attention and concentration. They also agreed with the findings of Reid (2018) in that meeting with the interviewer more than once might help them feel more at ease with the interviewer and facilitate talking openly about their experiences. Therefore, during the second consultation, the decision was reached by the group that each participant would be asked whether they would prefer one longer or multiple shorter interviews.

Demographical information regarding participants can be found in table five. There were seven participants in total consisting of five men and two women with an age range between 52 and 68 years of age. The time elapsed at interview from time of diagnosis ranged from two months to six years. Six participants described themselves as White Scottish and one as White Irish. All participants lived with a family member who provided significant support. Three participants stopped paid employment prior to receiving a diagnosis and four participants gave up paid employment upon receiving a diagnosis of FTD.

Of the 13 completed interviews, six participants took part in two interviews. One participant only took part in one interview as I felt that a second interview may have the possibility of creating distress. Participants chose the location of interviews with 11 interviews taking place in the participants' homes and two in private rooms in care facilities they attended. The mean duration of interviews was one hour and seven minutes but ranged from 50 minutes to one hour 19 minutes. The timings between the two interviews was agreed between the participant and myself and ranged between seven and 19 days taking account of participant's prior arrangements. The time elapsed between interviews allowed for transcription of the first interview before commencing second interviews.

4.7.2 Tape recordings and transcription

It is widely acknowledged in the literature that immersing oneself in the data through transcribing audio interviews verbatim can provide the researcher with a deeper understanding and awareness of the data (Bryman 2008; Chambers and Loubere 2017; Halcomb and Davidson 2006; Smith et al. 2010). At each interview, consent was obtained verbally and in written form before interviews commenced and were recorded using a digital voice recorder. Codes were generated at the beginning of interviews to ensure participant anonymity. The codes were used throughout the process so each transcript could be identified as to where the quotes had come from. This approach maintained confidentiality but also added to the transparency, rigour and robustness of the findings (Creswell 2014).

The interviews were transcribed verbatim by myself and included the input of participants, any support person or observers who were present, and me. All gaps or pauses were documented with notes taken of any interruptions or difficulties with external noise. Every transcription was identified with the participant code, with all lines of the transcription numbered and left and right margins utilised with spacing to ensure room for a working document containing three levels of analysis as required when using IPA and documented in Section 4.8 (Smith et al. 2010). However, as I began to work with the transcriptions, I added a pseudonym to each code as this felt more person-centred and in keeping with the idiographic element of IPA (Smith et al. 2010). The data protection policies of NHS Tayside, NHS Fife and the University of Stirling were adhered to keeping data for 10 years.

4.8 Data analysis

Data analysis within an IPA study involves a set of common processes to be applied flexibly by the researcher. As a novice researcher, I followed the analytical stages as described by Smith et al. (2010). The stages of data analysis are presented here in a linear style. However, it is important to note that the process was cyclical and involved me re-reading and re-examining

transcriptions and ongoing refinement of emergent themes up to and including the writing up stage (Smith et al. 2010).

I began by immersing myself in the data by listening and listening again to the audio recordings before attempting transcription. This provided me with a context within which I could locate particular comments. Once I had completed transcribing each interview verbatim, I commenced a close, line-by-line analysis of the data including the concerns and experiences as stated by the participant and how participants made sense of them. The analysis involved a three-stage approach: identifying the concerns and experience expressed; becoming more analytical about how the participants were making sense of their concerns and experiences; making notes regarding the terminology used or patterns noticed in language or pauses (Appendix 12). This process was carried out for each interview culminating in a list of emergent themes for each interview. Where participants had been interviewed more than once, their interviews were analysed separately initially and emergent themes generated separately. This decision was made because it was evident from the listening and re-listening stages through to the development of emergent themes that similar and different themes emerged from the two interviews. However, during the stage of cross-referencing the emergent themes from each interview were developed into superordinate themes, subordinate themes and themes Appendix 12). This process of refinement carried on throughout the study culminating in the development of a master table of themes (Table 6).

The organisation of the data and analysis allows others to follow the process from transcription through to writing up. The combination of probing further at the second interview using notes from the first interview ensured I had an enhanced understanding of the meaning of the content of the first interview with participants. The supervision from my supervisory team concurred with my analysis of transcripts; the coding framework; and the development and refining of themes was overseen by an IPA expert. The involvement of participants, supervisors and an IPA expert ensured the coherence and plausibility of my interpretation. The analysis culminates in a reflection upon my own perceptions, conceptions and processes (Smith *et al*. 2010).

4.9 Writing up

Smith et al. (2010) stated that writing up an IPA study should be creative but offered suggestions as to how to begin writing up. Their first suggestion was to move straight from analysis to writing the results section to maintain momentum. I found following this advice not only helped me maintain momentum but resulted in analysis continuing throughout the writing up of the results section producing a deeper interpretation of the narratives and subsequent refinement of themes. This process resulted in multiple drafts being written and stored.

Smith et al. (2010) state that the writing up of an IPA study is the most important part of the study. Therefore, it was imperative that the findings chapter explained to readers the key findings and provided a comprehensive and systematic account of the process. The rigour and quality criteria for the study were discussed in section 3.6. However, Donovan and Saunders (2002) report that as well as the quality of research being illustrated through the rigour and transparency of the methods used for data collection and analysis, attention must be given to the plausibility of the findings. As per Smith et al.*'s* (2010) guidance, sections 5.3.1 to 5.3.4 inclusive contain excerpts from the transcripts and a detailed analytical interpretation of the excerpts.

The results section starts with a table consisting of four superordinate themes; subordinate themes and emergent themes. The master table provides the reader with an overview of the chapter content. Each theme is explored in turn with excerpts and analysis provided. I followed the guidance of the key authors of IPA (Smith et al. 2010), in refining throughout the writing process and including some extracts taking on more prominence requiring fuller presentation and exploration. In producing several drafts of each theme, the analysis subsequently deepened and became more interpretative.

4.10 Conclusion

This chapter explored the aim of the study; the process used to select the data collection method; safeguarding and details of the data collection method; ethical issues and ethical approvals; access to potential participants and recruitment of participants; participant information, methods used to establish and gain initial and ongoing consent; data collection; data analysis; and the writing up of the thesis.

To conclude, I have followed the process outlined in this chapter and used semi-structured interviews and IPA methodology. The choice of semi-structured interviews and IPA methodology was the most appropriate method to address the research aim of understanding the lived experience of people with FTD and generated rich data from the person's perspective. Chapter Five will present the study findings.

Chapter 5 Findings

5.1 Introduction

This chapter describes the results of the data analysis and presents the findings, including the presentation of a framework developed to depict an understanding of the lived experience of FTD. Following an IPA approach, I have separated the discussion from the analysis (Smith et al. 2013). Thus, this chapter provides a detailed representation of what participants said during the interview. The discussion of findings regarding current literature, conclusions and recommendations for practice and research are presented in Chapter six. Seven participants have provided excerpts that will be used to demonstrate four superordinate themes. To provide context, demographic information is presented in Table 5.

Table 5: Participant demographical information

Pseudonym	Gender	Age	Ethnicity	Living Status	Employment Status	Time since diagnosis	Number of Interviews	Location of interviews	Length of Interviews	Timing Between interviews
Jim	Male	59 years	White Irish	With wife	Retired pre-diagnosis	2 years	2 (both with support worker as supportive observer)	At home	Interview 1: 52 minutes Interview 2: 1 hour 10 minutes	9 days
Mary	Female	53 years	White Scottish	With mother and sisters	Stopped working on receiving diagnosis	1 year	2	At home	Interview 1: 1 hour 18 minutes Interview 2: 1 hour 14 minutes	9 days
James	Male	67 years	White Scottish	With wife	Retired pre-diagnosis	2 months	2	At home	Interview 1: 53 minutes Interview 2: 50 minutes	13 days
John	Male	60 years	White Scottish	With wife and adult child	Stopped working on receiving diagnosis	3 years	2	Interview 1: At day care facility Interview 2: At home	Interview 1: 1 hour 18 minutes Interview 2: 1 hour	7 days
Norma	Female	68 years	White Scottish	With husband	Stopped working on receiving diagnosis	6 years	2	At home	Interview 1: 1 hour 18 minutes Interview 2: 1 hour 15 minutes	7 days

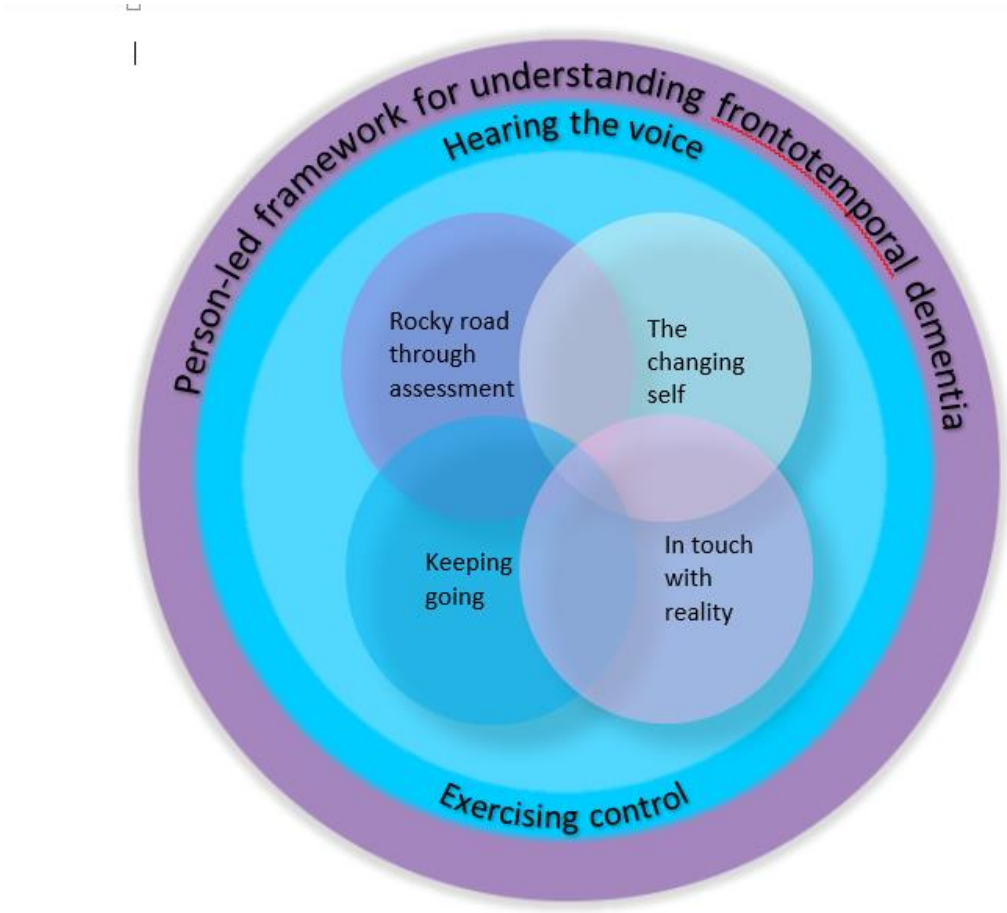
George	Male	68 years	White Scottish	With wife	Retired pre-diagnosis	3 years	2 (first with wife as supportive observer)	At home	Interview 1: 1 hour 3 minutes Interview 2: 1 hour 6 minutes	19 days
Sean	Male	52 years	White Scottish	With Adult child	Stopped working on receiving diagnosis	18 months	1	At day care facility	Interview 1: 1 hour 19 minutes	n/a

5.2 Living with a diagnosis of FTD: A person-led framework for understanding the experience of FTD

A framework is presented below to illustrate the findings of this study (Figure 1). Within the framework, the complexity, dynamism and interconnectedness of themes are captured. The themes are the rocky road through assessment; the changing self; in touch with reality; and keeping going. Each theme contains a number of subordinate themes and emergent themes. Two overarching themes of hearing the voice of the person with FTD and the person being able to exercise an element of control during their journey are found throughout the four superordinate themes.

As the current literature and research surrounding FTD predominantly represent family caregivers' or professionals' perspectives, as explained in Chapter Two, a framework has been developed to illustrate the perspectives and experiences of the person living with the diagnosis of FTD and the complexity, dynamism and interconnectedness of the themes which are experienced separately or together at different points during their journey. In order for the person to be heard, the person as far as possible must be empowered to exercise control in decisions made about their care and support throughout their journey. This is reflected in the use of a Venn diagram which demonstrates how the themes may remain separate or overlap with others. This framework will be discussed further in section 5.2.

Figure 1: The person led framework for understanding the experience of FTD



5.3 Findings: Themes

The themes from the data analysis are presented in Table 6.

Table 6: Master table of themes

Master table of themes			
Overarching themes	**Superordinate themes**	**Subordinate themes**	**Emergent themes**
Hearing the voice Exercising control	Rocky road through assessment	Something amiss	Seeking explanations
		Impact of assessment	A hidden disease
			Taking control
	The changing self	Sense of self	Holding on
			Feeling different
		Roles and relationships	Shifting responsibilities
		What I need to be me	Becoming me again
	In touch with reality	Insight and awareness	Recognising changes
		Thoughts, beliefs and emotions	Fluctuating feelings
			Emotional shifts
		Living with FTD	Symptoms that challenge
			Physical changes
			In the moment
	Keeping going	State of mind	Fighting FTD
		Strategies for living	Slowing down
			Living day to day
		Someone there	Experiencing support
			Needing others

The themes are described below and include verbatim quotes from participants with pseudonyms to preserve anonymity. The actual names of participants are only known to the researcher with pseudonyms used on transcripts.

5.3.1 Rocky road through assessment

Seven participants in this study spoke about their experiences of the rocky road through assessment which included receiving a diagnosis of FTD and an awareness that something was amiss. The feeling of something amiss was attributed to the experience of symptoms of which participants could not make sense. Although most participants went on to seek medical assessment, perplexing symptoms led to some participants being reluctant to seek diagnosis and for one participant, trying to hide symptoms from family members.

Something amiss

All participants had an awareness that something was amiss because of changes to their abilities and behaviour with six participants suspecting they may have dementia. This awareness is exemplified in the following quote from Norma who, prior to diagnosis, was making multiple mistakes at home and work. The quotation illustrates the disparity between what Norma thought she was capable of doing and what she had done. Here Norma explains how she tried to make sense of the changes in her ability that she was experiencing and her awareness that something was causing her forgetfulness.

> *Norma: I just thought, yeah I just thought, what what is going on in my head that I can't remember this and like one of the managers, I actually got pulled up, and this is when it sort of you know I thought, maybe there is something wrong with me ... but but eh she says I I got pulled up and I had to go through retraining when you know I'd been the manager for years [laughs] (Norma, Interview 1, page 6).*

For seven participants, the pre-diagnostic symptoms they described included noticing changes in their work performance. However, George and Norma also spoke about a loss of ability to cope with challenging situations generally and increased levels of anxiety. In Norma's case, she described a situation where she was being provoked in a pub. This quotation conveys her feeling of shock and fear at her behaviour and disbelief that she had behaved in such a way.

> *Norma: oh my God, it sounds terrible ... I I, I had said nothing and I just totally freaked out and I actually head-butted him so hard that I knocked him unconscious and I'm like afterwards again I'm like, oh my God, I'm going to get locked up. Em, and I'm, where is this coming from? ... I I really ... I mean that did totally scare the living daylights out of me. (Norma, Interview 1, pages 14–16).*

The changes participants were experiencing in ability and behaviour led to Sean and George trying to hide symptoms and avoid seeking diagnosis. Whilst

most participants went on to seek medical assessment independently, Sean and George were confronted by family and then sought an explanation.

Seeking explanations

Five participants independently sought a medical explanation for symptoms. However, for Sean and John, seeking diagnosis was prompted by family members who had noticed changes in behaviour and ability. Of seven participants, three speculated they might have dementia due to a family history of dementia. Mary found herself comparing her symptoms to those of others and knowing deep down she had dementia.

> *Mary: I had been looking for an answer as to the reason I was feeling the way I was feeling, to be honest, I'd probably made up or deduced myself that I'd some form of that (dementia) because I've seen relatives with whatever and it's not that I was mimicking what they had. (Mary, Interview 2, page 8).*

Six participants discussed the difficulties associated with receiving a diagnosis and could comprehensively recount receiving their diagnosis of FTD. Several participants spoke about difficulties in comprehending the diagnosis of FTD. In the following account from Sean, this excerpt illustrates how his priorities at the time of diagnosis may have inhibited him from taking on board information. Rather than understanding the disease process, the focus for Sean is the impact upon working life. However, the professionals' focus at the time of diagnosis appears to have been to provide information regarding the disease process. The following excerpt illustrates Sean's focus upon the need to continue to work and may provide an explanation as to why all participants had difficulty in retaining the information received at the time of diagnosis.

> *Suzanne: Em ... you mentioned that, it sounded as if you'd lost your job quite suddenly when you got the diagnosis.*
>
> *Sean: aye, the next day ... but obviously when Dr [name] said it was dementia and then ... so I was on the sick so really it was not really until the next day if you know what I mean. It was just that they had told me it was*

dementia then they told me it was like the frontotemporal blah blah blah and I said about work, and he said no. You could work but ... you cannot go back onto building sites. (Sean, Interview, pages 35–36).

Six participants spoke about their lack of knowledge about how FTD might affect them in the future, which led them to experience a range of emotions and uncertainty as to the impact of FTD upon their lives. No participants were familiar with FTD and all felt unsure about the information received. However, despite seven participants demonstrating levels of awareness regarding the prognosis of FTD, some excerpts highlighted a sense of confusion, which led to participants seeking more information about FTD immediately following diagnosis. On receiving the diagnosis of FTD, the following excerpt from Norma illustrates the belief that dementia is a disease that affects older people.

Norma: em and I really, I just laughed at her. I said it's old folk who get that (Norma, Interview 1, page 8).

The journey to receiving a diagnosis was a difficult and stressful time for several participants. However, each individual's reactions to receiving a diagnosis of FTD were based upon their existing knowledge base and beliefs about dementia. This led to varying degrees of confusion about FTD and people seeking further information. All participants had some basic knowledge about dementia but not FTD. Sean explains how his knowledge of dementia was based upon media portrayals of people in the later stages of their journeys.

Sean: I thought if you had dementia you were a ... cabbage basically, basically. I didn't know, I thought you see it on the telly, you see people with dementia and they sit on a chair and dribble. (Sean, Interview, page 1).

Several participants commented on the lack of written information provided at the time of diagnosis. Here, Mary demonstrates how she was given limited information at diagnosis and left to refer to websites suggested by her consultant.

Mary: em, I had actually never heard of it until I was given the diagnosis. And it was only through what my consultant had said or the information sheet he had given me and wrote a couple of different websites on them for me to get a bit more information about it. (Mary, Interview 2, page 2).

George explained that he had chosen not to seek information about FTD. However, he asked me for information about FTD during the second interview. There was a sense that George desired some information but had been reticent to ask previously.

George: I've never asked anybody. I just want to get on. Not that I'm frightened of the answer or anything like that. No, I just don't know. I've never looked it up or anything. No, what is the difference? (George, Interview 2, page 73).

Several participants discussed the rate of progression of the disease process. John talked about seeking information about the rate of progression in FTD. Jim demonstrated his awareness of the prognosis but his belief that his progression has been slow. John is aware of changes to his thinking, how he does things, and his processing. He goes on to discuss changes he has noticed such as becoming side-tracked during conversations. The following excerpt illustrates James's concerns over a diminishing quality of life which seems significant for him given the repetitiveness and hesitancy contained within the excerpt.

James: em, but I suppose what I'm saying is, is that you know if, if this continues to develop and get worse then you know then it is a a a a, it would, it would certainly diminish my quality of life if I wanted to do that (James, Interview 2, page 25).

In summary, all participants discussed their own notion of how dementia might affect them. Rather than base their notions upon information or explanation given at the time of diagnosis from health care professionals, participants' notions were mostly based upon their own experiences of others having

dementia or from the media portrayal of people at the end stages of their journey. There appear to be two issues: diagnosis requiring to be personalised to attend to the needs of the individual; and issues surrounding the access to and quality of information about FTD which would be of most use to people going through the diagnostic process.

Impact of assessment

Section 5.3.1 identified issues participants experienced having received a diagnosis of FTD. In this section, the impact upon the individual of assessments will be explored. Participants discussed their experiences of undergoing a battery of psychological tests concerning diagnosis; occupational health checks at work; fitness to work assessments; eligibility for state benefits; and driving assessments. Participants' confusion regarding FTD was compounded due to multiple assessments reaching conflicting decisions or not reflecting their experience of living with FTD. There is a strong thread running through all themes of the need for the person to have an element of control, however, in this section, the notion of control will be explored regarding multiple and conflicting assessments and results that do not reflect the participants' lived experience.

John and George highlighted the negative psychological effects of being formally assessed for FTD. They both experienced frustration over the repetitiveness of testing and feelings of being 'set up to fail'. This resulted in them fearing ongoing assessments and lowered self-esteem. A particular difficulty was when John's test results appeared to improve over time which resulted in him trying to minimise how well he had tested to protect himself from believing he was recovering. George identified doing well in tests as being problematic in that when he performed well on testing, the professional would tell him he was doing well. George then found himself becoming angry with the professional as he knew inwardly he was struggling with the task at hand which, before having FTD, he would have been able to perform to a higher standard.

George: they all kept saying the same thing. They're all saying "well done. Oh, well done. Oh well done, you're fast". And I just blew up when X [occupational therapist] said that. I says "I've not done well. I know what I was capable of before I done this". I says "It's not well done, you passed". I says "I know I've changed, I know my mind's changed. I can't do these sums. I cannot remember the name and places that you", you know they ask you the street and stuff like that. I says "I cannot remember that. I could have reminded that no bother before. It was part of my job to remind what streets and folk's names are. It's part of my, it's part of my remit and jobs and I cannot do it now ... cause that's when I said "listen, I'm not right. It's not right". (George, Interview 1, page 67).

The issue of George and John being told they are doing well when they are aware that their previous abilities had been much higher is reflected in other participants' narratives when they find themselves receiving conflicting advice from professionals carrying out assessments.

Four participants experienced receiving conflicting advice from various professionals, different services and employers following assessments. Mary, Sean, George and Norma all discussed receiving conflicting advice regarding their ability to continue to work and their entitlement regarding state benefits. This issue is demonstrated in the following excerpt from Mary who is talking about how she felt about her experience of being assessed regarding her fitness to work despite an earlier assessment by a consultant psychiatrist stating she was unable to return to work.

Mary: and I I suppose I felt really penalised I, you know for being, I've always been a healthy, active person. So because I might look healthy they think you're fit to work and when I spoke to Dr [name] he was quite annoyed, em, and thankfully because of a letter he wrote or report he wrote, em because in-between times I'd been sent for assessment at different places ... and I was rejected, and it was then, I think it was maybe after the second rejection that I, Dr [name] wrote the letter. So before I went to tribunal, em it was then I eventually got a letter to say it won't be going to tribunal and we're sorry

blah blah blah it will be more favourable for you. Then I got told I'd to go for a meeting, a statement meeting... (Mary, Interview 1, pages 28–29).

The issues identified around multiple assessments by several agencies and the subsequent conflicting advice resulted in four participants experiencing emotional distress, financial disadvantage and missed opportunities for accessing support to continue working.

Three participants discussed the impact of driving assessment on their lives. George and John spoke about feeling confused over their ability to drive as their abilities appeared to fluctuate. John received conflicting information from a qualified driving instructor as compared to the assessors at the driving assessment centre. John and George demonstrated high levels of awareness of potential safety issues around continuing to drive and both voiced concerns over causing an accident. This led to George stopping driving immediately upon receiving a diagnosis of FTD. However, he was formally assessed and started to drive again. Both George and John identified that they felt they were 'forced' to compromise regarding their driving ability.

John: Now when I was diagnosed with they were not really happy with me driving. Still had my licence. Now, to to sort of, em, dampen down their reactions I said right I'll stop driving myself ... I'll drive with Gwen [wife]. On a few occasions I've driven myself and I said right just to keep you munching my head right, I'll I'll do that. I wasn't happy with it. (John, Interview 1, page 15).

This section has identified and discussed participants' experiences of medical and non-clinical assessment. The conflicting advice received by participants from different assessments was significant difficulty in terms of employability and driving and caused high levels of distress for several participants. The next sub-section explores the confusion participants experienced in terms of the challenges of living with FTD following assessment.

A hidden disease

A difficulty raised by four participants was the 'hidden' nature of FTD and how this impacted upon telling others about their diagnosis and taking control of their journey. In the following excerpt, Sean discussed how the invisibility of the disease to onlookers and the lack of medical treatment compounded his difficulties in explaining FTD to others.

> *Sean: when you sit and think about it. It's when you sit and fucking, it's a cruel fucking illness cause you canny see it, it's no like cancer. They canny cut it out. Or they canny give you that fucking radiation stuff. Canny give you that. There's nothing for it. They'll maybe give you a wee pill that'll maybe slow it down but that's it. (Sean, Interview, pages 54–55).*

However, telling others about their diagnosis helped all participants come to terms with their diagnoses and exercise control in how to live positively with FTD. Several participants discussed to whom they had chosen to disclose their diagnosis. Here Norma reveals she has chosen not to disclose her diagnosis to anyone but her family circle.

> *Norma: I just tell, well, I I I told all my family. They, they all know obviously, eh, and really that's the only kind of ones that know. (Norma, Interview 1, page 48).*

The hidden nature of FTD is a factor that influenced John's decision as to whether to disclose his diagnosis of FTD. He explained the incongruity between how he is and how others see him and the incongruity between how he appears to function to other people and his awareness and knowledge about the prognosis of FTD and how this affects him internally. The following excerpt describes a comment made by care staff at a day care facility he attends.

> *John: I've had people saying, I said well there's no much wrong with you and they've said well there must be if you're in a place like this. [laughs](John, Interview 1, page 31).*

John continues by reflecting upon how the issue of incongruity makes him feel.

> *John: I know that for a fact because I've been on more than a few occasions I've been asked if I'm actually working in the premises that I'm there to use [laughs] as a user [laughs... it makes, it makes me feel I shouldn't be here then... you know I've... You know, am I am I pretending this? [laughs] Is this an act? But it does, it does go through your mind ... (John, Interview 1, pages 37–39).*

The above excerpt illustrates John's awareness of how he is being perceived and judged by others. There is a sense of John trying to maintain his sense of self in terms of retaining his sense of humour, whilst at the same time attempting to explain the incongruity between his appearance and behaviour to others. All seven participants' interviews contained the notion of FTD feeling like a hidden disease.

Norma described the effort required in not only explaining what FTD is to others, but guiding them as to how best to communicate clearly with her. There is a sense that in disclosing her diagnosis, people view her differently and interact with her less satisfactorily.

> *Norma: some of them "oh" and they they totally change in the way they speak to you. Where you know I'll I'll I'll tell them off. Why why are you speaking to me like that? ... [sighs] like they talk to me like em, they slow their words down ... sometimes I will say to them 'look, I I don't understand what you're talking about so you'll need to put it into simple terms for me that I can understand", but most of my family and that know anyway so. (Norma, Interview 1, pages 46–47).*

The difficulties participants identified in understanding FTD impacted upon who they disclosed their diagnosis to; their ability to explain the disease to others; and a fear of people not understanding the incongruity between how one presents and the symptoms experienced. The next sub-section will explore the need for participants to exercise an element of control throughout their journey.

Taking control

Seven participants spoke about the need to come to terms with their diagnosis of FTD to take back some control of their lives. Sean identified the need for each individual to find their own way to come to terms with the diagnosis. During his interview, he spoke about his journey from denial at the time of diagnosis as a process of coming to terms with the diagnosis and now taking back control.

> *Sean: I could sit here and say to you like when they told me I had a dementia I went, oh right, I've got it. I didn't. I said that at the time aye, but it killed me inside. It just fucking annihilated me inside ... to sit there and think I'm going to be a vegetable next week. Cause that's what you think dementia is, you think I've got that, I'm, but when they tell you, I don't know, it's ... I kind of done that and then I thought no ... about, not 10 minutes later, no I mean, I cannot have it. I've not got it. But you need to accept it. (Sean, Interview, page 62).*

Sean also spoke about feelings he experienced initially after diagnosis but went on to take a more active role in living with FTD. From initially feeling defeated, Sean explains that by taking control of his thoughts and attitudes and finding out more about FTD it becomes possible to live more positively.

> *Sean: so I'm as well just getting on with it. Mean, fair enough at first I was, I was depressed I'll tell you that I was, I just sat in the house and thought what's the point? What's the point of living? If I don't know how long I've got. This was before I found out more about it ... s, so I went into a kind of bummer then until, not until they told me, until I said, no – I'm not doing this, I'm not sitting about, I'm not letting the fucker beat me. (Sean, Interview, page 21).*

Conversely, Norma maintained that dwelling upon receipt of a diagnosis has never been a feature of her journey. Earlier in the interview, Norma discussed having difficulty accepting the diagnosis, struggling to make sense of the

diagnosis, and almost rejecting the diagnosis. In this excerpt, Norma appears to move on from denial to acceptance that she has received the diagnosis, but there is a lack of reaction and emotion to receiving the diagnosis. It is unclear whether Norma has a lack of understanding about what having dementia may mean or whether Norma is experiencing problems in processing the information in terms of how it may affect her. The use of language in the following extract, in particular, the word 'bothered' emphasises the lack of impact that diagnosis has had for Norma. 'Bothered' appears to indicate that dementia is an irritation. However, despite the issues around Norma's levels of understanding and awareness of the diagnosis, she does go on to identify a change in her behaviour which she cannot fully explain.

> *Norma: Em, but at the same time it didn't bother me, it's never bothered me ... that I had that diagnosis. I I never went 'oh, my God', you know and got all worried about it but my my temper that that was something as well that I thought that's not right with me. (Norma, Interview 1, pages 9–10).*

However, at the end of the first interview, Norma does appear to have accepted her diagnosis and is concentrating on making the most of her life. There is an implicit acceptance in the following excerpt that Norma acknowledged she cannot undo the condition but by learning to live with it, it is possible to live well with FTD. The repetitive use of "just" seems to emphasise the importance of acceptance and concentrating on living well. Norma goes on to concur with Sean's view that everyone will have their own way of coming to terms with a diagnosis of FTD. There is a sense that Norma believes she still has an element of control over her own journey and there is a choice to be made between making things easy or more difficult.

> *Norma: Just, I I think people just need to learn to live with it... it is a lot easier if you just accept it—you can get on with it—that's what I do. [laughs] But then again, that's maybe just me, not everybody's like me. (Norma, Interview 1, pages 88–89).*

Although all participants went on to discuss their determination to live well with a diagnosis of FTD which will be discussed later in this chapter, one participant in particular embraced the diagnosis of FTD as an opportunity to look at life differently. Here John talks about how receiving a diagnosis of FTD heralded a new beginning for him. John talks about trying to accept the diagnosis positively and sees diagnosis as an opportunity to renew his sense of self.

> *John: because all I hear is eh from, not other people, but when you you get a diagnosis of dementia, this, that's the end of the road for you which is, it it isn't. It's not the end of the road. Eh, I took that as a new beginning. [laughs] (John, Interview 2, page 6).*

Indeed, in seven participants there was a strong indication that being able to take control of their own journey, even in part, is an important step in coming to terms with having FTD. Here, John describes being able to take control of his life after receiving a diagnosis of FTD in terms of the impact upon his life view and having to slow down his thought processes. John talks about feeling more confident in himself now he has a diagnosis and knowing there is a reason for the issues he experiences. He begins to see life differently and appreciates the world he is living in. He talks about the need to slow down when you have FTD and the importance of slowing his thinking to maintain control and enjoy life more. Slowing down will be discussed in more detail later in this chapter.

> *John: Since my diagnosis I've felt, I've felt better in myself than I've ever did. Eh, previous to that em … em, well I feel more confident, and I I don't worry about what people think of me now...but since this dementia, s s something's, something's, a touch paper's been eh lit somewhere in my brain, cause I see things more brightly now, I see more, things more for instance, even small things eh instant given at things, you know I see beauty in everything ... em, and I think it's partly because I've slowed down a wee bit. (John, Interview 1, page 26).*

James also described taking control but in a different way from John. James believes that taking control of his life involves accepting experiencing

symptoms of forgetfulness but not allowing the symptoms or diagnosis of FTD to define him. He maintains a positive outlook on life.

James: em eh so, eh you know but I get over it because you know I have this condition and I I I'm going to live with it and I'm going to live well with it em and and be positive. Eh eh, I'll do the things that the activity things that eh I've I've described to you (James, interview 2, pages 19-20).

