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**LIVING WITH A DIAGNOSIS OF BEHAVIOURAL-VARIANT
FRONTOTEMPORAL DEMENTIA: THE PERSON'S EXPERIENCE**

Abstract

Research investigating behavioural-variant frontotemporal dementia (bvFTD) has concentrated on identifying and quantifying people's difficulties; yet few studies have considered how people with bvFTD make sense of their difficulties. Five participants were interviewed and interpretive phenomenological analysis used to analyse the data. Two super-ordinate themes emerged: 'Bewilderment' and 'Relationships with others'. 'Bewilderment' reflected the feelings of the participants from the start of their dementia, and was divided into two main themes (1) 'Awareness of change: What's the problem?', and (2) Threats to self: This is not me. The super-ordinate theme, 'Relationships with others', reflected difficulties with social relationships and comprised two main themes (1) 'Family and friends: Things haven't changed... but do I say anything wrong?', and (2) Coping with threats to self: Blame others or just avoid them. The themes were discussed in relation to literature evaluating the difficulties associated with bvFTD together with implications for clinical practice.

Key words: dementia, identity, interpretative phenomenological analysis (IPA), qualitative analysis, relationships.

Introduction

Behavioural-variant frontotemporal dementia (bvFTD) is a progressive neurological disorder which is associated with insidious changes in personality and behaviour (Hodges et al., 1999). The revised consensus criteria require that, for a diagnosis of possible or probable bvFTD to be made, there must be evidence of changes in behaviour and/or cognition which are progressive, coupled with three difficulties from: Behavioural disinhibition (e.g. socially inappropriate behaviour), apathy, lack of empathy, stereotypical or compulsive behaviour, hyperorality, and finally a cognitive profile, following neuropsychological testing, of deficits in executive function combined with relatively preserved memory and visuospatial abilities (Rascovsky et al., 2011).

Research with people with bvFTD has largely concentrated on identifying and quantifying areas of difficulty across multiple cognitive domains (e.g. Hodges et al., 1999; Rahman, Sahakian, Hodges, Rogers, & Robbins, 1999). Here, it has been demonstrated that the cognitive impairments associated with bvFTD in its early stages are difficult to detect on traditional neuropsychological tests which typically lack a social component. A second strand of research has concentrated on the differential diagnosis between people with bvFTD and those with Alzheimer's disease (AD; for a review see Hutchinson & Mathias, 2007). This research strand has highlighted the relatively preserved episodic memory of people with bvFTD compared with those with earlier stage AD. Finally, a third area of research has focussed on social cognition. Here deficits have been found in Theory of Mind (TOM) (Fernandez-Duque, Baird, & Black, 2007; Gregory et al., 2002; Snowden et al., 2003), moral reasoning (Mendez, Anderson, &

Shapira, 2005; Lough et al., 2006) and the recognition of emotions (particularly negative emotions such as anger) (Fernandez-Duque, & Black, 2005; Keane et al., 1999; Lough et al. 2006).

In contrast, there is a paucity of research investigating how people with bvFTD understand and make sense of the changes within themselves, and the effect the diagnosis has had on their lives; although the view of family members has been explored (Oyebode, Bradley & Allen, 2012). One reason for this is the assumption that people with bvFTD lack insight into their difficulties and so would have little to offer by way of reflective accounts (e.g. Rankin, Baldwin, Pace-Savitsky, Kramer, & Miller, 2005). Historically, a similar assumption was made about people with AD. Yet, in respect of people with mild AD, semi-structured interviews have been successfully employed to gain people's views on: Adjustment and coping (Clare, 2002; Pearce, Clare, & Pistrang, 2002), awareness of their difficulties and beliefs about the cause (e.g. Clare, 2003; Clare, Goater, & Woods, 2006; Devlin, MacAskill, & Steed, 2007), and the impact of the diagnosis on sense of identity (Beard, 2004; Sabat & Harre, 1992; Caddell & Clare, 2011; Menne, Kinney, & Morhardt, 2002; Phinney & Chesla, 2003). Also, similar methodologies, using naturalistic conversation rather than formal interviews, have been used to investigate the views of people with moderate to severe AD residing in residential care (e.g., Clare, Rowlands, Bruce, Surr, & Downs, 2008).

Some studies have considered the experiences of mixed samples of people with any type of dementia, e.g., Harman and Clare (2006). However, such samples are predicated on an assumption of similarities in experience across types of dementia and do not allow the extraction of issues of particular relevance to people with rarer types of dementia, such as bvFTD. Whilst

AD and bvFTD fall within the cluster of dementia disorders, there are important differences in presentations between the two conditions. AD is characterised by an initial amnesic syndrome with neuropathology focused in the medial temporal lobe structures that are important for encoding new memories (Braak & Braak, 1995). In contrast, bvFTD is associated with early pathology in the frontal cortex and is associated with difficulties in social relationships and disinhibited behaviour (e.g., Neary et al., 1998). Therefore, it would be anticipated that people's subjective experience of living with these two conditions would differ. Finally, whilst bvFTD is a relatively rare disorder, accounting for approximately 2% of all dementia diagnoses made, it is more commonly diagnosed in people between the ages of 45 and 65. Here the prevalence rate rises from 2% to 12% (Alzheimer's Society, 2012). Given the tendency towards a younger age of onset of bvFTD than for the overall cohort of people with dementia, this is a further reason for hypothesising distinct subjective experiences for those living with a diagnosis of bvFTD.

Understanding the perspective of the person with bvFTD is important both in terms of promoting engagement with services, and in designing and evaluating interventions that are sensitive to, and respectful of, the perspective of the person living with bvFTD. Therefore, this study sought to elicit the views of people with bvFTD regarding their experiences of living with this diagnosis.

