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The language of behaviour changes in dementia: A mixed methods survey exploring the perspectives of people with dementia.

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Title: The language of behaviour changes in dementia: A mixed methods survey exploring the perspectives of people with dementia.

ABSTRACT

Aims: The aim of this study was to explore the opinions of people with dementia, in relation to the language used to describe changes in behaviour associated with dementia.

Design: This study adopted a human rights approach within a mixed methods convergent parallel synthesis design.

Methods: Online and paper-based questionnaire data was collected between November 2019 and March 2020. A combination of convenience and purposive sampling was used to invite people with dementia to participate.

Results: 54 people completed the survey. There was no clear consensus on a preferred term, but 27.8% preferred the term 'unmet needs' to be used when describing changes in behaviour associated with dementia. Qualitative data, revealed important nuances and challenges for researchers and practitioners in relation to terminology for this paradigm. Participants felt that language we use to talk about changes in behaviour can influence how people with dementia are viewed and treated and also how people feel about themselves.

Conclusion: The majority of participants were familiar with a range of terminology. There was no universal agreement on a preferred term, but there was an overall preference for terms that reflected the unmet needs likely to underlie perceived changes in behaviour.

Impact: People with dementia raised concerns about the language used to describe changes in behaviour that can occur in dementia. There is scope for improvements in the language used for this paradigm in both research and practice. Clinicians need to take the time to explore an individual's preferences and understandings and to also share their own meanings and understandings.

Key words: survey, dementia, behaviour, BPSD, distress, psychological symptoms, language

Main paper

INTRODUCTION

International healthcare literature, public discourse and policy often use language about people with dementia that can be disrespectful, offensive and devaluing of their human rights (Cahill, 2018). Language has a powerful role in perpetuating stigma in the context of dementia (Swaffer, 2014). People with dementia have raised particular concerns about the language used in relation to 'behavioural and psychological symptoms of dementia' (BPSD), with international social media campaigns to #banBPSD. The pros and cons of the #banBPSD campaign have been

commented on (Cunningham, Macfarlane, & Brodaty, 2019) and dementia care professionals also disagree about terminology for this paradigm (Wolverson et al., 2019).

BPSD is perhaps the most common of the range of terms used to refer to changes in behaviour that can occur in dementia. BPSD and related terms like 'non-cognitive symptoms' and 'neuropsychiatric symptoms' arise from medical constructs where changes in behaviour are seen as dementia-related symptoms. Other terms such as 'challenging behaviour' or 'behaviours that challenge' arise from psychosocial constructs that explore the idiosyncratic causes of changes in behaviour and caregiver responses. Little is known about the perspectives of people with dementia about such terminology.

BACKGROUND

People with dementia experience a number of changes and challenges as a result of both dementia, and the way that others treat them (Patterson, Clarke, Wolverson, & Moniz-Cook, 2018). Changes in behaviour and mood are common and can be very distressing for the person with dementia and those around them (Alzheimer's Society, 2014).

In western societies dementia continues to be framed within a predominantly biomedical model, which views changes in behaviour as a symptom of dementia and a result of changes in the brain (see for example, Liperoti, Pedone, and Corsonello (2008)). This understanding is reflected in terminology such as 'behavioural and psychological symptoms of dementia' (BPSD) 'neuropsychiatric symptoms' and 'non-cognitive symptoms'. The most prominent competing explanatory model is that of 'unmet needs' (see for example, Stokes (2017)). From this perspective, behaviours are viewed as expressions of, for example, psychological distress, insecurity, discomfort or pain. Over time, understandings and models have attempted to consider a broader range of factors that contribute to, or exacerbate, the challenges of dementia care, such as the impact of the physical environment, the role of caregivers and social and political contexts that shape all human responses (James & Gibbons, 2019).

Contrasting perspectives have resulted in a plethora of terminology used across research and clinical settings. Moreover, some terms appear to have translated better than others, resulting in international differences. The language used in this paradigm, reflects fundamental differences in how changes in behaviour are understood and responded to by those delivering care. For example there have been calls to drop the term 'challenging behaviour' following concerns that this can lead to the labelling and stereotyping of people with dementia and is also associated with a crisis-driven approach to service delivery (Dupuis, Wiersma, & Loiselle, 2012). Recently, serious concerns have also been expressed in campaigns to #banBPSD with cautions about language that pathologises dementia, where people are seen as 'symptoms to be treated' potentially with drugs of unknown efficacy, but known to cause harm for some (Swaffer, 2019).