In summary, all participants spoke about the importance of coming to terms with the diagnosis of FTD in their own way. Coming to terms with the diagnosis was inextricably linked to exercising some control over each individual's journey. By taking some control of how they understood their diagnosis and how they made sense of living with FTD, all seven participants were able to experience life more positively.

This section has identified the first superordinate theme of 'the rocky road through assessment'. Two subordinate themes were identified, the first being 'something amiss', which explored how participants went about seeking explanations for the changes they were experiencing: from suspecting dementia to receiving a diagnosis of FTD. The emergent themes revealed issues around the focus of the information provided during diagnosis and a subsequent lack of knowledge in participants about FTD. The second subordinate theme of 'impact of assessment' highlighted the distress caused to participants by multiple assessments and a lack of inter-agency communication which resulted in participants receiving conflicting advice and experiencing distress. Adding to the challenges of living well with FTD was the incongruity of how participants present to others and the often invisible disease process of FTD with all participants identifying the importance of taking back an element of control in their lives in order to live positively with FTD.

5.3.2 The changing self

This section details the second superordinate theme of 'the changing self' and incorporates the subordinate themes of 'sense of self'; 'roles and relationships'; and 'what I need to be me'.

Sense of self

Six participants talked about their sense of self. Initially, participants felt they were able to maintain their sense of self and their personality was relatively unchanged. However, there was an acknowledgement from six participants that effort was required to 'hold on' to their sense of self and to try to maintain and preserve their sense of self despite 'feeling different'. In this excerpt, James illustrates how his sense of self is intact and the symptom of forgetfulness has not impacted upon how he relates to others.

> *James: I'll tell you I feel absolutely normal em, aye I think that's if you're if you're working with others em maybe I'm I'm just in the early stages but eh I yes my forgetfulness is a nuisance but it hasn't impaired my relationships with others (James, Interview 1, page 51).*

However, it was acknowledged by six participants that effort was required to maintain a sense of self due to the changes that they were aware were happening. The effort required to retain a sense of self amidst a changing self became confusing. This is exemplified in the following quote.

> *Norma: I was, I was on the bus ... and I was sitting there and I just happened to look out the window and I actually went 'oh there's Norma over there...and then I went "I wonder, I wonder what she's doing up here?" And I thought what what what am I doing? I'm Norma. How can she be Norma? And she looked very like me (Norma, Interview 1, page 19).*

This excerpt suggests Norma is trying to hold onto her old sense of self, whilst at the same time recognising her old self in someone else and normalising what

almost appears to be a dissociative experience regarding her emerging new self. This attempt to 'hold on' is explored in the next sub-section.

Holding on

Six participants spoke about changes to themselves and trying to 'hold on' to themselves. Participants spoke about feeling different, experiencing loss of identity and finding difficulties with the changes between the new and changed self. In the next exemplar, James acknowledges a change in his tolerance of others and how he reacts.

> *James: in the last few years where I could not tolerate what was being said and where I might have just sort have looked away and eh thought to myself that's fine em I would maybe challenge that person. Em, and the reason I wouldn't have done it before was partly because of you know my my job if you like, eh where you're not supposed to be controversial and keep things going along smoothly and you know there are certain norms that eh you ought to reflect and that's fine whereas now I'm [own name] and what I say is what I believe, em and eh if it comes out a bit too bluntly then tough, but I very very rarely am like that. (James, Interview 2, page 38).*

There is a sense of participants experiencing a loss of self and feeling out of synchronisation with themselves and the world. Here, Jim describes the enormity of the changes he has experienced.

> *Jim: Completely diff, eh changed my whole personality. I was easy going, not a care in the world type of, type of boy. Now everything seems so upset. (Jim, Interview 2, page 20).*

These changes, whether articulated explicitly or expressed more as a sense of general changes, caused confusion regarding the changed self for five participants. This sense of confusion can be seen in the following quote from Sean where he struggles to understand the changes to himself.

Sean: I cannot fucking help swearing. It comes out right. It's me, I cannot help it. Do you think I like swearing, no, I don't. It just does it. (Sean, Interview, page 47).

As well as not liking the changed self, this excerpt from George illustrates how his family's view of him has changed due to the disparity between how he once would have behaved and the mistakes he now makes. There is a sense that George is holding on to his old self whilst at the same time acknowledging a different self.

George: Well, I think I'm the same guy inside, but just wee mistakes comes up. As Susan says "it's the Mr, oh it's Mr so and so that's starting today", or "Mr sillyhead", or something like that (George, Interview 2, page 53).

This section has explored the changes which participants experienced to their sense of self and their efforts to 'hold on' to their old self. However, participants did acknowledge changing as a person and experiencing loss of their identity and difficulties coming to terms with the changes between the new and changed self. The next sub-section will explore the notion of 'feeling different' in more detail.

Feeling different

Six participants explicitly acknowledged that they felt different and their sense of self had changed. Some participants accepted the changes and described living well with FTD. However, to live well, participants described coming to terms with a sense of loss before being able to accept the new self. Here, John is talking about having to give up driving. There is a sadness and strong sense of multiple losses due to the changed self, but also an example of how one can still be empowered despite feeling different within oneself.

John: she said [occupational therapist] well I recommend you to … em … not drive. So, but the best thing she did—she empowered me to write to DVLA, said I am handing in my keys. Just a wee statement you know, no, nothing to

do, it didn't explain why ... so I did that. Eh, so I felt better, I I still wasn't happy I still you know, it was quite sad, you know it's another, I thought well that's another, that's a negative (John, Interview 1, page 22).

Six participants discussed and identified changes to self, while the new self was only acknowledged explicitly by John. Other participants could identify the changes but qualified their comments by comparing how the old self would have reacted or behaved differently. It was only John who explicitly identified with the new self without referring to the old self.

John: There's slight changes in my my cognitive things, the way I do things, the way I process things, em like I think you've found that today em … when you asked me a question, said something else, I got the wrong meaning, you know got took one, that's a that's a, that's typical of me (John, Interview 1, page 34).

This section has explored participants' experiences of changes to their sense of self and identity. Participants describe a journey where initially they strived to 'hold on' to their sense of self then acknowledged 'feeling differently' about themselves. Participants discussed how they tried to maintain a sense of self whilst at the same time acknowledging that changes were occurring. Several participants discussed their confusion and difficulty in assimilating the old and new self and the losses incurred throughout this process. The next section will explore the changes to life roles and relationships impacted by the changing self.

Roles and relationships

This section will explore the importance of roles and relationships and how both are impacted by the changing self, in particular, working and family roles.

Shifting responsibilities

Six participants discussed the importance of having a life role. Social roles that incorporate and maintain a particular purpose and facilitate opportunities to contribute meaningfully were significant. Six participants identified they still had life roles, however, the responsibilities attached to these roles had shifted and changed. In this following excerpt from James, the maintenance of role, but the shift in responsibility, is clearly illustrated. James explains that although he has just recently retired as president of a games group, he has been asked to partner with someone in the group. There is a strong sense that James believes he is a worthwhile person, feels needed, is valued and views his shifting role as one of some importance to others.

> *James: I've been asked to go down to the [group] and partner somebody on a Monday evening so that's that's, those are the kind of commitments for the week if you like. (James, Interview 2, page 13).*

However, other participants spoke about changes to their role and the difficulties in accepting shifting responsibilities. Mary talks about needing to have people with her when she goes out to less familiar places and identifies a reduction in her self-confidence and social role.

> *Mary: Probably to have someone with me. Em, and I know that's not always possible and from—I was always not a not an overly confident person but I was always a really confident kind of person em, but I'm maybe more, just, nervous about going places or do doing anything em (Mary, Interview 2, page 25).*

The changes to the working role were identified by seven participants. From a growing awareness of something being wrong at work to problems maintaining the working role, to the actual loss of their working roles, these changes were significant to participants and appeared to have fundamentally changed their sense of self and rhythm of life. Here, Mary describes knowing that something was wrong to a greater extent than her colleagues initially recognised.

Mary: they never told me I was a rotten worker or anything like it, but I knew myself I wasn't working the way I always had worked. (Mary, Interview 2, page 15).

Norma describes an awareness of issues in maintaining her working role and concludes that she is no longer able to continue.

Norma: I was getting myself too worked up that I was even I loved my job eh, but I was getting stressed at the thought of it. It was it was coming up to Christmas and they were going to be doing the points, the [rewards] and Christmas things... you know I'd be getting all panicky, all those people and whereas before I loved it. It was great. [laughs] talking to everybody and everything and I just couldn't do it anymore (Norma, interview 2, pages 44–45).

There is a sense of loss of a valued role in both Norma and Mary's excerpts. There appeared to be a lack of consideration from all parties that there was an opportunity for a shift in responsibility rather than a loss of working role. The sense of loss of working role and the impact on one's sense of self is best exemplified by Sean.

Sean: you feel kind of alienated, not alienated if you know what I mean, you just you feel different because everybody's out working, oh how you not working you lazy bastard? Aye, skiving again. That's, it kind of, I don't know, it's as if you've got a wee stamp on your head ... saying ... reject, [laughs] no, finished, forget it, get to the side, we don't want you. Cause you're not... yeah, it's you're living off the state and I've never done that. (Sean, interview, page 57).

As well as the importance of a working role, all seven participants spoke about the importance of their roles within the family unit. Here, Sean is discussing how it is still possible to retain family roles and responsibilities when you have dementia.

Sean: there is a life with dementia. It's like that advert, you're a dad, you're a dad with cancer, but you're still a dad—like that (Sean, Interview, page 83).

In the following excerpt, John is explaining how it is possible to be an active member of the family and maintain a positive outlook. The excerpt illustrates the importance of shifting responsibilities when adapting to changes in his role within the family unit.

John: just to enjoy each other's company, to enjoy, especially my family, there's a lot of things going on in here all the time you know and eh so it's just being like a cog—just mesh with them you know, make smooth running, and I know life isn't like that but I think we always we always try to, if there's something happens we'll try to not make it a negative but we'll do something else or alright that's happened, what can we do about it you know, not just shush it all and get angry. (John, Interview 1, pages 58–59).

However, in the following excerpt, George's experience is one of loss as head of the family. The role of family leader was discussed by all the male participants and seemed to be a significant loss. There is a sense of an altered view of self that is best exemplified in the narrative from George where he talks about feeling useless and accepting help from others to complete tasks that once would have been easy.

George: I felt useless as well if you understand because before I would have been able to cope with that no problem ... but because I had to get help, not just because it was [wife], but because I got help I felt a wee bit useless. You know it was eh, what would you say, it's not the power, power's the wrong word, it took me being the head of the family away from me. (George, Interview 2, pages 9–10).

Six participants discussed changes to marital or life partner relationships. Both positive and negative changes were reported. Several participants spoke about working as a team when decision-making and the importance of being honest

with each other. Here, John identifies that the bond between him and his wife is stronger as a result of life events (including being diagnosed with FTD).

> *John: There is a bond, you know, of all we've been through. Cause we've been, oh we've been through. Most marriages wouldn't survive the stuff that we've gone through, you know. Eh, and I wouldn't I wouldn't em blame her for leaving anyway you know, at any moment from this on this time onwards, I wouldn't. I wouldn't say that to her, because she's, that's offends her, you know (John, Interview 2, pages 22–23).*

Similarly, in his first interview, George spoke about feeling closer to his wife since diagnosis.

> *George: Well she's, we're more involved. Our lives eh? We've still got our own lives to lead obviously, but eh, we do seem to get on a lot better, well, we'll always love one another, know, and I don't think that will ever change, but we seem to be more, there's more friendship there. (George, Interview 1, page 58).*

However, in his second interview when George was interviewed alone, he spoke about feeling left out of making important decisions. The feeling of disempowerment links with the feeling of losing control which was discussed in earlier sections and permeates all themes.

> *George: Susan doesn't know she's doing it but I've no control over my own life. Susan's controlling my life, if you understand what I mean (George, Interview 2, page 12).*

Two participants spoke about a lack of companionship or intimacy within the relationship. Here, John is talking about having to sleep in a different room because of changes to his sleeping pattern.

> *John: me and my wife sleeping in different beds ... I mean that's not what you get married for. Ah, I don't mean anything sexual or that, it's mainly not*

being able to lie beside your own wife at night time, then it's not nice. (John, Interview 1, page 52).

In Sean's case, the diagnosis of dementia led to a break-up in a partnership.

Sean: Well, the lassie I was with ... when I got the dementia ... she walked out the next day ...and I didn't care. I didn't give a fuck ... that's, it didn't bother me. It's more upsetting now thinking about it than it was at the time. (Sean, Interview, pages 89–90).

This section has identified seven participants' experiences of changes and shifting responsibilities in their life roles. Where implemented, the shifting of responsibilities helped participants retain existing roles or develop new roles and had a positive outcome in terms of their working and family roles including the quality of relationships with life partners. However, a failure to consider the possibility of shifting responsibilities could lead to participants experiencing a loss of role. The next sub-section will identify what participants spoke about in terms of what they needed to feel whole and what they required from their family and friends to achieve feeling like themselves again.

What I need to be me

Having accepted that their sense of self was or had changed, six participants spoke about the needs they had in order to feel like a whole person again. The needs ranged from maintaining independence and ability, feeling needed by others and having a purpose, to being useful. To feel themselves, participants highlighted the importance of maintaining control of their lives to achieve personal aims and contributing to those around them. However, several participants identified the need for others to bestow acceptance and value upon them in order to experience a sense of self-confidence and self-esteem in their changed selves and becoming themselves once more.

Six participants spoke about the importance of remaining independent to achieve a positive sense of self. Here, Jim is talking about the positive feeling associated with being independent. There is a clear sense of him feeling confident and capable, but also of having a life purpose and being useful.

> *Jim: You've got to be able to keep, I would say a wee bit independence. You know being able to get out. I go to the B group which I explained to you last time. I'm able to do that. That's a big, big plus. That's a great organisation that, the B group. Ah, I get away on day trips and managing on my own ... (Jim, Interview 2, page 25).*

In the following excerpt, the sense of achievement experienced by George is evident when he talks about completing some home decorating for his family. There is a sense that George feels complete having a sense of purpose, feeling needed, being useful and maintaining his ability.

> *George: and I was papering and painting the whole flat and "have a day off", "No. I'm going to do that until it's finished". And I did, I done it all until it was finished. I didn't get any help and Connie come and said "come on I'll give you a hand", and I said "No, I'm fine, I'll do it myself, and I done it all myself. I was quite chuffed with it. (George, Interview 2, page 67).*

The above excerpt also demonstrates the importance of being able to contribute in some way to those around. In the following two excerpts John talks about attending a day centre and the label of 'service user' emphasising his sense of not being able to contribute.

> *John: I don't contribute. I don't think I contribute anything, eh, to society you know. Mm, it's a funny thing, eh, and I think em [clears throat] that's why I come here [day centre], that's why I I I try to fill, fill my day, so I can give something out. I I I feel I've been given everything, it's a funny. It's a funny feeling. (John, Interview 1, pages 25–26).*

In his second interview, John talks about the need to contribute in more depth. There is a sense of John's dislike of the change from contributor to service user. He calls himself a user, the word which for him has connotations of selfishness and taking.

> *John: that doesn't sit well with me, using, you know taking, it's like I'm drawing things out of people, making them, you know taking something away from them. I want to give something back [laughs], you know what I mean? [laughs]. It's it's strange, strange. (John, Interview 2, page 43).*

Participants also identified that to feel whole and feel like themselves again there were statuses they required that could only be bestowed upon them by others. Four participants spoke about the need to feel accepted and valued by others in order to feel validated. Here, Jim talks about how being trusted by his family and support workers to be left alone for increasing lengths of time has boosted his self-confidence, raised his self-esteem and made him feel happy within himself.

> *Jim: I'm quite pleased that I can be left on my own to be trusted on my own (Jim, Interview 2, page 58).*

This section has identified what participants need to feel complete and at ease with their new self. In order to achieve feeling whole, participants require to be able to think for themselves and believe in themselves, but also require validation from others to ensure they have self-confidence and improved levels of self-esteem.

In conclusion, the theme of 'changing self' explored participants' attempts to hold on to their sense of self despite their awareness of changes in personality and behaviour and feeling different. The changes to self initially resulted in confusion over their identity, but it was possible for participants to emerge successfully from this transition by the gradual integration of a new but intact sense of self. The changes to self had an impact upon the important life roles which participants held, in particular, working and family roles. An important

theme emerged of the need for ‘shifting responsibilities’ and how by embracing this concept, participants could take on new or adapted roles to feel complete. However, changes to role impacted upon the type and quality of relationships with others. Despite the fundamental changes to self, roles and relationships, participants could identify what they needed to achieve in order to feel themselves again.

5.3.3 In touch with reality

Participants experienced some fluctuation in their abilities to remain in touch with reality when coping with the challenges of living with a diagnosis of FTD. The superordinate theme ‘in touch with reality’ contains three subordinate themes entitled ‘insight and awareness’; ‘thoughts, beliefs and emotions’; and ‘living with FTD’. Each sub-theme contains emergent themes.

Insight and awareness

Seven participants demonstrated insight and awareness into how FTD was affecting them. Of the seven participants, five spoke explicitly about particular aspects with varying levels of awareness and insight. However, all participants were able to recognise changes in their thinking and behaviour. Participants discussed in detail issues ranging from short-term memory problems to inappropriate comments and behaviour. Being able to recognise such changes illustrated variance in participants’ levels of insight, but overall high levels of awareness into their behaviour and how they came across to others. All seven participants recognised and attributed changes in themselves to having FTD.

Recognising changes

As well as being aware of changes in their condition, all participants recognised deterioration in their abilities. This excerpt from John best demonstrates his insight and awareness into how his condition is affecting him and his awareness of his deterioration in ability.

John: There's slight changes in my my cognitive things, the way I do things, the way I process things, em like I think you've found that today em … when you asked me a question, said something else, I got the wrong meaning, you know got took one, that's a that's a, that's typical of me (John, Interview 1, page 34).

Throughout the interview process, Norma, John and Jim appeared to have fluctuating but overall high levels of insight and awareness into their condition, but they were able to recount details of situations where lack of insight and awareness of danger had placed them in unsafe situations. This excerpt from Norma, who speaks eloquently about her experience of FTD and dangerous situations affecting her family, demonstrates how she places the onus upon her family to understand and ask about her condition. She appears to absolve herself of responsibility to explain her difficulties associated with FTD. There is a sense of a lack of understanding that her family may struggle to make sense of her behaviour. Her attitude in this part of the interview may suggest a reduction of empathy and insight into how her condition affects her family despite talking about the effect her behaviour had on the family earlier in the interview.

Norma: I told all my family. They, they all know obviously, eh, and really that's the only kind of ones that know ... my family and if they don't understand it and they don't ask me, well [laughs] that's not my problem is it? (Norma, Interview 1, page 48).

However, in common with all other participants, Norma tried to make sense of the changes she noted. This excerpt illustrates Norma's difficulties in making sense of her behaviour and questioning herself whilst trying to reconcile her actions and thoughts. She is describing thinking that there is a glass pane in a shop so she avoids that route through the shop whilst knowing that the glass pane does not exist.

Norma: I I I just think that there's glass there and I can't walk through that bit. I've got to walk round. And I keep saying I'm I'm being stupid how, but I still

think it's there ... well, I don't know because in reality you know I'm telling myself it's not there, and that I can walk there but my brain's telling me different, it's telling me no you can't walk through that way because there's glass there, it's a big glass [laughs] sheet I thought (Norma, Interview 1, pages 33–34).

All seven participants' narratives included a discussion of their insight into and awareness of living with FTD. Although there is a narrative around fluctuating levels of insight and awareness in some participants, this did not appear to change between interviews. Overwhelmingly, the findings of this study indicate that all seven participants had fluctuating levels of insight and awareness but overall had high levels of insight and awareness. The next sub-section moves on to explore participants' thoughts, beliefs and emotions associated with living their lives with FTD.

Thoughts, beliefs and emotions

Seven participants spoke about their thoughts, beliefs and emotions associated with living with a diagnosis of FTD.

Fluctuating feelings

Six participants discussed feeling different and their difficulties fitting in with others. They tried to make sense of feeling different by exploring their thoughts, feelings and emotions associated with being different. Jim spoke about feeling damaged and feeling inadequate. Here, Jim is talking about not being able to assist his wife in carrying suitcases because of physical symptoms of FTD and how it made him feel.

Jim: That's mainly it but inadequate is mainly the main thing. Uh, inadequate, in, and it does, it makes you feel hurt. Terrible. Makes you feel terrible. (Jim, Interview 2, page 12).

As well as feelings of purposelessness and feeling inadequate, five participants spoke about feeling labelled and in particular a sense of heightened vulnerability. The frustration of being labelled vulnerable is best illustrated by John in the following excerpt.

> *John: Well that's what I've been, that's what some professional, that's what I've been classed as—a vulnerable person from the the powers that be em ... em, I asked my OT about that and she said yes, you are a vulnerable person. You know I can walk, I can talk, I can be, I'm not dangerous to myself or anybody else. I've said that a million times. (John, Interview 2, page 16).*

As well as being labelled as vulnerable, four participants spoke about feeling that they were a burden to others and worried about letting others down.

> *George: and you know it's bucketing of rain, och you're just a wee bit down in the dumps and 'I'm maybe just as well packing a bag and disappearing, leave everybody alone, know they'd have no worries then' (George, Interview 2, page 57).*

In the second interview, George discussed feeling like a failure because of his changing ability to carry out day-to-day tasks. Jim and John both spoke about feeling hopeless and being less of a person.

> *John: I'm not the full person. What's that, that's not the way em... Like you know in quality control, I'm not, I'm not the same as anybody else you know, I'm not, I don't fit the mark, I don't ... well nobody's perfect ... but even even as a human you know I'm less, you know what I mean? Em, because I haven't got full capacity I think I'm less than em anybody else you know (John, Interview 2, pages 41–42).*

Participants discussed the impact upon their day-to-day lives of their thoughts and beliefs. Five participants spoke about feeling frightened, upset and subsequent changes in their mood. For George, these feelings compounded

his fear of making mistakes and created an almost vicious circle for him in terms of maintaining his independence. Here, John explains how knowing and being able to recognise his change in ability caused him to feel sad and upset when he was trying to build a bird table (a task which previously would have been second nature to him).

> *John: and I couldn't work this out, and it was only about 15 slates or something, just a wee, a bird table and I was getting so angry with myself, really, I was really upset ... em, but I couldn't work it out. I couldn't work out where the slates were going to go. Like, laying them just like on top of one another you know not not doing it the right way (John, Interview 1, page 5).*

As well as experiencing feeling frightened and upset, participants spoke about shifts in their emotions and in the way they experienced emotions. Emotional shifts will be explored in the following sub-section.

Emotional shifts

Participants discussed a range of shifting emotions from feeling embarrassed and stupid to experiencing frustration. In the following excerpt, Sean describes how he feels when family members carry out tasks which he once did independently. By the end of the narrative, Sean has shifted from feeling frustrated to experiencing anger towards himself and others.

> *Sean: Frustrating. Cause I know I should be doing it myself but I don't (laughs). It's just. It's it just frustrates me because I've done it myself, I've done everything for everybody all their lives, my mother, my sisters, my brothers and my ex-wife ... but now I'm having to rely on people to make sure I go to appointments or make sure I pay a bill or silly things. It just annoys me ... I get angry. I'm just, but I, not angry because I know I canny help it. (Sean, Interview, page 16).*

This section has identified the thoughts, beliefs and emotions participants have experienced. Positive experiences include seeing improvements in activities of

daily living and the ability to learn new things which help participants live well with FTD. However, all participants spoke about the challenges of living with FTD. Most participants experienced feelings of vulnerability and feeling different and inadequate. All participants talked about the high level of impact having FTD had on their everyday lives. The next sub-section will discuss living with the particular symptoms of FTD which participants found especially challenging.

Living with FTD

Seven participants spoke in depth about their experience of behavioural and psychological symptoms of dementia (BPSD). This sub-section begins by presenting some of the 'symptoms that challenge' which were discussed by five participants. The BPSD include obsessive–compulsive traits; issues with emotions; difficulties with initiating actions and motivating self; and anxiety. Six participants spoke about short-term memory and communication issues. However, the largest part of this sub-section will be devoted to the physical symptoms and processing issues identified and discussed by all seven participants as these were highly significant to the participants in this study.

Symptoms that challenge

Five participants spoke about obsessive–compulsive traits. Examples included George's need to complete tasks interfering with family plans. However, the obsessive–compulsive traits are best described by Norma.

> *Norma: me, I'm obsessed with that front door and I'll lock it and I'll check it and I check it again and I I check it about four times and then I'll walk away, a couple of steps, and then I've got to check it again. (Norma, Interview 1, page 28).*

There is a sense that by starting this part of the interview with the word 'me', that Norma feels she needs to exert her position as an individual with worth and attempts to reduce the significance of checking behaviour on her sense of self. In other parts of the interviews, Norma talks about the similarities and

differences in symptoms which she experiences in comparison to other service users who have a diagnosis of a different type of dementia. The repetition of “I” emphasises that this symptom feels unique to her and that experiencing compulsive and obsessional behaviours is something that makes her different from other service users. Norma identifies a feeling of anxiety but attributed it to whether the door was locked or not. Norma does not seem to recognise that the anxiety she is experiencing could be the driver of the behaviour rather than the other way round. At no point does she consider whether the FTD is the cause of this checking behaviour as if she has implicitly acknowledged her checking behaviour as part of having FTD.

Five participants spoke about anxiety and changes in their mental well-being. Changes included an underlying feeling of agitation, anxiety and restlessness which although almost always present, tended to worsen in new social situations. Here Mary explains how meeting new people can lead her to anticipate difficulties and raise her anxiety levels.

> *Mary: Em I, I would say on the whole I love meeting, particularly friends and my family but at times I’ve felt overly anxious about, you know if I’m meeting my friends with other people I get overly anxious...if somebody asks me something I would take longer to answer and ... when I’m with people that I feel comfortable with I can speak quite fluently but if I’ve got to overly think about things I can maybe find something I want to say but not be able to say it. I can’t remember what I was going to say so it’s times like that [crying] that I get upset about. But if someone mentions a topic that is interesting to me I can talk about that you know. Em, so I would say I’m more anxious before I leave home to go but then once I’m there ... I’ll feel more relaxed. I’m maybe over-think things you know. (Mary, Interview 1, pages 23–24).*

Five participants spoke about changes to how they experienced emotions. Jim, Norma, Sean, James and John spoke about a reduced sense of emotion and a feeling of disconnectedness from others. Some spoke about inappropriate emotional responses to situations and blunting of emotion. Sean in particular

demonstrated a deep level of insight into his problems reacting appropriately to loss. Here Sean is being asked about changes to emotions.

> *Sean: I can still laugh and carry on and all that but I don't, it's just hard to explain. I don't know how to explain it. It's just ... it's like an emptiness, that kind of, I don't know, fucking stupid feeling (laughs). No, but it is. I don't know, it's hard to explain. Like, the stupidest of wee things ... can trigger you off ... but my mother dying never bothered me. (Sean, Interview, page 92).*

Four participants commented on becoming argumentative with others which was out of character. Their feelings of anger were strongly linked with intolerance of other people's actions and subsequent problems controlling their own angry responses.

> *John: em, argumentative, angry. Em, being very—black and white about things. Em, I guess sometimes it was anger I think em I had incidences with, driving incidences, getting angry with other road users, not em, for silly things but I I thought I was on the road to tell people what they were, mistakes they were doing, if they didn't do I'd say you know I'd flash them or peep them or so I guess that was a wee, cause I've always been a very em passive guy, not an angry person (John, Interview 1, pages 3–4).*

Six participants spoke in depth about problems retaining verbal information, word-finding difficulties, repeating the same story and general issues keeping up with the pace of conversations with others who talked too fast or when there were too many people talking at once. For some, the effort required led them to retreat from social situations to avoid feeling stupid. Here, Norma reflects upon situations where she felt unable to keep up with conversations.

> *Norma: like my, Ray's son, like if he's talking to me about something and I get confused about what he's talking about and then I'll start saying stuff and he'll go, no mum, that's that's not what I said, and I'll, what did you say then? So we've to go back to the beginning, and he's like "oh my God,*

you drive me nuts sometimes", you know, because you're you're not understanding what I'm saying (Norma, Interview 1, page 31).

Overwhelmingly the most discussed issue around conversations and communication was the loss of the conversational thread. Participants spoke about the effort required to keep up with conversations and the tiredness experienced after conversations. The physical symptoms experienced by participants is discussed in the following sub-section.

Physical changes

Seven participants spoke about physical symptoms which they felt were symptoms normally associated with the ageing process and reported feeling old before their time. For four participants, symptoms included experiencing physical changes and unexplained physical sensations. Seven participants spoke about feeling old due to becoming tired easily and slowing down physically. It was highly significant that five participants stated that the physical symptoms of FTD were the most problematic symptoms they had experienced in terms of reducing their quality of life as opposed to the more reported BPSD in the literature.

Here, Jim is trying to describe the strange physical sensations he experiences in his feet.

Jim: As far as I'm concerned the way it affects me is my feet are very, very light and they go in different shapes, I know that sounds silly but that's how it, that's how it affects me. (Jim, Interview 2, page 3).

These sensations in Jim's feet make getting on and off public transport and getting out and about difficult. His ability to walk is also affected depending upon the time of day.

Jim: At night time everything seems to tighten up and it's hard to get there. It's hard to get by. What's doesn't make sense but that's how that's how it is.

Your feet are light in the morning but at you get about the house not not too bad at all. Ah, get to the shop across the road. Ah come about 6 o'clock you're feeling a wee bit iffy (Jim, Interview 2, page 18).

Mary also talks about experiencing strange sensations. Here she describes a sensation that most often occurs on her wakening in the morning.

Mary: I feel as if my tongue is going to choke me or I've had a strange kind of, couldn't even say it's like cramp, kind of creeping, horrible feeling up here [points to shoulder/neck]. I've had it at that side but one of the mornings I've wakened up and you'd have thought my neck had been completely, I wouldn't be able to do it anyway, but it was as if my neck was completely twisted and I had to untwist and kind of stretch my limbs and things like that. (Mary, Interview 1, pages 19–20).

Participants spoke about concerns over their level of mobility. In the following excerpt, Norma is talking about a change in her mobility because of a fear of falling and how she tries to cope.

Norma: I I I don't know. I just, I've got to watch my feet when I'm walking ... so I'm not paying attention to anything else. I'm just watching where I'm walking. So it's kind of like I suppose having tunnel vision you know, this is where I am going and this is what I'm doing, but I watch my feet [laughs] I've no idea why [laughs] (Norma, Interview 2, page 2).

Seven participants spoke about feeling tired most of the time and an awareness that they had 'slowed up', and 'felt old'. Normal day-to-day activities took longer to achieve, often resulting in others taking over tasks leaving participants feeling disempowered.

Jim: I'm sitting, I can't now just get out of bed and off you go, used to do that when you, when young, used to jump out of your bed when you slept in and away you could go. It seems now you get up and put your feet on the

ground, get my bearings about me, and then I can walk. (Jim, Interview 1, page 16).

In the next excerpt, Sean talks about the physical changes in his walking speed.

Sean: I'm slower at doing things. Slower at walking. Eh, see like like as I said when we're out shopping , I'm packing the bag, no you're too slow. Get out of the way. There's a queue hurry up and get out of the road. She [sister] doesn't mean it. She, cause she works in a shop she's just wanting to get the bags packed and get out. And then I'll say to her and she'll I know but I just like to get out or if we're maybe in [town] or [town] at the shopping centre she's about three mile in front. She'll say oh fuck I forgot that you're with me, I'll need to slow down. Cause she's that used to me walking at a hundred miles an hour with her. (Sean, Interview, pages 69–70).

In the following excerpt, it can be seen that Sean is trying to make sense of his slowing down to no avail.

Sean: But you do, as I say when I walk I fucking feel like an old man when I'm walking. I cannot walk fast now. I just cannot do it. I've tried. No, I cannot do it. I'm like fucking driving Miss Daisy as well when I'm driving now I just toddle along (laughs). (Sean, Interview, pages 72–73).

This sub-section has explored the physical changes participants have experienced as part of having FTD. It is of clinical significance that the most problematic symptoms reported by participants were the physical changes associated with FTD as opposed to BPSD. The next section explores problems experienced with the processing of information when making decisions 'in the moment'.