Method

Participants

The participants comprised five people with a diagnosis of probable bvFTD (3 males and 2 females). The diagnosis was made in accordance with the relevant consensus criteria

(Rascovsky et al., 2011). A diagnosis of bvFTD was the main inclusion criterion. The second criterion was that participants had been informed of their diagnosis in line with best practice in dementia guidelines (National Institute for Health and Clinical Excellence, 2011). If participants had not been informed of their diagnosis it would not have been possible to discuss their experience of living with bvFTD. All participants who met these criteria were given information regarding the study by the clinical team responsible for their care. Of those initially approached, one declined. The first named researcher met with a further participant who she judged not to have the capacity to give valid consent and therefore was not recruited into the study. People were also excluded if their verbal English language skills were insufficient to enable them to take part in an interview, although no participants were excluded for that reason..

The participant demographics are shown in Table 1. All lived with a spouse or partner. Three participants also had an adult-child living at home. Four were seen in their own homes whilst one was interviewed in hospital. The study was approved by an appropriate NHS ethics committee and all participants gave written informed consent. No one was paid for their participation.

Design

This qualitative study interviewed people with bvFTD using semi-structured interviews. Whilst a schedule of topic areas and related prompts was devised to help guide the interviews, this was used flexibly to allow each participant to tell their own story in their own way in line with the principles of interpretive phenomenological analysis (IPA; Smith, Flowers, & Larkin, 2009).

The interviews were transcribed verbatim and the principles of IPA were used to analyse the resulting transcripts. Throughout, the focus is on ‘personal meaning-making’ rather than a comparison of subjectivity to ‘objective facts’. IPA is a double hermeneutic process with the participant making meaning of their experiences and then the researcher endeavouring to make sense of these experiences through the interviews and their transcripts (Smith et al., 2009). Thus the researcher’s interpretations are subjective since there are multiple possible interpretations and different researchers may place different meanings or emphases on different parts of the transcripts during the interpretative process. IPA is an idiographic approach with participants’ transcripts being analysed one-by-one initially, before the interpretations are integrated across participants.

To maximise the quality of the data and avoid overburdening participants, all were offered the opportunity to take part in either one interview or several interviews (Paterson & Scott-Findlay, 2002; Snyder, 2003). Additionally, since people with bvFTD often have communication problems which manifest themselves as poverty of speech and a tendency to introversion which makes social interactions difficult (e.g. Rankin et al., 2005; Levenson & Miller 2007), a number of methods were employed to help participants to express themselves. During the interviews, participants were offered the opportunity to discuss photographs and or objects that were important to them (Lloyd, Gatherer, & Kalsy, 2006; Robinson, 2000). When phrasing questions sometimes concrete prompts were used, such as referring to specific family members by name to ensure understanding, or asking about photographs or objects participants brought to the interviews. Also, closed questions were used to clarify answers. To reduce the potential bias that might be introduced by these methods the same issues were revisited in slightly different ways and the answers triangulated to ensure consistency.

Procedure

Potential participants were identified by clinical staff from a working age dementia service in a large urban centre in the UK. Staff briefly informed potential participants about the study and asked if they might be interested in participating. Those who expressed an interest were given an information sheet and consent form to take away. Permission was gained to give the potential participant's contact details to the researcher (first author) who contacted them a minimum of 48 hours later and arranged a meeting time. At this meeting the research was explained further and any questions answered. All were informed that choosing to either participate, or not, would have no effect on their ongoing treatment and that they could withdraw from the study at any time until the final write-up without affecting their current or future care.

If participants chose to take part, consent was then taken. To assess capacity (Mental Capacity Act, 2005), the researcher sensitively assessed the participants' understanding of the research, and its potential benefits and risks; their understanding that they were free to decline to take part and that they were free to withdraw at any time. Since, for some people, their level of understanding might vary throughout the day, all meetings were arranged for a time of day when the participant felt 'brightest'.

Analytic Process

The IPA analysis involved a series of steps, the first four of which were completed on a case-by-case basis whilst the final stage involved bringing the analysis together across cases (Smith et al., 2009). Firstly, each individual transcript was read multiple times (in conjunction

with notes regarding the photographs and personal objects one participant brought to the interview) and the first-named researcher recorded initial thoughts on the descriptive comments, linguistic content (use of pronouns, repeated phrases etc.), and conceptual comments. Secondly, this researcher identified emergent themes within each text which sought to encapsulate the initial notes made, which were grounded in the text. Thirdly, the researcher created a structure out of these by looking for connections, whether commonalities or polarities. This process was completed for all transcripts. Lastly, the themes were compared across participants and a final theme structure was produced.

Two methods were employed to increase the credibility of the analysis. Firstly, the two co-researchers, both of whom have extensive experience working with people with dementia, oversaw the analysis from initial coding through to the development of final themes. Secondly, regular meetings were attended with a peer group undertaking qualitative research where, after initial coding of the transcripts, fully anonymised, brief portions of the transcripts were shared with the other researchers, to facilitate reflexivity, discussion around the coding ascribed and discussion about how codes related to the emergent themes identified. The balance between co-researchers with extensive experience in the field of dementia and a peer group whose knowledge of bvFTD was more limited helped to increase the range of ideas and interpretations considered and reduce researcher bias.

Results

In this section the themes will be described together with relevant quotes and commentary on how the quotes illustrate the themes. The theme structure is displayed in Table 2. Four main themes emerged from the analysis. These were labelled ‘Awareness of change: What’s the

problem?', 'Threats to self: This is not me ', 'Family and friends: Things haven't changed... but do I say anything wrong?' and 'Coping with threats to self: Blame others or just avoid them'. These were further consolidated into the two overarching super-ordinate themes of 'Bewilderment' and 'Relationships with others'.

Super-ordinate theme: Bewilderment

This super-ordinate theme reflects the feelings of the participants from the start of their dementia through to their first contact with health professionals to diagnosis and beyond. It reflects how they had tried to make sense of changes in themselves and/or their lives but were still left feeling somewhat bewildered.