The growing international advocacy movement in dementia campaigning for changes in care policy and practice, has been a powerful force in highlighting the role of systematic labelling in human rights breeches (see for example, Swaffer (2019)). As researchers and practitioners we

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must accept that language we have used may inadvertently perpetuate stereotypes and prejudice towards people with dementia

Whilst changing a term may not in itself change practice, what the advocacy movement has taught us, is that any attempt to de-stigmatise dementia must include the realities and experiences of people with dementia. Improved understanding of the lived experiences of people when changes in behaviour are encountered, remains important if we are to provide efficacious support for this difficult and costly aspect of dementia that causes significant distress for people with dementia and caregivers.

THE STUDY

Aims

The aim of this study was to explore the views of people with dementia, in relation to the language used by healthcare professionals to describe changes in behaviour associated with dementia. It seeks to understand whether there are any preferred terms and /or terms that are disliked, and to understand more about what people expect from language in this area, including reasons for potential concerns about language in this area. The research questions were:

1. What terms have people with dementia heard being used to describe changes in behaviour associated with dementia?
2. What terms do people with dementia prefer to be used to describe changes in behaviour associated with dementia?
3. What terms do people with dementia dislike in descriptions of changes in behaviour associated with dementia?
4. Are there any differences in participants preferences related to age or gender?
5. Why and in what way does terminology for this paradigm matter to people with dementia?

Research Design

This study adopted a human rights approach within a mixed methods combined transformative and convergent parallel synthesis design, where quantitative and qualitative data from research questions are collected simultaneously, analysed and presented with interpretation occurring in the discussion (Noyes et al., 2019). Language preferences were collected quantitatively and were supported by qualitative, open-ended questions that explored the reasons for choices. Equal priority was given to the quantitative and qualitative data. The transformative aspect of our design (Hanson, Creswell, Clark, Petska, & Creswell, 2005) adopted a human rights lens, acknowledging people with dementia as a marginalised group and advocating for their recognition as stakeholders in this dialogue.

Survey Design

The survey consisted of 11 questions and was available in both online and paper-based formats. The first four questions asked participants to provide demographic information. The remaining questions were a combination of closed and open-ended questions that asked participants for their preferences and opinions (see appendix 1). Participants were asked to choose from seven different terms: five terms (behaviour that challenges, stress and distress, unmet needs, challenging behaviour and BPSD) arose from a UK professional stakeholder consultation on the topic (Wolverson et al., 2019). One was drawn from the advocacy movement Respond in Reasonable Ways to Adverse Conditions and Circumstances (RRAC) (Macaulay, 2019) and finally the term Behavioural and Emotional Expressions of Need (BEEN) emerged from a UK practitioner debate on the pros and cons of existing terms. Participants were also asked if there were any other terms not been considered here or whether they have their own phrase or term to describe changes in behaviour. Two questions related specifically to the term BPSD, since recently it has been singled out by people living with dementia as a term that should be banned.

Participants and setting

A combination of convenience and purposive sampling was used. The link to the online survey was shared via social media; people with dementia who share online blogs were invited to take part and share the survey. This allowed for a snowballing, cascading method where people from other parts of the world could contribute to the survey. Five groups of people with dementia (four based in the North of England and one from countries across Europe) were invited to take part in the paper-based survey. Four were social groups facilitated by local and national dementia charities. The international participants were part of a working group comprised of people living with dementia. The rationale for gathering data in this manner was to sample people who might not be regular users of social media and to mitigate over-representation of online users who may be more willing or interested in a topic (Sue & Ritter, 2012). The research team had contact with the groups through other projects but had not spoken with the groups about this topic in the past. Inclusion criteria included self-identifying as a person with dementia and aged 18 years old or over. No restrictions were made in relation to the type of dementia or age of onset, as the aim was to gather a broad range of opinions.