In the moment

Seven participants spoke about the incongruence between how they thought they would react in certain situations as opposed to their actual behaviour in the given situation. Traditionally thought of as disinhibition and described as such in the literature, this study involved seven participants trying to explain what they were thinking and processing 'in the moment' as they reacted to situations as they occurred. There was also a difference for participants between how they reacted 'in the moment' as compared to what they then thought they would have done when they reflected upon their actual reaction to the situation. This issue of problems with decision-making 'in the moment' is described by participants as more than a challenging symptom such as disinhibition but was made sense of by participants as a complete inability to consider the full range of information or options at the time of action. Problems 'in the moment' appeared to be more than disinhibited behaviour, but rather, a complex issue involving difficulties with processing information.

Here, John gives an in-depth account of a dangerous situation where 'in the moment' he felt his actions were justified, but in hindsight, he can empathise with his wife's fears. Despite being able to articulate her concerns, it is still apparent that the full danger of his behaviour is being somewhat dismissed by John.

> *John: Right, so we had to stop on the motorway, on the hard shoulder ... I put some [windscreen wash] on the passenger window outside and I go out. I felt I was, didn't go onto the motorway, right? I felt I was justified in going to the driver's side and pour it on the driver's side. Gwen was going ballistic—"Don't go near the motorway". I was going round and I was, I suppose I was onto the motorway a wee bit but because I had a high vis vest, they'll see me. The lorry was flying by, and when I think of it, they didn't really, some cars physically went you know "oh somebody" and moved but the lorries didn't and I think she got a fright because they're so close to me. But I, in that time when she was, and she was really screaming, she was really angry with me you know, em, I mean really angry with me and eh and I was*

assuring her "oh it's ok. I'm not that, I know I'm not that, you know I'm very conscious of health and safety, em because I was going a long way from the car, I was approaching the car, not on the blind side, but walking up to it so they could see me approaching ... but they're doing 70 miles per hour. Anyway, it took a lot of convincing that I was doing the wrong thing. You know and even ... at the time, at the time she could not convince me that that was not a normal thing to do being so close to the traffic on a motorway. You know? ... I was getting really really "wow, what are you doing". What, I I heard her ... but didn't … Mustn't have registered in my brain that that was a dangerous situation because I'd a high vis vest on and I was watching the traffic, didn't take my eye off the traffic one bit, em like I didn't have my back to them ... you know but em, so and she could not convince me all through the day that that was the wrong thing to do. So she just had to leave it and then as time goes by she thinks, we can talk about it together I can see the, how dangerous that was. But even just now, back of the mind I think that it wasn't all that dangerous but it was...yeah, but it is. I can see that, yeah, I can see it … but in the back of my head I can I can justify it. (John, Interview 1, pages 14–15).

Five participants spoke about awareness of being verbally disinhibited and being fearful of what they might say to others. Types of disinhibited behaviour included loss of a social filter and saying out loud what they were thinking, behavioural changes and impulsiveness. Sean and George described having no control over swearing whilst others spoke about making rude comments about other people. In the following excerpt, Norma is trying to describe what her thought processes are when she has said something inappropriate to others. It is noticeable that it does not appear that she is already aware of the thought in her mind, rather, that the thought coming into her mind and speaking it out loud occur simultaneously.

Norma: I'll I feel guilty because I think why did I say that? You know it just comes out my mouth before I realise that I've said it. Eh and then and then I feel really bad, like like that time with my mum I actually phoned her up after and I says "mum, I'm really sorry. You you know I didn't mean it like that" ...

You know—oh God I'm going to say something that's not right [laughs] ... it's out before I realise that I've said it ... I don't even think that I'm thinking it at the time ... it it just ... comes straight out my mouth before I realise, cause I'm like "oh, did I just say that"? [laughs] (Norma, Interview 2, pages 32–34).

Here, George explains what happens when he makes a verbally inappropriate comment. Unlike Norma, George states he is aware of the thought before verbalising it. Interestingly, George comments that the thought is not the type of thought that he would have had before having FTD.

George: I'm thinking it but I would never have thought that before ... but it's thinking it, it's coming out at the same time. (George, Interview 1, page 62).

In the next excerpt, Sean describes shouting out inappropriate comments. However, unlike George or Norma, he does not believe that it is problematic, but he does consider that shouting out may be a symptom of FTD.

Sean: It's like fucking Tourettes [laughs] ... ach, I don't see a problem [laughs] ... I know I'm doing it but I just do it ... [laughs] I don't know why. I've never done things like that in my life ... I don't know if it's just me getting fucking old and daft or if it's the dementia or I don't know (Sean, Interview, pages 80–82).

As well as verbal disinhibition, several participants provided examples of behavioural disinhibition. Here, John talks about a change in his behaviour at home whilst watching films.

John: Em, sitting watching a film, sitting watching a film. Now some films don't have big breaks in them, sometimes they go through. Now, instead of going to the toilet, I'd pee in the cup. (John, Interview 1, page 8).

As well as behaviour and impulsivity having an impact upon participants, here Norma describes the impact of her risky behaviour upon others and her lack of response to the situation.

Norma: I just [laughs] cut across the road and then I'll have somebody slamming their brakes on and then getting out their car and shouting and swearing at me, but the thing is, I don't, I I don't get scared, and I don't get, I don't feel anything and I I'm just like, [tuts] what's he shouting and swearing at me for?—and I just keep walking (Norma, Interview 1, page 77).

This sub-section has identified the superordinate theme 'in touch with reality'. Three subordinate themes have emerged regarding participants' 'insight and awareness'; 'thoughts, beliefs and emotions'; 'living with FTD'; and the challenging consequences of living with symptoms. Of particular clinical significance are the ability of participants to have insight into, and be aware of changes occurring; fluctuating feelings; emotional shifts; symptoms that challenge; physical changes and problems 'in the moment'. Section 5.3.4 will explore the fourth superordinate theme of 'keeping going'.

5.3.4 Keeping going

This section details the fourth superordinate theme entitled 'keeping going'. This theme contains three subordinate themes named 'state of mind'; 'strategies for living'; and 'someone there'. Each subordinate theme contains emergent themes which will be explored in turn.

Seven participants spoke about how using coping strategies enabled them to keep going and continue to live as well as possible with the symptoms of FTD. For all participants, using or adapting previous coping strategies helped them cope with everyday challenges as well as developing new ways of keeping going.

State of mind

Regardless of the actual strategy being utilised, seven participants spoke about the importance of keeping a positive state of mind. As well as using existing coping strategies and employing new types of strategies, in every interview

there is a powerful sense of each individual not just living with the symptoms of FTD, but fighting the symptoms of FTD.

Fighting FTD

Seven participants spoke about the need to fight FTD and finding their own way of doing so by employing a range of coping strategies including a determined mindset to cope with the symptoms of FTD. The fight with FTD required conscious mental effort to maintain one's positivity. This can be seen in the following excerpt from James.

> *James: I'm not living down to my diagnosis I'm living up to what I think I can get out of each day. (James, Interview 1, page 45).*

Similarly, Norma explains how she is taking responsibility for her own mental well-being and trying to ensure she has a good day every day. She views FTD as a challenge with everyday life requiring more effort, but importantly, the need to not give up.

> *Norma: so, I'll try anything I can, I'm I'm a fighter that way, I'm like, I'm not giving up you know. (Norma, Interview 1, pages 60–61).*

Norma goes on later in the interview to talk about being able to fight FTD because she has come to accept the diagnosis and inevitability of FTD. Although Sean shares Norma's sense of fighting FTD and sense of inevitability, being able to fight FTD seems to be linked to his determination that he can nevertheless beat FTD if he fights it anew each day.

> *Sean: I'm going to beat it. I told you. So, I don't need to worry about it. [laughs] ... Doctor [name] says I'm going to be the most famous person in the world cause I'm going to be the first one to beat dementia. I'm, I'm telling you right now, fucking note this on that [nods to audio recorder], in 20 years' time they'll say how the fuck is he still running about yet? [laughs]*

He's got dementia, because I'm going to beat it. That's the way I keep positive ... (Sean, Interview, pages 55–56).

Maintaining a positive mind involves turning negatives into positives. As well as having a positive mental attitude, all participants spoke about the need to make the most out of life. In both interviews with Norma, there is a powerful sense that Norma is at ease with herself and is enjoying life, living it to the full.

Norma: yeah, I know, it's weird eh? But I am, I'm really happy and content with my life as long as I don't get stressed I'm fine ... I've never been happier. It's it's really stupid but that's the way I am ... [sighs] I like ... I like my life (Norma, Interview 1, pages 53–54).

This section has explored the importance of having a positive mindset and turning negatives into positives in order to live well with FTD. The next sub-section will explore some of the particular strategies participants have developed to maintain their positive mindset.

Strategies for living

Seven participants used lists and writing things down in different ways. For some, writing down instructions was useful; for others, writing things down that occurred throughout the day so they could pass on messages later was helpful. There also seemed to be a sense of achievement for participants who ticked off tasks as they completed them.

By far the most commonly used strategy to maintain a positive mindset whilst living with FTD was the use of humour. Seven participants spoke at length about using humour as a coping strategy. In this excerpt, Mary is talking about her decreasing ability to navigate around the city in which she lives. From being visibly upset, she quickly uses humour to ground herself.

Mary: I can remember some things but not everything em ... and then I get annoyed at myself [crying] because I've never had a problem meeting

people or going out and about ... em I think I had gone and put something in to get altered and I'd gone down to, I think it was Main Street, to get it fixed and I went down to get it but then and I couldn't quite remember how to get back to the station, then I felt a bit like a tourist [laughing] asking directions back. (Mary, Interview 2, page 24).

An important finding was the need for seven participants to keep active and busy to remain positive. Being both mentally and physically active was fundamentally linked to being able to live well with FTD. Here, Sean is talking about the difficulty of occupying his mind if not keeping physically active and the resultant negative state of mind if he is unoccupied.

Sean: see if I'm not busy ... I kind of, I don't know I go into a wee trance. I just kinda sit and stare. I need to keep busy all the time. See if I've been out all day. If I've been out all day I'm alright at night. But see if I'm sitting about the house. I mean I sat down to watch the news one night and I came round at ten o'clock just...I just got into a wee trance. (Sean, Interview, pages 24–25).

Six participants discussed the importance of getting out and about, socialising and maintaining friendships. This is best exemplified by Jim.

Jim: A bad day is not being, is being stuck in the house all the time. That's a bad day. See when it's ... unfortunately in this country you get it quite a bit, when really bad weather and you're stuck in the house. That's a bad day. Just means you've not been able to get out and about ... you just sit on your bum all the time, and not doing anything active ... you get you get agitated... upset. Quite upset. I just feel useless. What has, what has the world thrown at you, eh, it's it's hard to describe, I, you just feel as if you can't can't cope. (Jim, Interview 1, pages 54–55).

This section has identified strategies for living which participants found most useful: writing things down; the use of humour; avoidance; and keeping active. The next sub-section will explore the strategy of 'slowing down'.

Slowing down

Slowing down as a strategy for living was a new concept for participants. There was a strong sense in the data that, unlike the strategies discussed in section 5.3.4, slowing down had been imposed upon participants as a physical symptom of FTD, but at the same time, had in itself become a useful strategy to cope with everyday living. Four participants spoke about the need to break down tasks into manageable chunks and work backwards. John tries to explain his understanding of the complexity of tasks and how he now approaches them.

> *John: it's strange the way I look at things, cause when you see things, I think oh that's easy to do but there's about 20 processes before it actually gets to that stage. You know, is that, am am am I making sense though? (John, Interview 2, page 37).*

Five participants spoke about the need to slow down and pace themselves in order to achieve daily activities. Slowing down included taking more time to respond to challenges and being systematic in how they tackled challenges. In this excerpt John is explaining how by slowing down he copes with and appreciates more, the smaller things in life. He now enjoys simplicity and derives pleasure from having slowed down his pace of life.

> *John: Like you're rushing, you know you can fit a lot of things in because you can get there quicker or you tend to rush things and that. I enjoy things more, so I'm down keeping an interest in even the smallest thing you know—walking in the woods or seeing [laughs] seeing the light on a a leaf or seeing something a wee bug crawling [laughs] em. it's amazing em, even just the way the branches form on a tree or sounds they make, sounds just em it seems to be em ... enhanced a wee bit you know. (John, Interview 1, pages 54–56).*

Not only has slowing his pace down helped John cope positively with the symptoms of FTD, but helps him maintain a sense of achievement.

John: I I think that's a good way of saying it. I can't multi-task ... if I've got a thing to do I'll do it, then I go on to another thing em ... it's still hard to explain cause ... em to all intense purposes I still feel the same as I've always found. You know, I've always been able to do things, work things out, and it's still, it's still the case today but it's a slower process. I take longer to process things. I know where I want to go but it takes longer to get me there. I'll get there maybe go the long way round but I'll eventually get there. You know... I'll maybe take the the tourist route you know ... rather than the straight, you know what I mean? You know ... but I still get there. (John, Interview 1, pages 35–36).

This sub-section has explored the importance of slowing down as an imposed, but helpful, coping strategy. The next sub-section is concerned with the issues around planning your life when living day to day with the symptoms of FTD.

Living day to day

This sub-section looks at the issues involved in advance planning. Planning ahead in the short term was found to be a useful strategy for coping with living with FTD for seven participants. For some participants, planning ahead involved planning on a weekly basis and for others on a day-to-day basis. All participants revealed ways in which they pre-empted potential problems and put in place coping mechanisms designed to prevent problems from occurring. The next two narratives from Jim demonstrate the need to know about plans in advance, however, the acknowledgement that this leads him to question his wife repeatedly about the plans. He was aware his questioning caused difficulties between him and his wife.

Jim: if we're going out somewhere, I have to know beforehand, and I've completely upset [wife's name] cause I ask her what time we're going at, don't I? (Jim, Interview 2, pages 52–53).

Conversely, planning ahead could cause upset for participants if things did not go to plan. In the following excerpt, Jim appears to attribute last-minute

changes as being somehow his fault. Here, Jim tries to explain his feelings when plans change at the last minute.

> *Jim: I seem to build myself up for it then there's a, it's a let-down [laughs], but ah, we get about. I'm sad I'd say, you just wonder whether the change is, the change because of my illness or that, worry whether people are putting themselves about because of my illness uh ...because of me (Jim, Interview 1, page 34).*

Seven participants talked about the coping strategy of living day to day and this was considered by participants to be an important coping strategy for living well with FTD. For some participants, planning was now the remit of the person with whom they lived. Here, George has been asked what important advice he would give to others facing life with a diagnosis of FTD. The following excerpt illustrates the everyday challenges of coping with FTD and the importance of him not planning in advance. He has abdicated this responsibility to his wife. In this narrative, George acknowledges that there would be difficulties involved if he had to plan ahead in the short term.

> *George: Take every day as it comes. Because that's about the best thing you can say. Just take every day, cause every day will be different ... mm hm. Aye, that's all you can do, take every day as it comes ... every day is different. It's all just new challenges. (George, Interview 1, pages 44–46).*

Similarly, in the next excerpt, John illustrates how he values the benefits of living day to day for him.

> *John: because I just live from day to day now, I don't look forward because I treat each day not as if, it's not very fair, I treat each day, as it's the first day I've experienced. You know as if it's a new day that I've never experienced that before, you know what I mean? There's new things, even walking out the door you meet somebody else somebody that you've never met before, something happens, for the good for the positive. I'm trying to think positively (John, Interview 2, pages 5–6).*

Although participants discussed the importance of planning ahead in the short term as an important coping strategy for living well with FTD, six participants felt strongly that planning ahead in the longer term was not helpful and actively avoided planning for the later stages of their journey. All seven participants had chosen not to have a dialogue with professionals or family members regarding anticipatory or advance care planning in preparation for the end stages of living with FTD. This can be seen in the following excerpts from John, Mary and Nancy who have been asked how they see the future. Their responses indicate that short-term planning occurs, but not long-term advance planning. There is a sense that not anticipating and not planning future care is a coping strategy in its own right. The strategy of not planning ahead may have significant implications for health and social care professionals who support people living with FTD.

> *John: I don't I don't, to be honest, I don't think about the future. That, and it's not a selfish thing, it's not looking at it selfishly, em, and it's not because I don't want to or I'm frightened. I'm not frightened from it em ... I think the one word answer is no, I don't think about the future...I don't tend to. Em, I look forward to things that I've arranged. (John, Interview 2, pages 7–8).*

> *Mary: But I don't overly dwell on what I've got. I just get on with stuff every day (Mary, Interview 1, page 44).*

> *Nancy: I try and sort of take everything sort of a day at a time, but everything to me is precious (Nancy, Interview 1, page 83).*

In the following excerpt, George is being asked about his views on planning for the future and the later stages of FTD. His response is similar to those of other participants in that he has not created an advance care plan or engaged in discussions about future wishes. By not discussing the later stages of the disease process, the individual can continue to focus upon the here and now, thus maintaining a positive mindset continuing to enjoy living well with FTD. The aforementioned excerpts and this following narrative raise important points for clinicians to consider in terms of whether advance or anticipatory care planning could be damaging to people living and coping with FTD.

George: You know I'm quite happy the way things are going. And I don't think too much of the future ... day by day, I'm quite happy with that. Or even week by week. It's certainly not, no ... If I think on that [future]I think it would get me depressed. (George, Interview 1, pages 50–52).

This sub-section has explored the theme of slowing down and living day to day. Living day to day was a strategy that affected not only the participant but the people supporting them. The next sub-section will explore the fundamental need for someone supporting each individual to live well with FTD.

Someone there

Seven participants spoke about the importance and value of receiving support from both paid and unpaid carers. Within this subordinate theme, there are two emergent themes: 'experiencing support' and 'needing others'.

Experiencing support

Six participants spoke about the importance of accepting support and the benefits of receiving formal services. John raises an important point of not being defined by his diagnosis but being seen as an individual. For him, it is important that the individual is seen before the disease. However, Norma spoke about her initial wariness of speaking about her experiences to new people who might not know about FTD. Norma felt it was important that staff knew about FTD. Four participants agreed with Norma and discussed the need to have faith in staff regarding their levels of understanding and knowledge of FTD. However, John discussed having to 'keep staff right' about FTD and highlighted that staff knowledge was based on people with a diagnosis of AD with predominately short-term memory issues.

John: most people think when they think of dementia you're, you've not got your senses you you know, which is wrong because no no dementia sufferers are the same, no one is em, so at first, at the [house], I won't mention any names cause I like the guy, em but em he eh, he was treating

me like a, like I hadn't my marbles. That's the only way I can describe it (John, Interview, page 28).

As well as the experience of formal support, participants also spoke about needing others.

Needing others

Seven participants in this study lived with a family member who was providing daily support. There was a strong sense in the narratives that not only was family companionship a key support that enabled participants to continue living well with FTD, but also participants felt able to rely completely on their family members. This level of unconditional support is best illustrated in the following excerpt from James who talked about the support his wife provided.

James: she's highly supportive, she doesn't treat me like a you know a dribbling buffoon or anything like that em em she knows I'm I'm far from that situation but she appreciates that the blanks of eh memory that I sometimes have and she does all sorts of eh wee things that that you know just almost slip into unconsciousness (James, Interview 2, page 16).

John agreed with the importance of spousal support and acknowledged his increasing dependence upon his wife, whilst, at the same time, making efforts to accept formal support to try to ease his dependency upon his family.

The fundamental need for family support discussed by all participants is described in the next two excerpts from Jim who not only acknowledged the extent of family support required for him to remain living at home but the need for professional staff to support family carers. He highlighted that family support is of more value than formal support, however, formal support has a crucial role to play in supporting families.

Jim: My family. My family support me 100%. Although I'm different than than they can understand more about I'm slow that they they that doesn't bother

them as long as I get there that's the, that's the main thing. So that's important, the support you get from your family (Jim, Interview 2, pages 31–32)

Jim: they'll take it out of [wife's] hands and I would be hospitalised (Jim, Interview 2, page 49).

In the second excerpt, Jim is discussing the consequences for him and his family if he did not accept formal support. The excerpt demonstrates the requirement for professional staff and family carers to work collaboratively to ensure Jim can continue to be supported at home with his family.

This section has presented the fourth superordinate theme which emerged from the data entitled 'keeping going'. The theme contained three subordinate themes, the first being 'state of mind' which highlighted that all seven participants experienced a need to fight FTD in order to continue to live well with the condition. Central to fighting FTD was the need to remain in a positive mindset. The second subordinate theme was entitled 'strategies for living' which identified particular strategies that were useful in living well with FTD. Two key strategies for consideration in terms of clinical practice were the need to 'slow down' and 'living day to day'. The third subordinate theme of 'someone there' included participants' experiences of formal support and the fundamental requirement of family support and 'needing others', to work collaboratively to support people living at home with FTD. Chapter Six will discuss the study findings.

Chapter 6 Discussion

6.1 Introduction

This chapter will include a detailed examination of the findings of the study following IPA guidance and will position the findings and analysis alongside the wider literature (Smith et al. 2013). The ‘person-led framework for understanding the experience of FTD’ will be discussed alongside a critique of the methodology, and a conclusion provided.

This study aimed to explore the lived experience of people with a diagnosis of FTD from their perspective. Seven participants with a diagnosis of FTD were able to consent to take part in semi-structured interviews. It is believed that, through understanding their experiences and views, current and future research, policy, health and social care interventions, educational programmes and general awareness-raising of FTD can be tailored to meet the needs of the person with FTD by incorporating their views.

6.2 Summary of research findings

An overarching finding in this study was the desire for all participants to have an element of control over their journey with FTD. This is an important finding as only one paper was found during the literature search which directly engaged with people with bvFTD (Griffin et al. 2015). This study extends the research by Griffin et al. (2016) in terms of exploring the lived experiences of people with any type of FTD diagnosis.

In this study, a complex and dynamic process was occurring within which participants were making sense of, and coping with, living with FTD. This process has been entitled ‘the person-led framework for understanding the experience of FTD’, which illustrates the interconnectedness of themes, the shifting and merging of themes throughout the journey of living with FTD, and the need to be recognised as an individual by those supporting them. It is this

level of understanding of the complexities and interconnectedness of the themes, alongside the fundamental requirement of understanding the experience of FTD from the person's perspective, that highlights the importance of empowering people with FTD to retain some control over their journey.

The method of interviewing the person with FTD demonstrated the ability of people with FTD to make their views known, empowered participants to be heard and is the most significant outcome from this study. This finding of the need to hear the voice of people with FTD and thus provide opportunities for people with FTD to retain some control over their journey is highlighted in the findings as an important aspect of living well with FTD and adds to the existing knowledge about the experience of FTD. Current research focuses upon family caregivers' perspectives (Johannessen et al. 2017; Kindell et al. 2014; Massimo et al. 2013; Nicolaou et al. 2010; Oyebode et al. 2013; Pozzebon et al. 2017; Pozzebon et al. 2018; Rasmussen et al. 2019; Riedijket et al. 2008; Rognstad et al. 2020; Rosness et al. 2008; Tyrrell et al. 2019); and professional perspectives (Edberg and Edfors 2008; Rasmussen and Hellzen 2013); with only one previous study exploring the lived experience of people with bvFTD from their perspective being found (Griffin et al. 2015).

Key findings have emerged from my study that resonate with the existing literature in a wider context such as research into people with early-stage AD or younger people with dementia. However, this study adds to the current knowledge base as it has identified significant key findings not currently reported in the literature. Key findings include the need for person-centred assessment processes that attend to the specific needs of people with FTD. Participants spoke about their sense of alienation and the need to shift roles and responsibilities to increase positive outcomes. Participants also discussed the use of the term 'vulnerable' which they felt was stigmatising and led them to experience heightened frustration and anger.

A particularly important finding was participants' views that the physical symptoms of FTD had the greatest negative impact on their quality of life whereas the existing literature focuses on behavioural and psychological

symptoms. In addition, in comparison to the findings in existing literature regarding levels of insights and awareness, the participants in my study demonstrated the ability to be insightful and have awareness of changes in themselves discussing issues with processing information 'in the moment' during decision-making situations.

In order to live well with FTD, participants spoke about the need to 'fight' FTD and discussed the importance of having a positive mental attitude and living 'day to day'. This is also an important finding in that participants coped with FTD by not engaging in advance care planning. Participants also discussed issues surrounding the lack of knowledge in people supporting them about FTD and having to educate family and staff about FTD.

The discussion concludes by highlighting the need to develop our understanding of FTD. Improving understanding of FTD can be achieved by raising awareness of FTD by placing the person with FTD at the heart of the support they receive. As well as including the person with FTD in a meaningful way in planning care, there is also a need for professional staff to enhance and develop FTD-specific clinical guidance and non-pharmacological interventions. The development of evidence-based educational programmes for a diverse range of professionals and organisations is required alongside key professionals becoming more active in influencing future policy. There is a need to incorporate the abovementioned requirements whilst working collaboratively with people with FTD. Working collaboratively and incorporating these steps will ensure that the experiences of the person with FTD, as opposed to people with other sub-types of dementia or other stakeholders' perspectives, are heard. These steps are necessary to address the needs of a marginalised group of people with a diagnosis of FTD. Each theme will be discussed in turn to position this study regarding its relevance and significance to the existing body of knowledge.

6.3 Theme 1: The rocky road through assessment

Theme one concerns the 'rocky road through assessment' process which all participants discussed. The subordinate themes of 'something amiss' and 'impact of assessment' will be explored in turn as they include pertinent issues for practice such as the need for person-centred assessment processes; an exploration of the information provided to people with FTD during the assessment process; how people feel whilst being assessed; the experience of multiple assessments; and the need for participants to have an element of control over their journey.

6.3.1 Something amiss and person-centred care

In this study, seven participants spoke about their experiences of assessment which included receiving a diagnosis of FTD as well as other assessment processes such as being assessed for fitness to work, driving assessments and accessing benefits. The feeling of something being amiss was attributed to the experience of symptoms of which participants could not make sense and the incongruence between how participants came across to others and how they felt inwardly whilst being assessed. There was a strong sense that assessment of any type needs to be less generic and focus upon the experiences and needs of the individual to satisfy the diverse and unique needs of people with FTD.

There is broad consensus in the literature that assessment and diagnosis of dementia should be person-centred, taking account of biopsychosocial issues (Arnold *et al*. 2012; Khayum and Rogalski 2018; Klinkman and van Weel 2011; Manthorpe *et al*. 2013; Mitchell et al. (2013); Salloum and Mezzich 2010), with authors arguing for specific assessment services for younger people with dementia (Braudy Harris 2008). Arnold et al. (2012) advocated for a person-centred assessment but placed the onus on the patient being prepared for consultation. However, the model incorporates person-centred principles found in other models. Mitchell et al. (2013) called for access to information about the condition and enabling future planning which will be discussed later in this

chapter. To provide useful information and discussion about FTD, the need for person-centred assessment becomes even more important in terms of explicitly addressing the individual concerns and experiences of each patient which may be different for each person, e.g. the ability to continue in employment or how to access benefits (Arnold et al. 2012).

In contrast to Arnold et al. (2012) who placed the onus of asking the right questions on the patient during the assessment, Manthorpe et al. (2013) identified a model which could help professionals support patients through the diagnostic process. Manthorpe et al. (2012) concurred with Arnold et al. (2012) in that people undergoing assessment often do not know what questions to ask to make the assessment process meaningful to their own quality of life. Acknowledging this, Salloum and Mezzich (2010) presented a model that included the identification of internal and external risk and protective factors to best support the person during and after diagnosis. The model specifically targets the need for GPs to understand the diagnostic journey from the person's perspective and explore the benefits of early diagnosis, but what particularly resonated with my study was the need to explain the diagnostic process to the person to prepare them for assessment.

My study has revealed that people with FTD have not felt able to discuss their most important issues during assessments. Typically, the diagnostic process for people with FTD consists of taking a detailed history of their symptoms, exploring family history for similar presentations, physical examinations and scans to screen out other potential differential diagnoses, and a battery of neuropsychological tests. The process takes place in the clinical environment and is led by medical staff. The person is asked multiple questions and it can take several years to reach a diagnosis of FTD.

Based on the experiences of participants in this study, it has been highlighted that support for people with FTD to prepare them for assessment and the diagnostic process would lead to a more person-centred process. This is partly in accord with the findings of Bailey et al. (2019) who explored the differing perspectives of professionals, the person and relatives and highlighted the

need for multiple stakeholders' expectations to be explored regarding the purpose of assessment and support throughout the assessment process. Furthermore, as some participants of my study sought assessment because of concerns raised by family members and are all dependent upon family caregiver support, the focus of the assessment requires to be considered in terms of meeting the needs of multiple stakeholders, whilst at the same time, keeping the person at the centre of the process. The need for preparation for the assessment process could be met by adopting an approach that discusses the assessment process with the person and their family before formal assessment commences and could be a key role for clinicians to undertake.

Several participants in my study discussed not being able to understand what professionals were explaining to them and feeling disempowered. There was a sense that to provide person-centred support, professional staff may have to develop new skills and ways of communicating. Bailey et al. (2019) emphasised the need to consider how, and what, a person should be told about their diagnosis. In reading the literature, it became apparent that the elements that have been identified and need to be incorporated into assessment processes to achieve a person-centred assessment were similar to the components of pre-diagnostic counselling (La Fontaine et al. 2013).

However, in order to achieve a person-centred assessment where the person is prepared as far as possible for the process, all professionals must have the ability to be self-aware in terms of how they make people feel during assessment (Bailey et al. 2019; Zaleta and Carpenter 2010). Professionals require to be aware of the impact that their attitudes and focus are having upon the person with FTD and have a comprehensive knowledge of the symptoms of FTD. One way in which to ensure needs are met during assessment processes is for professionals with an advocating role to be with the person throughout their consultations. The next sub-section will discuss the provision of FTD-specific information that could assist the assessment process.

Provision of FTD-specific information

In this study, participants spoke about a lack of FTD-specific information being accessible during the assessment process. Participants who did not receive FTD-specific information found themselves seeking information independently. Although there have been publications designed to be provided at the time of diagnosis, they are mainly in electronic form and require downloading or printing (Alzheimer Scotland [no date]).

In this study, participants who were provided with generic information about dementia spoke about their confusion over their lived experience of symptoms in comparison to those documented in the information they received. This finding concurs with Manthorpe et al. (2013) who highlighted the generic nature of the information given to people with dementia during assessments. In my study, several participants were given written information based upon the needs of people with AD, to which they could not relate. This study strengthens the need for both literature and support which is FTD-specific to meet participants' needs.

Participants who did receive FTD-specific information during the assessment process spoke about the negativity of the information provided and the terminology contained within. Participants described feeling frightened after reading the information as they thought they would experience all challenges and symptoms concurrently and immediately upon diagnosis. These findings have clinical significance, not only about the quality of the information provided, but also about when information is provided, and the availability of support to ensure people with FTD understand the information provided accurately.

Only one participant in my study understood that there are several subtypes of FTD, with other participants reading the information provided about bvFTD. The domination of bvFTD in the FTD-specific information available is a key finding in my study, however, I could not find any discussion of this in the literature. This finding is concerning given that of seven participants in my study, six had not been diagnosed with a subtype of FTD but had been given the broader

diagnosis of FTD. Participants who accessed information about FTD were discussing symptoms of bvFTD, some of which they had not experienced. Physical symptoms were not included in the information they had accessed. This led to participants being unsure about how their disease may progress, what symptoms they might experience and this raised their anxiety. The findings of my study indicate that more information requires to be developed that explains the term FTD and the subtypes of FTD in order for people to access appropriate information.

To conclude, this study has highlighted the lack of FTD-specific information available to people at the point of diagnosis. The lack of FTD information has been acknowledged by Tyrrell et al. (2019) but my study illuminates the need for FTD-specific information to be offered to people upon diagnosis in an accessible form of their choosing. Furthermore, to make sense of the information throughout the journey, there is a need for ongoing support to be provided by staff with knowledge of FTD.

Additionally, this study has found that FTD-specific information is considered to be negative in terminology and outlook and can have a negative impact upon those reading the information. The FTD-specific information found is dominated by descriptions of symptoms of people with a diagnosis of bvFTD, therefore, further research and development of resources for people with all forms of FTD is required. Section 6.3.2 will explore the impact of negative experiences of assessment upon participants.

Impact of assessment

In this study, the negativity of assessments was discussed by participants. Issues included how perceived attitudes of professionals carrying out the assessment could have a negative impact upon participants' mental wellbeing and left them feeling disempowered. Although studies exist that explore the subjective experiences of people recently diagnosed with dementia (Xanthopoulou and McCabe 2019), I could find no studies that explored how the beliefs or understanding about a disease amongst professionals could

impact upon the experience of the person being assessed. This study has highlighted that there is a need to recognise the impact of assessment upon the person with FTD due to the beliefs or understanding of FTD of the professionals carrying out assessments and create awareness amongst professionals of this impact.

