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## **Living with a diagnosis of frontotemporal dementia**

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*Published in:*  
Dementia

*DOI:*  
[10.1177/14713012221148527](https://doi.org/10.1177/14713012221148527)

*Publication date:*  
2023

*Document Version*  
Peer reviewed version

[Link to publication in Discovery Research Portal](#)

### *Citation for published version (APA):*

Gray, S., Shepherd, A., & Robertson, J. (2023). Living with a diagnosis of frontotemporal dementia: An interpretative phenomenological analysis. *Dementia*, 22(3), 514-532. Advance online publication. <https://doi.org/10.1177/14713012221148527>

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## **Living with a diagnosis of frontotemporal dementia: An interpretative phenomenological analysis**

### **Abstract**

Frontotemporal dementia describes a spectrum of disorders which include behavioural changes, changes to affect, speech difficulties and physical issues. Although literature exists which identifies the need for the voices of people with dementia to be heard, there is a paucity of research which 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 persons' perspective using interpretative phenomenological analysis. 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 themes 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. Recommendations are presented 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 neuron disease (MND), corticobasal degeneration (CBD) and progressive supranuclear palsy (PSP) (Kertesz et al. 2000; Lillo and Hodges 2009).

Alzheimer's disease (AD) accounts for 60% of all cases of dementia (Graham 2007). According to Hogan et al. (2016), FTD accounts for 2.7% of all dementia cases in people aged 65 years and over. However, the incidence and prevalence of FTD in people over 65 may be under-estimated (Graham 2007). FTD is the second most prevalent cause of dementia in people under the age of 65 affecting up to 15 people per 10,000 (Alzheimer's Society 2019).

The median survival for people with FTD is 6 years from diagnosis which is shorter than those with a diagnosis of AD (Hodges et al. 2003). In addition, people with FTD can experience symptoms such as changes in personality, problems in decision-making and language issues early in the trajectory of FTD 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 for the purposes of diagnosing FTD which are still used today. FTD symptoms 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 asponaneity. Changes in behaviour and affect can lead to problems in maintaining relationships. People with FTD also experience speech issues which 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 research (Gove et al. 2017; Scottish Dementia Working Group Research Sub-group 2014). Research has been conducted which 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, MacAskill, and Steed 2007; Dewitte et al. 2020; Frank and Forbes 2017; Jensen et al. 2020; Pearce et al. 2002; Phinney and Chesla 2003; Sabat and Harre 1992). However, in comparison to research focussing upon the subjective experiences of people with AD, there is a paucity of research which 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. (2015) 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 at the time of the study.

Being able to understand the persons' subjective experience of FTD is important in order to increase engagement with services and service design but also 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 and the importance of applying findings to clinical practice.

## **Methods**

### *Participants*

A purposive approach to recruitment was adopted due to the need to recruit people who had lived experience of FTD. The study inclusion criteria sought participants who had a diagnosis of frontotemporal dementia or a sub-type of frontotemporal dementia provided by a consultant psychiatrist, consultant neurologist or consultant psychologist; participants who could communicate verbally and were able to discuss their thoughts; participants who spoke English; and participants who were able to provide informed consent to the study.

The Diagnostic and statistical manual of mental disorders – fifth edition (DSM-5 1994) classifies major or mild frontotemporal neurocognitive disorder differently to the Lund and Manchester Groups (1994) by differentiating between FTD with or without behavioural disturbance. The ICD-11 (2019) classifies FTD as another degenerative nervous system disease entitled circumscribed brain atrophy which includes frontotemporal dementia, Pick disease and Progressive isolated aphasia. For the purposes of this study, five participants had a diagnosis of FTD, one participant had a diagnosis of Frontotemporal Syndrome, and one participant had a diagnosis of C9orf72 (Table One).

Seven participants were recruited to the study all who had received a diagnosis of FTD and were known to services providing dementia support in Scotland (see Table One). Only one participant had been provided with information regarding the subtype of FTD they were experiencing. All other participants had been given the diagnosis of frontotemporal dementia. Pseudonyms were used to protect the anonymity of participants throughout.

