Age and Ageing 2022; 1–8
https://doi.org/10.1093/ageing/afac047

RESEARCH PAPER

Family carer perspectives on the language of behaviour change in dementia: an online mixed methods survey

Emma Wolverson[1,2], Esme Moniz-Cook[1], Rosie Dunn[1], Rebecca Dunning[2]

AQ4 AQ5 [1]University of Hull, UK
[2]Humber Teaching NHS Foundation Trust, UK

AQ6 Address correspondence to: Email: rebecca.dunning@nhs.net

Abstract

Objective: following the #BanBPSD campaign there has been critical interest in common terminology used for ‘changes in behaviour’ associated with dementia. However, commentaries and emerging studies have not fully considered family carer perspectives. This study explores the views of family carers on terminology and language for this paradigm.

Method: a mixed methods online survey was conducted with family carers. Language preferences were scoped and examined with supporting open-ended questions that explored the reasons for choices.

Results: about 229 family carers completed the survey. Terms such as Challenging Behaviour, Behaviour that Challenges and Behavioural and Psychological Symptoms of dementia were mostly disliked. The most preferred term was a new concept called ‘Behavioural and Emotional Expressions of Need’ that few people had previously heard of. Overall, carers preferred positively construed, easily understood, person-centred terms that attributed changes in behaviour to unmet need, which also acknowledged the carer’s role in management.

Conclusions: given that carers are often the agents of change for this paradigm—where they may also be called on to act as proxy decision makers, it is important that professionals take time to explore their understandings and give due consideration to the language used when offering tailored interventions. These findings suggest that frequently used terms for changes in behaviour associated with dementia, such as Challenging Behaviour, BtC and BPSD, should be avoided.

Keywords: Family carers, dementia, language, behaviour, older people

Key Points

- Carers prefer terminology that reflects the unmet needs experienced by their relative and those that reflect their role in management of the interpersonal environment.
- Carers would prefer terms such as Challenging Behaviour, Behaviours that Challenge and Behavioural and Psychological Symptoms of dementia (BPSD) to be avoided.
- Effective communication between professionals and families is essential for provision of good care. The manner in which clinicians use language can have a significant impact on carers’ understanding and has the scope to signpost first-line psychosocial intervention for research and practice.

This is a pre-copyedited, author-produced version of an article accepted for publication in Age and ageing following peer review. The version of record Emma Wolverson, Esme Moniz-Cook, Rosie Dunn, Rebecca Dunning, Family carer perspectives on the language of behaviour change in dementia: an online mixed methods survey, Age and Ageing, Volume 51, Issue 3, March 2022, afac047, is available online at: https://doi.org/10.1093/ageing/afac047.

Introduction

In recent years the #BanBPSD social media campaign has stimulated letters and debates in both peer review and practice journals [1–3]. Studies are emerging on the perspectives of professionals', people with dementia their families [4–8]. Efforts over 25 years to capture this paradigm include concepts such as 'Need-driven Dementia-compromised Behaviour (NDB)' [9], 'Behavioural and Psychological Symptoms (BPSD)' [10], 'Neuropsychiatric symptoms (NPS)' [7], 'Challenging Behaviour (CB)' [11] and 'Behaviour that Challenges (BtC) [12]. Terminology, which often arises from different professional disciplines can have implications practice. For example the NDB model, that was initially conceived by nurses [9] and later integrated within psychosocial person-centred approaches, signposts the individual's unmet personal needs. Psychiatric conceptualisations of BPSD/NPS outline symptoms to be treated, geriatric medicine professionals understand this as 'distress' [13] and psychologists conceived CB/BtC to emphasise caregiver challenges. Although a plethora of terms exist for the paradigm, BPSD remains dominant across the literature.

Criticism of the term 'BPSD' has noted its historical sponsorship by the pharmaceutical industry and drugs that have raised concern about health risks and chemical restraint [14–16]. Debate on the term 'BPSD' is not new, largely due to the mixing of symptoms which may have different neurobiological and interpersonal aetiologies, which then undermines knowledge about the causal mechanisms by which specific symptoms exert more or less impact on caregiver challenges and associated interventions [4, 17–19]. The search for organic causation of BPSD and associated drug treatment remains current in the psychiatric literature [2], but other medical literature focuses on helping staff to recognise distress [13] and to avoid nihilism through a 'socialised sense of care futility' about meeting needs when people with dementia are distressed [20]. There are also examples of individually tailored approaches where caregivers achieve some success with needs-led emotion—orientated communication, when psychiatric phenomena such as 'hallucination and delusionary' behaviour occur [17].