Participants discussed interactions with professionals which were unsatisfactory until family members intervened or they themselves confronted the professional regarding their attitude. One participant discussed how he was infantilised by a GP and ignored by a hospital consultant. He felt strongly that both professionals dismissed him because of his diagnosis of FTD and their perceptions of people with this condition. Karnieli-Miller et al. (2012) explored the nature of the interaction between the person, unpaid carer and professional in consultations taking place in memory clinics. They found that the focus of communication changed from the beginning of the consultation when the professional was communicating directly with the person with dementia, to focus upon the family caregiver as the consultation progressed. They called for empathic and effective communication to support the caregiver to meet the demands of their caregiving role. My study has indicated that there is a need to explore how this shifting of communicational focus during assessment makes the person receiving the diagnosis feel and how this shift can be prevented. Clinicians with an advocacy role could prevent people with FTD from becoming disempowered. In this study, participants spoke about how they felt during neuropsychological testing. Participants described being praised by professionals and being told they were ‘doing well’. There was a sense of frustration and anger from participants who were aware that their current performance was far short of their norm.

However, despite the negative experiences of being assessed and undergoing testing, participants experienced positive aspects of living with FTD. Mast (2012) discussed assessments where people described their life positively, but this was interpreted by clinicians as a lack of awareness. His findings concur with Mezzich et al. (2010) who highlighted that assessments are weighted towards exploring ill health rather than the quality of life. Mast (2012) called for

standardised batteries to include instruments to measure the quality of life, thus, attending to the personalised needs of individuals rather than focusing on deficits. The findings of my study build upon those of Mast (2012) and Mezzich et al. (2010) in highlighting a need for assessors to understand that insight and awareness may be high and that asking people to participate in tests that will identify deterioration in one functional area may be psychologically damaging to the person as a whole. There is an ethical discussion to be had as to the usefulness and purpose of repeated tests from the participant's perspective and an emphasis required on a more holistic approach to assessment, including a broader focus on well-being and quality of life. The next sub-section will explore the impact of multiple and repeated assessments upon participants.

The impact of multiple assessments

Seven participants discussed being assessed on numerous occasions by different services with conflicting outcomes. This was evident when participants were undergoing medical assessment seeking diagnosis; occupational health assessments regarding the ability to work; accessing the benefits system; and ability to drive following diagnosis. Although embracing the principles of person-centred elements in the models discussed may benefit people going through the medical diagnostic process, it does not address the experience of people undergoing assessments outwith the NHS. There is a paucity of literature in terms of guidance for professionals carrying out assessments involving driving, fitness to work, or assessments to access benefits systems. There is a need to enhance awareness of FTD across multiple agencies which could be addressed through targeted education for specific assessors outwith the health and social care sector; FTD-specific clinical guidance for health and social professionals; and embedding the rights of people with FTD in wider policy locally and nationally.

Participants discussed the lack of communication between agencies involved in assessment, particularly between NHS diagnostic services, their employer's occupational health services and the benefits agency. It was commonplace for participants to be assessed by consultants as being unfit for work only to find

themselves attending multiple interviews with benefits agencies who had assessed them as being fit to work; for employers' occupational health staff to assess participants as unfit to work prior to a clinical diagnosis being made; and problems in accessing benefits.

Braudy Harris (2008) and Molony et al. (2018) called for a wider notion of person-centred assessment and care planning to incorporate legal and financial planning. Although it is acknowledged that the integration of health and social care services in Scotland has helped reduce organisational barriers regarding sharing of information, there is no discussion of how to include other organisations such as benefits agencies, driving assessment centres and housing colleagues given the physical needs of people with FTD. The findings of my study add to the existing literature in calling for the development of a pathway that incorporates a wider range of organisations; the need to minimise repetition of assessment; and subsequently reduce conflicting outcomes associated with multiple assessments.

Participants discussed the financial and social impact of stopping working. Financial problems and repeated failed attempts at accessing benefits were commonplace. My findings concur with Mordhart (2011) and Wheeler et al. (2015) with participants in my study experiencing difficulties meeting financial commitments due to enforced early retirement. Wheeler et al. (2015) recommended the inclusion of a Citizens Advice worker into a specialist welfare advice and advocacy service for younger people with dementia. Issues surrounding access to welfare support were previously highlighted by the Carers Policy Team (2010) who called for family carers to be made more aware of their relative's statutory rights and benefit entitlements. There is a need to empower carers and establish a partnership between health services, social welfare advice, advocacy and a range of wider organisations leading to a holistic assessment process.

According to the experiences of participants, socio-economic issues associated with living with the symptoms of FTD still exist, suggesting that multiagency collaboration should be encouraged. However, the practicalities of collaborative

working for individual professionals require changes to be made at a national and strategic level to empower individual professionals to share information and make changes to assessment processes. Mordhart (2011) reported upon a targeted campaign by advocates of people with FTD in the USA who got FTD listed as a condition, which enabled people to access benefits more timeously; reduced multiple reviews; and reduced misunderstandings of symptoms upon working ability. From these findings, it could be argued that a similar campaign in the UK may benefit people with FTD. My study adds to the existing literature in that there is a need for professionals with specialist knowledge of FTD to increase awareness of FTD and highlight the particular issues that people with FTD face regarding the impact of multi-agency multiple assessments and the need for clinicians to become involved in developing and influencing policy and legislation at a national level. Such activity could facilitate effective changes to multiagency assessment processes which will result in meaningful changes at the point of assessment and reduction of repeated assessments.

The final area of concern regarding assessment discussed by participants was driving assessment. The conflicting advice resulting from multiple assessments was highly distressing and resulted in two participants giving up driving, despite having been assessed as being ‘fit to drive’ by driving instructors, and consequently, experiencing reduced quality of life.

Participants were accepting of decisions made by driving assessment centres to stop driving, but upset by the perceived ‘unfairness’ of driving assessment processes and the lack of communication between agencies involved. These findings resonate with Piersma et al. (2016) who concluded that there is no current valid or reliable single driving test, but all tests should take into account the differences in driving difficulties that people with dementia of particular sub-types may face. Piersma et al. (2016) call for tests for people with FTD to focus upon decision-making and risk-taking with annual reassessment as opposed to tests that focus upon memory impairment. This concurs with the experiences of three participants in my study who undertook different and multiple driving assessments and received confusing and conflicting advice. My study highlights that despite evidence being available on the specific driving

assessment needs of people with different types of dementia, they need to be more fully incorporated into practice. My findings suggest that by raising awareness and knowledge of FTD amongst professionals undertaking driving assessments, the distress and reduced quality of life for people with FTD may be reduced.

This section has highlighted the impact upon people with FTD regarding lack of communication between agencies and issues sharing relevant information. People with FTD experience socio-economic difficulties as a result of job loss. There is a role for clinicians to support people with FTD and their employers in the workplace and to advocate for evidence-based driving assessments. The next sub-section will explore FTD as a 'hidden disease' and highlights the need for people with FTD to retain some control over decisions being made throughout their journey.

FTD: A 'hidden disease' and the need for control

In my study, there was a strong sense of the importance of the person with FTD having some element of control over decisions being made and a sense of unfair or unjust decisions being made during assessments on their behalf by professionals and family caregivers who did not understand how symptoms of FTD were affecting them as individuals. In addition, participants found it difficult to discuss the incongruity between what professionals assessed, the caregiving experiences of family members, and how they were experiencing FTD. Frontotemporal dementia was described by several participants as a 'hidden disease', with participants commenting on how others would state how well they looked whilst they were feeling very different inside. This incongruity compounded the difficulties involved in participants having to try to explain their condition to others. There appear to be two issues: the incongruity between how people with FTD appear and their actual ability to function; and people with FTD feeling as if they have little say in decision-making and experiencing loss of control in their lives.

Truscott (2004) wrote about her own experiences of the early stages of dementia and described it as an ‘invisible’ disease highlighting the same experience of incongruity. More recently, the need to hear the voice of the person with dementia has been advocated widely by groups such as Alzheimer Scotland and the Scottish Dementia Working Group, however, people with FTD may be under-represented in such groups. It appears there may be a particular issue around people with FTD being given the opportunity to be heard and exercising control over their journey. This lack of opportunity may be explained in part by the diagnostic criteria regarding FTD which suggest all people with FTD experience lack awareness and insight. The participants in my study were all able to discuss their journey and demonstrated high levels of insight into and awareness of their difficulties throughout the interviews with evidence of only slight fluctuations in insight and awareness. The findings from my study have demonstrated that people with FTD can discuss their experience of living with FTD. Possible ways of continuing to hear the voice of people with FTD include disseminating the findings of this study through conference presentations, publishing findings in peer-reviewed journals, and working in collaboration with existing dementia organisations at local, national and international levels to ‘champion’ the voices of people with FTD.

My study has highlighted the issue of the views of people with FTD not being heard. This is despite participants being able to articulate their experiences and views. Pozzebon et al. (2017) explored the experience of one spouse who cared for her husband who had semantic variant primary progressive aphasia (svPPA). The person with svPPA lost control in all life matters and each phase of losing control involved feelings of vulnerability and uncertainty for the spouse. To my knowledge, there are no studies that explore the notion of losing control from the person’s perspective. This lack of opportunity to be heard or keep some control is further demonstrated by the paucity of research that directly involves discussion with people with a diagnosis of FTD. This may highlight a need for educating family caregivers on ways in which to advocate effectively for their family member and the need to educate professionals about the human rights of all people receiving support. In engaging with the perspectives of people with FTD, my study has added to the existing research

regarding loss of control and decision-making experienced by people with FTD and provides evidence of the importance of hearing the voice of people with FTD, and an example of how to include people with FTD in future research.

Furthermore, my study builds upon the work of Griffin et al. (2016), who interviewed people with bvFTD, and further illustrates the ability of people with any subtype of FTD to take part in meaningful discussion of their views and experiences of living with FTD. To my knowledge, my study is the first to interview people with any subtype of FTD regarding their lived experience. Directly engaging with people with FTD is one way of empowering people with FTD and provides an opportunity for the person to tell their story from their own perspective, and places them at the centre of research.

Increasing control over people's lives has been shown to reduce distress. Griffin et al. (2016) highlighted a contrast between participants' reactions to life changes which they felt they had no control of and those of which they felt they had an element of control. Life changes such as loss of employment where decisions were suddenly dictated resulted in participants experiencing distress, whereas changes which took place more gradually and participants had been involved in, such as changes in the way in which they socialised, did not cause similar levels of distress. These findings are suggestive of participants' beliefs that having control over their life path was of high importance in living well with FTD and concurs with the findings of my study.

Overall, the findings of my study have highlighted new insights into the experience of people with FTD undergoing assessment. As well as identifying a need for person-centred assessment, this study has discussed the need for the appropriate development of FTD-specific information to meet the needs of people with FTD. The study has identified a need for future research into the experience of being assessed and how the knowledge and skills of professional staff can impact upon the experience of the person. Importantly, the study has identified the distress caused by multiple assessment processes with conflicting outcomes and the need for agencies to work together collaboratively to reduce the distress experienced by people with FTD. Finally, the need to hear the

voices of people with FTD has been highlighted in order for people to retain an element of control over the decisions made throughout their journey. Professionals have a role in ensuring that the development of policies, processes, support and future research directly engages with the person living with the diagnosis of FTD. A person-centred assessment process requires an understanding of the person's sense of self and social identity, as will be discussed in the section 6.4.

6.4 Theme 2: The changing self

Theme two concerns the changing self which all participants spoke of during their interviews. The issues of 'sense of self'; 'roles and relationships'; and 'what I need to be me' will be explored in turn. Emergent issues from my study will be discussed and include changes to the sense of self, feelings of alienation, and the losses and changes participants faced in their family relationships and working roles.

6.4.1 Sense of self

In this study, six participants spoke explicitly about their sense of self. They described being able to maintain their sense of self initially, however, they acknowledged that effort was required to 'hold on' to their sense of self whilst, at the same time, feeling different. As their journeys progressed, participants experienced confusion and difficulties in assimilating the old self with the changed self, in particular, accepting the losses incurred throughout this process. The recognition and supporting expression of self has been reported as facilitating the maintenance of well-being in people with dementia (Kelly 2009) and furthering understanding of how the self is embodied in everyday experiences (Kontos 2004, 2005).

To understand the embodiment of self in people with dementia in their everyday lives, an exploration of the wider literature was undertaken to compare and contrast participants' experiences in this study with existing theories of self and

research involving people with early-onset dementia and other types of dementia such as AD which revealed similarities and differences.

However, there is no consensus regarding the meanings of the concepts or definitions of identity, self, personhood or selfhood in the existing dementia literature (Caddell and Clare 2011; Caddell and Clare 2013; Clare *et al*. 2012; Fontana and Smith 1989; Harris and Keady 2009; Hedman et al. 2012; Higgs and Gilleard 2016; Hutmacher 2020; Kitwood and Bredin 1992). In the wider dementia literature, the theory of Sabat and Harré (1992), which is based upon a social constructionist theory of selfhood, is frequently cited. The self is described in three parts: self one is how we are and how we view the world as an individual such as when we talk about ourselves using the word “I” and first-person terminology; self two requires individuals to be able to reflect upon their own personality; and self three is how we exhibit ourselves appropriately in social situations.

The explanation of self 2 particularly resonates with the findings of my study. Participants initially claimed to have maintained their sense of self (self one) but then went on to discuss trying to hold on to self, with feelings of confusion and feeling different coming across strongly in their stories (self two). Self two is concerned with how we perceive ourselves and our beliefs regarding our own attributes. Sabat and Harré (1992) explain that self two can be restricted to belief ‘within the moment’ whereas unrestricted, self two can include self-beliefs about the past, present and future. This multiple set of self twos may explain the confusion and sense of changing self that participants discussed in my study. Participants were able to discuss their awareness of changes to their identity and sense of self and started on a journey of adapting to the new self, whilst at the same time, talking about the original self. Self three may explain how participants made decisions regarding continuing with certain social situations and avoiding others. In addition, self three includes the perspective of the individual and onlookers. How self three is presented is dependent upon how the person interprets the situation or environment. Thus, self three is constantly changing and being adapted to cope with different situations. Although participants in my study share some experiences with people with AD

and vascular dementia (VD), this study has also highlighted differences in how people with FTD think about themselves in the future.

An additional difficulty in comparing the experiences of the participants in this study to the existing research is the paucity of research regarding people with FTD. Several studies explore the experience of living with young onset dementia (Clemerson et al. 2014; Thorsen et al. 2020), but they predominantly involve people with AD. Identity is discussed by Clemerson *et al*. (2014) in terms of how younger people with dementia viewed themselves and found that sense of identity was profoundly affected by how others viewed and responded to them. In addition, Busted et al. (2020) found younger people with dementia felt they were losing control of themselves and worried about becoming a burden to family as their sense of self eroded. However, the coping mechanisms identified in the studies do concur with the findings of my study and include 'holding on', whilst at the same time participants are trying to redefine themselves by accepting changes to their identity and minimising the impact of loss. These findings resonate with the experiences of six participants in my study which add to the findings of previous studies in that the experiences of people with FTD in terms of the changing self are similar to those of younger people with dementia, but the similarities may not be acknowledged due to the stigma attached to the behavioural changes linked to changes in personality and the assumption of people with FTD lacking insight and awareness into changes to self.

In my study, participants acknowledged similarities to other people with dementia in that their personalities had changed but, at the same time, they had assimilated the old self into a new self that incorporated both identities. In the wider literature, Boniolo (2021) suggests that the self persists before and after diagnosis. Similarly, Beard and Fox (2008) found that people with dementia incorporate the diagnosis into self-identity to retain some control of their lives and to be able to interact with others. They argue that diagnosis threatens the sense of self whilst, at the same time, preserves and provides an explanation of the changing current self-identity. Chrichton and Koch (2007) offer a slightly different explanation of how the sense of self is 'curated' into

past, present and future selves involving telling about, for, and with the person in order to reconfirm the person's identity.

However, participants in my study did not identify the existence of their 'future' selves. Two participants briefly referred to people in the later stages of dementia but stated they did not think about the future which in itself was a way of coping with the neurodegenerative nature of FTD. These findings differ from those of Crichton and Koch (2007) who suggest 'curation' occurs in the three Selfs of Sabat and Harré (1992) or Busted et al. (2020) whose participants feared a humiliating future. Therefore, my study demonstrates a more nuanced understanding of how the sense of self changes for people with FTD and how the assimilation of the old and new self is similar but might incorporate different aspects compared to those with AD and VD in that people with FTD acknowledge their personalities have changed.

Of the studies regarding self that did include people with FTD, Rankin et al. (2005) compared people with frontal variant FTD (fvFTD), early AD and a control group. Their study demonstrated significant differences in self-awareness with people with FTD showing the greatest magnitude of error in personality dimensions such as dominance, cold-heartedness and introversion. However, participants in my study did not display or discuss these tendencies. Potential explanations for the disparity between my study and Rankin et al. (2005) may be the use of self-reporting questionnaires, which limited opportunities for an in-depth discussion of changes. An alternative explanation may be the lack of self-awareness or insight of participants in their study. The subjects in the Rankin et al. (2005) study had a clinical dementia rating scale of 2.0 or higher which indicates that participants were at the moderate stage of their illness. Similar measures were not used in my study, with participants having been diagnosed with FTD between a few months and seven years prior to interviews taking place. Therefore, the stage of illness in participants in my study was unknown. Levels of self-awareness and insight will be discussed later in this chapter but are not considered by me to fully explain the disparity between the two studies.

Rankin et al. (2005) went on to state that people with FTD were shown to exaggerate positive qualities and minimise negative qualities such as introversion and insight into personality changes. The minimising of negative qualities concurs with the findings of my study and was a widely used coping strategy. Rankin et al. (2005) also suggested the self-reports of people with FTD closely matched their premorbid personalities and attributed this to difficulties in updating their identity and sense of self as their journey progresses. This is an alternative way of understanding the experiences of the changing self and is different from the multiple self twos proposed by Sabat and Harré (1992). However, in my study, the experiences of participants do not fully concur with the findings presented by Rankin et al. (2005), differing in that participants in my study were able to reflect upon and discuss changes in detail; or fit with the self two described by Sabat and Harré (1992). Participants in my study exhibited similarities regarding loss of future self as reported by Duval et al. (2012). In my study, the assimilation of the old self and the changed self resonate more closely with the findings of people with semantic dementia (SD) by Duval et al. (2012). They confirmed the persistence of a 'feeling of identity' for past and present selves but highlighted the loss of the future self.

It appears that the differences in sense of self in the participants in my study, in comparison to other studies, are important in that the potential of the loss of future self is something which was alluded to, but not discussed explicitly by participants, thus, it requires more sensitive exploration to ensure participants are not experiencing silent losses of which clinicians are unaware. This will be discussed as part of theme four in this chapter. Section 6.4.2 will explore the changes to roles and relationships and how responsibility shifts during the journey with FTD.

6.4.2 Roles and relationships: shifting responsibilities

Seven participants spoke about changes to roles and relationships in the interviews and in particular, the difficulty in accepting changes to ability in terms of family relationships and loss of employment role.

In this study, participants spoke at length about changed family roles and how family members had to take on roles that had previously been within participant's remit and capabilities. This shifting of responsibilities impacted upon participants' feelings of being useful, having a purpose and being able to give to others. Although participants were able to recognise changing roles within their relationships, they maintained that their satisfaction with the quality of their relationships had not altered. This finding concurs with Hellström et al. (2007) who found that couplehood was maintained through involving the person with dementia in day-to-day activities and accepting changes in the relationship. Similarly, Lee et al. (2019) found carers had increased awareness of relationship changes and the taking on of new responsibilities. Perry and O'Connor (2002) found that carers put in the effort to maintain the person's self-esteem and sense of agency regardless of the person's changing ability to contribute. O'Connor (1996, 1999) agrees and emphasises the importance of the person retaining an element of control in decision-making.

The literature suggests that the relationship between the person with dementia and their family caregiver changes in different ways. Kaplan (2001) and Chesla et al. (1994) found that the relationship either continues, is transformed or discontinues. This is similar to the findings of Keady (1999) and Keady and Nolan (2003) who described family caregivers as either working alone, separately or together with the person with dementia. The notion of working together concurs with this study, however, it is important to understand that the views and experiences of family caregivers and the person with dementia may differ. Forbat (2003) interviewed one care dyad of a woman with dementia and her caregiver daughter who gave different accounts of similar events. Therefore, it seems important to understand the care relationship from both perspectives. Given that the findings in the wider literature are mostly from the caregiver's perspective, my study highlights a need for future research to explore how people with FTD experience changing roles and relationships and how best to support people experiencing such changes.

Participants in my study were able to detail the roles and responsibilities that their family members had taken over from them once the symptoms of FTD

became more apparent. My findings accord with Pozzebon et al. (2018) who interviewed family carers of people with PPA and found that family members made adjustments to reconcile the new issues they face to maintain their identity as a couple. Pozzebon et al. (2018) identified four themes: relatives beginning to cope with their family member's declining skills; readjusting sense of self; living the decline (where the quality of their relationship declines); and acknowledging a disconnect in the spousal relationship. Of the four themes, participants in my study acknowledged that spouses had taken on roles they were previously responsible for and were readjusting their sense of self as a consequence. However, there is a difference in perspectives regarding spousal relationships in my study as compared to the existing literature. Participants in my study acknowledged changes in spousal/family relationships but not a deterioration in the relationship. This is particularly interesting as it illustrates a difference of experience in roles, relationships and responsibilities between the person and the spouse's perspectives which requires further exploration. This finding indicates that the family members of people with FTD may require targeted support in not only taking on additional roles and responsibilities but also coping with a less satisfying relationship.

In this study, one participant had been told which subtype of FTD they had been diagnosed with. The reason for the broader diagnosis of FTD is unknown and requires further exploration but was outwith the remit of this study. In considering the findings of Pozzebon et al. (2018), it must be acknowledged that the study only included people with PPA. The speech and language impairments experienced by people with PPA as opposed to bvFTD may account for the differences between the two studies. More recently, Strikwerda-Brown et al. (2019) explored how distinct alterations in the continuity of the self presented in different types of dementia. They found that people with SD were found to have good recent episodic retrieval, however, accounts of memories of earlier episodes lacked detail. Episodic memory impairments are not a core diagnostic criterion of bvFTD but impairments in episodic auto-biographical memory are evident and breakdown in the sense of self occurred due to difficulties in the retrieval of information about the self. Strikwerda-Brown et al. (2019) highlighted that in everyday life, the issues surrounding retrieval of

information about self could result in deterioration in social functioning and problems in important relationships. This finding resonates with my study, where participants discussed changes in self that resulted in reduced social activity, in particular, avoiding social situations which they knew could be challenging. However, changes in self were not considered to have had a significant impact upon the quality of marital and family relationships from participants' perspectives. It is important to note that there is a lack of research that aims to explore the changes to self, identity or changes in satisfaction or quality of family relationships from the perspective of the person with FTD. However, several studies of family caregivers of people with FTD conclude that additional and specialist support in comparison to caregivers of people with other subtypes of dementia is required (Chow et al. 2011; Johannessen et al. 2017; Nunnemann et al. 2012; Oyebode et al. 2013; Rosness et al. 2008; Ulflacker et al. 2015; Van Vliet et al. 2010). My study has highlighted that although participants experienced changes to relationships, the extent of changes discussed did not reflect the impact reported by family caregivers in the literature suggesting support to family caregivers of people with FTD may be an important role for clinicians in order to ensure caregivers can maintain the support they provide to their family member.

6.4.3 The changing self: What I need to be me and alienation

This study has found that people with FTD experience a sense of alienation. Throughout this study, there was a strong sense of participants coming to accept their changing and changed sense of self and increased isolation from others. However, participants were able to articulate what they required to feel, such as having a purpose, feeling valued and exercising an element of control in their lives. This feeling of alienation is echoed in the work of Sagbakken et al. (2017) who concluded that people with FTD can present with challenging and complex needs and there is a risk of loss of dignity and alienation.

To my knowledge, this is the only study that has interviewed people with any subtype of FTD regarding their lived experience. The only study that interviewed people with a diagnosis of FTD regarding their lived experience

was conducted by Griffin et al. (2016) and only included people with a diagnosis of bvFTD, but did identify threats to self as a theme. Griffin et al. (2016) identified events that impacted negatively upon the sense of self and resonate with my study. Such events include changes in driving status, loss of job and loss of control in decision-making. This loss of control features to varying degrees in all four main themes in my study and requires to be taken account of by health and social care professionals at every stage of the journey with FTD as it seems inextricably linked to participants' sense of self, self-esteem, self-confidence and feelings of alienation.

In this study, alienation was experienced by participants whilst accessing formal support. The alienation was related to two aspects: first, being younger than others attending the same support services; and second, having a diagnosis of FTD as opposed to other more common subtypes of dementia. This finding concurs with Sagbakken et al. (2017) who interviewed family members of people with FTD accessing day care and long-term care and found service users experienced a sense of isolation due to being younger and having different support needs. A key example of this is activities being offered to participants in my study that were designed to compensate for memory issues, which is an early symptom in AD. There is a key role for clinicians to provide age-appropriate and FTD-specific support.

Participants in my study did not feel alienated in their relationships despite changes occurring. Oyebode et al. (2013) found that alienation of people with early-onset dementia or FTD could occur via proxy, that is, as a result of the alienation of the person's caregiver by others due to their inability to manage the person's changed behaviour. Alienation via family member was not found in my study, however, this may be due to only the person with the diagnosis being interviewed who may not be fully aware of family members' experiences. The findings related to impact upon family relationships resonate with the findings of my study. However, there are some differences in findings, in that participants in my study implicitly acknowledged changes to their family role but went on to say they did not feel their quality or satisfaction with family relationships had changed.

Seven participants in my study acknowledged the necessary levels of support from family members and identified family caregiver strategies. Caceres et al. (2016) identified family caregivers' coping strategies which could reduce the alienation of people with FTD. The strategies included participating in hobbies together; educating others regarding the reasons for disinhibited behaviour; availability of online support groups; and caregivers coming to accept changes in their relationships. These findings are important as throughout the interviews in my study, participants acknowledged the support from family caregivers as fundamental to them being able to live well with FTD and suggests that as clinicians, support must be relevant and specific in order for family members to help avoid the alienation of their relative (Carter et al. 2018).

Shifting responsibilities

In this study, a prominent finding was that participants spoke about the loss of working role, as a result of having either a diagnosis of FTD or experiencing the symptoms of FTD, as being the most disrupted role and change in responsibilities they had experienced. The importance of the loss of working role may be accounted for by the younger age of several participants who had either lost their employment due to having FTD, experiencing the symptoms of FTD or had taken early retirement as they were aware of something being amiss. Ritchie et al. (2017) interviewed people diagnosed with dementia before the expected age of retirement regarding their experience of their workplaces. Despite symptoms such as memory loss and issues around communication, visuospatial awareness, and learning and retaining new information, they found that successful adjustments were possible in the workplace as long as they were based on employers' clear understanding of dementia through educational sessions. Some participants in their study experienced a sense of connection by continuing to work and felt they managed their symptoms better. However, Ritchie et al. (2017) and Andrew et al. (2018) call for the impact of supporting people with dementia in the workplace on the person and their employers to be fully considered for the best outcomes to be achieved.

The impact of the loss of working role appeared to have been more significant than the changes previously discussed in family relationships. Griffin et al. (2016) explain that this may be due to people with bvFTD being more able to express basic emotions such as fear, happiness and sadness (typically related to personal relationships), as opposed to the more complex emotions such as embarrassment and shame which could be associated with working relationships (Sturm et al. 2006; Sturm et al. 2008). The latter emotions are cognitively complex and require the person to be able to follow and take part in more social situations. If participants in my study were unable to express or discuss the more complex emotions, then distress could be heightened around the loss of the working role, thus explaining the significance of the loss of the working role found in this study.

Although participants in this study overwhelmingly tried to retain a positive outlook on living with FTD (which will be discussed later in this chapter), throughout the interviews the sense of loss which accompanies FTD was strongly articulated when participants reflected on their previous employment. This sense of loss was discussed alongside the shift in responsibilities the person experienced, both positive and negative. For one participant, their employer had reduced their responsibilities gradually in response to their changing abilities, thus facilitating a gradual transition to early retirement. However, several participants had experienced a sudden loss of employment as a result of receiving a diagnosis of FTD which left them feeling distressed and negatively impacted upon their sense of self.

Silvaggi et al. (2020) reviewed the literature around keeping people with dementia in paid employment. They found that cognitive difficulty, as opposed to motor dysfunction, reduced the ability to work. This mirrors the experiences of participants who found that despite physical changes being the most significant symptom of FTD in terms of quality of life, they did not consider this to affect their ability to work. Unlike people with AD, memory loss was not a significant factor leading to loss of working role. Instead, participants spoke about problems with attention and concentration and having difficulties assessing risk. The two main themes in Silvaggi et al. (2020) that emerged

were how to manage people with dementia in the workplace and the impact of symptoms on working status. They concluded that support in the workplace and the input of occupational health professionals could help people with early-onset dementia continue working as long as possible. However, the studies included in their review mostly involved older women and may not be representative of younger people with FTD or reflect their particular needs.

In my study, only one participant had received support from their employer which enabled them to stay in paid employment for as long as possible. Several participants discussed the suddenness of the transition from working to not working and the impact this had on their sense of self. Although research regarding how to support people with FTD in employment has not been explored, studies do exist that have explored the employment support needs of people with other subtypes of dementia. Andrew et al. (2019) reviewed the impact of dementia upon occupational competence, participation and identity for people who experience the onset of symptoms whilst in paid employment. Although the evidence is limited in person-centred approaches, they found giving choices in participation and redefining occupational identity could reduce the negative experiences of transitioning from paid workers' roles.

However, the loss of working role experienced by participants in my study was found to have had a significant impact upon participants' sense of self. There is a role for professional staff to work with employers to implement strategies that shift and gradually reduce responsibility for people with FTD. This may help people with FTD retain a sense of usefulness and bolster their sense of self. Such support could also assist with a planned transition from the working role as opposed to sudden changes as described by participants in my study. However, further research is necessary to investigate how the needs of people who have not yet received a diagnosis of FTD can be supported to remain in employment during assessment or how their return to similar roles could be facilitated.

To conclude, this study has identified that people with FTD experience similar changes to their sense of self as compared to those with other types of

dementia. However, how people with FTD consider their 'future' self in my study requires further exploration. The difficulties in imagining the future self are significant as this has resulted in people with FTD avoiding taking part in planning for their future needs as their journey progresses. This study has also revealed that people with FTD may not recognise changes in their family relationships to the extent reported by family members in other studies, however, people with FTD experience an increased sense of alienation and require support to reduce their sense of being somewhat removed from day-to-day life. There is also a need for professionals to support employers of people with FTD to keep them in their working roles for as long as possible and to manage a smooth transition between working and stopping work. Section 6.5 will explore the third superordinate theme of 'in touch with reality'.

6.5 Theme 3: In touch with reality

Theme three concerns the varying degrees of being in touch with reality which seven participants in this study discussed. Of particular relevance are the issues around participants feeling labelled as 'vulnerable' and their strong feelings of anger and frustration experienced in comparison to their views of experiences of other people with different subtypes of dementia; the significance of physical changes and sensations experienced; and participants' varying levels of insight and awareness which can impact upon the decision-making process.

6.5.1 Vulnerability and anger

In this study, five participants spoke about feeling labelled as 'vulnerable' by others. They highlighted how receiving a diagnosis of FTD had bestowed a label of vulnerability on them which impacted upon their rights and freedom to engage in activities independently. Five participants spoke about their experiences attending formal care, being observed closely and being treated as if they could not look after themselves or keep themselves safe. Participants were aware that family members were taking increasing responsibility for decision-making.

Participants felt this new status of vulnerability that had been bestowed upon them was accompanied by a fear of becoming a burden to others and letting people down. In considering the literature, legislation and policies in Scotland, it appears vulnerability may be widely embedded in several policies and acts such as the Adult Support and Protection Act (2007) The comparison between those with and without illness, albeit designed to protect the person, may inadvertently create silent psychological harms for people with FTD (Clarke et al. 2012; Department of Health and Social Care 2010). The findings of my study have identified that participants feel that the label of 'vulnerable' is stigmatising and results in a reduction of opportunities to participate in activities. This is an important finding as the term 'vulnerable' is used frequently by health and social care professionals and may be inadvertently causing a reduction in opportunities in activities in which people with FTD would wish to participate.