## **Design**

Interpretative phenomenological analysis (IPA) is an approach to qualitative inquiry which aims to explore how people make sense of their lived experience (Smith et al. 2009). IPA contains no explicit theoretical orientation with studies beginning by the researchers gathering information from participants with the intention of establishing a sense of the lived experience from the individual's perspective (Pringle et al. 2011). Rather, IPA is underpinned by three theoretical perspectives: phenomenology (Heidegger 1962; Husserl 1982; Merleau-Ponty 1962; Sartre 1948); hermeneutics (Gadamer 1960; Heidegger 1962; Schleiermacher 1998); and idiography (Harré 1979), therefore providing a philosophical 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. 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. Of fundamental importance to gaining ethical approval for the study was demonstrating clear procedures around the issue of establishing and gaining consent. The process for establishing, gaining and reviewing consent throughout the study followed the guidance from the guide for social work and health care staff (Scottish Government 2008), the principles of the Adults with Incapacity (Scotland) Act (2000) and the process consent for people who have dementia method (Dewing 2007). This approach 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 or under protective. The method for process consent was adhered to throughout the study with the lead researcher establishing oral and written consent from each participant before each interview and observing for any signs of fluctuations in capacity to consent throughout all interviews. All participants were deemed able to consent to participate before each interview and provided written and oral consent. Gatekeepers provided information regarding previous distressed behaviours which may suggest a fluctuating capacity but at no point did any participant display such behaviour or become unable to discuss their experiences which may have indicated a fluctuating capacity and a need to

reconsider capacity to consent. Therefore an ongoing assessment for fluctuating capacity was incorporated into the interview process (Dewing 2007).

In this study, the concept of 'lived experience' involves the researcher's understanding of the representation and understanding of a person's human experience, decisions based upon their experiences and how these variables influence the perception of knowledge and how this affects the person's response to each situation. In studying the lived experience of individuals, the authors sought to understand the distinctions between lives and experiences and the differences and similarities of lived experiences for individuals living with FTD. (Boylorn 2008; McIntosh and Wright 2018).

In keeping with an IPA approach (Smith et al. 2010), data was collected through semi-structured interviews informed by an interview schedule and lasted between 1 hour and 1 hour 30 minutes with people with a diagnosis of FTD (Table 2). All participants were interviewed by the lead researcher and audio-recorded. Six participants were interviewed twice, and one participant was interviewed once, culminating in 13 interviews. The interviews spanned a 15 month period between June 2017 and September 2018, with the interval between first and second interviews typically being one to three weeks. This provided the lead researcher with the opportunity to transcribe all interviews verbatim; making notes on the transcription of the first interviews in order to further explore areas of interest in the second interview and to immerse herself in the data. Data was then analysed on an interview by interview basis using a 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 (Smith et al. 2009), 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) The analytic process was initially undertaken by the lead author who read each transcript of each interview multiple times, then brought the analysis together across cases with the other authors carrying out independent analysis. There was then discussion around the emergent themes and the grouping and naming of themes. The process was overseen by an IPA expert in order to add trustworthiness to the analytical process. An unanticipated, but important finding was the usefulness of second interviews. Smith et al. (2010) make suggestions as to the number of interviews required in IPA studies as opposed to numbers of participants. Participants who were interviewed twice seemed to feel more connected to the lead researcher during the second interview and were able to discuss themes arising from the first interview in more detail in the second interviews, thus enhancing the richness of the data gathered and subsequent depth of analysis of their lived experience (Burkard and Knox 2014). There was a sense

of a relationship developing between the lead researcher and participant which required the lead researcher to reflect upon the need to remain the interviewer whilst at the same time utilising her mental health nurse skills, but not becoming a therapist or clinician during interviews (Haverkamp 2005).

Having collected rich data from interviews, the lead researcher made initial notes on the transcription at three analytical levels: firstly noting descriptions in the transcript; secondly taking notes regarding the linguistic content (i.e. repetitive words or phrases or gaps etc.); and thirdly notes regarding related concepts and interpreting the content taking account of the context of the full interview transcription. Following this three level analysis, the lead researcher identified emergent themes within each transcription which incorporated the initial comments made which emanated from the transcript. The lead researcher then grouped together any similar themes. This process was repeated for each interview, then across interviews and a final thematic structure was developed and agreed with her supervisors (Smith et al. 2009).

