Australian Journal of DementiaCare **Research Focus**

This section aims to provide a channel of two-way communication between researchers and practitioners in the expanding field of social, psychological and nursing research in dementia care, including all aspects of nursing and care practice, communication and the environment.

The Research Focus section of the *Australian Journal of Dementia Care* aims to keep readers up to date with the fast expanding field of social, psychological and nursing research in dementia care. By this we mean every aspect of person-to-person communication, nursing and care practice and organisation, and the influence of all aspects of the environment. The aim is to provide a channel of two-way communication between researchers and practitioners, to ensure that research findings influence practice and that practitioners' concerns are fed into the research agenda. We would like to hear from you, specifically with:

- notice of the publication (recent or imminent) of peer reviewed papers with practical relevance to dementia care;
- research reports available for interested readers;
- requests or offers for sharing information and experience in particular fields of interest.

Frontotemporal dementia: the real lived experience

Severe symptoms are to be expected in people with behavioural variant frontotemporal dementia, at least according to the official diagnostic criteria. But is this always the lived experience? **Reinhard Guss** and colleagues conducted interviews which told a rather different story

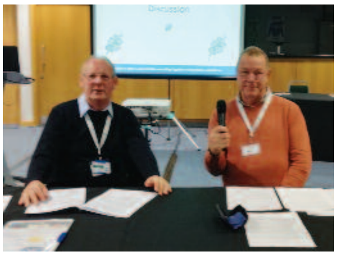
Diagnostic criteria for behavioural variant frontotemporal dementia (bvFTD) give a rather disturbing list of symptoms. Yet there is limited research on the experience of living with this form of dementia and how it impacts on aspects of everyday life such as relationships, sociability and wellbeing. In the research reported here, we wanted to find out to what extent the lived experience fitted with the diagnostic criteria.

It is no surprise that the diagnostic criteria (Alzheimer's Society 2017) for bvFTD have led to a somewhat negative portrayal which can be daunting for someone newly diagnosed with the condition, especially while they are coming to terms with their diagnosis and learning strategies to live well with it. Moreover, it affects others' perceptions and expectations of them.

Frontotemporal dementia is an umbrella term for a varied group of progressive neurological disorders, including bvFTD, which affect the frontal and temporal lobes of the brain causing atrophy and deterioration of function (Mayo Clinic 2016). People with FTD can undergo changes in their personality and behaviour, some of the most prevalent behavioural changes including an absence of basic and social emotions, disinhibition, decline in grooming and hygiene, generalised apathy, hyperorality, gluttony, altered preference for sweet foods and stereotypical utterances (Snowden *et al* 2001).

More specifically, bvFTD itself results in dysfunction in portions of the brain that regulate socioemotional behaviour such as the orbitofrontal cortex and amygdala (Scherling *et al* 2017, Kipps *et al* 2009). Diagnostic literature lists symptoms such as making inappropriate jokes and comments, impulsive and rash behaviour, and atypical emotional expression (Alzheimer's Society 2017; Dementia UK 2017).

Additionally, some accounts focus on antisocial and criminal behaviour such as theft, trespassing, public urination, violence (Lilijegen *et al* 2015, Miller *et al* 1997), aggression, obsessive and compulsive behaviour (Alzheimer's Society 2017, Dementia UK 2017) and sociopathic acts (Mendez *et al* 2005). Further research has shown links with hypersexuality, sexually disinhibited behaviour (Alzheimer's Society 2017, Mendez & Shapira 2013, Liljegren *et al* 2015, Mendez *et al* 2005, Miller *et al* 1995), and sexual attraction to minors and animals (Boutoleau-Bretonnière *et al* 2015).



■ Reinhard Guss is a clinical psychologist at Sussex Partnership Foundation Trust and the dementia workstream lead for the British Psychological Society's Faculty of the Psychology of Older People; Chris Norris (left above) is Kent and Medway NHS and Social Care Partnership Trust (KMPT) service user envoy; Chris Ryan (right above) is a member of the Dementia Engagement and Empowerment Project (DEEP) network; and Morgan-Wallis Egremont and Megan Roby are psychology students at the University of Kent, on placement in KMPT Psychology Services for Older People. All are based in the UK.

In our research, two people with a diagnosis of bvFTD took part in semi-structured interviews to explore how their personal experience of the disorder corresponded with the diagnostic criteria, which were formalised in 2011 under an agreement known as the international consensus. We wanted to generate a better understanding of bvFTD among those with a new diagnosis, their families and friends, healthcare professionals and the wider public.

Our interviews challenged misconceptions and stereotypes. We were able to explore behavioural and cognitive presentations of symptoms, how our

Chris Norris: my views on the project

The more that Chris Ryan and I discussed things with Reinhard and the students, the greater the realisation dawned on all of us that although Chris and I had many of the characteristics of bvFTD, neither of us had behaviour patterns at the extremes outlined in the textbooks such as throwing our clothes off or making untoward advances/comments to or in front of the general public.

Neither of us shout, scream and swear at others or have become violent. It's said that people with FTD don't have awareness or insight around what we say and do but, for us, that wasn't the case. On the majority of occasions we displayed that we had insight into what we were saying or doing at the time or were able to reflect on what had occurred afterwards and realise/remember what had happened when things were outlined to us.

Sometimes we could be a bit snappy with others and, when the words were out, mostly we realised what we had said. If this was not at the time, then when someone immediately afterwards pointed it out, we were able to recognise that what we had said, or done, was maybe outside the parameters of normal acceptable behaviour. We both agreed that although these things were normal when living with FTD, neither of us would want to use this excuse for bad behaviour and we generally pay extra attention to keeping things in check.