The participants in this study went on to discuss how they felt that safety measures had been applied to them regardless of their capabilities. Bailey et al. (2013) noted that risk and resilience are important concepts when considering someone to be potentially vulnerable. There is a disconnection between these concepts and policies that emphasise a physical safety-orientated approach for vulnerable people. The Department of Health and Social Care (2010) report made recommendations for risk enablement approaches in supporting people with dementia and called for vulnerability to be assessed as a particular situation the person may be in, rather than the person being labelled as vulnerable because of their diagnosis, and made suggestions about the use of personalised risk strategies taking account of the person's abilities. Despite the evidence for a vulnerability-theoretic approach to dementia, this does not appear to be embedded in policy (Petherbridge 2019). My study strengthens the literature calling for a vulnerability approach in supporting people with dementia but goes further in suggesting that the term 'vulnerable' in itself is stigmatising for people with FTD and requires to be reconsidered.

The findings of my study indicate that supporting people with FTD requires an enabling approach to promote equality and respect human rights. Willetts et al. (2013) called for an anti-oppressive approach to practice to reduce

vulnerability. The approach involves promoting the person without the constraints associated with a diagnosis of a disease. However, in implementing such an approach, there would be a need to educate and improve the levels of awareness and knowledge of practitioners supporting people with FTD both in terms of their understanding of the disease and the concepts of discrimination and labelling.

Anecdotally, in practice, behaviour or decision-making by people with FTD that involves an element of risk-taking has not been tolerated well by clinicians and/or family members. In my experience, this has led to people with FTD becoming frustrated and angry when freedoms are reduced. This anger was evident in the interviews with participants. Although understandable from a clinician's or family member's perspective, the restriction in the decision-making of people with FTD can exacerbate difficult situations. Rasmussen and Hellzen (2013) described how people with FTD were identified by staff as being vulnerable due to episodes of aggressive behaviour and staff developing strategies to manage aggression by being a 'step ahead'. Thus, there seems to be a vicious cycle of the person's freedoms being reduced because they have been diagnosed with FTD and therefore labelled as vulnerable, which, in turn, makes the person frustrated and angry, which is then interpreted by family or staff as heightened vulnerability, which then results in further restrictive measures being put in place. My study has highlighted the need for interventions based upon risk enablement as opposed to risk aversion.

The issue of anger is demonstrated by a participant in my study being arrested by the police and another participant admitting to physically assaulting a person in a pub. These findings concur with those of Chandra et al. (2016) and Tyrrell et al. (2019) whose studies revealed higher levels of aggression and agitation in people with FTD as compared to other people with other types of dementia. They concluded that the presence of aggression and agitation can threaten the safety of the person and their family, therefore, support should be developed around the individual's needs rather than the diagnostic category. My study has highlighted that participants were aware of, and able to, discuss their issues around increased frustration and anger but had not had the opportunity to vent

these feelings constructively. A recommendation for practice is to explore ways in which people with FTD can be supported to manage their emotions constructively.

Participants in my study were able to reflect upon their feelings of anger and often regretted their previous actions. Edberg and Edfors (2008) interviewed paid caregivers of people with frontal-lobe dementia in a special housing unit and identified that often the person's anger would be described as being 'out of control'. The anger demonstrated by the person with FTD was interpreted by staff as an expression of frustration that the person could not process or self-manage. Following the angry outburst, residents often regretted their actions. This regret concurs with the experiences of participants in my study. The ability of people with FTD to reflect upon a previous action and situation will be discussed in more detail later in this chapter. However, a key finding is that people with FTD require support in managing emotions such as frustration and anger and clinical staff have a key role in developing and implementing approaches that positively support people with FTD experiencing difficulties managing their emotions.

With regard to how to best support people with FTD experiencing frustration and anger, there is a lack of suggestions in the literature. A few studies exist which suggest behaviour management approaches for people with FTD (Chan et al. 2011; Manoochehri and Huey 2012; Wong et al. 2018). Further research that tries to understand anger from the person's perspective is required to enhance current therapeutic interventions for people with FTD and develop ways of reducing risk for people with FTD, but at the same time, acknowledging the causes of people's frustrations and anger and taking account of individuals' resources and resilience. This study has highlighted that in taking such an approach, people with FTD may feel more in control of their lives and reduce negative feelings about their abilities and how others perceive them. Nevertheless, the issue of anger and aggression is an important clinical issue requiring further consideration. This finding of high levels of anger in people with FTD requires further research from the person with FTD's perspective as

well as family caregivers' and staff perspectives to create a more balanced understanding of this issue.

Physical symptoms

This is the first study, to my knowledge, to find that physical changes experienced by people with a diagnosis of FTD were the symptoms that had most adversely affected quality of life. Seven participants spoke about physical symptoms including slowing down and things taking longer; getting old before their time; and unexplained physical sensations. The finding in this study of physical problems being the most challenging symptom for people with FTD to cope with is significant in that this is different from the perspectives of family members and professional staff who typically highlight the BSPD as being the most challenging symptoms (Nunnemann et al. 2012; Feast et al. 2016; Ulstein et al. 2007). This finding highlights an aspect of supporting people with FTD which is not recognised, assessed, understood, explored or supported in practice.

Studies exist that explore the relationship between pathological changes in the brain and the effect on movement and gait (Downey et al. 2014; Mitsuyama and Inoue 2009; Tolea et al. 2016; Mendez et al. 2005; Tolea et al. 2016; Pijnenburg et al. 2004; Scherder et al. 2007). One person in my study was aware of having the C9ORF72 genetic mutation causing FTD. She discussed her experiences of strange physical sensations such as feeling her neck had been twisted like a corkscrew when she woke up from sleep; a creeping sensation over her shoulder; and changing abilities in being able to hold and manipulate cutlery. Another participant (type of FTD unknown), spoke at length about how he felt his feet were changing shape as he tried to walk, making him lose balance and fall.

Downey et al. (2014) reported on the concept of body schema processing in people with C9ORF72 mutations. C9ORF72 genetic mutations can result in the person developing FTD or motor neurone disease (MND). Altered body schema processing is described by Downey et al. (2014) as an internal state involving

our postural and spatial sense of ourselves and how we compare sensory changes. The process is related to perceptual and cognitive functions and disordered processing of sensory information and is further associated with problems in tactile and proprioceptive signals and body part representation. Although this may account for bodily sensations experienced by two participants in this study, it does not account for the other physical changes discussed by other participants.

Several studies in the field of MND acknowledge that people diagnosed with MND experience cognitive changes and some go on to develop FTD (Bock et al. 2016; Caga et al. 2019; Wicks and Frost 2008). The studies explore the type of cognitive changes that occur. Mitsuyama and Inoue (2009) identified a difference in the psychiatric symptoms between Pick's disease and FTD with MND. In FTD with MND psychiatric symptoms develop first, with neurological symptoms presenting within 6–12 months after onset. The symptoms can include muscle wasting and changes in physical state. In the field of FTD research, there is growing evidence that explores the relationship between FTD, corticobasal degeneration (CBD) and progressive supranuclear palsy (PSP) which suggests the overlap of symptoms between the subtypes occurs more often than was previously understood (Devenney and Hodges 2014; Kertesz and Munoz 2004). This is of clinical importance as current diagnostic criteria for FTD and subsequent support do not assess physical changes such as gait routinely. My study is the first to identify the significance of physical symptoms for people with FTD. Changes to existing assessments and support for people with FTD require to reflect the physical symptoms reported by participants due to the profound negative effect physical changes have had upon seven participants' quality of life.

Seven participants in this study spoke about a feeling of 'slowing up', in particular slowed gait and taking longer to achieve physical tasks such as getting up in the morning. The feeling of getting old before their time caused participants to experience distress. However, participants seemed to accept 'slowing up', as part of having dementia and confused this symptom with the process of ageing and their beliefs that dementia was an older persons'

disease. In attributing ‘slowing up’ to ageing, they did not discuss this symptom with clinicians. Tolea et al. (2016) explored whether physical decline can differ by dementia type. They reported that although people with all types of dementia experience mobility decline, those with non-AD dementias declined faster and therefore, people with non-AD dementia should be targeted for interventions to prevent, maintain and improve gait and balance.

Several studies explore the relationships between gait, cognition, and dual tasking which may account for the physical changes seven participants in this study have reported. Scherder et al. (2007) reviewed the relationship between gait and cognition in the ageing process and associated dementias. They identified that slight disturbances in gait can be found in preclinical subtypes of dementia not known for motor disturbances including FTD. However, the study by Pijnenburg et al. (2004) found a subgroup of people in the early stages of fvFTD experiencing involuntary trunk movements not found in people with AD. Involuntary trunk movements have been attributed to problems with balance when walking (Mendez et al. 2005). Although further research is necessary regarding the relationship between FTD and gait issues, there is an argument for clinicians to discuss physical symptoms and offer exercise and physical activity programmes for people with FTD as the physical changes and deterioration reported in my study were considered to be the symptom that most reduced quality of life.

As well as the relationship between gait and cognition, Rucco et al. *(*2017) hypothesised that specific gait patterns are induced by frontal or temporal degeneration. They compared gait pattern in people with bvFTD and AD and found people with bvFTD became more unstable and slower compared to people with AD and healthy controls. When asked to dual-task, people with bvFTD experienced deterioration in both velocity and stability of gait.

Despite the research discussed above, which identifies links between FTD and physical changes, the findings tend to be reported in journals that are targeted at medical professionals and researchers rather than frontline health and social care staff. Thus, the pathological findings do not appear to have been

transferred into recommendations for clinical care or disseminated to practitioners who directly support people living day–to-day with FTD.

Physical symptoms have been found in my study to be the most challenging symptom to cope with from the person's perspective and the symptom which impacts most on their quality of life. Although studies that present the symptoms that caregivers and clinicians find most challenging are important, they do not include the issue of physical symptoms. My study has highlighted the need for further research exploring the physical symptoms of FTD that lead to the development of interventions designed to improve the physical health of people with FTD, which could significantly improve the quality of life of people with FTD.

6.5.2 Insight, awareness and processing

Seven participants in this study demonstrated an ability to recognise changes in their thinking and behaviour despite diagnostic criteria and literature classifying lack of insight and awareness as symptoms of FTD (Lund and Manchester Group 1994; Massimo et al. 2013; Mendez and Shapira 2011; O'Keefe et al. 2007; Rankin et al. 2005). According to Alexander et al. (2019), the terms lack of awareness, insight, anosognosia and metacognition are all used interchangeably in the literature. Therefore, for this thesis, awareness and insight are considered broad and neutral terms as defined by Clare (2010) "the ability to hold a reasonable or realistic perception or appraisal of, and/or respond accordingly to, a given aspect of one's environment, situation, functioning or performance" (Claire, 2010 p.20).

Participants in my study spoke about changes including problems understanding other people's viewpoints, making inappropriate comments about others (which they would never have done previously), and deterioration in everyday life skills including decision-making. However, research into family caregivers' perspectives of caring for a person with FTD revealed a widespread belief that the person with FTD lacked insight (Tyrrell et al. 2019). Johannessen et al. (2017) carried out interviews with family caregivers of people with young-

onset FTD. A subtheme from their study is “lack of self-insight’. Family caregivers describe the person as having no insight into their functioning or well-being. However, family caregivers then went on to provide examples of the person ‘covering up’ their mistakes. The ‘covering up’ of mistakes concurs with findings in my study, however, in contrast to Johannessen et al. (2017), the ‘covering up’ of mistakes seemed to indicate participants’ awareness of changing ability. This difference in interpretation of findings requires further research. To the best of my knowledge, my study is the first to explore the concepts of self-awareness, awareness or insight in people with any subtype of FTD from their perspective.

From paid carers’ perspectives, Rasmussen and Hellzen (2013) interviewed ten hospital-based health care staff with experience of caring for people with FTD. Although no information was provided regarding the stage of FTD in the people they had supported, the fact that all people were hospitalised suggests the presence of symptoms that were unable to be managed at home, thus, indicative of the person being in the later stages of FTD. It is important to note that even in hospitalised people with FTD, staff identified ‘clear moments’ which were short times when people with FTD were able to converse and appeared fully orientated. These moments were used by staff to get to know the person better to be able to understand and empathise more with the person.

The findings of my study are similar to the findings of Griffin et al. (2016) who interviewed five people with bvFTD. In my study, seven participants spoke about their awareness of changes, albeit in varying degrees. Four participants in the study by Griffin et al. (2016) were able to recognise changes in their behaviour. Further exploration is required to understand the levels of insight and awareness at different stages of the journey.

Furthermore, differences in levels of insight and awareness could be influenced by the type of FTD each participant is experiencing. In the study by Griffin et al. (2016), all participants had bvFTD, whereas, in my study, only one person knew the subtype of FTD they had with all others being given a broader diagnosis of FTD without specifying the subtype. This may mean that people

with different subtypes of FTD experience symptoms to a greater or lesser degree than others and leads to the need for more research around all subtypes of FTD.

In my study, all participants recounted details of situations where they believed, in retrospect, that they had exhibited poor judgement and/or problems with decision-making. All participants discussed issues in reconciling their actions and decisions with their reflective thoughts as there was an incongruence between what they thought they would do in certain situations and what they actually did. The incongruence between how participants thought they would react in a given situation and what they actually did was discussed by seven participants during interviews and all participants were able to reflect comprehensively and deeply upon their decision-making. Participants' reflections included being able to recount their stories in detail to me; commenting about why their own decision-making might have been wrong; discussing how they would change their behaviour (in response to the previous experience and associated learning) if they were to find themselves in a similar situation again; and how their decisions differed from those of their family members. However, there was a sense that participants felt their family members' reactions were exaggerated.

All participants were able to explore, in retrospect, reasons for their decision-making being flawed but could not recall what they had been thinking during the situation; or what, if any, knowledge they drew upon to make their decisions at that time. Six participants stated they did not think they had been thinking at all at the time of the situations. In listening to participants and subsequent analysis of the data, there was a strong sense that there was more complexity to the decision-making process participants were describing than variable or reduced levels of insight and awareness. Participants were demonstrating a deep ability to reflect and yet not being able to act upon learning from past experiences when facing similar situations 'in the moment'.

In my study, the distinction between being able to reflect fully and yet not be able to take on board past learning or others' perspectives to change decision-

making is important to understand. Ruby et al. (2007) found that people with FTD could not correct themselves based on others' interpretations of their actions. Therefore, further research is required to understand the exact nature of theories of mind and how processing issues are experienced by people with FTD (Poletti 2008; Rahman et al. 1999; Ruby et al. 2007; Stone et al. 1998). This is important in that increased understanding of the decision-making process could lead to the development of helpful coping strategies.

There is a body of literature that seeks to understand how decision-making in people with FTD is linked to pathological changes in the frontal areas of the brain (Fong *et al*. 2016; Hughes and Rowe 2016; Massimo et al. 2013; Mendez and Shapira 2011; O'Keefe et al. 2007; Ruby et al. 2007; Seeley et al. 2012; Scherling et al. 2017). However, these findings have been used to inform diagnosis and understanding of the link between damage to certain parts of the brain and reduced ability, but do not appear to have been disseminated to increase front line clinicians' understanding of the decision-making process. Dissemination to frontline clinicians of the research around the pathological changes to the brain and how these manifest in the behaviour exhibited could lead to increased understanding of FTD and more person-centred support.

Instead, what is commonly found in clinical practice is a belief that people with FTD lack insight and awareness, which is exacerbated by the diagnostic criteria and clinical guidance (Lund and Manchester Groups 2004; SIGN 2006). The findings of my study concur with the views of Evers et al. (2007) who explored the diagnostic criteria of 'loss of insight' for people with FTD and concluded that loss of insight should not form part of the core criteria for FTD but should be considered a supportive criterion for diagnosis of FTD due to the existence of different types of insight. The findings in my study strengthen the evidence base around different types of insight relating to FTD.

In addition, the belief that people with FTD lack insight and awareness may explain why people with FTD have not been asked to participate in qualitative research studies. Further research involving the person with a diagnosis of FTD is important as the voice of people with FTD is under-represented in research

and practice (Levy et al. 2018). More understanding is necessary to develop meaningful clinical interventions that meet the needs of people with FTD by building on the findings in my study, through interviewing other people with FTD to strengthen the voice of people with FTD in future research.

In conclusion, participants felt strongly that in being labelled ‘vulnerable’, they were less likely to be involved in decision-making processes. The study concurs with the literature around taking a vulnerability approach whereby the situation rather than the person is deemed vulnerable. However, my study goes further by recommending that the term ‘vulnerable’ should be considered in terms of how appropriate this is given the impact upon people with FTD. The study has also identified the issues regarding people with FTD managing significant levels of anger and frustration and the importance of clinical staff developing strategies to support people with FTD to manage their emotions safely. In addition, this study is the first to identify the impact of physical symptoms as the most damaging symptom of FTD in terms of quality of life for people with FTD. This is highly significant for clinicians in terms of assessing, planning, implementing and evaluating the support offered to people with FTD. Finally, the high levels of insight and awareness demonstrated by participants led to the identification of difficulties in processing information “in the moment” and requires further exploration. Section 6.6 will discuss the need for people with FTD to ‘keep going’.

6.6 Theme 4: Keeping going

Seven participants in this study spoke about the need to keep going and identified a range of coping strategies from keeping positive to slowing down. There was a strong sense that all participants were ‘fighting FTD’. Fighting FTD involved participants discussing the coping strategies they used to cope with the challenges of living with FTD from day to day. However, when asked about the longer-term future, no participants had discussed the later stages of their illness; the impact of this upon themselves or family members; or their future wishes with families or professional staff. This lack of anticipatory or advance care planning was seen as a coping strategy in its own right. Someone being

there to support participants was of the utmost importance, but in order to keep going and live well with FTD, participants spoke about having to educate families and professional staff about the particular needs of people with FTD.

6.6.1 Fighting FTD

Seven participants in this study spoke about the need to 'fight' FTD and the importance of keeping a positive state of mind. The coping strategies employed by participants to remain positive are similar to those used by people with AD, such as writing things down as prompts, the use of humour in difficult circumstances, keeping busy and remaining active, making the most out of life and turning positives into negatives (De Souza-Talarico et al. 2009; Diaz et al. 2020; García-Alberca et al. 2013). The benefits of staying positive and creating a calm environment for people with FTD was highlighted in a study by Edberg and Edfors (2008) and led to a feeling of closeness and trust between service users and paid staff.

There is a strong sense in my study that participants felt as if they were entering a fight. The word 'fighting' is explicit in the study by Clare (2002) which aimed to identify and conceptualise the coping strategies used by people with early-stage AD. She identified coping strategies on a continuum from self-protection to integrative responding and findings concur with my study. Xanthopoulou and McCabe (2019) explored the concept of 'fighting' and link this to the changes in self experienced by people receiving a diagnosis and 'fighting' to be seen as a person rather than the disease. The fight described by Xanthopoulou and McCabe (2019) is evident in my study and involves people adapting to a new way of life whilst trying to remain positive by demonstrating competence and successfully adopting coping strategies which bolster a sense of control and independence. This is important as having some control over decision-making has been expressed by seven participants in my study as central to living well with FTD.

Living day to day

In this study, seven participants spoke about living day to day and not planning in advance was an important coping mechanism. However, Xanthopoulou and McCabe (2019) found that participants planned for particular situations which might occur in the longer term such as putting finances in order and where to live. However, in my study, no participants had planned ahead as this caused distress. Not planning ahead was a coping mechanism in its own right. My study suggests that living day to day and not planning ahead is a key coping mechanism that facilitates living well with FTD. However, several studies from the perspectives of family caregivers (Kindell et al. 2014; Massimo et al. 2013; Oyebode et al. 2013), and paid staff (Edberg and Edfors 2008) indicate the need for caregivers to be a step ahead and to plan ahead on behalf of the person.

In this study, it was commonplace for all participants to avoid planning ahead and when asked, participants were unaware of advance care planning, anticipatory care or advance statements. This concurs with the study by Ashworth (2020) who interviewed people with AD exploring people's outlooks on their futures. As well as focusing on positives, she found people with AD coped by taking a 'one day at a time' approach. Ashworth (2020) calls for a review of policies that encourage planning and exploration of ways to support people to plan, whilst at the same time, focus upon daily life. The findings in my study concur with Ashworth (2020) in that trying to implement advance planning may have a negative effect on coping mechanisms used by people with FTD in their day-to-day lives.

To the best of my knowledge, there are no studies that explore the person's perspective regarding future planning whilst having a diagnosis of FTD. Tan *et al*. (2019) call for more research to inform policy. Tan et al. (2019) investigated the support needs of people with young-onset dementia and concluded that advance care planning requires more research. Whilst this finding may not pertain to people with FTD, more research surrounding people with FTD coping by 'living day to day' is required.

In order to consider future planning, professional staff will require to understand the changes to self that people with chronic conditions experience. The issues identified regarding future planning link with several themes in the study. Changes to self were fundamentally linked to receiving the diagnosis of a neurodegenerative disorder. Charmaz (1995) explored the process of adapting to how a chronic illness undermines the unity between body and sense of self and forces identity changes. Her theory accounts in part for the physical changes in living day to day described by participants of my study alongside the theory of self proposed by Bryden (2020), which supports the need highlighted in my study for a person-centred approach to understanding changes in self. The issues surrounding future planning are demonstrated in the interplay between the emergent themes of the study which add to the complexity of ensuring the person's voice is heard regarding how they wish to be supported, whilst at the same time respecting the individual's wishes of not planning ahead, and recognising that not planning ahead is in itself an important coping mechanism.

Charmaz (1995) describes a coping strategy that involves the person altering ones' life and sense of self to accommodate loss and limits, thus resolving the incongruence between body and self. The adaptation process has three stages: first the experience of and defining the impairment (all participants in my study have experienced receiving a diagnosis of, and living with, FTD); second, making bodily assessments, identifying trade-offs and revising identity goals (all participants in my study discussed the use of strategies to make the most of their current abilities and came to terms with a new and altered sense of self whilst retaining the old self too); third, surrendering to the sick self by giving up control of the illness and by going with the experience. At no point in my study did I sense that participants had given up control of FTD as they were all 'fighting FTD'. This 'fighting' may explain why participants in my study have not yet reached Charmaz's (1995) stage three and therefore, the need to live day to day and not plan ahead.

Van Rickstal et al. (2019) explored whether family caregivers of younger people with dementia had commenced future planning and family caregivers'

preferences as to how to engage in this process. Reasons for non-participation included not believing planning was useful and the adoption of a ‘day to day’ attitude. However, Van Rickstal et al. (2019) also found that professionals’ lack of knowledge in advance care planning for younger people with dementia leads to a lack of opportunity to participate in it. They went on to state that policy developers, organisations and professionals should consider their responsibilities in providing a choice as to whether to participate in advance care planning or not. This is an important point for clinical guidance and policy makers to consider given the current emphasis on services for people with chronic illnesses engaging in future planning with service users.

In summary, being able to discuss future planning, in its various guises, in a sensitive way that does not cause untoward distress to people living with FTD, appears to be a role which professionals are urged to undertake. More research is necessary to ascertain and understand the views of people with FTD regarding their reluctance to engage in this process. Given the sensitivity of the topic, it seems likely that frontline staff will require support and education to be able to assess when it may be beneficial to broach future planning with people with FTD and how to go about this process sensitively but also, importantly, to help people with FTD who choose not to plan the future retain some control over future decisions. The following sub-section will explore people’s knowledge of FTD and the issues regarding the provision of appropriate services.

Knowledge and appropriate services

In this study, seven participants spoke about the importance and value of receiving support from formal services. Six participants discussed the need for both family and formal support. Participants in my study spoke about having to explain their behaviour, their needs and their abilities to staff due to experiencing problems with the type of support offered. There was a strong sense this may have been due to their differing needs from people with other types of dementia. This concurs with Snowden et al. (2006) who found that service providers’ prior conceptions of FTD were based upon their knowledge

and experience of supporting people with AD. Similarly, according to Roach and Keady (2012), there is no standard provision of care for younger people with dementia, which often results in them being misplaced into existing services developed for the needs of older people, mostly with memory-based deficits. My study extends the findings of Carter et al. (2018) and Nickels and Croot 2014) in highlighting the need for access to appropriate support with particular emphasis placed upon the symptoms and needs peculiar to younger people and unusual types of dementia. My study strengthens the evidence calling for specialised FTD services with staff with expert knowledge of best practices in supporting people with FTD (Edberg and Edfors 2008; Rasmussen and Hellzen 2013). In addition, my study identifies that people living with FTD want caregivers who have a deep understanding of how FTD affects them as an individual in order to support each person positively.

Two participants in my study accessed the same specialist services for younger people with dementia. Despite the specialised service, one participant commented that this was the first time he had realised there was another service user with the same diagnosis as himself. He indicated that although he welcomed the chance to talk about FTD in the interviews, he would also like the opportunity to speak to another person who has the same diagnosis. He hoped that in doing so, they would be able to explain to the formal services they accessed, their particular needs. My study has identified a need for peer support for people living with FTD. Peer support groups for people with dementia have been found to improve access to information, provide empathic support and help people cope better with living with a long-term condition (Femiola and Tilki 2017). Although support groups for carers of people with FTD exist, I was unable to find similar peer support groups for people with FTD. My study has highlighted that although some services are designed specifically for people with FTD, most support and services accessed by participants cater for people with all types of dementia with some services specialising in supporting younger people with dementia. There is an opportunity for services to consider whether peer support for people with FTD could be facilitated within existing services.

This study has identified the need for person-centred care planning to meet the needs of people with FTD. The findings of Kortte and Rogalski (2013) suggest a multi-disciplinary approach with professionals sharing their knowledge regarding behavioural, compensatory and restorative interventions to empower the person to function in daily living activities with minimal assistance within the least restrictive environment possible. My study builds upon the findings of Kortte and Rogalski (2013) in that both the explicit and implicit needs expressed by the participants in my study identify the need to empower people with FTD to ensure the person can retain some control over decisions.

However, in addition to the need for a multi-disciplinary approach, Nickels and Croot (2014) and Wylie et al. (2013) call for care and management pathways to signpost people to appropriate and specialised services. Whilst Nickels and Croot (2014) suggest a management pathway for people requiring health and social care with PPA, Wylie et al. (2013) call for a wider pathway including more diverse organisations to meet the holistic needs of people with FTD. This concurs with findings in my study, in particular, the need for health and social care staff to work in collaboration with other organisations such as employers and benefit agencies. This wider notion of a care pathway is something that should be brought to the attention of those developing care pathways and is an initiative that requires both operational and strategic attention at local and national levels. In doing so, awareness and understanding of FTD would be disseminated more widely.

Five participants in this study spoke about their frustration at having to explain to paid caregivers about the symptoms of FTD and how they were personally affected. The lack of knowledge on the part of paid staff regarding FTD is acknowledged in the literature (Morhardt 2011; Sagbakken et al. 2017; Tyrrell et al. 2019), with personal accounts of those supporting people with FTD calling for increased awareness and knowledge about the condition (Gayda-Chelder 2013; McFarland 2010; Rutherford 2014). Dinand et al. (2016) carried out a scoping review regarding the level of knowledge about the subjective needs of people with bvFTD and concluded that there was a lack of scientifically based knowledge concerning the perspective of people with bvFTD.

Participants in this study have highlighted the need for FTD-specific training for staff, which concurs with the findings of Smith et al. (2017), and also for family caregivers to promote a sense of usefulness and engagement in day-to-day life for their family member (Van Vliet et al. 2017). Shnall et al. (2013) explored three successful initiatives developed to meet the needs of spouses and children of younger people with dementia including an online spousal support group; a website for children and parents; and an FTD-specific day programme for people with FTD. A particular strength is they were all developed in collaboration with family caregivers. Whilst the collaboration with family caregivers in developing services is encouraging, there appears to be a need to develop services in collaboration with people with FTD being meaningfully involved at all stages of development.

In conclusion, this study has identified the sense of fighting FTD which involves maintaining a positive outlook and using coping mechanisms which do not involve planning ahead. This is a significant finding as nurses are encouraged to engage clients in advance care planning. Throughout the interviews, there has been a need identified for people with FTD to be provided with opportunities to retain control over the decisions being made regarding their support. In order for professionals to support people with FTD, staff must develop specialist knowledge about the specific needs of people with FTD and promote opportunities for peer support in existing services. Finally, this study has demonstrated that people with FTD can express their views and opinions and can be meaningfully involved in research. This ability of people with FTD to participate in research should be broadened out to include people with FTD in the development of practice, services, policy-making and future research.

6.7 Summary of discussion

This study presents a “person-led framework for understanding the experience of FTD” with clinical relevance for people supporting people with FTD. This is illustrated in Figure 1 which represents the complexity, dynamism and interconnectedness of the lived experience of FTD. Participants can experience

needs in all or any number of the four themes simultaneously and changes in one theme can impact upon others.

Overall, the findings of my study have highlighted the need for the voices of people with FTD to be heard throughout their journey in an area with limited research to date. In addition to this study adding to the existing body of knowledge by being the first to interview people with any type of FTD regarding their lived experience, the findings contribute to the knowledge regarding living with FTD such as the significance of the physical changes associated with FTD as having the most negative effect on participants' quality of life in comparison to the views of other stakeholders who find the BPSD as being most problematic. In the thesis, I have suggested there are alternative ways to support people with FTD to meet the specific needs of this marginalised group which I will present below.

The first key area is the 'rocky road through assessment'. By shifting the focus of assessment from the needs of the professionals to a more person-centred approach, the concerns of the person with FTD may be addressed. Key factors identified include the need to develop FTD-specific information; research into the experience of being assessed and how the knowledge and skill level of professionals impact upon the experience of being assessed; the distress caused by repetitive assessments by multiple agencies with conflicting outcomes; and a need for collaborative assessment over multiple agencies. In order to make such changes, there is a need for increased knowledge, skills and a role in advocating for the person.

Second, from the literature, it has been identified that people with FTD experience similar changes to self as reported in people with other subtypes of dementia. However, the opportunity to discuss changes in self is limited by the stigma attached to FTD regarding the symptom of lack of insight and awareness. My study has shown that the loss of a working role is a source of distress to people with FTD and there is a need for professionals to support people to remain in employment by shifting responsibilities and planning for a smooth transition when departing the working role. It has also been identified

that people with FTD may not appreciate the changing role of their family carers, hence the need for professionals to support family caregivers. In doing so, the sense of alienation experienced by people with FTD may be reduced.

Third, this study suggests that the term ‘vulnerable’ has led to participants feeling disempowered throughout their journey. Feeling vulnerable is related to the significant levels of anger and frustration experienced by people with FTD. There is a role for professionals to develop strategies for supporting people with FTD to manage their emotions safely. Of particular significance is the identification of physical symptoms being the most harmful symptom for people with FTD in terms of reduction in quality of life. Consequently, this study suggests a need for physical symptoms to be addressed in assessment processes, planning, implementation and evaluation of care and support. My study has also identified that people with FTD can have high levels of insight and awareness but difficulties in processing information ‘in the moment’ and require support in decision-making processes from family caregivers and frontline staff.

A final key issue identified in the study is the need for people with FTD to ‘fight’ FTD by staying positive and not planning ahead. The need to live day to day has significance for clinical staff given the focus on advance care planning in best practice guidance. The study has demonstrated that people with FTD can articulate their views and experiences and can be meaningfully involved in research. This finding illustrates that people with FTD should be actively involved in making decisions about their care. A challenge for clinicians is how to involve people with FTD meaningfully in making current and future decisions about their care without distressing them by planning too far ahead which may require further research.

The development of the person-led framework for understanding the experience of FTD illustrates the findings of the study, presenting the findings in a diagram and represents the complexity, dynamism and interconnectedness of the experiences of participants living with FTD (Figure 1). There was a strong sense that emanated from the data analysis of a need for those supporting

people with FTD to understand the experience from the person's perspective, as far as is possible, to increase awareness of the most distressing symptoms of FTD, which seemed best captured in developing a framework.

The framework and findings concur with many theorists and researchers regarding the need for the person's voice to be heard but there is a paucity of research hearing the voice of the person with FTD. The framework presents the four areas: the rocky road through assessment; the changing self; in touch with reality; and keeping going, which must be considered by clinicians when trying to meet the needs of people with FTD using a person-centred approach.