Awareness of change: What's the problem?

All the participants, in varying degrees, were able to report some changes that either they had noticed, or which had been reported to them by members of their families. However, two participants thought that these changes did not warrant medical intervention, whilst a third thought any changes in behaviour noticed by his wife were the result of a fall. Tom, for example, specifically questioned the need for medical help. He talked about difficulties he experienced with expressive language and, at the start of the first interview, he kept fiddling with papers on the coffee table and made statements such as:

I was trying to get it out without making ... getting too many words in (laughs). Em. When I, sorry, when I try to get some words individually, I'm not as good at (laughs) what I do, what I do, when I do it. If you understand that? (laughs)

Tom

Yet, despite this marked expressive language difficulty, Tom seemed bemused as to why he had needed to see his GP or be referred to specialist services. He talked about how he “wasn't sure of the need” and how he “just sort of got into it” and “literally, I don't know how they knew”. He used the word “strange” and “weird” on multiple occasions when describing how he felt about his involvement with mental health services, for example, in reference to “going to see

people two or three times and don't know why". He described health professionals visiting him at home as "weird people just turning up" and "like it is some sort of mistake that's how I sort of make sense of it".

Tom also identified dramatic reductions in previously enjoyed activities, for example, leisure pursuits that previously had occupied large amounts of his free time. He chose to show the interviewer pictures of himself taking part in a number of outdoor activities such as gliding, white-water rafting and skiing which he described as "absolutely brilliant", "just the sort of good day of fun" and "thrilling". He also showed pictures of holidays abroad where he enthusiastically described activities such as going for walks and horse-riding. He also showed a medal he had won for running and talked about the importance of obtaining good performance times and going running with a local club several times a week. Although these activities had clearly been very important in Tom's life, he had stopped all of them. He described these huge changes in his activity levels casually ("don't get to do that stuff now"), and he did not seem overtly bothered by them, nor to reflect on them or feel any need to explain them to the researcher:

I'm, I mean I'd like to do loads of stuff but sometimes you can't be, be, cannot get up off the seat like, get, get the motivation to get out there and do it, like.

It's just one of those things. It's changed hasn't it? Things are not really the same. You just don't get to do those things these days. You think to yourself I want to.

Tom

Similarly, David talked at length about his passion for sports cars saying "I love high-speed cars". He talked about the number of sports cars he had owned (e.g. make, type, colour) and the numerous pleasure trips he had taken in them. For example:

I used to drive it all over the place, because I used to go down to Ramsgate, Margate, all along the coast and I used to just drive round and then ... I used to go down on a Friday, Friday night, and then come back on Sunday. Yeah, it was great.

David

Yet, these detailed descriptions of his love of cars and driving were incongruent with the brevity of his explanation for not driving anymore: “I haven’t got a car now, because once I left work I got rid of my car.” In a similar vein, David talked about his love of golf and went through a list of golf courses which he had played at. Again, his explanation of why he no longer played “because I don’t have anyone to play with” was brief compared with his narrative about playing golf. He also talked about his former busy job and gave lots of concrete details about the nature of his work, the responsibility it entailed and the amount of travel involved. However, when asked what he now does during the day he said “I don’t do hardly anything in the daytime because I don’t go to work”. He explained that he often takes the bus to a local shopping centre and wanders around because “when I’m at home I’m on my own all the time, because my wife, she’s at work, and my daughter’s at work”. Despite David being able to give detailed descriptions of changes in his behaviour and of giving up activities which sounded as if they had been very central to his life and a major source of excitement; when asked “Do you think you’ve changed at all?” and “Do you think some of your hobbies have changed?” David responded “No”. His simple monosyllabic response to being asked about whether he had changed, seemed totally at odds with the factual description he had given.

Despite showing no concern or reflectiveness over the behavioural changes he described, David explained how his wife took him to the doctor, who “just wanted to check my brain”. This illustrates the contrast between David’s personal awareness of changes, and his awareness, at some level, of his wife’s concerns; and the striking lack of personal concern or emotional

response in his narrative. David, who was in hospital when interviewed, gave the reason for being there as “I have frontal lobe dementia but it has not affected me.” A statement he repeated several times during the interviews. Also, David explained that the people in hospital with him “had problems with their brains” but then continued to say the doctor had said he “must have that [frontal-temporal dementia] but I haven’t because they do things wrong, but I don’t do things wrong”. This explanation did not seem to reflect a lack of understanding of his diagnosis at a cognitive level since David showed a rudimentary understanding of this (Interviewer: What do you think frontal-temporal dementia is? David: Well, that affects like how you think.). Rather, it suggests difficulty in fully appreciating and understanding the impact of the diagnosis on himself. In other words, he did not seem to recognise any changes in his own behaviour.

Patrick described in detail his first contact with the Health Service following a fall and demonstrated awareness both that his wife was concerned about him and that he now has a diagnosis of fronto-temporal dementia:

I had a fall. We... had a leak in the conservatory, and so I went up on to the conservatory roof to see if I could cure the problem. And it was damp so I thought, right, I shall dry that off, I’ll then put white spirit on it, and I’ll then seal it. That’s all I remember doing. The next thing I can recall was I was on the patio below; I had fallen off, hit my head on the wall and knocked myself out. I fractured my left arm. And [my wife] was on the telephone, when I came to, and she’s speaking to paramedics, and they came to collect me in an ambulance. I was taken down on a board, down the steps, and taken to hospital. I had my arm dressed, they put a cast on it, and a fortnight later [my wife] said, ‘You’ve been affected. You need to go and see a doctor.’ Okay. So I went to see my GP and she referred me to a psychiatrist. And the psychiatrist said, ‘Right, I’m just going to do a scan,’ which she did, and this was in the millimetres, or centimetres rather, and she said, she believed I had frontal lobe dementia.