Data collection

Online and paper-based survey data was collected between November 2019 and March 2020. The online data was collected using JISC Online Surveys software, exported to Microsoft Excel (March 2020). Researchers attended dementia groups to explain the purpose of the survey and invite those that were interested to complete the consent form and the paper-based questionnaire. Group members had the opportunity to ask questions. Those who wanted to take part but needed support to complete the questionnaire were assisted by the researchers or their own supporters, who recorded responses verbatim. The meeting of the European groups was conducted in English, those who needed support with English had a familiar (to them) person who was fluent in English. The paper-based English language version was read out verbatim by the supporter in

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the person's native language and their responses were translated and recorded in English. The paper-based data was typed into Microsoft Excel and merged with the online version. Next quantitative and qualitative data were sorted into two files and analysed separately.

Ethical considerations

Surveys were completed anonymously. Participation was voluntary and participants could withdraw by either closing down the online survey or discontinuing the paper-based survey without giving a reason. Both versions had a participant information sheet, so participants could make an informed decision about taking part. This contained the researchers' contact details should they wish to ask questions or have any concerns. For the paper-based version capacity to consent was assessed by the researchers. Online survey participants consented by reviewing the information sheet and indicating agreement before proceeding to take part. The study was granted ethical approval by (name removed) (FHS116).

Data analysis

Quantitative data

Frequency data recorded how many participants had heard of, preferred or disliked a term. This nominal data was examined using the maximum likelihood ratio chi-square test of independence (McHugh, 2013) to see whether there was a relationship between age, gender, survey format (online or paper-based) and the choice of terminology. A p value of <.05 was considered significant.

Qualitative data

Thematic content analysis (Braun & Clarke, 2006, 2013) was used, since this inductive approach allows for analysis to be driven by the data rather than pre-existing theory (Braun & Clarke, 2006). Qualitative responses for each question (see Appendix 1 for numbers of respondents for each question) were combined into one document. The data was coded independently by two members of the research team (EW and RD). Transcripts were initially coded according to the explicit content of the participants' responses to questions i.e. derived from the data. During this process initial codes were grouped into coherent themes based upon their emerging congruence with other codes. This was done by hand, following which the two data coders came together to share themes and worked together to form larger categories which were reviewed and revised through iterative discussions with the wider research team. Key themes were named, defined and iteratively checked against the data for internal consistency. Finally, a thematic narrative was created to ensure a meaningful 'fit', with clear distinctions, and that data was not used within multiple themes.

Validity and reliability/Rigour

We attempted to maximize the credibility and trustworthiness of the research in a number of ways, firstly through piloting the survey to gather feedback from people with dementia and this was used to make changes to the survey. However, as participation was anonymous it was not possible to conduct participant checking of themes. Secondly, the researchers worked independently to identify themes before coming together to reach a consensus through discussion. Thirdly, in presenting the results, we have illustrated our account with relevant quotations to demonstrate that the results are grounded in the data. Finally, throughout the stages of planning, data collection, and analysis, the researchers attempted to remain alert to our own perspective and identify the preconceived ideas and beliefs that we brought to the study, and to address the impact of this through discussion.

RESULTS/FINDINGS

Sample characteristics

Fifty-four people (average age 65.4 years, *SD* = 9.4) completed the survey, of which 59.3% were female. One participant reported their diagnosis as MCI, however the decision was made to include this data given that MCI is a risk factor for dementia and that the participant identified with a survey advertised for people with dementia. Thirty-one were online respondents, and 23 used the paper-based version. The average age for online respondents was 62.1 years (*SD* = 7.7) and for paper-based respondents this was 70.1 years (*SD* = 9.7). 63% were from England. See Table 1 for participant demographics.

[insert table 1 here]

Quantitative results

The top two preferred terms to describe changes in behaviour associated with dementia were 'unmet needs' (27.8%, N=15) and 'behavioural and emotional expressions of need' (BEEN) (22.2%, N=12). The two most disliked terms were 'challenging behaviour' (48.1%, N=26) and 'BPSD' (20.4%, N=11). Most participants had heard of the term 'challenging behaviour' (81.5%, N=44) and many had heard of BPSD (48.1% N= 25) and other terms such as 'stress and distress' (68.5%, N=37) and 'behaviours that challenge' (61.1%, N=33). Of note is that three survey respondents had not heard of any of the terms, seven respondents were either unsure or did not select a preferred term, and three were either unsure or did not select a disliked term.