The findings of the study present the lived experience of people with all types of FTD. The very nature of IPA means the researcher can find participants discussing areas of uncharted territory (Smith et al. 2019). In this study, significant new findings have emerged which have formed the elements included in the framework. However, more research is required to increase clinicians' understandings of how best to support people with FTD.

In conclusion, the need for people with FTD to exercise an element of control over the decisions made in their journey and the need for their perspectives to be heard and respected is paramount. The common belief that people with FTD lack insight and awareness may explain why there is a paucity of clinical practice, policy-making and research that includes the views and experiences of people living with FTD. However, my study demonstrates that people with FTD can be meaningfully involved in research and clearly articulate their experiences. Section 6.8 will reflect upon the methodology of IPA.

6.8 Reflections on the methodology

This study explored the views of seven people living with a diagnosis of FTD through 13 interviews and robust and transparent use of IPA methodology. With the benefit of reflection, there are some aspects of the study which could have been done differently. This study aimed to recruit people with a diagnosis of FTD. Of the seven people recruited, only one participant was aware of the sub-

type of FTD with which they had been diagnosed. The generic diagnosis of FTD provided to clients following assessment means it was not possible to identify the FTD subtype for six participants. It may have been beneficial to try to recruit people who were provided with a subtype FTD diagnosis, however, this was not practicable given the remit of the study. There is a small body of research regarding PPA and bvFTD that indicates both similar and dissimilar symptoms to participants in my study, however, given the practical constraints of a doctoral study and the difficulties in recruitment of people with any type of FTD, there was insufficient time to recruit a more purposive sample. Section 6.9 will identify and discuss the strengths and limitations of the study.

6.9 Strengths and limitations

6.9.1 Strengths

A major strength of my study is that it makes a contribution to the limited knowledge base regarding the lived experience of people with FTD from the person's perspective. People with FTD have been recognised as having symptoms that family caregivers and clinicians find difficult to support and the views of people with FTD are under-represented in the development of clinical services, policy development and research. My findings have relevance to all people supporting those with a diagnosis of FTD. My study extends previous literature around FTD, but as the first study to explore the lived experience of people with any subtype of FTD, it offers new knowledge regarding how FTD can be understood and how support can be enhanced. The study demonstrates how people with FTD can be engaged in research, which is indicated by the depth of data collected during the interviews. The convenience sample of seven people with any type of FTD included people with a range of length of time since diagnosis; age; and geographical area. Data saturation was reached by the 13th interview, when no new themes emerged supporting the confirmability of the emerging themes and conclusions.

Using IPA, participants have been able to articulate their own experiences. In becoming a researcher, I have brought with me my experiences from my

previous clinical roles, continuing professional development activities and my own experiences. Being aware of my beliefs and experiences, I was aware they could affect my interpretation of the research, therefore, a reflective journal was completed throughout the research process. This deep level of reflection and following the guidance of Smith et al. *(*2010) has assisted me in countering bias and subjectivity and developing reflexive strategies.

It is important to acknowledge that the research questions arose from my own perceptions of my clinical experience. In order to reduce my preconceptions and biases, I used reflective practice throughout the study. This helped me consider how I thought about issues, whilst at the same time, access my clinical knowledge and experience to connect with the participants during interviews. An example of this is when participants identified the physical symptoms of FTD as having the most profound effect upon quality of life, as opposed to my belief that the BPSD were the most challenging symptoms. My skills as a mental health nurse assisted me in communicating in a meaningful way whereby participants felt able to discuss their experience in detail. This example demonstrates the importance of hearing the voice of the person and the need to bracket off your own beliefs and to be open to new perspectives whilst drawing upon relevant skills and experience (Smith et al. 2010).

In regard to ensuring the quality of the study, transcripts were agreed upon by two supervisors to ensure consistency of coding. The method of data analysis aimed to facilitate reliable, trustworthy and credible findings which could be replicated. Examples of the process involved in analysis are provided in Appendix 12 and were used to develop the person-led framework for understanding the experience of FTD.

6.9.2 Limitations

The study has two main limitations. The first limitation of my study is that due to issues with the diagnostic process, six participants were not diagnosed with a particular subtype of FTD. Whilst the study is the first to hear the voices of people with any subtype of FTD, it was not possible to attribute experiences to

a particular subtype of FTD. Furthermore, the recruitment of people with a diagnosis of FTD was problematic and took over one year to achieve. Thus, recruiting people for the study who were aware of their subtype was unachievable. Notwithstanding the potential challenges of recruiting people with a diagnosed subtype of FTD, future studies that include people who have a diagnosed subtype of FTD are recommended in order to explore whether FTD is experienced differently depending upon subtype. Recruiting people with particular subtypes of FTD may require considering a wider geographical area in comparison to this study and collaborating with NHS specialist memory clinic services.

Second, all seven participants lived with a family member. It is acknowledged in the literature that people with dementia living alone is associated with decreased levels of activity (Svanström and Sundler 2015) and in people with AD, an increased risk of earlier hospitalisation and institutionalisation compared to those living with family members (Soto et al. 2015). Given that this study has identified the high levels of support provided to people with FTD by their family members and participants' acknowledgement of the importance of this, it may be that the experience of people living with FTD alone may differ from the experiences of the participants in this study. Section 6.10 will present recommendations for clinical practice.

6.10 Recommendations for clinical practice

1. People with a diagnosis of FTD should be meaningfully involved in decisions regarding their care and support

Supporting people with FTD in a way that empowers people to maintain or develop an element of control over their journey should be a priority. The voices of people with FTD should be heard or represented throughout the journey. As there is a general belief that people with FTD have a lack of insight and awareness, which can lead to people with FTD not being involved in the decision-making process, education of clinical staff regarding the different levels of insight and awareness and difficulties in processing information 'in the

moment' should be included in educational programmes. Education and training around equality and diversity and the human rights of people with FTD may require revisiting. As well as educational initiatives, clinicians should be made explicitly aware of the need to advocate on behalf of people with FTD who may experience difficulties in having their voices heard. These recommendations will support clinicians to work collaboratively with people with FTD and ensure the voices of people with FTD are included in all stages of support including assessment, planning, implementation and evaluation.

2. Raising awareness of FTD should be implemented in training for frontline clinicians supporting people with all types of dementia

Frontline clinicians supporting people with dementia are not always aware of the type of dementia a person has and the different symptoms associated with dementia subtypes. Training for frontline staff about dementia should be evidence-based and emphasise that people with FTD do have differing levels of insight and awareness but have difficulties in processing information 'in the moment'. In doing so, the specific needs of people with FTD could be identified and a person-centred approach adopted. Involving clinicians in educational programmes would provide them with opportunities to reflect upon their preconceptions about FTD and the impact this has upon the person. Implementation of such measures has the potential to significantly reduce levels of distress currently experienced by people with FTD who feel misunderstood, alienated and stigmatised.

3. Specialist clinicians and educators of clinical staff should review risk assessment processes

In order to live well with FTD, there is a need to reconsider the terminology used by clinical staff, in particular, the terminology around vulnerability and risk assessment processes. Involving staff in opportunities to review terminology may result in an enhanced understanding of how terminology can impact negatively upon people with FTD. Clinicians responsible for risk assessment processes involving people with FTD could review processes as a priority to

ensure a risk enablement approach prevails. In taking a risk-enabling approach, a balanced approach can be reached that considers both the need to preserve the physical safety of people with FTD alongside the need to provide opportunities for positive risk-taking to promote psychological well-being.

It is recognised that supporting people with FTD can be difficult for staff. Staff supporting people with FTD would benefit from supervision from clinicians who have specialist knowledge regarding the symptoms of FTD and how to best support people with FTD. The development of a national FTD clinical interest group is recommended to provide a forum where clinicians can be supported but also share best practice.

4. All assessments involving people with probable FTD or possible FTD should be person-centred

There is a need for assessment processes to focus on the needs of the person as opposed to meeting the needs of the clinician or service. Clinicians are well placed to prepare a person with FTD for the assessments and tests involved in seeking a diagnosis. Multiple and repetitive assessments should be minimised by the sharing of information between organisations. To prevent multiple assessments, clinicians should be involved in developing lifetime pathways for people with possible and probable FTD that are not restricted to health and social care services, but include a wider range of partners such as work occupational health services, driving assessment staff, benefits agency assessors and housing practitioners, given the physical adaptations that might be necessary due to physical symptoms. In doing so, clinicians can share their knowledge of FTD with others and ensure that assessments are fit for assessing people with FTD.

5. Physical assessment of people with FTD should be incorporated into all assessment processes, planning, implementation and evaluation of support.

Physical symptoms of FTD have a significant and negative impact upon the quality of life of people living with FTD. Current assessment processes should

be reviewed to ensure questions about the physical symptoms of FTD such as slowing down, problems with gait, strange physical sensations and motor difficulties are all asked explicitly during assessment processes. Planning and implementation of physical exercise programmes as part of support could be beneficial to people with all types of FTD. Clinical networks that bring together specialists working with people with FTD and MND could facilitate the sharing of expertise and the development of therapeutic interventions.

6. Advance care planning processes should be reviewed to meet the wishes of people with FTD

It has been identified that people with FTD cope with living with FTD by taking life day by day. The coping strategies used by people with FTD include not planning ahead or thinking about what the future holds. All clinicians responsible for advanced planning (in any guise) should ensure that people with FTD have the right not to take part. However, there is a need to ensure that the future needs of people with FTD are met. Clinicians must have the knowledge and skills to broach discussions about future planning with people with FTD sensitively and respectfully.

7. Current national clinical guidance should be reviewed to reflect the needs of people with FTD

Current clinical guidance such as SIGN 86 (2006) which sets out guidance for managing the needs of people with dementia requires review to ensure each section has evidence-based information pertaining to people with FTD. A review of the guidance could take the form of people with FTD and specialist clinicians supporting people with FTD being invited onto review groups. The review process could enhance and develop FTD-specific psychosocial interventions.

8. People with FTD and family caregivers of people with FTD require access to FTD-specific information

It is important that people with FTD and their caregivers can access appropriate and evidence-based information about FTD. There is a need for FTD-specific information to be easily accessible. This could be achieved by appropriate information being available in hard copy in health and social care settings. Clinicians involved in developing information given to people during assessment processes should review the information to ensure that the needs of people with FTD and their family members are met. Staff with an ongoing remit of support should be aware of the resources available and local arrangements put in place to ensure easy access.

An initiative or campaign to highlight the need for the development of FTD-specific information provided at the right time, by the right person, should be led by specialist clinicians and involve all appropriate stakeholders. The campaign could be championed by existing dementia groups and disseminated nationally.

9. Communication and sharing of information between organisations and agencies

Processes need to be developed that allow the communication and sharing of information pertaining to people with FTD between organisations and agencies providing assessment and/or support. This is important in reducing the conflicting advice and associated distress experienced by people with FTD in touch with various organisations. Lead clinicians should be empowered to liaise more closely with contemporary partners to ensure that people with FTD experience smooth life transitions and appropriate support throughout their journey. The pathways should extend beyond the remit of health and social care agencies and include more partners such as benefits agencies, driving assessment centres, employers, communities, occupational health and housing professionals. Ways to develop this could include lead clinicians chairing multi-agency meetings and becoming involved in special governmental committees whereby any individual or group can petition the government to take a view

upon a matter of public interest or concern. This would both raise the profile of a marginalised group and bring the issues to the notice of a forum that has the strategic ability to make changes to existing processes.

6.11 Recommendations for research

Future research should focus on including the perspectives of people with a diagnosis of FTD. Given participants' ability to take part in this study and the depth of data collected, it is particularly important to generate more research on the lived experience of FTD from the person's perspective.

Given that only one participant in this study had been provided with a specific subtype of FTD at the time of diagnosis, more research is necessary to explore the lived experience from both a broad FTD diagnosis and for each subtype of FTD. This would improve understanding of whether people with different subtypes of FTD experience similar symptoms.

To the best of my knowledge, there are no studies that explore the lived experience of FTD in people who live alone. Literature involving research from people with AD and older people suggests people living alone experience earlier hospitalisation. Given the nature of the symptoms experienced by participants in my study, further research is necessary to explore the type of support that might enable people with FTD living alone to remain well-supported in their own homes for longer.

My study has highlighted differences in experiences between the person living with a diagnosis of FTD and the literature surrounding the views of family caregivers of people with FTD. Further research exploring the difference in perspectives in family roles and relationships is important in that it could help clinicians develop more support for both the person and their family caregivers.

Further research is necessary to understand the physical symptoms that people with FTD experience. This has been discussed in the current study as the most significant symptom impacting negatively upon the quality of life. There is an

opportunity for MND and FTD researchers to come together to share and develop knowledge.

There is a paucity of research into how people with dementia can be supported to remain in paid employment. I could find no such studies which included people with FTD. This is an important area for future research as the loss of working role caused significant distress to people with FTD.

Other areas that require further research include the views of people with FTD on clinical issues such as advance care planning, levels of insight and awareness, processing problems and how people with FTD can be supported to manage their emotions. A significant issue for researchers is how to ensure that the quantitative research into the pathology of FTD is disseminated into useful practical guidance which can be utilised by frontline staff to improve the frontline support offered to people with FTD.

In summary, the findings identified and discussed in this study represent the lived experience of people with a diagnosis of FTD from their perspective. To ensure that the research recommendations from this study reflect the needs of people living with FTD, future research should ensure the voices of people with FTD are at the centre of all future research.

6.12 Final Reflection

Initially I commenced upon the doctoral journey for two reasons. The first reason was to continue on my journey from completing a Masters in Dementia where I explored the needs of younger people with dementia to a more focused understanding of the experiences of people with FTD. This was driven by clinical experience whereby I supported people with a diagnosis of FTD and the lack of knowledge and awareness of this condition that I encountered both in general and specialist services. The second reason was of a more personal nature in that I wanted to demonstrate that I was capable of studying at doctoral level.

Regarding the need to understand the experiences of people living with a diagnosis of FTD, I now feel I have explored this over the last seven years and in doing so, have developed a comprehensive understanding of the experiences of the seven participants who took part in the study.

With regards to the second reason of demonstrating capability of studying at doctorate level, I have some mixed feelings about this now. Initially, having discussed the requirements of the clinical doctorate programme with several academics, I remember one conversation with a retiring nurse lecturer clearly. I expressed my fears of not being clever enough to study at this level and how other academics seemed to be much clearer and articulate in comparison to myself in expressing their knowledge and views. Her response was as follows:

"It's not just about knowledge. It's about stickability".

I now reflect upon my emotional journey through the doctorate and agree whole-heartedly with her response. A doctorate programme can be described as a journey (McCulloch 2013) which helps with the attainment and application of knowledge. However, I have discovered you can never know everything and my experience of this doctoral journey has very much been that the more you learn, the more you realise you do not know.

I have had to change my expectations of becoming an 'expert' in a field because of completing doctoral study of a particular phenomenon to an acknowledgement of a developing awareness that the only true experts are experts by experience. I have developed more knowledge about the lived experience of FTD and ideas of how to apply this knowledge to clinical practice. However, on a more personal note, I have come to develop resilience which resonates closely with the retired lecturer's notion of 'stickability'. I now understand how important these concepts are not only in clinical practice but in all walks of life. It has taken me seven years to complete this doctorate and much of this time has been due to unforeseen personal issues which resulted in less time devoted to study. Had I not engaged in a phenomenon that I had been truly passionate about and was clinically relevant, my 'stickability' would

have crumbled around me. Therefore I am indebted to the advice of the nurse lecturer who introduced me to, and started me on my journey. Stickability is fundamentally dependent upon and inextricably linked to the correct choice of topic for each individual student.

There have been several positive aspects to completing the doctorate. For me, developing confidence in my own knowledge about FTD and the ability to complete this journey has resulted in me leading new projects and presenting at international conferences. I have now, found a balance between being confident in myself in terms of knowledge of FTD, whilst at the same time, having developed confidence to question others and enter into academic debate.

Initially, I found the experience of supervision quite intimidating. My supervisors were experienced academics and during a discussion of the difficulties in recruiting participants, suggested I also interview family caregivers. I found myself in the uncomfortable position of fundamentally disagreeing with this suggestion and feeling I was disrespecting my supervisors when arguing the importance of hearing the voices of people living with FTD as opposed to caregivers. However, reflecting back on this discussion, I now acknowledge this was a key moment in my doctoral journey where I learnt to stand by my rationale for the study and use the research gap as evidence in itself as to why the study should only focus on the lived experience of people with FTD. Far from being the negative experience I felt it was initially, it has paved the way for me developing as an academic and the ability to make and stick to decisions which are fundamentally important to me (Barnett 2007; Ellis 2004).

Having reflected upon the journey, I now realise that my confidence has gradually increased to a point where receiving all forms of feedback and criticism has improved my intellectual agility and I have begun to adopt a more mindful approach to all aspects of my professional life both academic and clinical. I have developed the ability to be curious, test my findings in a clinical setting and develop resilience. As suggested by Fulton et al. (2013), I have created learning spaces where I can test and debate my thoughts with other

professionals. In the future, my intention is to create more learning spaces for myself and colleagues and encourage the use of research evidence as a basis for decision making in frontline clinical practice.

However, none of this learning would have been possible without the seven participants who took part in the study. I am extremely grateful to each expert participant who have deepened my understanding of the lived experience of FTD. I hope that this enhanced understanding will assist me in making meaningful changes to clinical practice.

6.12 Conclusion

In this thesis, I have presented and discussed the findings of the first study to interview people diagnosed with any subtype of FTD about their lived experience. This study contributes new knowledge regarding the rocky road through assessment, changes to self, being in touch with reality and keeping going. The voices of people with FTD have been placed at the centre of the research study and have increased knowledge of an under-researched and misunderstood area of dementia care.

I believe I have developed as a researcher throughout the study. My clinical background involved supporting people under the age of 60 presenting with the behavioural and psychiatric symptoms of dementia and I had concerns about the lack of knowledge in clinicians as to how to best support people with FTD throughout their journey. Therefore, I decided to pursue research in order to better understand the experience of living with FTD from the person's perspective. The participants in this study helped me understand how it might feel to live with a diagnosis of FTD. Over the interview processes, I believe I gave people with FTD the opportunity to be heard and I learnt about aspects of their lives and challenges that I had not identified, far less understood, as a clinician. I firmly believe as I take up a new role with clinical responsibilities that I will be a better clinician because of undertaking this study.

The findings of this study have the potential to inform and enhance the development of support offered to people with FTD. By including people with FTD in decision-making processes, support and services can be refined and tailored to the needs of this marginalised group of people.

I believe it is only once clinicians understand the experience from the person's perspective that they can begin to offer truly person-centred care. This can only be achieved by working collaboratively with the person. Priority must be given to hearing the voice of people with FTD if the quality of life is to be improved.

Recognising the particular issues identified by people with FTD, which differ from those providing support, strengthens the need to involve people with FTD in a meaningful way in order for them to retain some control in their journey and help them live well with FTD. This will help ensure the support provided to people with FTD meets their specific needs. My study has demonstrated that people with FTD can reflect upon their experiences and make suggestions as to how others may best support them in their journey. As advocates for our patients, nurses are ideally placed to empower individuals with FTD and to influence future practice, policy and research (NMC 2018). The key findings of this study are important in terms of improving assessment processes; understanding how a changing sense of self impacts upon people with a diagnosis of FTD; recognising that the experiences of living well with FTD from the person's perspective are different from the views of family members and professionals reported in the literature, and how people with FTD cope on a day-to day-basis with the symptoms of FTD.

In conclusion, the key insights of this study highlight a need to personalise and reduce duplication of the assessment process to ensure the focus of assessments meet the needs of people with FTD. To provide person-centred assessments, professionals require to be aware of how their beliefs and knowledge impact upon the experience of people being assessed. Alongside the development of person-centred assessments, the provision of FTD-specific information is necessary to support people receiving a diagnosis of FTD.

The study has found that people experience a changing sense of self, which impacts upon the roles and relationships people with FTD have with significant others. Loss of roles and relationships can be reduced by introducing strategies that shift responsibilities and roles rather than sudden removal of roles. Such strategies could lessen the feelings of alienation reported by participants in this study.

Participants have also discussed their feelings of anger and the issues around being labelled as vulnerable people. This study has identified that the physical symptoms of FTD have the most significant and negative impact upon the quality of life and is an important finding which differs from the current literature that reports the behavioural and psychological symptoms of dementia as being the most challenging aspect of FTD from family and professionals' perspectives. The study has also highlighted that participants demonstrated high levels of insight and awareness into their experiences but had difficulties in processing information in decision-making situations, which have significant implications for how professionals and family members support people with FTD.

Participants discussed the need to fight FTD which included living day to day and avoiding planning ahead for their future needs. The challenge for professionals is how to ensure the views and wishes of people with FTD are heard sensitively and embedded into the support they receive in the later stages of their journey, whilst, at the same time, respecting the need for people with FTD to continue to live well with FTD by using the coping strategy of not planning ahead.

This study has demonstrated that people with FTD have insight into their condition and can articulate their experiences of living with FTD. By increasing our understanding of the lived experience from the person's perspective, this research has shown that people with FTD want to be meaningfully engaged in making decisions about their journey. By placing the experiences of people with FTD at the centre of practice, this thesis makes recommendations for developing FTD-specific interventions to improve support and quality of life for

those living with the condition. With attention to their lived experience, people with FTD have useful insights to offer the clinicians who support them.

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Appendix 1: Literature review studies

First Author and Year of Publication	Country of Study	Study design	Study Population	Methodology	Research Question/Study Aim	Methods	Outcomes Measured /Findings	Conclusion/recommendations	Strengths/ Limitations
Edberg and Edfors (2008)	Sweden	Primary research qualitative	All (n=10) nurses who had been working for at least two years training as assistant nurses. Special housing in a unit for people with frontal lobe dementia (FLD in this case can include alcohol-related brain damage and vascular dementia. Therefore FLD refers to having frontal type symptoms rather than a diagnosis of FTD.	Content analysis	To describe nurses' experiences of difficulties and possibilities in caring for people with dementia diseases with frontal lobe dysfunction.	Semi-structured interviews	Themes which emerged:- 1. Difficulties relating to the residents' behaviour:- • When inhibition and judgement fail • When anxiety is prevalent • When anger is out of control • When the ability to cope with physical needs is reduced • When the ego takes centre stage • When the balance between	Nursing people with FLD can create ethical issues where the person's integrity is balanced against a safe and secure environment Nursing care is a sensitive and demanding position but can reduce distress Staff must be supported to manage work and to avoid emotional exhaustion	Therefore, FLD refers to having frontal type symptoms rather than a diagnosis of FLD. Only 1 unit involved, therefore, narratives could have been influenced through discussion

							rest and activity is unstable • When dejection becomes un controllable 2. Possibilities relating to the nurses' actions (positive learning experiences that can translate into action):- • Being clear and consistent • Being a step ahead, being flexible and seizing the moment • Being calm, creating a positive atmosphere • Being close and building trust • Being and doing things together • Receiving continuous feedback and support		
Griffin et al.	UK	Primary	Five people with	IPA	To	Semi-	Themes that emerged:-	The difficulties in	Potential bias

(2016)		research qualitative	diagnosis of probable bvFTD (behavioural FTD), identified by clinical staff in a working-age dementia centre in a large urban UK centre.		understand the lived experience of bvFTD from the perspective of the person diagnosed with bvFTD.	structured interviews	1. Bewilderment • Awareness of change – what's the problem? • Threats to self-this is not me 2. Relationships with others • Family and friends—things haven't changed but do I say the wrong thing? • Coping with threats to self: blame others or just avoid them.	the early stages of bvFTD of processing information at an emotional level may be overlooked when capacity is being assessed therefore people with bvFTD may have limited ability to understand possible impacts of their decision-making—support required to take account of this. bvFTD specific interventions are required which are not based on cognitive needs of people with other types of dementia but interventions re. impact of social interactions are required—family-based interventions	from adjustments in the interview process which permitted objects/prompts
Johannessen et al. (2017)	Norway	qualitative	16 caregivers' (wives, husbands and cohabitants) of people with a diagnosis of young-onset FTLD. All recruited through 7	Grounded theory	To examine spouses of young-onset-FTLD Themes which included experiences and needs for assistance	Semi-structured interviews	Themes that emerged:- 1. Sneaking signs at the early stage of dementia • Incompreh ensible early signs • Lack of self-insight 2. The torment,	Sneaking signs of early stage—driving and anger were prominent issues Torment—included increasing dependence upon family Issues around the	Findings are transferable Small sample size. Need to engage over a longer time frame

			memory clinics, dementia specialist teams or specialist nursing home		in daily life.		3. interference with work and vanishing social relations 3. Needs for assistance through all stages • Relief of diagnosis • Support at home • Path to nursing home care	person not applying for benefits and impact on family finances GP lack of knowledge of FTD Alzheimerisation od family support groups Preference for support from younger-onset specialist services as they had greater knowledge More information required about FTD Need for inter-disciplinary, individualised and specialist support throughout the journey More knowledge required in health personnel IT can help develop better support Need for support around benefits/financial assistance and guidance	

								Need for whole family support	
Kindell et al. (2014)	England	Primary research Case study	The wife and son of a person with a confirmed diagnosis of semantic dementia from a specialist centre. The condition needed to be having an impact on communication within everyday life observed by mental health community team service staff during visits to the home.	Thematic Narrative analysis	To explore and describe the everyday experiences of people living with semantic dementia.	Case study Semi-structured interviews Standardised assessment of communication difficulties Conversation analysis Narrative analysis	Themes which emerged:- 1. Living with routines 2. Policing and protecting 3. Making Connections 4. Being adaptive and flexible Changes in communication Loss of inhibition—socially embarrassing behaviours Need to promote quality of life Loss of the person Loss of relationship	Generalising the experience of dementia caregivers may mask particular needs of caregivers of people with SD Living with routines (not through choice) but as part of symptoms that had to be assimilated into everyday life—to provide effective care services must understand the importance of this. Caregivers need support in managing emotional challenges A need for wider communities to understand about SD Need to increase understanding of SD in professional caregivers Support that includes practical strategies for	One family—cannot be generalised

								managing communication—essentially this is about fostering emotional connections and relationships Interventions involving reminiscence of past events were not always positive for people with SD—current events were just as, if not more, important—models for other types of dementia need to be adapted Need for accessible information about SD-specific support	
Kindell et al. (2017)	UK	Primary research Mixed methods Case study	1 woman with a diagnosis of semantic dementia and her husband visited at home over 18 months with 20 visits made.	Mixed methods Conversational analysis and narrative analysis	To gain in-depth insight into the everyday experiences of the family. To use this knowledge to plan and deliver an individually tailored intervention	Semi-structured interviews Videos of everyday conversations	The importance of individualising interventions—helped create a positive identity and uses remaining skills Music can provide positive opportunities for people with SD to interact positively and participate Music facilitates a different range of interactional skills compared to everyday conversation—increased	More attention required in the benefits of interventions which create 'in the moment' benefits Importance of developing interventions for people with SD that focus on enhancing participation as opposed to language function	Case study of 1 family—cannot be generalised

					to enhance interaction in the home situation. To explore the effects of the intervention on interaction and participation		well-being in the moment		
Massimo et al. (2013)	USA	Primary research Qualitative	2 wives of people diagnosed with probable FTD who were established patients at a specialised cognitive neurology clinic in a large university health care setting. Spouses had under 2 years of disease duration.	IPA	To enable the caregiver to give an account of caring for her spouse with FTD. To begin to explore spouses' perceived experiences of, and responses to, living with a person with FTD. To reveal caregivers' stressful incidents, articulated meanings	Semi-structured interview Questions included:- How did you first understand the diagnosis of FTD? What does the diagnosis of FTD mean for you now? Are certain behaviours difficult for you to manage?	Themes that emerged:- 1. Identity and role change 2. Isolation 3. Anger 4. Facing the future 5. Reframing FTD caregivers experience loss of previous identity; marital connections; loss of shared meaningful future	Need for greater understanding of behaviour and emotional responses of caregiver Caregiver burden associated with anger and emotional detachment Special attention and support should be offered to caregivers early in the disease to identify coping strategies; provide alternative interpretations and facilitate discussion of losses Help caregivers 'read' social	2 interviews only which limits generalisability More research necessary

					and strategies to cope with behaviours that are common in FTD.	What has been most difficult for you as a caregiver? What does a good day look like for you?		situations Research on the effectiveness of interventions	
Nicolaou et al. (2010)	Australia	Primary research Cross-sectional design	30 Carers of people with diagnosed FTD and 30 carers diagnosed with Alzheimer's Disease (AD).	Quantitative Non-experimental	To explore the needs, level of burden, depression and anxiety of FTD carers and AD carers.	Multiple valid and reliable caregiving scales—Revised memory and behaviour problems checklist; Camberwell assessment of need for the elderly; Zarit Burden interview; Depression, anxiety and stress scale.	Length of time to get diagnosis—no significant difference Length of caring—no significant difference FTD carers have greater levels of household activities; food; self-care; daytime activities; communication; continence; psychological symptoms; information; deliberate and accidental self-harm; abuse; behaviours; social company; money; information for carers and carer distress—all significantly greater for FTD carers and perceived as unmet needs as compared to AD carers.	FTD-specific information and support regarding behaviour for carers and raising community awareness (risks and insight) Provision of domiciliary, activities and social company should be targeted for FTD carers Education programmes for FTD carers Future research to consider differentiating type of dementia when investigating carer well-being	RMBPCL may not adequately assess characteristics of FTD Carer-rated frequency of behaviours may be influenced by the level of burden experienced, thus may be innaccurate

							Memory—similar over 2 groups Caregivers FTD received more informal help Formal help similar for 2 groups FTD-specific needs—younger onset; financial issues; access to services, information, support; symptoms of FTD; need for FTD-specific information; biggest area of concern is behavioural symptoms. Greater risk of threatening behaviours Higher levels of carer distress Similar levels of carer burden	Future studies need to include measures that include symptoms of FTD Recruitment was through a service that supports carers therefore, findings may not represent the experience of carers who are not in receipt of such support. Development of interventions specifically for people with FTD	
Oyebode *et al*. (2013)	UK	Primary research qualitative	Participants recruited through clinical staff at 2 specialist, working-age dementia services.	IPA	To explore experiences of having a relative with fvFTD with a view to improving awareness	Semi-structured interviews	11 Themes identified—into 3 groups:- Changes in behaviour and habits witnessed in people with fvFTD (overeating; walking excessively)	Experience of structural stigma highlighting need to provide support	Small sample—6 Sample sourced by clinicians who may have been

			6 first-degree relatives of people who had received a diagnosis of fvFTD (frontal variant FTD)		of the challenges for relatives and potentially enabling services to better meet the needs of these families. To take an in-depth look at the experiences of those with a family member with fvFTD to discover whether there were distinctive features and to explore the way the condition impacted their lives and relationship with the person with fvFTD.		Loss of drive and motivation (personal hygiene) Lack of forward planning—work; organising and seeing out tasks Loss of inhibition—social embarrassing behaviour Risky behaviou—lack of common sense and judgement Communication problems Managing behaviours: Carers taking on tasks and roles Defending, asserting and explaining Promoting quality of life Working around lack of awareness Relationships: Loss of person, relationship and heartbreak Sources of support, solace and hope		overprotective of clients in crisis—biased sample May be particular needs for spousal caregivers

							FTD—offered nursing homer stays more often FTD carers less satisfied with information provided about disease compared to AD FTD less satisfied with counselling and follow-up advice		
Pozzebon et al. (2017)	Australia	Qualitative case study	One spouse who supported her husband with semantic variant primary progressive aphasia (svPPA)	Narrative analysis	To explore the experience of a spouse who supported her husband with svPPA throughout the course of the condition, with a particular focus on how she dealt with the relational changes svPPA imposed on them.	Semi-structured interview	Themes that emerged:- 1. Us 2. The way he was.and.the way he is now 3. Floundering with unpredictability 4. Adjusting and accepting support 5. Taking control	Learning to live with someone so changed was traumatic in terms of coping with unpredictability; adjusting and accepting support; and having to take control. Clinicians must remain sensitive to the role the spouse plays and offer support to help them adjust to changes in the relationship throughout the journey.	Small sample cannot be generalised Female caregiver may be different experience from a male caregiver
Pozzebon et al. (2018)	Australia	qualitative	13 spouses of people with a diagnosis of primary	grounded theory	To gain an understanding of the personal	Semi-structured interviews	Themes which emerged:- 1. Acknowledging disconnect in the spousal	Assist couples to reframe their relationship	Volunteers may have had strong relational

			progressive aphasia (PPA)		experiences of spouses living with a partner diagnosed with PPA		relationship—episodes of overt anger 2. Living the decline—carer sense of self decline; reduced quality of spousal relationship; reduced social world 3. Readjusting sense of self 4. Getting on with living—rekindling social networks	Greater understanding of spousal relationships could help develop interventions that aim to sustain emotional and relational connections Clinicians should initiate discussion rte. Needs, wants and day-to-day difficulties Tailored interventions to help to adjust to ongoing change Recognise the importance of declining language Most enduring caregiving challenge is dealing with relational disconnect Need for early information/support	bonds. Accounts could be influenced by current experiences—single interview Small number of recruits All spouses were married, mainly women and all English-speaking
Rasmussen et al. (2019)	Norway and Sweden	Qualitative	14 family caregivers of people diagnosed with FTD	Hermeneutic approach	To explore the family caregivers' experiences of the pre-diagnostic	Semi-structured interviews	Themes that emerged:- 1. Becoming distant 2. Becoming insecure 3. Becoming	Becoming distant—gradual changes which were not obvious—differential diagnoses	Small sample cannot be generalised but findings transferable

			2 hospital psych-geriatric units and 1 hospital neurological unit		stage of FTD		devastated 4. Becoming a stranger	Becoming insecure—symptoms not always picked up on by GP Becoming devastated—issues around safety particularly driving. Reduced carer working hours due to concerns around safety. Becoming a stranger—conflicting feelings of —require support in their role Biggest difference between pre-diagnostic stage of FTD and other dementias was a delay indiagnosis and having to adapt to situations and finding resolutions. Clinicans could pay attention when spouses are concerned about personality and behavioural changes of loss of function	

								Need to raise awareness of FTD amongst GPs and specialists	
Rasmussen and Hellzen (2013)	Norway	Primary research	A geriatric psychiatric unit in a nursing home in Norway. 10 staff members working with patients with frontal lobe dementia (FLD), chosen in cooperation with the unit leader. Participants had worked in the unit for at least one year. Participants had different professional backgrounds. At time of study 4 patients were diagnosed with FLD.	Phenomenological hermeneutical approach	To explore the experiences of staff through their everyday work with people with FLD	Semi-structured interviews	3 main themes emerged:- 1. Being aware of the relationship with the patient: being close to the patient 2. Being insecure: being scared of present situation getting worse; being uncertain about caregiving 3. Being safe: being aware of patient having a good moment; being a step ahead and handling aggressive behaviour professionally	Be a step ahead Be flexible and calm Create a positive atmosphere Do things together Pick up on non-verbal cues Staff need support Special chemistry between staff The need to build up a relationship with the person	At time of study there were only 4 people with FLD All staff worked in the same place—daily discussions could have influenced narratives
Sagbakken et al. (2017)	Norway	Qualiltative Descriptive	Interviewed 9 relatives of people with FTD and similar	Phenomenology and hermeneutics approach	To develop knowledge related to dignified or	Semi-structured interviews	The importance of dignity theory Preservation of carer	People with FTD are often young and physically fit but still require special care	Recruitment by head nurses in nursing

		Explorative design	conditions living in nursing homes 2 relatives of people with FTD living at home attending day centre x5 days/week		undignified care of patients with FTD and similar conditions from the perspective of close relatives Illuminate factors that help preserve patient digntiy		roles and activities Relatives feeling alienated Individual confirmation aand influence—dignified care is linked to personalised care The importance of the person having influence in their own care Living in a closed system—specialised units and feeling humiliated	because of aggression/impulse issues—specific needs Close relationship between dignity, autonomy and integrity—the need for the person to influence decisions Need for FTD-specific nursing home provision Importance of providing information about FTD Staff competence needs to be enhanced Links to the outside world need to be maintained	home—could lead to biased sample. Not all patients had FTD—7 diagnosed and 4 people with other types of dementia but similar behavioural symptoms

Appendix 2: Ethical approval letter: GUEP

UNIVERSITY of STIRLING

Suzanne Croy
Faculty of Health Sciences and Sport
University of Stirling
Stirling FK9 4LA

19 April 2017

General University Ethics Panel (GUEP)
University of Stirling
Stirling
FK9 4LA
Scotland UK

E: GUEP@stir.ac.uk

Dear Suzanne

Re: Ethics Application: Living with a diagnosis of frontotemporal dementia (FTD); What helps and hinders (GUEP100)

Thank you for making the requested revisions to your submission of the above to the General University Ethics Panel.