He showed some understanding of his diagnosis saying: “I’ve got a medical diagnosis now which is I’ve got frontal lobe dementia, and I recognise that people who have frontal lobe

dementia must behave in a different way, I suppose”. However, the way he distances himself from the diagnosis by talking about ‘people with frontal lobe dementia’ and the qualifying phrase ‘I suppose’ imply that he is reciting information he has learnt whilst either minimising or not fully appreciating its application to his own self. Patrick repeatedly stated that he “didn’t feel any different”. For example:

To be perfectly honest, I don’t feel any different now than I did before I was diagnosed. I don’t do anything different. The only thing that appears to have been a factor is my short-term memory. My long-term memory is fine; I can still remember what I did 20 years ago.

I felt confused and annoyed because I believe that it was the fall and I hit my head on a brick wall to cause the problem. [The doctor] said, ‘That was probably just coincidental,’ and I probably had frontal lobe dementia before that, that picked it up.

In contrast to the three male participants, both Christine and Jayne reported changes that they felt required medical intervention. However, both reported somatic health complaints rather than features typically associated with bvFTD. This shows an ability to recognise some health related changes and yet also illustrates why they might be bewildered either by the symptoms or by the medical response to them. Christine said that both she and her husband were concerned about headaches she was experiencing and problems with her memory. These difficulties led her to visit her GP:

Christine: It’s because I have these terrible headaches, here [points to right temple], and then it came on to across my forehead [draws figure across forehead from right to left], and that just kind of ... I can’t really express it but the headache was just driving me barmy, because I can’t understand why it doesn’t stop doing it.

I couldn’t remember a lot of things and that wasn’t very good.

Christine hoped that she would be prescribed medication:

Christine: Well, I went to the doctor's, and the doctor then said, 'You probably need just to take some tablets' to like reduce the pain in my head. And then I went to [specialist's name] because by then it was getting worse, if you know what I mean!

Interviewer: Okay, so taking tablets to reduce the pain wasn't working?

Christine: Wasn't working. So I went to see [name of specialist] and he didn't put me on anything, he didn't put me on any tablets - I don't think he did, I don't think he did, I don't think he ever did.

Jayne, who had worked in a delicatessen during the day and instructed adult fitness classes in the evening, reported that it was her partner and work colleagues who first noticed that she had become slower at doing things. She agreed with them noticing that: "Yeah, I became a lot slower and things... I was doing generally you know like walking a lot slower. Um. That was it really". She described "having guessed something was wrong" and how she "wanted an answer".

Jayne's responses also seemed paradoxical. Her concern about walking more slowly was inconsistent with her lack of concern about changes in her lifestyle. She talked about previously instructing four evening fitness classes and participating in additional classes. In contrast, her only exercise, at the time of the interview, was walking the family pet dog with her partner around the housing estate on which she lived. Despite her stating that she "missed it" and that she was "missing the physical activity", there was no sense of concern about the magnitude of the change. Jayne explained "As long as I'm keeping active I don't mind really."

In summary, the theme of 'Awareness of change: What's the problem?' captures participants' subjective experiences of change and whether they viewed these changes as problematic. Although all five could recount their diagnosis, they all shared a seeming lack of emotional reaction and reflectivity at having both a progressive brain disease and a complete

change of lifestyle. This could perhaps be seen as understandable given that none of them perceived that they had cognitive or emotional difficulties requiring medical help. If you perceive no difficulties why would you expect to receive a diagnosis and how would you make sense of it?

Threats to self: This is not me

This theme encompasses participants' narratives about events which have threatened to negatively impact on their sense of self. Some participants struggled with the label of bvFTD whilst for others the threat came from their reduced abilities or from lifestyle restrictions imposed upon them due to their illness.

In respect of the diagnostic label of bvFTD, for example, Jayne became tearful when discussing her diagnosis. Her wish had been to find out what was wrong yet the diagnosis was overwhelming for her. Jayne's daughter, who lived at home, worked locally in a home for older people with dementia and Jayne had visited the home and heard stories about her daughter's work. Her bewilderment seemed to arise from being unable to process the discrepancy between her previously physically fit 46-year-old self who had noticed walking more slowly and her mental model that 'dementia equals old people.' She described feeling "Well I'm okay in myself, I'm not odd or nothing. I'm just a bit slower really" and:

Jayne: They could not give a diagnosis at first. And then as the time went on dementia started to be mentioned.

Interviewer: Okay. How did you feel when they first mentioned that?

Jayne: Horrified.

Interviewer: Okay. Can I ask what images came into mind? What did you think?

Jayne: Christ (wells up with tears). That's for old people.

In contrast, Christine's language when describing her diagnosis was blasé, for example, "I do get this frontal lobe thing" which suggests that she may have seen the condition as transient, like a headache, which would fit with her initial report to the doctor. Christine had recently been offered some medication as part of a medical trial and seemed happy with this, perhaps seeing it as an appropriate treatment for headaches:

Interviewer: So how did you feel when [the specialist] offered you medication?

Christine: Much happier because it's just like, I mean I can't, and now it's because I've kind of lost, I mean because I was really, when I was at work and things like that, I used to do everything for everybody, I worked for loads of people, everybody. And um, I can still remember going back to those days when I was at the [names past employer], I could do everything, but that suddenly just all disappeared for me.

Christine was accepting of the diagnosis and associated medication, however she seemed to experience a threat to her sense of self from the impact of the loss of her driving license on her independence.

For example: "I can't do anything, I can't go out. Well, [partner's name] takes me out, he always tries to accompany me, but ..." and

I used to go shopping, then we used to go with, we used to all, we used to (talking about two of her sisters) always take it in turns, I used to go up in my car, and then, like do things like that. And then we used to all like take it in, like my sister wanted to come here, she'd come here, then we'd go over to my other sister, we'd go to places like that, which was really nice.