We realise this is our condition currently and that changes are likely and are occurring gradually to us. Both of us are past the five-year point since diagnosis and, although our behaviour filters are gradually deteriorating, we are by and large aware of what we say or do.

We also established that the textbooks stated that memory loss was not a real factor of FTD but that we both have difficulty with the memory and recollection of recent events and facts etc, contrary to what is taught around FTD.

There were other aspects around the condition of FTD that we appeared to experience differently from that stated in the textbooks but, as the article is concentrating on behaviour and insight, I will not go into them here. I hope what I have written above will go some way towards making the article a success for this journal.

interviewees interpreted and perceived these symptoms, what impact the symptoms had on their everyday lives, what emotions they felt, how they were treated by others and what they found beneficial and therapeutic.

How did we prepare?

In preparation for our workshop at the UK Dementia Congress in 2017, we researched bvFTD, exploring journal articles, dementia educational websites, textbooks and the clinical features set out in the international consensus criteria (Rascovsky *et al* 2011). As a result of this research we drafted semi-structured interview questions, shaped in part by the following six clinical features:

- early behavioural disinhibition
- early apathy or inertia
- early loss of sympathy or empathy
- early perseverative, stereotyped or compulsive/ritualistic behaviour
- hyperorality and dietary changes
- neuropsychological profile changes, i.e. executive/generation deficits with relative sparing of episodic memory and visuospatial skills (Rascovsky *et al* 2011).

What did we find?

There were some surprises in our key findings from the semi-structured interviews, arising from the fact that some of the cognitive and behavioural symptoms were presented in a way that contrasted with the diagnostic criteria and the research literature. The surprises we have chosen to focus on are insight, socially disinhibited behaviour and memory.

Past research has tended to give precedence to the carer's perspective rather than that of the person with bvFTD (Goldsmith 1996). The common assumption has been that people with bvFTD lack insight into their behavioural presentation and difficulties (Bozeat *et al* 2000) and that their experience is consequently without much value to researchers (Rankin *et al* 2005). Our interviews, in contrast, indicate that both participants were able to acknowledge how their behaviour had changed and recognised when it was offensive, inappropriate or harmful to themselves and others.

One of our interviewees, Chris Norris (co-author), said:

> *We think we've got insight – me and Chris [fellow interviewee]. Because we can see what's happening and tell what's happening and stuff like that, but they say we can't. And we can. We want to prove to them that you can have insight. Because we know what's going on – but we're not meant to know all that. So it's yeah, we've definitely got insight.*

Chris N also talked about his reaction to the condition:

> *The apathy has got worse, I just feel like sometimes I can't be bothered, I think "why do I have to do this?" I deliberately do not watch daytime television; if I do I could just sit there for hours. Because of this, I try to keep myself busy.*

Socially disinhibited behaviour was described by both interviewees as speaking out of turn, becoming agitated with others and talking to strangers with familiarity. But neither was comfortable with some of the standard examples given in the literature. Our second interviewee, Chris Ryan (co-author), commented:

> *We deviate from the standard description of FTD; especially socially inappropriate behaviour. It is suggested that people with FTD run around naked without clothes on – we shout, scream and swear at everyone, but that is not the case. We do show socially inappropriate behaviour, but it's more like sometimes we say things that could be considered rude or should not be said.*

Chris N was concerned about how his behaviour would be perceived by others:

> *I do feel worried about how people feel and think about my behaviour. When it comes to jokes, I sometimes feel like people do not think I'm joking and this worries me. I don't want to be somebody people pick their words around or avoid certain topics as they may fear my reaction and, in turn, my behaviour.*

In relation to episodic memory, both participants commented on how their short-term memory had worsened and made everyday tasks increasingly difficult. For Chris N, some of the claims made in the literature were mistaken:

> *I feel like my memory has worsened, so I feel like to say FTD doesn't affect your memory is wrong. For example, if I go to a meeting, I don't tend to remember much of it afterwards. Also, my writing skills have worsened so now I don't tend to take notes because it takes too long for me formulate words to paper.*

Chris R gave an everyday example of a memory lapse familiar from his own experience:

> *My wife will say "I want to go to the post office" and I'll get in the car to go to the post office and I'll go straight past it. She'll go "Post office?" and I'll go "oh, Christ" and I'm already going onto Sainsbury's or Canterbury or wherever, you know. I forgot the post office. It happens quite a lot.*

Conclusions

From these interviews we were able to draw a number of inferences, at least some of which contradicted the prevailing view in the literature about bvFTD. Among our conclusions, several of which are indicated by the quotes given above, were:

- Socially disinhibited behaviours were far less extreme than the examples given in the bvFTD literature.
- At times, our interviewees had insight into how they behaved, how their behaviour affected others and why people might behave differently towards them because of their diagnosis.
- Memory deterioration has more of an impact on everyday life than the diagnostic criteria and literature suggest.
- Psychosocial interventions are therapeutic and beneficial, allowing individuals with bvFTD to learn from others with dementia
- An understanding of dementia among family members and the wider public was seen by the interviewees as important for communication with these groups.
- While there were similarities between the two interviewees, there were also distinct differences in their behavioural symptoms, i.e. how bvFTD manifests itself is dependent on the individual.

We believe our research is another example of why it is so important to listen to people with dementia themselves. By doing so, we often cast a very different light on the experience of dementia and challenge some of the orthodoxies that have come to dominate the thinking of professionals. ■

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