I am pleased to confirm that GUEP has approved your application, and you can now proceed with your research.

Please note that should any of your proposal change, a further submission (amendment) to GUEP will be necessary.

If you have any further queries, please do not hesitate to contact the Committee by email to guep@stir.ac.uk.

Yours sincerely,

p.p.

On behalf of GUEP
Professor Margaret Maxwell
Deputy Chair of GUEP

THE QUEEN'S ANNIVERSARY PRIZES FOR HIGHER AND FURTHER EDUCATION 2013

www.stir.ac.uk

Appendix 3: Ethical approval letter: *EoSRES*

NHS SCOTLAND

East of Scotland Research Ethics Service *(EoSRES)* **Research Ethics Service**

TAyside medical Science Centre
Residency Block Level 3
George Pirie Way
Ninewells Hospital and Medical School
Dundee DD1 9SY

Mrs Suzanne R Croy
School of Mental Health Nursing and Counselling,
Kydd Building
Abertay University,
Bell Street
Dundee
DD1 1HG

Date: 26 January 2018
Your Ref:
Our Ref: LR/AG18/ES/0003
Enquiries to: Arlene Grubb
Direct Line: 01382 383848
Email: eosres.tayside@nhs.net

Dear Mrs Croy

Study title: **Living with a diagnosis of frontotemporal dementia (FTD): What helps and hinders?**
REC reference: **18/ES/0003**
Protocol number: **N/A**
IRAS project ID: **231798**

Thank you for your letter of 26 January 2018. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 18 January 2018.

Documents received

The documents received were as follows:

Document	Version	Date
IRAS Checklist XML [Checklist_26012018]		26 January 2018
Email regarding recommendations/Suggestions]		26 January 2018
Participant consent form [Participant consent]	2	23 January 2018
Participant information sheet (PIS) [Participant Information Sheet v2 26 01 18]	v2	22 January 2018

Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	Version	Date
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [Approval letter]		26 September 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [NHS research governance]		08 November 2017
Interview schedules or topic guides for participants [Interview schedule]	1	01 December 2017

disability confident EMPLOYER

1

Interview schedules or topic guides for participants [Interview Schedule v1 1 12 17]	v1	01 December 2017
IRAS Application Form [IRAS_Form_06122017]		06 December 2017
IRAS Application Form XML file [IRAS_Form_06122017]		06 December 2017
IRAS Checklist XML [Checklist_01122017]		01 December 2017
IRAS Checklist XML [Checklist_06122017]		06 December 2017
IRAS Checklist XML [Checklist_26012018]		26 January 2018
Letter from sponsor [Approval from sponsor]		26 September 2017
Other [Email regarding recommentations/Suggestions]		26 January 2018
Participant consent form [Consent form support person]	1	01 December 2017
Participant consent form [Participant consent]	2	23 January 2018
Participant information sheet (PIS) [Patient Information Sheet]	1	01 December 2017
Participant information sheet (PIS) [Support person information sheet]	1	01 December 2017
Participant information sheet (PIS) [Support Person Infomration Sheet v1 1 12 17]	v1	01 December 2017
Participant information sheet (PIS) [Participant Information Sheet v2 26 01 18]	v2	22 January 2018
Research protocol or project proposal [Research Protocol full]	1	01 December 2017
Summary CV for Chief Investigator (CI) [Curriculum Vitae SC]		27 July 2017
Summary CV for student [Curriculum Vitae SC]		27 July 2017
Summary CV for supervisor (student research) [Curriculum Vitae AS]	1	01 December 2017
Summary CV for supervisor (student research) [Curriculum Vitae JR]	1	01 December 2017

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

18/ES/0003	**Please quote this number on all correspondence**

Yours sincerely

Arlene Grubb

Arlene Grubb
Assistant Co-ordinator

Email: eosres.tayside@nhs.net

Copy to: Dr Amanda Wood, NHS Fife

Appendix 4: Participant information sheet 1

Information Sheet for Alzheimer Scotland Service Users

UNIVERSITY OF STIRLING

'Living with a diagnosis of frontotemporal dementia: What helps and hinders?'

INFORMATION SHEET

Suzanne Croy

This leaflet is about a study which involves asking people what life is like living with a diagnosis of frontotemporal dementia.

Suzanne Croy is a doctoral student at the University of Stirling and would like to understand what helps and hinders living well with frontotemporal dementia.

To understand more about what life is like living with frontotemporal dementia, I would like to organise some interviews with you to discuss your experience and views. I would like to ask your permission to include you in these interviews.

Do I have to take part?

It is important to make it clear that you do not have to take part if you would prefer not to. You do not have to explain or say why. Your decision to take part or not to take part will have no effect on the support you receive.

What happens if you take part?

If you agree to take part, I will visit you three times and audio-record each interview. I expect each interview to last for about one hour.

If you agree to take part, you can stop taking part at any time and without explaining why.

The information that I collect will be used to understand how you experience life and what helps and hinders you to live well. All information will be stored securely and I will not use any names or information that might identify you.

You will receive a summary of the findings at the end of the study. I will also publish the study results in a journal and at conferences. Although I cannot guarantee this, I hope that the information I find out through this study will help services to support people with frontotemporal dementia more effectively in the future.

The study is self-funded as part of my doctoral studies at the University of Stirling.

What if I would like more information?

If you would like to ask questions about the study you can contact Suzanne Croy at Abertay University (01382 308576 or s.croy@abertay.ac.uk). You can also contact my supervisors for further information – Dr Ashley Shepherd (01786 473171 ashley.shepherd@stir.ac.uk) and Dr Jane Robertson (01786 466322 j.m.robertson@stir.ac.uk).

If you have any comments or concerns that you would like to discuss with someone not connected to the project, please contact Dr Kath Stoddart, who is the Programme Lead of the Clinical Doctorate: Doctor of Nursing programme, University of Stirling (01786 466395 or k.m.stoddart@stir.ac.uk)

You can also share this information leaflet with a friend or relative if you would like to discuss taking part with them.

If you decide you would like to take part in this study, please complete the consent form with Suzanne or a member of staff at Alzheimer Scotland. You can ask questions if you would like more information and you can change your mind about taking part at any time.

THANK YOU FOR READING THE LEAFLET

Appendix 5: Participant information sheet 2

V2 22-1-18

UNIVERSITY OF STIRLING

'Living with a diagnosis of frontotemporal dementia: What helps and hinders?'

PARTICIPANT INFORMATION SHEET

Suzanne Croy

This leaflet is about a study which involves asking people what life is like living with a diagnosis of frontotemporal dementia.

Suzanne Croy is a doctoral student at the University of Stirling and would like to understand what helps and hinders you living well with frontotemporal dementia.

Purpose and background to the research

To understand more about what life is like living with frontotemporal dementia, I would like to organise some interviews with you to discuss your experience and views. I'm doing this research because there is very little information available about how people experience frontotemporal dementia and their views about what helps and hinders living well with this condition. Exploring your experiences and views is important as the symptoms of frontotemporal dementia are different to other types of dementia. I am hoping to recruit between six and ten people with a diagnosis of frontotemporal dementia to be interviewed up to three times.

Do I have to take part?

It is important to make it clear that you do not have to take part if you would prefer not to. You do not have to explain or say why. Your decision to take part or not to take part will have no effect on the support you receive.

What happens if you take part?

If you agree to take part, I will ask you to consent to up to three visits and audio-record each interview using a digital recorder. I will only record after you have agreed and I will let you know when the recording is being stopped. The recording will be transferred from the digital recorder to a password protected computer and the audio recording on the digital recorder deleted. I will transcribe the recording ensuring that any identifiable information is changed to make the transcription anonymous.

The information that I collect will be used to understand how you experience life and what helps and hinders you to live well. I understand that you will be speaking about sensitive issues. If you wish, you can stop taking part at any time and without explaining why. You may ask for the recording to stop at any time. I expect each interview to last for about one hour.

Should you become unable to consent during the study I would not ask you to participant in another meeting. However, I would use the existing interview data which had been collected up to that point. You will be able to contact the researcher and ask for your data to be withdrawn from the study for a period of three months following our final meeting. After three months the link between your interview and your identifying details will be destroyed and it will not be possible to identify your data after this date and you will be unable to withdraw from the study.

Is my information kept confidential?

The information you provide during the interview will be kept confidential by the researcher. All participants have the right to confidentiality. However, challenging situations can arise when confidentiality rights must be balanced against duties to protect and promote the health and welfare of participants. Under these circumstances I would explore the reasons with you for the need to disclose confidential information with you and follow the NHS polices and procedures.

Will I benefit from taking part?

It is unlikely that you will receive any direct benefit from participating in this research. Previous studies have shown that some participants have found taking part in similar research helpful or therapeutic; however, this is very dependent on individual circumstances and it cannot be guaranteed that participants in this study will derive the same or similar benefit.

You will receive a summary of the findings at the end of the study. I will also publish the study results in a journal and at conferences. The study is self-funded as part of my doctoral studies at the University of Stirling.

Who has reviewed the study?

The East of Scotland Research Ethics Service REC2, which has responsibility for scrutinising all proposals for medical research on humans, has examined the proposal and has raised no objections from the point of view of research ethics. It is a requirement that your records in this research, together with any relevant medical records, be made available for scrutiny by monitors from the University of Stirling and NHS Fife, NHS Greater Glasgow and Clyde or NHS Tayside, whose role is to check that research is properly conducted and the interests of those taking part are adequately protected.

What if I would like more information?

If you would like to ask questions about the study you can contact Suzanne Croy at Abertay University (07565 972038 or s.croy@abertay.ac.uk).

You can also contact my supervisors for further information – Dr Ashley Shepherd (01786 473171 ashley.shepherd@stir.ac.uk) and Dr Jane Robertson (01786 466322 j.m.robertson@stir.ac.uk).

If you have any comments or concerns that you would like to discuss with someone not connected to the project, please contact Professor Jayne Donaldson, Dean of Faculty, Faculty of Health Sciences & Sport at jayne.donaldson@stir.ac.uk

How do I make a complaint about the study?

If you believe that you have been harmed in any way by taking part in this study, you have the right to pursue a complaint and seek any resulting compensation through the University of Stirling who are acting as the research sponsor. Details about this are available from the research team. Also, as a patient the NHS, you have the right to pursue a complaint through the usual NHS process.

For people living in the NHS Tayside area, you can submit a written complaint to the Patient Liaison Manager, Complaints Office, Ninewells Hospital, Dundee (Free phone 0800 027 5507).

For people living in the NHS Fife area, you can submit a written complaint to the Patient Relations Department, Fife NHS Board, Room 104, Hayfield House, Hayfield Road, Kirkcaldy, KY2 5AH (Telephone 01592 648153 Ext. 28153).

For people living in the NHS Greater Glasgow and Clyde area, you can submit a written complaint to the Complaints Department, West Glasgow Ambulatory Care Hospital, Dalnair Street, Glasgow, G3 8SJ (Telephone 0141 201 4500).

Note that the NHS has no legal liability for non-negligent harm. However, if you are harmed and this is due to someone's negligence, you may have grounds for a legal action against the NHS but you may have to pay your legal costs.

You can also access support to complain through the Patient Advice and Support Service (PASS). Tel. 0800 917 2127

What happens if I decide to take part in this study?

You can also share this information leaflet with a friend or relative if you would like to discuss taking part with them.

If you decide you would like to take part in this study, you will be asked to complete the consent form with Suzanne or the member of staff who approached you about this study. You can ask questions if you would like more information and you can change your mind about taking part at any time.

THANK YOU FOR READING THE LEAFLET

Appendix 6: Interview schedule

INTERVIEW SCHEDULE

My name is Suzanne. Thank you for agreeing to speak with me today. I am looking to explore your experiences of living with a diagnosis of frontotemporal dementia (FTD). I want to hear your views about what helps and hinders you live well. Thank you for agreeing to the interview being audio-recorded and we can stop the interview at any time.

Topics and themes to explore:

1. Can you tell me a bit about yourself?
2. How have you been getting on since being diagnosed with FTD?
3. How do your family and friends feel you are getting on since being diagnosed with FTD?
4. Can you explain what life is like for you right now?
5. How would you describe a bad day?
6. Can you tell me what leads to bad days?
7. How do you think your life might be if you didn't have FTD?
8. How do you feel about the future?
9. How would you describe a good day?
10. Can you tell me what helps you have a good day?

Appendix 7: Consent form 1

UNIVERSITY OF STIRLING

'Living with a diagnosis of frontotemporal dementia: What helps and hinders?'

CONSENT FORM

Please tick each item in the following checklist to confirm agreement

1. I confirm that I have read and understood the information sheet.	
2. I agree to take part in this study.	
3. I understand what is involved in taking part.	
4. I know that I can stop taking part and do not have to say why.	
5. I know that taking part or stopping taking part will have no effect on the service I receive here or elsewhere.	
6. I understand that all information will be kept confidential and made anonymous.	
7. I understand that all information will be stored securely and accessed only by the researcher and her two supervisors.	
8. I give consent for audio-recording to be undertaken. The voice files may be kept for ten years in line with data protection requirements.	

Consent form for participants

Your name:_____ Your age: _____

Your signature: _____ Today's date: _____

Researcher's or
Alzheimer Scotland staff 's name: _____ Organisation_____

Researcher's
or Alzheimer Scotland staff's signature:_____ Today's Date_____

Appendix 8: Consent form 2

v2. 23-01-18 |

UNIVERSITY OF STIRLING

IRAS ID:231798

Centre Number:

Study Number:18/ES/0003

Participant Identification Number for this trial:

CONSENT FORM - PARTICIPANT

Title of Project: Living with a diagnosis of frontotemporal dementia: What helps and hinders?

Name of Researcher: Suzanne Croy

Please initial box

1. I confirm that I have read the information sheet dated..... (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. 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. ☐
3. I understand that all information will be kept confidential and made anonymous. ☐
4. I give consent for audio-recording to be undertaken. The voice files will be deleted following transcription. The transcription from the voice files may be kept for up to 10 years in line with data protection requirements. ☐
5. I understand that all information will be stored securely and accessed only by the researcher and her 2 supervisors. ☐
6. I understand that data collected during the study, may be looked at by the Researcher and research team, the Sponsors or regulatory authorities where it is relevant to my taking part in this research. I give permission for the Researcher and research team, the Sponsors and regulators to have access to my data. ☐

When completed: 1 for participant; 1 for researcher site file

7. I understand that the information I provide during the interview/s will be kept confidential by the researcher. All participants have the right to confidentiality. However, challenging situations can arise when confidentiality rights must be balanced against duties to protect and promote the health and welfare of participants. Under these circumstances the researcher would explore the reasons with you for the need to disclose confidential information with you and follow the NHS polices and procedures. ☐

8. I agree to take part in the above study. ☐

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Name of Person taking consent	Date	Signature

When completed: 1 for participant; 1 for researcher site file

Appendix 9: Letter to participants

Division of Mental Health Nursing and Counselling
School of Health and Social Sciences
Kydd Building
Abertay University
Bell Street
Dundee
DD1 1HG
13TH August 2018

Dear x,

I hope this letter finds you well. Some time ago you kindly participated in my research study about living with a diagnosis of frontotemporal dementia. I am writing to you to let you know that the study is progressing well albeit taking a bit longer than I had anticipated. I have interviewed six people so far and hope to recruit a few more people soon. At the moment, I am analysing the interviews in which you took part.

I am hoping to be able to provide you with more information next year. Once again many thanks for your support in this project.

Kind regards,

Suzanne Croy

Appendix 10: Support person information sheet

UNIVERSITY OF STIRLING

'Living with a diagnosis of frontotemporal dementia: What helps and hinders?'

SUPPORT PERSON INFORMATION SHEET:
(Staff; family; unpaid carers; other support persons)

Suzanne Croy

This leaflet is about a study which involves asking people what life is like living with a diagnosis of frontotemporal dementia.

Suzanne Croy is undertaking a clinical doctorate at the University of Stirling and would like to understand what helps and hinders living well with frontotemporal dementia.

Purpose and background to the research

To understand more about what life is like living with frontotemporal dementia, I would like to organise some interviews with people with a diagnosis of frontotemporal dementia who access specialist support services to discuss their experience and views. I am doing this research because there is very little information available about how people experience frontotemporal dementia and their views about what helps and hinders them to live well with this condition. Exploring the person's experiences and views is important as the symptoms of frontotemporal dementia are different to other types of dementia.

I am hoping to recruit between six and ten people with a diagnosis of frontotemporal dementia to be interviewed up to three times. I would like to ask professional staff for their help in identifying potential participants for the study; providing them with an information leaflet; and with their consent, support in completing the consent form if they wish to be involved in the study. Although preferable to interview the person privately, if wished, the person may request the support of a family member or staff member to be present during the interviews.

Do I have to take part?

It is important to make it clear that you do not have to help if you would prefer not to. You do not have to explain or say why. Your decision to take part or not to take part will have no effect on any care the person receives, the support accessed by unpaid carers or family members, or your professional position.

What happens if you decide to help?

If staff agree to take part and identify a suitable potential participant, you may be involved in supporting the person to read through the information leaflet and complete the consent form. Alternatively, if

the person indicates they would like to take part in the research and agrees to you providing me with their contact details, you would provide me with the contact details and I will arrange to visit the person to discuss the study further and to assist with completing the consent form.

Once the consent form is completed, I will interview the person on up to three occasions. On each occasion, a consent will be sought and a consent form completed and each interview audio-taped using a digital recorder. I will only record after you have agreed and I will let you know when the recording is being stopped. The recording will be transferred from the digital recorder to a password protected computer and the audio recording on the digital recorder deleted. I will transcribe the recording ensuring that any identifiable information is changed to make the transcription anonymous. I understand that you will be speaking about sensitive issues. If you wish, you can stop taking part at any time and without explaining why. You may ask for the recording to stop at any time. I will make clear that this decision will have no effect on the services they receive now or in the future. I expect each interview to last for about one hour.

If you are supporting the person during interviews, you would not be asked any questions, but you may be able to reassure and support the person throughout the interview. If you agree to take part in supporting a person during the interviews, you will also be asked to read and sign a consent form at each interview and all interviews will be audio-recorded. As we will be speaking about sensitive issues, you could be required to provide some emotional support to the person during and after the interviews. However, if it was felt the person was becoming distressed, the interview would be ended.

What happens to the information?

The information that I collect will be used to understand how the person experiences life with frontotemporal dementia and what helps and hinders them to live well. All information will be stored securely and I will not use any names or information that might identify any person involved or mentioned in the interviews.

Although I cannot guarantee this, the person may benefit from providing their views about living with frontotemporal dementia by contributing to an under-researched area. It may be that the results of the study can be used in the future to complement existing support available and develop new interventions.

The person will receive a summary of the findings at the end of the study. You may be asked to support the person by discussing the summary with them.

I will also publish the study results in a journal and at conferences. The study is self-funded as part of my doctoral studies at the University of Stirling.

What if I would like more information?

If you would like to ask questions about the study you can contact Suzanne Croy at Abertay University (01382 308576 or s.croy@abertay.ac.uk). You can also contact my supervisors for further information – Dr Ashley Shepherd (01786 473171 ashley.shepherd@stir.ac.uk) and Dr Jane Robertson (01786 466322 j.m.robertson@stir.ac.uk). If you have any comments or concerns that you would like to discuss with someone not connected to the project, please contact Professor Jayne Donaldson, Dean of Faculty, Faculty of Health Sciences & Sport at jayne.donaldson@stir.ac.uk.

THANK YOU FOR READING THE LEAFLET

Appendix 11: Supportive observer consent form

UNIVERSITY OF STIRLING

IRAS ID:

Centre Number:

Study Number:

Participant Identification Number for this trial:

CONSENT FORM – SUPPORT PERSON (Staff; family; unpaid carers; other support person)

Title of Project: Living with a diagnosis of frontotemporal dementia: What helps and hinders?

Name of Researcher: Suzanne Croy

Please initial box

1. I confirm that I have read the information sheet dated..... (version 2.1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without the person I am supporting medical care or legal rights being affected. ☐
3. I understand that all information will be kept confidential and made anonymous. ☐
4. I give consent for audio-recording to be undertaken. The voice files will be deleted following transcription. The transcription from the voice files may be kept for up to 10 years in line with data protection requirements. ☐
5. I understand that all information will be stored securely and accessed only by the researcher and her 2 supervisors ☐
6. I agree to support a participant to take part in the above study. ☐

Name of Support Person	Date	Signature
Name of Person taking consent	Date	Signature

When completed: 1 for participant; 1 for researcher site file

Appendix 12: Stages of analysis

Stages of Analysis

Example: Participant 4; Interview 1.- Process begins with a transcription of the interview (column 3), numbering of transcript (column 2), initial noting/coding (column 4 - normal font = what has been stated; underlined = interpretation of what has been stated; italics = use of language/non-verbal/words),emergent themes (column 1). Bold in column 3 indicates a particularly potential quote for use in the findings.

Emergent themes	Line number of transcript	Transcript	Initial noting/coding
	589	P: yes	
	590	I: ask you. How, eh how are you	
	591	feeling about that?	
P4 I1 592 Loss of independence	592	**P: yeah, ah yeah it it's what it**	P4 I1 592 Loss of independence.
P4 I1 592 A sense of unfairness	593	**makes me feel is I'm not, see I I'm a**	Hanging on to independence. Not
P4 I1 592 Feeling judged by society	594	**quite independent, I'm still quite**	feeling as if he is a danger to others
P4 I1 592 Being labelled as	595	**independent and I think I'm not, I'm**	but being treated as if he is. A sense
vulnerable	596	**not em a danger to anyone else,**	of unfairness. Feeling judged by
P4 I1 592 Lack of control	597	**but... in in the em , in the society, in**	society. Feeling society has labelled
P4 I1 592 Forced change of identity	598	**the the structure of dementia and**	him as vulnerable. Not feeling
P4 I1 592 Stigmatisation	599	**things I'm classed as a vulnerable**	vulnerable but being treated as if he
	600	**person. [laughs] Now I don't class**	is. Again – control issues. Changed
P4 I1 600 Labelled	601	**myself as a vulnerable person cause**	identity – forced upon him.
P4 I1 600 The need to give	602	**I can walk and talk ok you know, I**	Stigmatisation.
P4 I1 600 Being stopped from	603	**can help people, still got things to**	
contributing	604	**give to people. I think I think.... still**	
P4 I1 600 Loss of societal role	605	**have got a use... [sighs]... [sighs]...**	P4 I1 600 Not identifying with the
P4 I1 600 The need for purpose	606	**Sometimes I don't think, I don't**	label society has bestowed upon
P4 I1 600 The need to feel useful	607	**know my role in life. You know if**	him. Still being able to give. Being
P4 I1 600 The need to contribute		**I'm, because I don't work you know**	able to contribute to society but this
	608	I: mm hm	not being recognised. *Sighs – sounds like he is sad; tired; and resigned to being reduced somewhat as a person.* Loss of role. Not
P4 I1 600 Feeling pointless	609	P: I don't contribute. I don't think I	

P4 I1 51 Black and white thinking
P4 I1 51 Over-reacting
P4 I1 51 Changed personality
P4 I1 51 Changed behaviour
P4 I1 51 Minimising symptoms
P4 I1 65 The changing self
P4 I1 65 Sense of detachment
P4 I1 65 Emotional bluntness
P4 I1 70 Changing marital relationship
P4 I1 70 Arguing
P4 I1 70 Forgetfulness
P4 I1 70 The changed self
P4 I1 77 The old self
P4 I1 86 Losing ability
P4 I1 86 Processing issues
P4 I1 86 Confusion
P4 I1 86 Profound effect of losing ability
P4 I1 95 Loss of ability (upset)
P4 I1 95 Feeling emotional

Stages of analysis – example: Development of superordinate, subordinate and emergent themes

SUPER-ORDINATE THEME	SUB-ORDINATE THEMES	THEMES
1. Diagnosis, assessment and Support: Experience of support throughout the journey??????	The journey to diagnosis	Seeking diagnosis Not seeking diagnosis Difficulty getting a diagnosis Pre-diagnostic symptoms Hiding symptoms Knowing something is amiss

		Suspecting dementia Receiving a diagnosis Telling others Incongruity Awareness of prognosis and progressive nature of FTD Lack of medical intervention Residential care Confusion at or after diagnosis Knowledge and beliefs about FTD Seeking information about FTD FTD as a hidden disease Feelings at time of diagnosis Coming to terms with diagnosis Maintaining control
	The impact of assessment	Impact of testing Conflicting advice Driving assessment
	Being a patient or service user	Experience with GP Hospital care Feeling stigmatised/labelled Injustice and unfairness Infantilisation Objectification

Stages of analysis – example: Cross analysis of theme 1: Diagnosis, assessment and experiences with care professionals – A. Diagnosis

Sub-topic	Sub-emergent theme number	Sub-emergent theme description	How many times does it appear	Does it jump out?
Seeking diagnosis	P1 I1 16-19	The journey to diagnosis	1	
	P5 I1 14;30;38;40;398	Getting/receiving a diagnosis; journey to diagnosis	5	
	P2 I2 527; 527	Frustration (diagnostic process); irritability (diagnostic journey)	2	
	P2 I1 313; 110; 194	The diagnostic process; journey to diagnosis; lack of clarity over referrals	3	
	P2 I1 334; 326; 110; 153; 784; 237; 334	The problems getting a diagnosis; difficulties getting a diagnosis; symptoms not being taken seriously; incongruence between diagnosis and appearance; coping with testing; timescale regarding	7	

		diagnosis		
	P2 I2 68; 236; 209; 456; 431; 421; 510	Searching for a diagnosis; needing to know; seeking explanations; the diagnostic process	7	
	P3 I1 59; 24; 177	Seeking explanations; seeking explanations for short term memory loss; seeking diagnosis	3	
	P2 I1 89; 143; 302	Seeking explanations for symptoms; seeking answers	3	"Seeking answers" – mini theme???

Stages of analysis – example: Cross analysis of superordinate theme: The rocky road through assessment; sub-theme: journey through diagnosis; themes: knowing something is amiss

THEME	JIM 1	MARY 2	JAMES 3	JOHN 4	NORMA 5	GEORGE 6	SEAN 7	COMMENT
5.1.1.1 Knowing something is amiss		x	x	x		x	x	COULD ALL COME UNDER Knowing something is amiss rather than number individually
5.1.1.2 Pre-diagnostic symptoms			x		x	x		COULD ALL COME UNDER Knowing something is amiss rather than number individually
5.1.1.3 Hiding symptoms and		x		x		x	x	COULD ALL COME UNDER

not seeking diagnosis								Knowing something is amiss rather than number individually
5.1.1.4 Suspecting dementia	x	x	x				x	COULD ALL COME UNDER Knowing something is amiss rather than number individually

Appendix 13: Draft publication

Living with a diagnosis of frontotemporal dementia: What helps and hinders? An interpretative phenomenological analysis

Abstract

Frontotemporal dementia describes a spectrum of disorders that include behavioural changes, changes to affect, speech difficulties and physical issues. Although literature exists that identifies the need for the voices of people with dementia to be heard, there is a paucity of research that includes hearing the experiences of people diagnosed with FTD.

The purpose of this research was to explore the lived experience of frontotemporal dementia from the person's perspective using interpretative phenomenological analysis and to identify what helps and hinders people in living well with this condition. The themes that emerged in the analysis were: the rocky road through assessment; the changing self; in touch with reality; and keeping going. Two overarching needs emerged which were the need to hear the voice of people with frontotemporal dementia and for people with frontotemporal dementia to exercise some control over the decision-making process throughout their journey. Our findings present the person-led framework for understanding frontotemporal dementia and recommendations for future practice and research.

Keywords

dementia, frontotemporal dementia, lived experience, interpretative phenomenological analysis, qualitative analysis, relationships

Introduction

Frontotemporal dementia (FTD) is a clinical syndrome used to describe a spectrum of disorders and includes three main clinical variants: frontal or behavioural variant FTD (bvFTD), semantic dementia (SD), and progressive non-fluent aphasia (PNFA) (Hodges 2010). Other disorders overlap which include FTD with motor neurone disease (MND), corticobasal degeneration (CBD) and progressive supranuclear palsy (PSP) (Kertesz et al. 2000: Lillo and Hodges 2009).

Although Alzheimer's disease (AD) accounts for 60% of cases of dementia, FTD is the second most prevalent cause of dementia in people under the age of 65 and affects up to 15 people per 100,000 (Alzheimer's Society 2019). However, the incidence and prevalence of FTD in people over 65 may be underestimated (Graham 2007).