[figure 1 here]

Gender

Respondents included 21 men and 32 women (one person identified their gender as 'other'). The top two terms for men were 'stress and distress' and 'unmet needs'. The top two terms for women were 'unmet needs' and 'Behavioural and Emotional Expressions of Need (BEEN)' -see Figure 1. The preferred term for one individual with an identified gender as 'other' was 'Behavioural and Emotional Expressions of Need' (BEEN). No significant differences between gender and preferred terms, X^2 (7, N = 53) = 9.82, p = .2 or gender and disliked terms, X^2 (7, N = 53) = 6.76, p = .45 were found.

Age

Participants' ages were divided as 64 years and below (N=25) and 65 and above (N= 28). This cut-off was chosen, based on respondents' average age of 65.4 years (SD = 9.4). The top term for the younger age group was 'unmet needs' and for the older age group this was 'behavioural and emotional expressions of needs' (BEEN). There was a significant difference between age and preferred terms, X^2 (7, N = 53) = 16.13, p = .02, φ_c =.49 but not between age and disliked terms, X^2 (7, N = 53) = 8.1, p = .33.

Survey format

A significant association between survey formats (online versus paper-based) and preferred terms X^2 (7, N = 54) = 27.54, p < .001, φ_c = .66 was noted, where participants using the two versions differed in their choices for their preferred terms. Online respondents preferred the term 'unmet needs' whilst paper-based respondents preferred 'stress and distress'. There was no significant difference for disliked terms between the online and paper-based versions X^2 (7, N = 54) = 3.33, p = .85.

Qualitative results

Three superordinate themes and nine sub-themes were identified, these are described below with illustrative quotations.

Super-ordinate Theme: Personal relevance

A common reason that participants liked or disliked a term, was whether they considered it to be personally relevant. Participants liked terms that they felt reflected their experience of dementia. Where participants did not identify with terms they often reported that terms were of little concern to them.

Subtheme: That is me

Preferred terms were described as being 'accurate' or 'true'. Many described the term unmet need as accurate, sharing insight into their own unmet needs such as feeling ignored; 'I have lots of unmet needs and often feel ignored' and 'I often feel my requests and needs are ignored'. Participants felt it was accurate to describe needs as unmet because of inadequate support 'I

cannot avail of my health service' and 'there is just not enough support'. Here participants relate a broader range of unmet needs to why they experiences changes in their own behaviour beyond the more basic needs such as hunger, or tiredness or pain, that are often attributed to changes in behaviour by health care professionals.

For others stress and distress was preferred with a recognition that 'I have stressed a lot' and 'I can be stressed and distressed'. Other participants identified with terms related to changes in behaviour: 'I can become angry very quickly' (referring to BPSD). Whereas others reported that the term 'behaviour' was incorrect and inaccurate; 'it's not a behaviour but a symptom of the disease' and 'it's a response not a behaviour'. One participant felt that BPSD was 'quite accurate in indicating the major changes seen in someone coping with dementia'.

Where participants identified with a term, they stated that they 'would not feel insulted' by the terminology being used about them; 'it's a bit of a mouthful and sounds rather medical but in essence it is accurate' (referring to BPSD). One participant stated that if someone used the term BPSD about them, they would be 'glad that those difficulties are being acknowledged'. However some participants were less positive about such difficulties being acknowledged; two participants disliked the term stress and distress because 'stress sucks' and 'we make efforts to overcome it and reminding us about it will not help'.

Subtheme: That is not me

Seven participants stated that they disliked terms because these did not apply to them - 'I do not feel I have behaviour issues' (referring to BPSD) and 'I do not think this is me' (referring to BPSD). Some participants felt the term BPSD might refer to 'a condition far worse than me' and 'I cannot identify with this'. One participant commented 'I'm not like that myself. If I do lose my rag, it's not because of the dementia it's because of something that's happened' (referring to BPSD). Two participants reported that as the terms did not apply to them, they were 'not bothered' about the terms used.

Superordinate theme: Ease of use

Preferred to terms were easy to make sense of, familiar to participants and perceived as 'kind'.