For Patrick and Tom the threats to self appeared related to loss of their professional job roles which had afforded them status and a sense of worth, for example:

I've lost my job because I was told I couldn't do my job any longer because of my medical condition, so rather than going to 65, which I wanted to, I had to retire at 62, or 61, which I was annoyed at.

Patrick

Both Patrick and Tom reported missing work saying: "I did love my work, I must confess; I did love my work. I missed it." (Patrick) and:

Interviewer: Do you want to tell me about the work you did?

Tom: I used to be, or when I say I used to be it sounds like your life's gone (laughs).

Tom

When Tom was asked "So, what did you feel about finishing work?" he became very tearful and did not reply for several minutes at the end of which he stated "It's difficult". He expressed the importance of doing qualifications to "get on in work" and explained that he had completed an Open University degree in his spare time to help secure promotion. He showed the interviewer a medal he had received for work-related achievements together with a picture of him being presented with this medal by the then Prime Minister. Likewise, Patrick emphasised his multiple degrees and his professional role which he had held for forty-three years "man and boy". He also described how he did all the work himself and "never had an assistant".

Both Tom and Patrick's feelings of loss of control extended to other areas of their lives. In terms of day-to-day activities, Tom referred to deferring to his wife and described feeling that he was not given choices about activities:

It's like [partner's name] is doing something and you know, this yourself. You just have to be quiet and do the same in a way you wouldn't be in days gone past. When you'd say I don't fancy that [laughs]

For Patrick losing his driving licence was difficult: “My driving licence, I’m affected by that, I loved driving and I miss not being able to drive. Nothing I can do about it”. The difficulty was not on a practical level, as he explained that getting around by bus was easy for him and explained the local bus routes in some detail; however, emotionally it was difficult for him feeling reliant on others especially given that he did not perceive his driving ability to be compromised. He said his wife did not mind driving but that he felt it was “an impertinence for me to expect her to do it”. Patrick was aware that his family did not like his driving, with his wife telling him that “The children don’t like your driving. They won’t come if you’re driving, they wouldn’t come with you.” He minimised this by explaining that his wife “was a perfectionist”.

In a similar vein, Patrick was annoyed that he had been unable to renew his shotgun licence:

The other thing is, I’ve got a shotgun certificate and my shotgun certificate was about to expire in about a month’s time, and so I applied for another certificate to be sent to me. The chap came out from the [name of force] police in [name of local station] to see me, to look at the guns in the cabinet here, and he put a report in. I had a letter come last week to say that because of my medical condition, they’re not renewing my shotgun certificate; that will now go when it expires. The good thing is that the shotgun is still in my possession because my son has a shotgun certificate and I’ve transferred it to him. That’s another thing that annoys me.

Again on a practical basis this was not problematic but affected Patrick due to the perceived loss of control it implied:

Patrick: It doesn’t particularly bother me now, the shotgun is up in the cabinet upstairs in my study, and it stays there. I’ve never ... I’ve never used it, I haven’t used it for about four years, I suppose. You get a shotgun to go rabbit shooting perhaps sometimes, shotguns into the wood. . . .

Interviewer: . . . So when you described earlier it was annoying for you when they wrote to you saying you can’t have your shotgun licence, in terms of what you do day to day, it wasn’t the sort of thing that you were doing regularly?

Patrick: No. It hasn't affected me at all, it's just I feel a little bit aggrieved that I no longer have a shotgun certificate. If I want to go out and do some shooting with my son, for company, I couldn't now go with my shotgun certificate because I don't have a certificate now so I couldn't use it, so I'll just go with him and just watch what he does. That's rather annoying, but that's academic, I haven't shot for about four or five years anyway.

In summary, the theme of 'Threats to self: This is not me' represents changes that negatively impact on participants' sense of self whether due to the label of dementia, a reduction in abilities, or lifestyle restrictions imposed upon the participants due to their illness.

Super-ordinate theme: Relationship with others

This super-ordinate theme reflects the narrative about relationships running through all the participants' interviews whether it be due to not understanding the effect of their behaviour on family and friends or arising from difficulties in interacting with people within their wider system.

Family and friends: Things haven't changed... but do I say anything wrong?

This theme looks at relationships with those with whom it would be expected that participants would have a reasonable social relationship. This sub-theme really illustrates the paradox between participants not understanding that their relationships had changed yet at the same time having a vague feeling that something about their social interactions was not quite as it used to be.

All participants said there were no changes in their relationships with close family and friends. However, this statement was incongruent with three participants' descriptions of feeling that the way people behaved towards them had changed. For example, Tom's relationships with

friends had been important to him. He showed the interviewer pictures of himself with groups of friends who he described as “nice friends, sort of lovely” and talked about “getting a good bunch of friends together” and “everyone mucking in”. However, he described how he now picks up “vibes” from people and is aware that people treat him differently which he described as a “bit, um stressful” and that this is “when you get down”. He keeps these feelings to himself and copes by “trying to get out of the situation”. He said he no longer sees friends regularly but was unable to explain why that might be. Neither did he demonstrate any awareness of whether changes that he had described in himself might be related to the reduction in socialisation, leaving him with a sense of perplexity and mild anxiety about why his friendships had faded.

Similarly, Jayne when asked whether her relationship with her two daughters (one of whom lives with her) had changed said:

Jayne: “You know I don’t think so. I’m quieter with them’

Interviewer: Okay. In what way quieter? Can you give me an example?

Jayne: I don’t speak very much to them’.

Interviewer: Is that a change?

Jayne: I think so. Yeah. I like peace and quiet.