Given the ethical challenge of remaining a researcher rather than becoming a clinician during interviews, the lead researcher was aware of her experience as a registered mental health nurse who has supported people with a diagnosis of FTD. Smith et al. (2010) discuss the underlying qualities required of an IPA researcher as open-mindedness, flexibility, patience, empathy and the ability to enter and respond to the world of the participant. As the lead researcher had experience of supporting people with FTD which could influence the interpretation of findings, a reflective journal was completed throughout the study process. In using a reflective model, the lead researcher was able to consider important findings in a deeper and systematic way which resulted in new ways of considering the data, and the identification of unexpected findings which had not previously been a feature of her clinical practice. Although Husserl (1982) discusses the need for the researcher to 'bracket' oneself off from the data in order to prevent pre-conceptions whilst analysing data, the lead researcher found that immersing herself in the data and reflecting at a deep level on the findings, lead to a richer interpretation of the participant's experiences.

The credibility of the analysis was further enhanced through the inclusion of the other two authors who are experienced researchers and 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 together 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





Jim	Male	59 years	Lives with wife	Retired pre-diagnosis	Frontotemporal syndrome	2 years	2
Mary	Female	53 years	Lives with mother and sisters	Stopped working on receiving diagnosis	C9orf72	1 year	2
James	Male	67 years	Lives with wife	Retired pre-diagnosis	Frontotemporal dementia	2 months	2
John	Male	60 years	Lives with wife and adult daughter	Stopped working on receiving diagnosis	Frontotemporal dementia	3 years	2
Norma	Female	68 years	Lives with husband	Stopped working on receiving diagnosis	Frontotemporal dementia	6 years	2
George	Male	68 years	Lives with wife	Retired pre-diagnosis	Frontotemporal dementia	3 years	2
Sean	Male	52 years	Lives with daughter	Stopped working on receiving diagnosis	Frontotemporal dementia	18 months	1

Table 2: Interview schedule

<p><b>Interview schedule:</b></p> <ol style="list-style-type: none"> <li>1. Can you tell me a bit about yourself?</li> <li>2. How have you been getting on since being diagnosed with FTD?</li> <li>3. How do your family and friends feel you are getting on since being diagnosed with FTD?</li> <li>4. How do you think your life might be if you didn't have FTD?</li> <li>5. Can you explain what life is like for you right now?</li> <li>6. How would you describe a bad day?</li> <li>7. Can you tell me what leads to bad days?</li> <li>8. How would you describe a good day?</li> <li>9. Can you tell me what helps you have a good day?</li> <li>10. How do you feel about the future?</li> </ol>
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Table 3: Master table of themes

Overarching needs	Superordinate themes	Subordinate themes
	Rocky road through assessment	Something amiss

Hearing the voice		Impact of assessment
	The changing self	Sense of self
		Roles and relationships
What I need to be me		
Exercising control	In touch with reality	Insight and awareness
		Thoughts, beliefs and emotions
		Living with FTD
Keeping going		State of mind
		Strategies for living
		Someone there

### *Rocky road through assessment*

The superordinate theme entitled 'Rocky road through assessment' reflects the experiences of participants of through the process of multiple assessments and testing in multiple areas of their lives . The subordinate theme of 'something amiss' presents the particular experience of realisation that not only are their level of functioning changing and deteriorating but that this may be as a s result of an illness such as dementia. The subordinate theme of the 'impact of assessment' developes this theme in more depth concentrating on how the person felt during and after multiple assessments and the impact the assessments had on their awareness of their functional ability All 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. As the interview with Norma progressed, she becomes more aware of how her experiences as described below, relate to her eventual acceptance of the findings of her cogntive assessment and diagnosis of FTD"

*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 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; participant's 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; and assessments regarding eligibility for benefits; and driving assessments. Participant's 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 found 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 bla bla bla...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*

The superordinate theme of the 'changing self' describes how participants experienced changes to their own sense of self whilst striving to hold on to their uniqueness and their understanding of themselves. The subordinate theme of 'sense of self' describes coming to terms with the changing self and how several 'roles and relationships' were maintained but at the same time altered due to their changing self and abilities. The subordinate theme entitled 'what I need to be me' explores how participants transitioned between the old and new self and the support and needs of the individuals which were required to facilitate this emergence of the new self whilst at the same time, incorporating the old 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 in order 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 1).*

Seven participants spoke about the importance of family roles. Here George is talking about loss of 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 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 life roles which 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*

The superordinate theme of 'in touch with reality' relates to the high levels of 'insight and awareness', demonstrated by all participants. The subordinate theme of 'thoughts, beliefs and emotions' explores the underlying thoughts, beliefs and emotions of participants which demonstrate an ability to reflect upon their experiences and decision-making processes and highlights that although participants had high levels of insight and awareness, they experienced difficulties using this awareness and insight to influence future decision-making in similar situations. The subordinate theme of 'living with FTD' goes on to explore the particular symptoms which the participants found they had to live with on a daily basis.