Subtheme: Understandable

Participants preferred terms were 'understandable'. Stress and distress was 'simple and to the point'. Participants disliked terms that were 'too long' and 'wordy' and many disliked acronyms; 'more acronym BS sorry' (referring to BPSD). Twelve participants reported that they did not understand the term BPSD which was described 'meaningless' and 'too medical'. Along

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the same lines, RRAC was also described as 'too long and hard' and 'meaningless'. Preferred terms were described as 'easy to remember' and 'simple but informative'. However, there was an additional a layer of language differences here, with some terms having different linguistic meanings. For example a participant from Portugal stated that the term BEEN could be seen to have connotations of addiction and that 'expressions of need' didn't translate well into Portuguese.

Subtheme: Familiar

Participants preferred terms were also selected on the basis that they were familiar with, 'it's the only one I know' (referring to stress and distress) and 'psychologist said it' (referring to RRAC). Unfamiliar terms were described as 'weird' and 'ugly'.

Subtheme: Kind

Participants reported preferences for terms that they felt were 'kind'. Stress and distress in particular was described as a 'nicer term' and the 'least offensive', whilst some terms could make people feel 'guilty' or 'daft'. Kind terminology was respectful, it 'makes me normal' (referring to BtC) and 'doesn't make me sound like a nut case' (referring to BEEN), demonstrating again there was no clear agreement of which terms were considered kind.

Superordinate theme: Consequences

Participants described a range of consequences which could result from the use of certain language. There were concerns that the wrong label could threaten personhood, place fault with a person and 'lead to degrading, inappropriate, restrictive treatment'.

Subtheme: A person just like everyone else

Participants preferred terms that indicated 'an underlying factor for my behaviour' and thus would ensure that they were treated 'as a person just like everyone else' (referring to unmet needs).

Concerns were expressed by some about terminology that some participants felt dismissed behaviour as simply being the result of dementia. Common responses were that changes in behaviour might be 'more about the person's biography than dementia' and should not be 'dismissed as automatically part of the disease'. Participants spoke about there being 'a reason and a purpose behind every behaviour' and that professionals 'need to take into consideration

what's going on in my life at this time' and 'I'd say look further…am I hungry thirsty scared bored- needing to exercise or have a change of scenery'.

Some participants had strong reactions to terms that undermined personhood, with one participant reporting that the use of such terms made them feel 'extra angry, patronised, dismissed, or dehumanised'. For some participants the use of the term BPSD meant that they 'would not feel like I was a person' but 'an object' and 'that I am damaged in some way'. In reference to the term BtC one participant stated 'It is somehow not valuing the people, it lowers the self-esteem….using it doesn't promote personhood'. Short hand, acronyms were commonly described as dismissive; 'it is a meaningless term and if used to describe us then that would make us meaningless to' (referring to BPSD).

In recognising the need to see the person not just the dementia-diagnosis, one participant responded that some terminology reflected; 'easy umbrella terms for lazy practitioners who can't or won't look beyond the external physical movements of a body to the individual in pain within their mind and soul' (referring to BPSD). Insightfully, some participants recognised that staff using certain terms might be 'distancing themselves from the person' (referring to BPSD) and one participant commented that they were always concerned when language implied that professionals considered 'me a patient and not a person'.

Subtheme: Blaming

The terms BtC and challenging behaviour were frequently described as blaming; 'it blames the person and suggests they are challenging' (referring to challenging behaviour) and 'I don't like to think that I am a challenge' (referring to BtC). Some participants preferred terms that recognised that others were involved in what was happening. One participants preferred term was stress and distress because this was felt to capture 'different expectations me and my wife'. Another participant commented that 'the behaviour might be challenging for others but for me it's because I'm unable to explain something' (referring to disliking the term challenging behaviour). Others wanted terms that recognised others as the cause of behaviours; 'most challenging behaviours comes from other people not me, people who don't understand dementia' (referring to challenging behaviour). Some participants also wanted language to reflect that role of the 'surroundings', and the 'events leading up', rather than suggesting that the person was to blame because 'it wouldn't be through choice';

'I am not behaving challenging I am behaving normally due to circumstances I cannot control' (referring to challenging behaviour)

'When in fact we are displaying, in the only way we can that we're distressed' (referring to challenging behaviour).

Taking this further, some participants preferred terms that they felt 'put the onus on professionals' (referring to unmet needs) to makes sense of what was happening 'because my behaviour is a way of signalling that something is wrong' (referring to unmet needs) and 'people should be asking why' (referring to unmet needs).