Jayne recognised a change in her own behaviour, but showed neither recognition nor concern for how that might feel from her daughters’ perspective. This narrative continues when she describes the relationship with her partner, which she also felt had not changed. Her partner had recently given up work to care for her and Jayne described that “she loves it” when talking about having her partner home all day. She continued by describing him as “really helpful” and saying “He does the cooking and the erm washing and he’s basically taken over everything”, reflecting a practical connection rather than an emotional one. She described how “[My partner] would go, out of his way to make a conversation with me and I am just like, ‘yeah’, ‘no’

(laughs)". Jayne was the only participant who had requested her partner be present during the interview, hence these comments, which imply a lack of effort to converse, were made in front of him, violating social norms. Jayne also talked about how she used to go out a lot with her partner and friends but stated that now "I just can't be arsed really", and she minimised the importance of these friends: "They were never like really close, close friends anyway".

Only one participant made reference to the effect his condition had on his family. However, the emphasis was on their concerns for him, rather than his concern as to how they may have been affected:

Interviewer: I'm wondering, how do you think it's affected your family, all these changes?
Patrick: Well, my family are concerned that I have this dementia, they sympathise with me, but there's nothing they can do for me. It's getting people to accept it, basically. I don't think they think I've changed in any way. I don't believe I've changed, and

Patrick

Paradoxically, both Jayne and Christine raised concerns that they might say the wrong thing, which suggests some level of social awareness.

Christine: Um, I mean sometimes I can talk to [partner's name] quite openly, because he's quite good with me, um but um I never knew what to say, never, I never know [emphasised this] what to say and what to do or anything, or ...

Interviewer: So I'm wondering, when you say you don't know what to say, is it that you're not sure what [partner's name] is asking, or whether you worry about saying the wrong thing?

Christine: Yeah, I think that's it, yeah

Interviewer: You worry about saying the wrong thing?

Christine: Mm.

Interviewer: Do you think that happens a lot?

Christine: Um, Yeah, I would say so.

Christine

I listen carefully in case I say the wrong thing or something. It's a thought in the back of my mind that if I was to say the wrong thing I would upset somebody and the conversation would go all flat and quiet wouldn't it.

Jayne

In summary, the theme of ‘Relationships with others: Things haven’t changed... but do I say anything wrong?’ illustrates the participants’ difficulties in maintaining social relationships and appreciating the effect their behaviour has on others.

Coping with threats to self: Blame others or just avoid them

This theme brings together different ways participants sought to cope with threats to their identity, reflecting two dominant coping styles; firstly externalising the problem by blaming others, and secondly avoiding situations where difficulties have been encountered.

For example, Tom externalised the reasons for his job loss. From his perspective it resulted from the unreasonable actions of others. He described having no warning that his work performance was unsatisfactory, feeling that he did not know what was expected of him and that his workload was unreasonable: “The first part that I knew about it was when I was called in. And as a result I just had to go with it” and “They’re kidding themselves if they believe you can get just one person to do all that stuff in one job.”

Tom described feeling that perhaps one motivation behind the loss of his job was that people had become disrespectful of his position since he had been promoted: “People don’t think good things about you. Your name might be there but it does not mean to say they think you are at the top.” Tom also talked about feeling “manipulated”, that people “don’t see who they are talking to” and of not knowing “who’s been a shit to him”. He felt that he had done his best and people from work had not supported him.

Similarly, Patrick used externalisation to explain difficulties he had experienced securing alternative employment:

I've written to the [professional] Society to ask if I can go into private practice by myself, and because the way the [profession] is going at the moment, and [my field] particularly, the [professional] Society has reduced the number of [people] who can do [this work] now, they have to have a franchise, and the [professional] Society has reduced the amount of money coming into the [system] by 20%. So I've spoken to my friends who ...work in private practice, 'Can you give me a job?' And so because the income's gone down by 20%, they can't afford to employ me. I only want to work two days a week, but they can't afford to employ me. So I've written to the [professional] Society to ask if I can go into private practice by myself, and they'll reply to that and they'll decide whether I can or not. They'll probably say no because you have to go into private practice by yourself for three years, generally, worked with others not by yourself, so I, suspect they'll say 'No you can't.'

Patrick also gave a detailed descriptive account of failing a driving assessment:

The assessor didn't like that I drove in the nearside line of the carriageway, and I then went to the nearside to turn left. Nowadays they drive and go in the centre of the island. I was taught to drive to the left, a different way. When I was taught to drive, of course, to a crossroads, crossing this way, I went round the back of cars, and now they go in front of the cars; a different way of doing things now. And I have a hearing difficulty, my left ear is particularly difficult, and so he said, 'I want you to carry on in a straight line, I'll tell you to turn right or left.' He told me to turn right, I didn't hear him, and so I carried on. He didn't like that. I explained my difficulties afterwards but it didn't affect it. And then on an island, we came to an island, and there was a car coming to my right, so I was just slowing down, I wasn't going to stop, I was slowing down, but he did an emergency brake. I knew what I was going to do, he obviously didn't, and that annoyed me.

He externalised this failure on two levels. Firstly, he repeatedly stated that "this was how I was taught to drive 45 years ago" as well as blaming his deafness. Secondly, Patrick's use of language when describing his interactions with the driving assessors suggested conflict with repeated use of "I" and "them". These statements were augmented by his narrative of repeatedly writing to the DVLA to question the decision to revoke his driving licence; letters in which he queried the competence of the assessors asking "Are they medically qualified?"

In terms of coping by avoidance, to avoid saying what they perceived to be “the wrong thing”, both Jayne and Christine talked about changes in the way they behaved. Jayne talked about how she “prefers to listen” and “not to join in so much”. Whilst, Christine said she let her partner do the talking because “he is better at it”. She said that at times she would like to ask questions but does not do so, for example, when describing visiting a health professional:

Christine: Well, I think [partner’s name] is much better off than me, he knows what to say, and when he says to me, he says ... I don’t because I know that he’s so good at talking, but I’m not and I have to like kind of think about it, and then I’ll just think, oh I don’t know what to say now! (laughs)

In summary, the theme of ‘Coping with threats to identity: Blame others or just avoid them’ reflects the two main coping strategies participants described using to manage the threats to their identity.