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 into 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 communicational issues. However, seven participants identified physical changes normally associated with the ageing process as the symptom which 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 up. 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 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, conversely the participants in this study described 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' is 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 on hindsight he can empathise with his wife's fears. The full danger of his behaviour are being 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*

The superordinate theme of 'keeping going' reflects the 'state of mind' and the positivity with which each participant faced living with FTD. This involved the development and use of several 'strategies for living' successfully with FTD. The subordinate theme of 'someone there' explores the importance and necessity of someone being with the person to provide person-centred support in order for the person to live well with FTD.

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 as well as developing 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 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 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 family companionship was a key support which facilitated 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 which directly engages with people with FTD. In this study, there was a complex and dynamic process occurring, within which participants were making sense of, and coping with, living with FTD. This process 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, which 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 and empowered participants to be heard and provided opportunities for people with FTD to retain some control over their journey and thus 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; Riedijk et al 2008; Rognsstadt et al. 2019; 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 (Griffin et al. 2015).

There are key findings which have emerged which 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 which 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 which discusses the assessment process with the person and their families 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 also requires to reflect all types of FTD, therefore further research and development of resources for people with all forms of FTD is 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 out with 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 sense of self had changed, but at the same time, had assimilated the old self into a new self which incorporated both identities. It appears that the difference in sense of self in the participants in my study, in comparison to other theories of self by Sabat and Harré (1992), and studies by Crichton and Koch (2007), and Busted et al. (2020) are important in that the potential of the loss of future self is something which was eluded to, but not explicitly discussed, by participants thus requires more sensitive exploration in order 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 which had previously been within their remit and capabilities. Examples from participants included spouses planning holidays and everyday activities, taking on responsibility for finances and taking over as the head of the family. 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 which specifically addresses roles and relationships. However, Edwards et al. (2018) conducted a systematic review of the quality of family relationships and outcomes of dementia. Despite a paucity of research available, they found there was an association between strained relationship factors and people with dementia exhibiting distressed behaviour. As distressed behaviour can be common in people with FTD, the need to explore the relationship between distressed behaviour and the subsequent effect upon the quality of family relationships is highlighted. There is a need for future research to explore the ways in which 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 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 were 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 which shift and gradually reduce responsibility for people with FTD. This may help people with FTD

retain a sense of usefulness and bolster 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 be facilitated to return to similar roles.

Physical symptoms most adversely affected quality of life and is significant in that this is different to 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 which 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 regards to insight and awareness, participants spoke about changes including problems understanding other peoples' viewpoints, making inappropriate comments about others and deterioration in everyday life skills including decision making. However literature regarding family caregiver's perspectives revealed a widespread belief that the person with FTD lacked insight (Johannessen et al. 2017; Tyrrell et al. 2019). Therefore, this research demonstrates that people with FTD do in fact have awareness, even if this is after the event.

Literature exists which 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 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 manifests in behaviour exhibited, this enhanced understanding could lead to improvements in existing support and 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 this 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 as a supportive criterion. This concurs with the findings of this study in that 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 into their condition.

In addition, the belief of lack of insight and awareness may explain why people 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 in order to develop meaningful interventions which 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" to changes in self experienced by people receiving a diagnosis and 'fighting' to be seen as a person rather than the disease. This study concurs with Zanthopoulou 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 advanced care planning, anticipatory care or advanced statements. This concurs with Ashworth (2020) who interviewed people with AD exploring peoples' outlooks on their futures. As well as focussing 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 which encourage future 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 advanced 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 future planning, in its various guises, in a sensitive way which does not cause untoward distress to people living with FTD, appears to be a role which 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 in order to be able to assess when it may be beneficial to broach future planning with people; how to go about this sensitively; but also help people with FTD who choose not to plan the future, 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. 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 above mentioned requirements whilst working collaboratively with people with FTD to 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 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 but oversimplified belief that people with FTD lack insight and awareness may offer an explanation as to why there is a paucity of clinical practice, policy making and research which 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 clearly articulate their experiences.

## **Declaration of conflicting interests**

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of the article.

## **Funding**

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: Partial funding for this research study was provided through research grants from the University of Stirling and the Scottish Dementia Research Consortium.

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