Subtheme: Intent

Participants disliked terms felt to 'imply that we're difficult' (referring to challenging behaviour). One participant disliked the term BtC as they felt it 'gives the impression that the individual is consciously being obstructive to your aims'. The term 'behaviour' was described by participants to imply that someone was being deliberately 'aggressive', 'rude' or 'naughty'. Some participants disliked the word challenge; 'I'm not challenge anybody', whilst others liked word because 'life is always a challenge' and 'challenges can be positive'. Demonstrating once again individual differences in the interpretation of not just phrases, but words within the terms.

Some participants worried that rather than implying intent, some terms suggested people were out of control, with concerns that terms had psychiatric connotations, suggesting that people were violent or aggressive. There were shared fears that language implying deliberate intent or fault, 'puts you on a certain pathway' that would 'lead to unnecessary medication' (referring to BPSD) and 'medication to sedate/calm down person' (referring to challenging behaviour). BPSD in particular was described as a term that has 'terrible long-term outcomes for the distressed/ scared /unmet needs person' and that 'this term is probably been a large part of why chemical and physical restraint has been so rampant'. One participant stated that the wrong language could put a person with dementia on 'a pathway that leads to physical/chemical restraint, sectioning/safeguarding and involuntary care' (referring to BPSD).

Subtheme: Nothing can be done.

In addition to fears about chemical and physical restraint, some participants raised concerns that language could result in people with dementia being offered no support 'as though we have nothing to offer in treatment' (referring to challenging behaviour) and 'imply that nothing can be done for me'. One participant stated that BPSD had 'allowed ordinary staff not to be trained in simple interventions'.

DISCUSSION

This is, as far as we know, the first study to explore the views of people with dementia on this topic. The quantitative data explored participant's language preferences and the qualitative data

sought to explore the reasons underlying these preferences. The majority of participants had encountered the term challenging behaviour, but many were familiar with a range of terminology. There was no universal agreement on a preferred terminology and it is important to highlight the individual differences here, as people with dementia continue to be seen as a homogenous group. The qualitative data suggested an overall preference for terms that reflected the unmet needs likely to underlie changes in behaviour. The notion of unmet needs was well understood and familiar to many participants. This finding is similar to a recent professional stakeholder survey, which also did not reach consensus, but where unmet need was most frequently ranked as participants' preferred term (Wolverson et al., 2019).

Although relatively few respondents rated disliking the term BPSD, the qualitative data demonstrates that those that did were vociferous in the intensity of their dislike. This is only a small sample, yet within it there were participants' who spoke with passion and determination about the need to change language which they believe exacerbated the risk of, implied 'intent' and 'blame' and resulted in nihilism within care-practices. These finding echoes concerns raised across social media by people living with dementia (Mitchell, 2015; Swaffer, 2019).

The qualitative findings demonstrate that words are not merely empty signifiers but have referents. The language we use to describe changes in behaviour can influence how people feel about themselves and could make some people concerned about how they might be viewed and treated by others. Consistent with language guides produced by people with dementia (The Dementia Engagement and Empowerment Project, 2014), participants preferred words that are accurate, balanced and respectful. However some terms such as such as challenging behaviour, that were previously regarded as 'positive' in language guides (Alzheimer's Society, 2018), were disliked by half of our participants. 'Long-winded' terms and acronyms were also not seen as either meaningful or helpful in promoting good care. There will be an ongoing need to review, alter and refine language, as it inevitably becomes misused and obsolete over time (Chan et al., 2012).

An important implication is the need to take the time to explore an individual's understandings, adopting the language used by the person themselves (Rogers & Way, 1980). Given current guidance is for first-line non-pharmacological approaches to this paradigm (National Institute for Health and Care Excellence, 2018)) we suggest that improved terminology taking the perspective of those affected by dementia is a rational starting point for offering support and advancing research and practice.

Limitations

This was a relatively young sample in the context of dementia and not therefore representative of the views of all people with dementia. The online promotion of the survey may have resulted in a sample bias (Talbot, O'Dwyer, Clare, Heaton, & Anderson, 2020) since the average age of

online respondents was 62.1 years. No information was collected on the 'level' or 'degree' of dementia, as these clinical consideration were not ones that we expected people with dementia to provide information about. The study was perhaps limited to people who are in the earlier stages of dementia and therefore may have not captured those with clinically significant behavioural changes. However a study in England noted high numbers of people with mild dementia and clinical significant 'behavioural symptoms', living at home (Moniz-Cook et al., 2017). Notably our qualitative data suggests that many people were aware of behavioural changes and we suggest that irrespective of dementia severity their viewpoints have relevance.