Discussion

This study explored the subjective experiences of people living with a diagnosis of bvFTD. The super-ordinate theme of ‘Bewilderment’ reflects how whilst all participants showed some awareness, albeit in varying degrees, of changes in their behaviour or lifestyles, they all experienced difficulties in making sense of changes and relating them to their medical diagnosis and their view of themselves. This is illustrated by the two main themes of ‘Awareness of change: What’s the problem?’ and ‘Threats to self: This is not me’. In respect of ‘Awareness of change: What’s the problem?’ it was noticeable that whilst all participants were able to report some changes, albeit not necessarily ones they felt required medical intervention, none of the participants directly reported being aware of personality changes, despite changes in personality

being one of the hallmark features associated with bvFTD (Hodges et al., 1999; Rascovsky et al., 2011). This suggests a lack of self-awareness. Indeed, Rankin et al. (2005) demonstrated that when people with bvFTD self-rated their personality traits these ratings were less congruent with those of informants than was the case for either those with mild Alzheimer's disease or healthy older adults; with people with bvFTD tending to over-estimate positive personality traits such as gregariousness and extraversion whilst underestimating negative traits such as cold-heartedness and introversion. However, people with bvFTD's description of their personality traits were congruent with their informants' retrospective evaluation of their personality prior to the onset of bvFTD suggesting an impairment in self-awareness. Abu-Akel (2003) suggested that self-awareness involves a three-stage process. Stage one entails information being received in parietal brain regions; stage two involves evaluating this incoming information for personal and emotional meaning, processes which he suggests are mediated by the limbic and paralimbic systems; whilst stage three involves executive function such as error-monitoring and identifying discrepancies which rely on the integrity of dorsal medial and dorsolateral pre-frontal brain regions. Abu-Akel (2003) purported that impairment in the paralimbic and dorsolateral pre-frontal regions, which are commonly seen in those with bvFTD, means that the process of self-awareness is disrupted at stages two and three of the process. This fits with the ability of participants to recall receiving a diagnosis and, at some level, report some changes in their lifestyles due to the relative sparing of damage to parietal structures early in the disease process. It may also explain why they find it difficult to ascribe that diagnosis to themselves; hence leading to a sense of bewilderment.

Difficulties with self-awareness also link with the second main theme of 'Threats to self: This is not me' which represents changes that negatively impact on participants' sense of self.

What is noticeable is the contrast between the participants' reactions to changes over which they felt a degree of control, e.g. decreased leisure activities; and changes that were imposed upon them (outside of their control) e.g. losing their jobs or other lifestyle restrictions. The results of this study illustrate an important difference between the experiences of people with bvFTD and those of people with AD. It has been shown that people with AD tend to have awareness of their memory difficulties but often attribute them to ageing rather than illness (e.g. Clare, 2003; Clare et al., 2006; Devlin et al., 2007). In comparison, people with bvFTD are doubly disadvantaged. Firstly, limited awareness of their difficulties with respect to the markers for bvFTD makes attributions concerning the possible cause difficult. Secondly, lay-beliefs linking memory difficulties and ageing are common-place (Devlin et al., 2007) and seem to provide people with AD with a plausible explanation for their difficulties. These lay-beliefs may serve a protective function against threats to their self-identity early in dementia and avoid them becoming overwhelmed (e.g. Harman and Clare, 2006). However, no such lay-beliefs exist to help people with bvFTD for whom age of onset tends to occur prior to retirement age and for whom memory is relatively spared.

The second super-ordinate theme of 'Relationship with others' illustrates the difficulties participants have relating to others, whether within the context of family and friends or people within their wider network. The first main theme of 'Family and friends: Things haven't changed... but do I say anything wrong?' illustrates the paradox between participants' narratives that their relationships had not changed; yet their awareness that people's behaviour towards them had changed which resulted in some participants feeling that they might be doing something wrong. In terms of emotional responses, participants displayed some emotions when describing events that directly appertained to them, but not in relation to their interactions with others. These

subjective experiences are consistent with the findings that people with bvFTD, rather than showing a global impairment in the expression of emotion, are able to express simple emotions such as happiness, sadness and fear (Levenson & Miller, 2007; Werner et al., 2007) but are impaired on what Sturm, Rosen, Allison, Miller and Levenson (2006) and Strum, Ascher, Miller and Levenson (2008) referred to as “self-conscious emotions” such as embarrassment, fear and shame. They hypothesised that these emotions are more cognitively complex and require an understanding of social interactions. The participants’ experiences are also congruent with the identified deficits people with bvFTD display on Theory of Mind tasks (Fernandez-Duque, Baird, & Black, 2007; Gregory et al., 2002; Snowden et al., 2003) which neuro-imaging studies have shown to be mediated by a neural circuit including the frontal lobes. In a similar vein, people with bvFTD have been found to have an impaired ability to recognise emotions, particularly negative emotions in others (Rankin et al, 2006; Werner et al., 2007) which might be reflecting in some participants’ experiences of feeling that they might be doing something wrong but without being able to work out what this might be. Finally, neuro-imaging studies have shown that integrity of the frontal lobes is important for empathy, which has also been found to be impaired in people with bvFTD (e.g. Vollm, et al., 2006). This suggests that people with bvFTD would have difficulty with inter-personal relationships, which is reflected in some participants’ having had difficulty in seeing things from the perspective of others.

Lack of awareness and empathy also link with the second main theme of ‘Coping with threats to self: Blame others or just avoid them’. Blaming others is conceptualised as a fight response and a response to feelings of injustice, and in these participants may have arisen from difficulties in recognising changes in themselves. Here, to protect the sense of self, others are blamed for the situation that participants find themselves in. This is an understandable response

given that participants who reported a tendency to cope in this way were unable to identify any valid reasons for restrictions made to their preferred lifestyle. In contrast, avoidance is conceptualised as a flight response where participants coped by avoiding situations thus protecting themselves from further assaults on their self-identity. This coping style tended to be adopted by participants who had an inkling that they might be acting in ways that were socially inappropriate.