In comparison to AD, the prognosis for people with FTD is poorer, with a median survival of 6 years from diagnosis (Hodges et al. 2003). Although some symptoms of dementia are found in all subtypes, there are particular symptoms which people with FTD face with memory loss occurring typically at a later stage in the disease process as compared to AD (Hodges et al. 2003). The Lund and Manchester Groups (1994) produced clinical symptoms to diagnose FTD which are still used today. Symptoms of FTD include behavioural changes incorporating loss of social awareness, disinhibition, mental rigidity, stereotypical behaviour, impulsivity and reduced insight. Affective changes include emotional changes, somatic preoccupation and aspontaneity. Changes in behaviour and affect can lead to problems in maintaining relationships. People with FTD also experience speech issues that include reduction in speech, repeating words or phrases and later on, mutism. The physical symptoms of FTD include incontinence, low blood pressure, late akinesia and early primitive reflexes (Lund and Manchester Groups 1994).

Historically, it had been assumed that people with dementia lacked insight and could not recount their experiences or voice their views (Rankin et al. 2005). However, there has been an increasing call for the views of people with

dementia to be included in the research (Gove et al. 2017; Scottish Dementia Working Group Research Sub-group 2014). Research has been conducted that includes the perspectives of people with a diagnosis of AD (Beard 2004; Caddell and Clare 2011; Clare 2002; Clare 2003; Clare, Goater, and Woods 2006; Pearce, Clare and Pistrang 2002; Devlin et al. 2007; Dewitte et al. 2020; Frank and Forbes 2017; Jensen et al. 2020; Pearce et al. 2002; Phinney and Chesla 2003; Sabat and Harré 1992). However, in comparison to research focusing upon the subjective experiences of people with AD, there is a paucity of research that incorporates the subjective experiences of people with FTD. A potential rationale may be the assumption that people with FTD lack insight and, therefore, cannot contribute (Rankin et al. 2005). The existing FTD literature explores the perspectives of family caregivers (Kindell et al. 2014; Lima-Silva et al. 2014; Massimo et al. 2013; Mioshi et al. 2009; Nicolaou et al. 2010; Oyebode et al. 2013; Rasmussen et al. 2019; Riedijk et al. 2008; Rosness et al. 2008) and professional staff (Edberg and Edfors 2008; Rasmussen and Hellzen 2013). One study by Griffin et al. (2016) interviewed five people with a diagnosis of bvFTD and found that despite the clinical symptoms, including lack of insight and awareness, people with bvFTD could articulate their views and experiences.

Being able to understand the persons' subjective experience of FTD is important to increase engagement with services and service design and in evaluating and developing therapeutic interventions which are acceptable and helpful from the perspective of the person diagnosed with FTD. Therefore, the purpose of this research was to explore the lived experience of people with a diagnosis of FTD to identify what helps and hinders them in living well with FTD.

Methods

Participants

A purposive approach to recruitment was adopted due to the need to recruit people who had lived experience of FTD. Seven participants were recruited to the study all of whom had received a diagnosis of FTD and were known to

services providing dementia support in Scotland (see Table 1). Pseudonyms were used to protect the anonymity of participants throughout.

Design

Interpretative phenomenological analysis (IPA) is an approach to qualitative inquiry that aims to explore how people make sense of their lived experience (Smith et al. 2009). Interpretative phenomenological analysis contains no explicit theoretical orientation with studies beginning with the researchers gathering information from participants to establish a sense of the lived experience from the individuals' perspective (Pringle et al. 2011). Interpretative phenomenological analysis is underpinned by three theoretical perspectives: phenomenology; hermeneutics; and idiography, therefore, providing a framework upon which researchers can interpret why certain issues or experiences are more important to individuals than others.

Procedure

Potential participants were identified by third sector and local authority service managers providing specialist dementia care services. Managers acted as gatekeepers using their prior knowledge of service users to identify potential participants who met the inclusion criteria (Table 2). Potential participants were provided with a participant information sheet by the service managers and their contact details passed to the researcher once consent was agreed.

The study received University of Stirling General University Ethics Panel approval (Reference: GUEP100); the University of Stirling NHS, Invasive or Clinical Research Committee (Reference: NICR16/17–Paper No.77); and NICR and the Research and Development (R&D) Management (Reference: LR/AG18/ES/0003).

Of fundamental importance was demonstrating clear procedures around issues of establishing and gaining consent. The process for establishing, gaining and reviewing consent throughout the study followed the guide for social work and health care staff (Scottish Government 2008), principles of the Adults with Incapacity (Scotland) Act (2000) and the process consent for people who have dementia method (Dewing 2007), which was developed in acknowledgement of

the importance of empowering people with fluctuating capacity to participate in research whilst at the same time ensuring that safeguards are in place that are neither over- nor under-protective (Dewing 2007).

In keeping with an IPA approach, data was collected through semi-structured interviews lasting between 1 and 1 hour 30 minutes with people with a diagnosis of FTD. Six participants were interviewed twice, and one participant was interviewed once, culminating in 13 interviews. The interviews were conducted between June 2017 and September 2018, with the interval between first and second interviews typically being one to three weeks. This provided the researcher with the opportunity to transcribe the first interview, make notes on areas for exploration in the second interview, and immerse herself in the data. Data was analysed on an interview-by-interview basis using systematic, qualitative analysis, and later presented as narrative accounts including the researcher's interpretation of the analysis supported with excerpts from participant interviews. In order to attend to the double hermeneutic process, the lead researcher kept a reflective journal to record thoughts, feelings and observations at every stage of the process.

Analysis

The analytical process involved a series of steps as suggested by Smith et al. (2009). Initially the lead researcher read each transcript of each interview multiple times, then brought the analysis together across cases. The lead researcher made initial notes on the transcription at three levels: noting descriptions in the transcript; taking notes regarding the linguistic content (e.g. repetitive words or phrases or gaps); and taking notes regarding related concepts. Following this three-level noting, the lead researcher identified emergent themes within each text incorporating initial comments which emanated from the transcript. The lead researcher then grouped any similar themes. This process was repeated for each interview, across interviews and a final thematic structure was developed.

The credibility of the analysis was enhanced by two experienced researchers who oversaw the analysis from the initial coding through to the development of themes. Portions of the transcript were shared with the two experienced

researchers, which facilitated reflexivity, and discussion around how codes were identified and how codes were grouped to form themes. Of the two experienced researchers, one had extensive knowledge about the field of dementia and the other researcher had a wide experience of research designs, both of which helped to extend the thinking around the development of initial coding and emergent themes, which reduced researcher bias. The reflexive approach undertaken by the lead researcher ensured the lead researcher was deeply engaged in the data, regularly participated in peer review with supervisors and personal perceptions and context were employed to enhance robustness.

In addition, the analysis incorporated the quality criteria of Yardley (2000, 2008) to ensure transparency, rigour and trustworthiness in the research process. The quality criteria of Yardley (2000, 2008) incorporates four principles: sensitivity to context; commitment and rigour; transparency and coherence; and impact and importance.

Findings

Two overarching needs and four superordinate themes emerged from the data regarding the lived experience of FTD. Table 1 presents the master table of themes and the subordinate and emergent themes associated with each superordinate theme. The themes have been presented in a framework that captures the complexity, dynamism and interconnectedness of the themes (Figure 1). The themes are the rocky road through assessment; the changing self; in touch with reality; and keeping going. Each theme contains a number of subordinate themes and emergent themes. Two overarching needs of hearing the voice of the person with FTD and the person being able to exercise an element of control during their journey were found throughout the four themes.

Table 1: Participant demographics

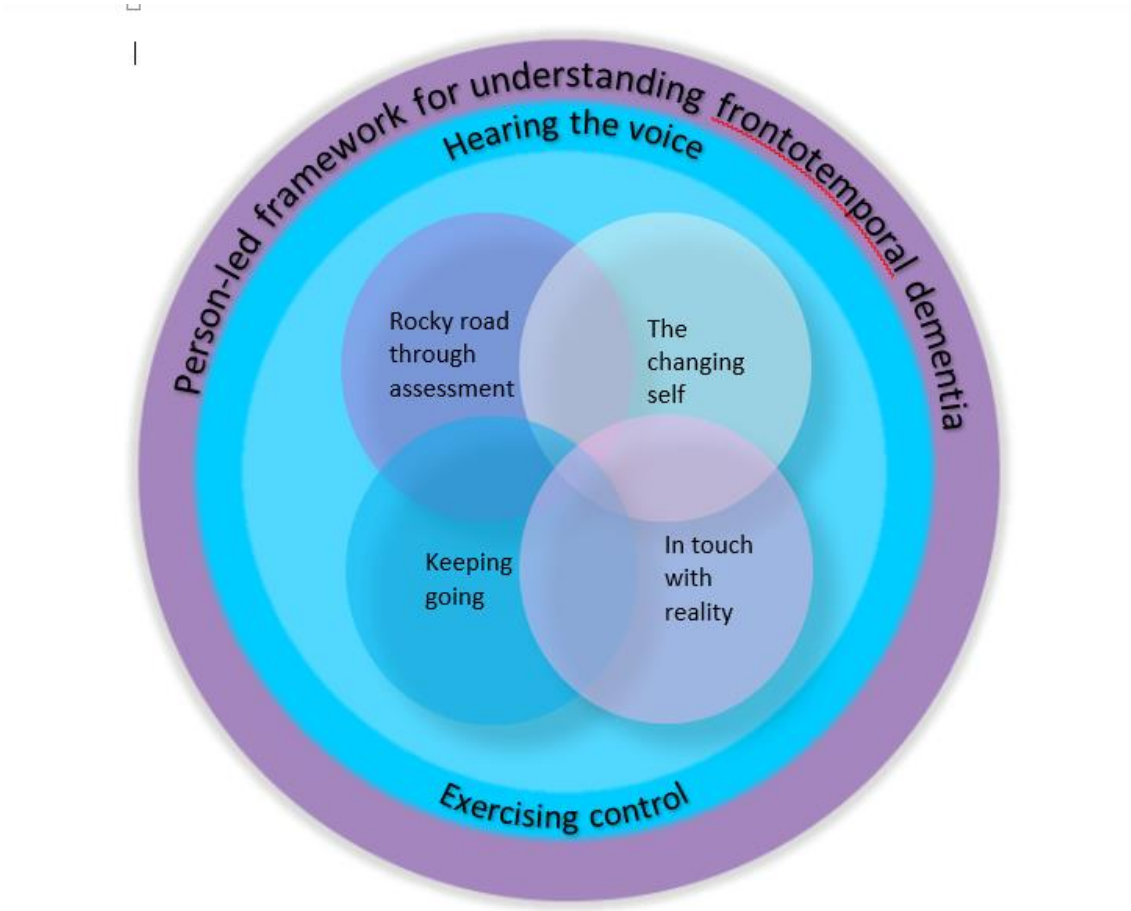
Pseudonym	Gender	Age	Living status	Employment status	Time since diagnosis	Number of interviews
Jim	Male	59 years	Lives with wife	Retired pre-diagnosis	2 years	2

Mary	Female	53 years	Lives with mother and sisters	Stopped working on receiving a diagnosis	1 year	2
James	Male	67 years	Lives with wife	Retired pre-diagnosis	2 months	2
John	Male	60 years	Lives with wife and adult daughter	Stopped working on receiving a diagnosis	3 years	2
Norma	Female	68 years	Lives with husband	Stopped working on receiving a diagnosis	6 years	2
George	Male	68 years	Lives with wife	Retired pre-diagnosis	3 years	2
Sean	Male	52 years	Lives with daughter	Stopped working on receiving a diagnosis	18 months	1

Table 2: Master table of themes

Master table of themes			
Overarching needs	**Superordinate themes**	**Subordinate themes**	**Emergent themes**
Hearing the voice	The rocky road through assessment	Something amiss	Seeking explanations
		Impact of assessment	A hidden disease
			Taking control
	The changing self	Sense of self	Holding on
			Feeling different
		Roles and relationships	Shifting responsibilities
		What I need to be me	Becoming me again
Exercising control	In touch with reality	Insight and awareness	Recognising changes
		Thoughts, beliefs and emotions	Fluctuating feelings
			Emotional shifts
		Living with FTD	Symptoms that challenge
			Physical changes
			In the moment
	Keeping going	State of mind	Fighting FTD
		Strategies for living	Slowing down
			Living day to day
		Someone there	Experiencing support
			Needing others

Figure 1: Person-led framework for understanding frontotemporal dementia



The rocky road through assessment

Seven participants spoke about experiences of the rocky road through assessment and an awareness that something was amiss due to changes to their abilities and behaviour, with six participants suspecting they may have dementia. This awareness is exemplified in the following quote from Norma who, prior to diagnosis, was making mistakes at home and work. The quotation illustrates the disparity between what Norma thought she was capable of doing and what she had done.

Norma: I just thought, yeah I just thought, what what is going on in my head that I can't remember this and like one of the managers, I actually got pulled up, and this is when it sort of you know I thought, maybe there is something wrong with me ... I had to go through retraining when you know I'd been the manager for years [laughs] (Norma, Interview 1).

In addition to participants being aware of difficulties arising at home and in their working roles, five participants went on to seek a medical diagnosis, whilst two participants were prompted by family to seek explanations for changes. Six participants discussed difficulties surrounding understanding and comprehending the diagnosis of FTD. Issues surrounding the focus of the assessment; lack of FTD-specific information; participants' lack of knowledge about FTD; and issues regarding the lack of or limited quality of the written information provided about FTD were identified. Here, Mary demonstrates how she is given limited information at diagnosis by her consultant.

Mary: em, I had actually never heard of it until I was given the diagnosis. And it was only through what my consultant had said or the information sheet he had given me and wrote a couple of different websites on them for me to get a bit more information about it. (Mary, Interview 2).

As well as issues of seeking diagnosis and receiving a diagnosis, the impact upon individuals of being assessed was explored. Participants discussed their experiences of undergoing a battery of psychological tests concerning diagnosis; fitness to work assessments; assessments regarding eligibility for benefits; and driving assessments. Participants' confusion regarding FTD was compounded due to multiple assessments reaching conflicting decisions or not reflecting the participant's experience of living with FTD. John and George highlighted the negative psychological effects of being formally assessed for FTD. They both experienced frustration over the repetitiveness of testing and feelings of being 'set up to fail'. This resulted in them fearing ongoing assessments and lowered self-esteem. A particular difficulty was when John's test results appeared to improve over time, which resulted in him trying to minimise how well he had tested in order to protect himself from believing he was recovering.

George: they all kept saying the same thing. They're all saying "well done. Oh, well done. Oh well done, you're fast". And I just blew up when X [occupational therapist] said that. I says "I've not done well. I know what I was capable of before I done this". I says "It's not well done, you passed". I says "I know I've changed, I know my mind's changed ... cause that's when I said "listen, I'm not right. It's not right". (George, Interview 1).

The experience of George and John is reflected in four other participants' narratives when they find themselves receiving conflicting advice from professionals carrying out assessments. Here, Mary is discussing assessment regarding working.

Mary: I might look healthy ... they think you're fit to work and when I spoke to {psychiatrist} he was quite annoyed, em, and thankfully ... he wrote [a report]. I eventually got a letter to say it won't be going to tribunal and we're sorry blah blah blah ... Then I got told I'd to go for a meeting, a statement meeting ... (Mary, Interview 1).

The issues around multiple assessments by several agencies and the conflicting advice led to four participants experiencing emotional distress, financial hardship and missed opportunities for accessing support to continue working.

In summary, participants spoke about the importance of coming to terms with the diagnosis of FTD in their own way and exercising some control over their journey. In taking some control of how they understood and made sense of their diagnosis, seven participants were able to experience life more positively.

The changing self

Six participants felt they were able to maintain their sense of self and felt their personality was relatively unchanged. However, there was an acknowledgement from participants that effort was required to 'hold on' to their sense of self and to maintain and preserve their sense of self despite 'feeling different'.

Norma: I was, I was on the bus ... and I was sitting there and I just happened to look out the window and I actually went 'oh there's Norma over there ... and then I went "I wonder, I wonder what she's doing up here?" And I thought what what what am I doing? I'm Norma. How can she be Norma? And she looked very like me (Norma, Interview 1).

This excerpt suggests Norma is trying to hold onto her old sense of self, whilst at the same time recognising her old self in someone else and normalising what almost appears to be a dissociative experience regarding her emerging new self.

As well as participants identifying and coming to terms with changes to self, six participants discussed the importance of roles and relationships. Changes to working role were of particular significance with missed opportunities for shifting responsibility as opposed to loss of role.

Sean: you feel different because everybody's out working, That's, it kind of, I don't know, it's as if you've got a wee stamp on your head ... saying ... reject, (laughs) no, finished, forget it, get to the side, we don't want you.

(Sean, Interview).

Seven participants spoke about the importance of family roles. Here, George is talking about the loss of their role as 'head of the family'.

George: I felt useless as well if you understand because before I would have been able to cope with that no problem ... but because I had to get help ... it took me being the head of the family away from me. (George, Interview 2).

In conclusion, the theme of 'changing self' explored participants' attempts to hold on to their sense of self despite their awareness of changes in personality, behaviour and feeling different. The changes to self initially resulted in confusion over identity but participants could emerge successfully from this transition by the gradual integration of a new but intact sense of self. The changes to self had an impact upon life roles that participants held and an important theme emerged of the need for 'shifting responsibilities' and how by

embracing this concept, participants could take on adapted roles. However, changes to role impacted upon the type and quality of relationships with others.

In touch with reality

Seven participants demonstrated insight and awareness into how FTD was affecting them. Five spoke explicitly about particular aspects with high but fluctuating levels of awareness and insight. All participants were able to recognise changes in their thinking and behaviour.

> *John: There's slight changes in my my cognitive things, the way I do things, the way I process things ... that's a that's a, that's typical of me (John, Interview 1)*.

Seven participants discussed their insight and awareness regarding living with FTD demonstrating overall high levels of insight and awareness. Participants spoke about the challenges of living with FTD including vulnerability, feeling different and a sense of inadequacy. Seven participants talked about the high level of impact having FTD had on their everyday lives and the symptoms of FTD which they found especially challenging.

Participants spoke in depth about their experiences of behavioural and psychological symptoms of dementia (BPSD). Six participants discussed short-term memory and communication issues. However, seven participants identified physical changes normally associated with the ageing process as the symptom that impacted most negatively upon their quality of life. For four participants, symptoms included experiencing physical deterioration and unexplained physical sensations. Five participants discussed tiring easily and slowing down. Here, Jim is trying to describe physical sensations.

> *Jim: my feet are very, very light and they go in different shapes, I know that sounds silly but that's how it, that's how it affects me. (Jim, Interview 2).*

Participants also spoke about problems around the processing of information and making decisions 'in the moment', with seven participants speaking about incongruence between how they thought they would react in situations as opposed to their actual behaviour. Traditionally thought of in the literature as

disinhibition, this study involved seven participants trying to explain what they were thinking and processing 'in the moment' as they reacted to situations as they occurred. There was a difference for participants between how they reacted 'in the moment' as compared to what they thought they would have done when they reflected upon their reaction. Problems with decision-making 'in the moment' are described by participants as more than disinhibition, but as a complete inability to consider the full range of information or options 'in the moment' and was a complex issue involving difficulties with processing information and decision-making.

Here, John gives an in-depth account of a dangerous situation where 'in the moment' he felt his actions were justified, but in hindsight, he can empathise with his wife's fears. The full danger of his behaviour is somewhat dismissed by John.

> *John: I heard her ... but didn't … Mustn't have registered in my brain that that was a dangerous situation. I was watching the traffic, didn't take my eye off the traffic one bit, em like I didn't have my back to them ... you know but em, so and she could not convince me all through the day that that was the wrong thing to do. So she just had to leave it and then as time goes by she thinks, we can talk about it together I can see the, how dangerous that was. But even just now, back of the mind I think that it wasn't all that dangerous but it was ... yeah, but it is. I can see that, yeah, I can see it … but in the back of my head I can I can justify it. (John, Interview 1).*

This superordinate theme has identified a range of symptoms with which people with a diagnosis of FTD must contend. The next superordinate theme identifies how people with FTD 'keep going'.

Keeping going

Seven participants discussed how using coping strategies enabled them to keep going and continue to live as well as possible with FTD. For all participants, using or adapting previous coping strategies helped them cope with everyday challenges and develop new ways of keeping going. Regardless

of the strategy being utilised, seven participants discussed the importance of keeping a positive state of mind and fighting FTD. Here, John is talking about turning what is perceived to be a negative diagnosis into a new opportunity.

> *John: I'm trying to think positively ... when you you get a diagnosis of dementia, this, that's the end of the road for you which is, it it isn't. It's not the end of the road. Eh, I took that as a new beginning. [laughs] (John, Interview 2).*

Planning ahead in the short term was found to be a useful strategy for living with FTD. Seven participants revealed ways in which they pre-empted potential problems and used coping mechanisms designed to prevent problems from occurring. However, six participants felt strongly that planning ahead in the longer term was not helpful and actively avoided planning ahead. Seven participants had chosen not to have a dialogue with professionals or family members regarding anticipatory or advance care planning in preparation for the end stages of FTD. There is a sense that not anticipating and not planning future care is a coping strategy in its own right.

> *George: And I don't think too much of the future ... day by day, I'm quite happy with that. Or even week by week. It's certainly not, no ... If I think on that [future] I think it would get me depressed. (George, Interview 1).*

Significantly, seven participants spoke about the importance of someone being there for them. All participants in this study lived with a family member who was providing daily support. There was a strong sense that not only was family companionship a key support that enabled participants to continue living well with FTD, but participants felt able to rely completely on family members. This level of unconditional support is illustrated in the following excerpt from James.

> *James: she's highly supportive ... she appreciates that the blanks of eh memory that I sometimes have and she does all sorts of eh wee things that that you know just almost slip into unconsciousness (James, Interview 2).*

John concurred with the importance of spousal support and acknowledged his increasing dependence upon his wife, whilst at the same time, making efforts to accept formal support in order to try to ease his dependency upon his family.

Discussion

An overarching finding in this study was the desire for all participants to have an element of control over their journey with FTD. This is an important finding due to the limited literature that engages directly with people with FTD. In this study, a complex and dynamic process was occurring within which participants were making sense of, and coping with, living with FTD. This process has been entitled 'the person-led framework for understanding the experience of FTD', which illustrates the interconnectedness of themes, the shifting and merging of themes throughout the journey of living with FTD, and the need to be recognised as an individual by those supporting them. It is this level of understanding of the complexities and interconnectedness of the themes, alongside the fundamental requirement of understanding the experience of FTD from the person's perspective, that highlights the importance of empowering people with FTD to retain some control over their journey.

The method of interviewing the person with FTD demonstrated the ability of people with FTD to make their views known, empowered participants to be heard and provided opportunities for people with FTD to retain some control over their journey, thus, adding to the existing knowledge about the experience of FTD. Current research focuses upon family caregivers' perspectives (Johannessen et al. 2017; Kindell et al. 2014; Massimo et al. 2013; Nicolaou et al. 2010; Oyebode et al. 2013; Pozzebon et al. 2017; Pozzebon et al. 2018; Rasmussen et al. 2019; Riedijk et al 2008; Rognstad et al. 2020; Rosness et al. 2008; Tyrrell et al. 2019); and professional perspectives (Edberg and Edfors 2008; Rasmussen and Hellzen 2013); with only one previous study exploring the lived experience of people with bvFTD from their perspective being found (Griffin et al. 2015).

Key findings have emerged that resonate with the existing literature in a wider context such as research into people with early-stage AD or younger people with dementia (YPWD). There is broad consensus in the literature that assessment and diagnosis of dementia should be person-centred, taking account of biopsychosocial issues (Arnold et al. 2012; Khayum and Rogalski 2018; Klinkman and van Weel 2011; Manthorpe et al. 2013; Mitchell et al.

(2013); Salloum and Mezzich 2010), with some authors arguing for specific assessment services for YPWD (Braudy Harris 2008). Key findings from this study include the need for person-centred assessment processes that attend to the specific needs of people with FTD and the focus of the assessment to be considered in terms of meeting the needs of multiple stakeholders, whilst at the same time, keeping the person at the centre of the process (Bailey et al. 2019). The need for preparation for the assessment process could be met by adopting an approach that discusses the assessment process with the person and their family prior to formal assessment commencing and could be a key role for clinicians to undertake. However, in order to achieve a person-centred assessment where the person is prepared as far as possible for the process, professionals must have the ability to be self-aware in terms of how they make people feel during assessment (Bailey et al. 2019; Zaleta and Carpenter 2010). Professionals require to be aware of the impact that their attitudes and focus are having upon the person with FTD, and have a comprehensive knowledge of the symptoms of FTD. One way in which to ensure needs are met during assessment processes is for professionals with an advocating role to be with the person throughout their consultations. This study has indicated that there is a need to explore how shifting of communicational focus during assessment consultations can make the person receiving the diagnosis feel disempowered and how this shift of focus from the person can be prevented.

Additionally, this study has found that FTD-specific information is considered to be negative in terminology and outlook and can have an adverse impact upon those reading the information. The FTD-specific information should also reflect all types of FTD, therefore, further research and development of resources for people with all forms of FTD are required.

Regarding the issue of multiple and repeated assessments by various organisations, the findings of this study suggest there is a need to enhance awareness of FTD across multiple agencies, which could be addressed through targeted educational packages for specific assessors outwith the health and social care sector, FTD-specific clinical guidance for health and social professionals, and embedding the rights of people with FTD in wider policy both locally and nationally. According to the experiences of participants in this study,

socio-economic issues associated with living with the symptoms of FTD still exist, suggesting that further multiagency collaboration should be encouraged.

In this study, participants acknowledged that their personalities had changed but, at the same time, had assimilated the old self into a new self that incorporated both identities. It appears that the difference in sense of self in the participants in my study, in comparison to other studies, is important in that the potential loss of future self is something that was alluded to but not explicitly discussed by participants, thus requires more sensitive exploration to ensure participants are not experiencing silent losses of which clinicians are unaware.

In this study, participants spoke at length about changed family roles and how family members had to take on roles that had previously been within their remit and capabilities. This shifting of responsibilities impacted upon participants' feelings of being useful, having a purpose and being able to give to others. Although participants were able to recognise changing roles within their relationships, they maintained that their satisfaction with their quality of relationships had not altered. There is limited research exploring the views of people with FTD that specifically addresses roles and relationships. Therefore, this study highlights a need for future research to explore how people with FTD experience changing roles and relationships and how best to support people experiencing such changes.

Several participants in this study had lost their jobs as a result of FTD. Silvaggi et al. (2020) reviewed the literature around keeping people with dementia in paid employment. They found that cognitive difficulties, as opposed to motor dysfunction, reduced the ability to work. The two main themes were how to manage people with dementia in the workplace and the impact of symptoms on working status. They concluded that support in the workplace and the input of occupational health professionals could help people with early-onset dementia continue working as long as possible. The loss of working role experienced by participants in my study was found to have had a significant impact upon participants' sense of self. There is a role for professional staff to work with employers to implement strategies that shift and gradually reduce responsibility for people with FTD. This may help people with FTD retain a sense of

usefulness and bolster their sense of self. Such support could also assist with a planned transition from the working role as opposed to sudden changes as described by participants in my study. However, further research is necessary to investigate how the needs of people who have not yet received a diagnosis of FTD can be supported to remain in employment during assessment or their return to similar roles can be facilitated.

Physical symptoms most adversely affected the quality of life, which is significant in that this is different from the perspectives of family members and professional staff who typically highlight BSPD as the most challenging symptoms (Nunnemann et al. 2012; Feast et al. 2016; Ulstein et al. 2007). This finding highlights an aspect of support that is not consistently recognised, assessed, understood, explored or supported in practice. Changes to existing assessments and support for people with FTD require to reflect the physical symptoms reported by participants due to the profound negative effect upon seven participants' quality of life.

With regard to insight and awareness, participants spoke about changes including problems understanding other people's viewpoints, making inappropriate comments about others and deterioration in everyday life skills including decision-making. However, literature regarding family caregivers' perspectives revealed a widespread belief that the person with FTD lacked insight (Johannessen et al. 2017; Tyrrell et al. 2019).

Literature exists that seeks to understand how decision-making in people with FTD is linked to pathological changes in the frontal areas of the brain (Fong et al. 2016; Hughes and Rowe 2016; Massimo et al. 2013; Mendez and Shapira 2011; O'Keefe et al. 2007; Roca et al. 2013; Ruby et al. 2007; Seeley et al. 2012; Scherling et al. 2017). However, these findings have been used to inform diagnosis and understanding of the damage to certain parts of the brain and reduced ability, but require to be disseminated to frontline clinicians. In increasing frontline clinicians' understanding of how pathological changes manifest in behaviour exhibited, this enhanced understanding could lead to improvements in existing support and the development of new interventions.

Instead, what is commonly found in clinical practice is a belief that people with FTD lack insight and awareness exacerbated by diagnostic criteria and clinical guidance (Lund and Manchester Groups 2004; SIGN 2006). The findings of my study concur with Evers et al. (2007) who explored the diagnostic criteria of 'loss of insight' for people with FTD and concluded that loss of insight should not form part of the core criteria for FTD but should be considered a supportive criterion. This concurs with the findings of this study in those people receiving a diagnosis of FTD may have different needs due to the subtype of FTD they are experiencing and can have high levels of insight and awareness regarding their condition.

In addition, the belief of lack of insight and awareness may explain why people with FTD have not been asked to participate in research. Further research involving the person with a diagnosis of FTD is important as the voice of people with FTD is under-represented in research and practice (Levy et al. 2018). More understanding is necessary to develop meaningful interventions that meet the needs of people with FTD.

Additionally, participants felt they were entering a fight. The word 'fighting' is used explicitly by Clare (2002) who aimed to identify and conceptualise coping strategies used by people with early-stage AD. Coping strategies ranged from self-protection to integrative responding. Xanthopoulou and McCabe (2019) linked the concept of "fighting" the changes in self that are experienced by people receiving a diagnosis and 'fighting' to be seen as a person rather than the disease. This study concurs with Xanthopoulou and McCabe (2019) and involves people adapting to a new way of life whilst trying to remain positive by demonstrating competence and successfully adopting coping strategies which bolster a sense of control and independence. This is important as having some control over decision-making has been expressed by seven participants in this study as central to living well with FTD.

It was commonplace for participants to avoid planning ahead and participants were unaware of advance care planning, anticipatory care or advance statements. This concurs with Ashworth (2020) who interviewed people with AD exploring people's outlooks on their future. As well as focusing on positives,

she found people with AD coped by taking a ‘one day at a time’ approach. Ashworth (2020) calls for a review of policies that encourage planning and exploration of ways to support people to plan whilst, at the same time, focus upon daily life. The findings in this study concur with Ashworth (2020) and Tan et al. (2019) in that trying to implement advance planning may have a negative effect on coping mechanisms used by people with FTD in their day-to-day lives, and strengthens the evidence calling for further research.

In summary, being able to discuss planning, in its various guises, in a sensitive way that does not cause untoward distress to people living with FTD, appears to be a role that professionals could undertake. More research is necessary to ascertain and understand the views of people with FTD regarding their reluctance to engage in this process. Given the sensitivity of the topic, it seems likely that frontline staff will require support and education to be able to assess when it may be beneficial to broach planning with people; how to go about this sensitively; but also help people with FTD who choose not to plan to retain some control over future decisions.

Conclusion

Improving understanding of FTD can be achieved by raising awareness of FTD by placing the person with FTD at the heart of the support they receive. As well as including the person with FTD in a meaningful way in planning care, there is a need for professionals to enhance and develop clinical guidance and therapeutic interventions specifically meeting the needs of people with FTD. The development of evidence-based educational programmes for a diverse range of professionals and organisations is required alongside key professionals becoming active in influencing future policy. There is a need to incorporate the abovementioned requirements whilst working collaboratively with people with FTD to ensure that the experiences of the person with FTD, as opposed to people with other subtypes of dementia or other stakeholders’ perspectives, are heard. These steps are necessary to address the needs of a marginalised group living with a diagnosis of FTD.

In conclusion, the need for people with FTD to exercise an element of control over the decisions made in their journey and to be heard and respected is paramount. The common belief that people with FTD lack insight and awareness may explain why there is a paucity of clinical practice, policy-making and research that includes the views and experiences of people living with FTD. This study demonstrates that people with any subtype of FTD can be meaningfully involved in research and articulate their experiences.

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