Our study gained international responses, but we did not collect data on ethnicity. Translating meaning across languages requires careful study, particularly when words in one language may have a different meaning in another (Holle, Köller, Moniz-Cook, & Halek, 2018). Qualitative data indicated some differences in the translation of meaning, suggesting that linguistic validity may have been compromised through linguistic interpretation by supporters within our international group data. Aside from linguistic translation, future research should also explore cultural differences associated with conceptualisations of changes in behaviour.

An important perspective missing is that of family carers and supporters, since their views about the types of support offered to their relative can differ from those of practitioners (Janus, van Manen, Van Til, Zuidema, & IJzerman, 2017) and may well also differ from people with dementia.

As a research team, we entered the research with an awareness of the importance of language in dementia and of the growing concerns shared by people with dementia in regard to BPSD. However, we were still profoundly moved by the depth and thoughtfulness of the qualitative data. Participants shared feelings of sadness, loneliness and fear the future, given changes in their own behaviour and awareness of the challenges faced by others. There is a lack of research exploring the lived experience of changes in behaviour in dementia. The insight and awareness of our participants in this small study suggests that such research is possible and could help to bring some humanity into such narratives.

CONCLUSION

Person-centred approaches to dementia care have, over two decades, focused on communicating with and about people with dementia, to bestow a 'standing or status' that promotes dignity and demonstrates respect (Kitwood, 1997). In this small study a number of participants shared concerns that the language used to describe changes in behaviour placed them at significant risk of harm, particularly where such changes were regarded as 'symptoms to be treated' without adequate consideration of the person or their context. Focussed ongoing engagement with people of all ages who live with dementia is essential to address these concerns.

Conflict of Interest statement

The authors have no conflict of interest to declare.

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Table 1: Participant demographic characteristics

Gender (N=54)	Female:	32 (59.3%)
	Male:	21 (38.9%)
	Other:	1 (1.9%)
Age (N=53)	Age range:	49 – 92 years
	Average age:	65.4 years
	Standard deviation:	9.4
No of years diagnosed (N=51)	Range:	0.75 – 14 years
	Average:	4.9 years
Dementia type (N=25):	Alzheimer's disease	6 (24%)
	EOAD	1 (4%)
	FTD	4 (16%)
	MCI	1 (4%)
	Mixed – Vascular and Alzheimer's	4 (16%)
	Mixed – Vascular and Lewy Body	1 (4%)
	PCA	2 (8%)
	Vascular	6 (24%)
Country (N=54)	Australia	4 (7.4%)
	Austria	1 (1.9%)
	England	34 (63%)
	Finland	1 (1.9%)
	Germany	1 (1.9%)
	Ireland	2 (3.7%)
	Portugal	1 (1.9%)
	Scotland	4 (7.4%)
	Singapore	1 (1.9%)
	Sweden	1 (1.9%)
	USA	2 (3.7%)
	Wales	2 (3.7%)