These two coping strategies have strengths and limitations in respect of effectiveness. The fight response of blaming others gives participants a sense of power through taking action. Whilst understandable on a cognitive level, (i.e. if you are unaware of an internal change then it follows that the problem must be due to something external), the failure to recognise change coupled with a reduced capacity to recognise the reciprocity needed to build and maintain relationships is likely to render this strategy unsuccessful. Rather than achieving the aim of regaining control, the more likely outcome is that this will antagonise and may result in increasingly more punitive responses from others; thus reinforcing and intensifying the feelings of injustice when the participants' efforts are thwarted. Indeed, this explanation fits with informant reports that people with bvFTD have a tendency towards negative personality traits such as coldness (e.g. Rankin et al., 2005). The second coping strategy of avoidance or fleeing, either by talking less or letting others talk for them, may help reduce instances of faux pas. However, this social withdrawal may be misconstrued as rudeness or disinterest (Rankin et al., 2005) leading to a negative reaction from others which the person with bvFTD will struggle to understand, hence further exacerbating their already problematic social relationships and increasing levels of family stress (e.g. de Vugta et al., 2006; Merrilees et al., 2012).

The themes that have been inductively drawn from the interviews show some common reactions to being diagnosed with bvFTD. Bewilderment and sense of threat to self are not unique reactions to bvFTD and may also be experienced by people receiving a diagnosis of AD (e.g. Clare, (2003)) or other illnesses such as cancer (Hench & Danielson, 2008). However, the particular subjective experience of people with bvFTD appears distinctive due to the paradoxical combination of cognitive appreciation of the situation with a lack of reflexive and emotional understanding. These experiences appear different from the experiences of those with moderate to severe Alzheimer's disease who are able to form and sustain social relationships (e.g. Sabat (2012)). Similarly, fight and flight are widely recognised coping strategies, found in many human situations. In the context of the cognitive changes of bvFTD, it seems that, due to lack of awareness of self and other, participants resort to them on the basis of a perspective that is not shared by the 'other' and which can therefore lead to conflict and tension.

In terms of implications, this study raises an interesting question about how mental capacity is assessed (Mental Capacity Act, 2005). Under the Act, capacity to make a decision is assumed unless there is evidence to the contrary. If people with bvFTD, at least in the early stages of the disease, show a cognitive understanding of the decision to be made it is possible that their struggle to process information at an emotional level may be overlooked. This suggests that there may be situations where people are deemed to have capacity even though emotionally they may have limited ability to understand the possible impact of their decision. Therefore, this should be considered when assessing capacity and provision made for supporting people with bvFTD in the decision-making process.

In terms of interventions, it is argued that people with bvFTD require specialist interventions tailored to meet their particular needs. Currently the guidelines on best practice in dementia care (National Institute for Health and Clinical Excellence, 2011) encompass all forms of dementia and recommend group-based cognitive stimulation therapy for treating the cognitive symptoms of people with mild to moderate dementia. For people with bvFTD, for whom, at least earlier in dementia, cognitive symptoms are not so troublesome; this type of therapy may not hold the same benefits as for those people with a diagnosis of AD or vascular dementia. Interventions are required which seek to reduce the impact of their difficulties with social interactions. For example, future research could look at the use of family based interventions (which include the person with bvFTD) with a psycho-educational component. These have been demonstrated to have efficacy in other groups for whom social relationships are difficult, e.g. people with schizophrenia (Pitschel'Wcdz, Leucht, Bduml, Kissling, & Engel, 2001).

One limitation of this study is the potential increase of bias arising from adjustments made from the standard way interviews are routinely conducted in qualitative research. These adjustments were made in order to minimise the impact of the communication difficulties such as poverty of speech routinely observed in this client group. So the risk of bias, when designing the study, was balanced against the need to give participants appropriate support to maximise the opportunity for their voices to be heard. A further difficulty was that the narratives of the participants were more brief and fragmented than those which might be obtained from individuals without communication difficulties, hence making synthesis of their personal accounts challenging. Also, it is acknowledged that the interpretation of the participants' experiences is reliant on the reflectivity of the researchers; despite the safeguards employed to reduce biases

arising from this. A further limitation of this study is that the results cannot be generalised, due to the methodology chosen which considers the experiences of small numbers of participants. The decision to use this methodology, whilst appropriate, was driven primarily by the objective of seeking to understand the experiences of those with bvFTD. However, it also reflects a degree of pragmatism. BvFTD is a relatively rare sub-type of dementia and engaging people with this diagnosis in research is difficult. Nevertheless, given that this area is under-researched it is hoped that this study will lead to more research in this area.

In conclusion, this study has demonstrated that engaging people with bvFTD in conversations about their subjective experiences is possible. The results show how hard it is for those who have a limited awareness of changes that impact on their interpersonal relationships and illustrates ways that people with bvFTD try to make meaning of their situation and the coping mechanisms they employ.

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List of Tables

Table 1: Participant demographics

Table 2: Theme Structure

Table 1: Participant demographics

Pseudonym	Gender	Age	Time since diagnosis	Number of interviews conducted
Patrick	Male	62	1-2 years	1
Tom	Male	60	< 1 year	3
David	Male	62	1-2 years	3
Christine	Female	58	<1 year	1
Jayne*	Female	46	< 1 year	1

* Requested that her partner was present during the interview

Table 2: Theme Structure

Super-ordinate themes	Main Themes
Bewilderment	Awareness of change: What's the problem? Threats to self: This is not me
Relationships with others	Family and friends: Things haven't changed... but do I say anything wrong? Coping with threats to self: Blame others or just avoid them