EOAD = Early Onset Alzheimer's Disease; FTD = Frontal Temporal Dementia; MCI = Mild Cognitive Impairment; PCA = Posterior Cortical Atrophy
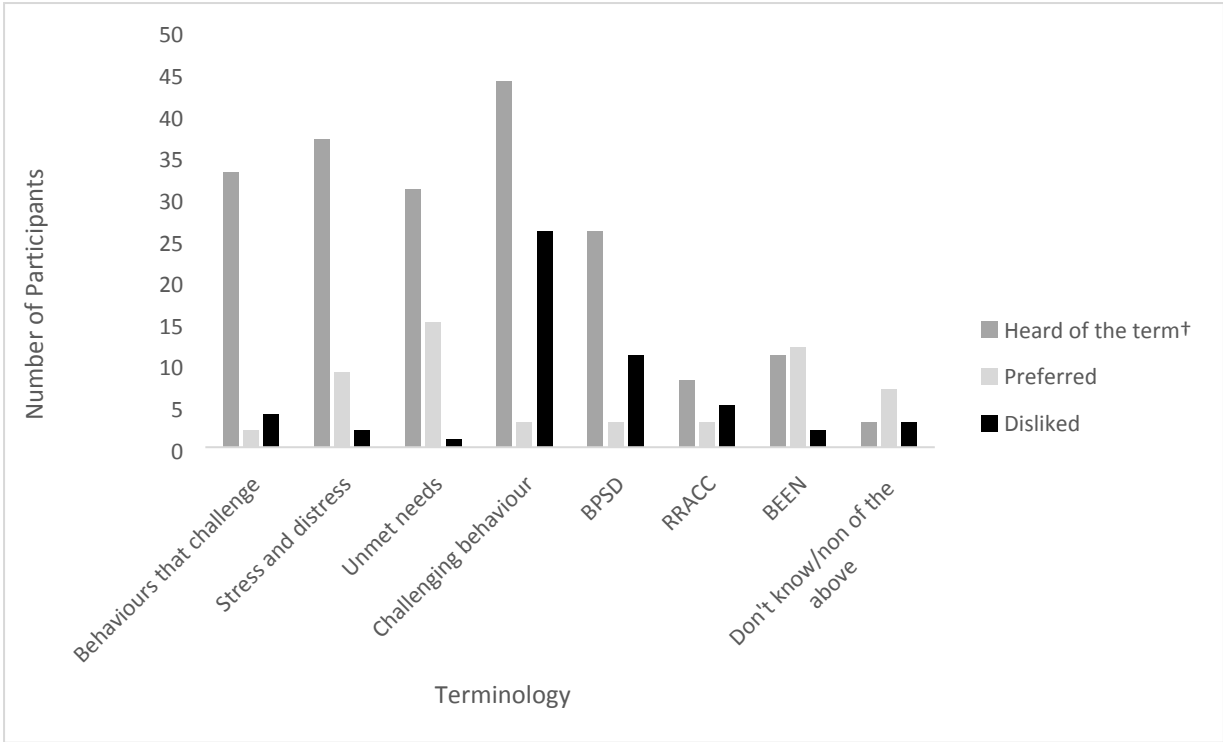
Figure 1: Participants familiarity with terms, preferences and disliked terms

†survey respondents could choose more than one term

Appendix 1: Survey Questions

Questions 1-4 were related to demographic data
  1. Gender
  2. Age
  3. Country of residence
  4. How long have you been living with dementia

Questions on terminology

5. Have you heard of any of these terms used to describe changes in behaviour in dementia?

Behaviours that Challenge
Stress and distress
Unmet needs
Challenging Behaviour
Behavioural and Psychological Symptoms of Dementia (BPSD)
Respond in Reasonable Ways to Adverse Conditions and Circumstances (RRACC)
Behavioural and Emotional Expressions of Need (BEEN)

6. Of these terms, which one would you *prefer* to be used if referring to you?

6a. Please give a reason why this is your preferred term *(n= 52)

7. Of these terms, which one would you *least* prefer to be used if referring to you?

7a. Please give a reason why this is your least preferred term.*(n= 48)

8. What comes to mind when you hear the expression 'Behavioural and Psychological Symptoms of Dementia' (BPSD)?*(n= 52)

9. How would you feel if someone described you as having 'Behavioural and Psychological Symptoms of Dementia' (BPSD)? * (n=50)

10. Are there any other terms that you like that have not been considered here? Do you have your own phrase or term? * (n= 36)

11. Is there anything else you would like to say about this topic? * (n=32)

*denotes number of participants who completed the 'open' (qualitative data) questions

Impact Statement

Title: The language of behaviour changes in dementia: A mixed methods survey exploring the perspectives of people with dementia.

To our knowledge this is the first study exploring the perspectives of people with dementia about the language used to describe changes in behaviour.

We think clinicians will benefit from this study by being encouraged to reflect on their own language use and consider the effect this might have on the people with dementia they are supporting.

We think the paper adds to the growing research that recognises people with dementia as stakeholders in line with the growing human rights movement in dementia care. The research has arisen from concerns expressed by people with dementia.

We think the paper will highlight to researchers that it is possible to speak with people with dementia about changes in behaviour, that people do have insight and concerns and that future research should engage them as stakeholders.