Recent studies exploring language preferences of people with dementia [6] and professionals [4] suggest a preference for terms which includes the word 'need', such as 'unmet needs'. These reflect a conceptual shift from older terminology through preferences of newer terms with embedded person-centred causal features (such as 'meeting needs', 'treating distress') which were seen as 'less pathologising'. Terms such as CB and BtC were strongly disliked by people with dementia [6], but less so by professionals [4]. Other contrasts included differing levels of support for the term 'stress and distress' (preferred by people with dementia) and BPSD, preferred by many professionals, but not by people with dementia. Family carers are often closest to the person with dementia [3]. Surveys exist about their views on use of psychotropic drugs [16] but not about terminology. This study aims to explore the views of family carers on the language used to describe changes in behaviour associated with dementia. It seeks to examine what their preferred and least preferred terms for the paradigm might be and to understand more about what families expect from language in this area.

This study addresses the following research questions:

1. What terms have family carers heard being used to describe changes in behaviour associated with dementia?
2. What terms do family carers prefer to be used to describe changes in behaviour associated with dementia?
3. What terms do family carers do not prefer 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 family carers?

Methods

Study design

This study adopted a mixed methods convergent parallel synthesis design. Ranked preferences regarding 'language usage' were collected and cross-referenced with qualitative, open-ended questions that explored the reasons for carers' choices. Equal priority was given to quantitative and qualitative data.

Survey

The survey was available in online and paper-based formats. Four questions asked about demographic information and four about preferences and opinions about the language used to describe changes in behaviour associated with dementia. Participants were asked to choose from seven terms [BtCs, stress and distress, unmet needs, CB, BPSD, Respond in Reasonable Ways to Adverse Conditions and Circumstances (RRACC) and Behavioural and Emotional Expressions of Need (BEEN)]. These arose from previous advocate blogs and professional consultations (see Appendix 1).

Sampling and subjects

Inclusion criteria included self-identifying as a family carer of a person with dementia and aged 18 years and over. To gather a broad range of opinions, no restrictions were made on caregiving hours/years, or to the type of relationship with the person with dementia.

A snowballing, cascading recruitment approach was used, combining convenience and purposive sampling. The online survey was shared via social media to facilitate international participation. Organisations known to support carers of people with dementia were also contacted. Carers from five organisations took part in a paper-based version of the survey

(4 in the North of England and 1 drawn from countries across Europe). These groups were known to the research team and some had engaged in previous research studies but had not been consulted on this topic before.

Data collection

Data were collected between November 2019 and March 2020. Online data were collected using JISC Online Surveys software, exported to Microsoft Excel (March 2020). Researchers attended groups to explain the purpose of the research and invited those that were interested to complete the consent form and the paper-based survey. 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 participant responses verbatim. The paper-based data was typed into Microsoft Excel and merged with the online version. Quantitative and qualitative data were sorted into two files for separate analysis.

Ethical considerations

Surveys were completed anonymously. Participation was voluntary and participants could withdraw from taking part by either closing down the online survey or discontinuing the paper-based survey without giving a reason. Both versions included a participant information sheet, so participants could make an informed decision about whether to take part. This contained the researchers' contact details should participants wish to ask any 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. The study was granted ethical approval by The University of Hull Faculty of Health Science Ethics Committee (FHS116).

Data analysis

Quantitative data

Frequency data recorded how many participants had heard of, preferred or 'least preferred' a term. These nominal data were examined using the maximum likelihood ratio Chi-square test of independence [22] 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 [23, 24] was used to identify, analyse and report patterns and themes in the data. Qualitative responses were combined into one document and examined up to three times before generating codes. Codes were systematically generated across the entire data set by two researchers working independently (Wolverson and Dunning). These initial codes were grouped into themes based upon their congruence and themes were clustered into higher categories, which were reviewed and revised through whole team discussions. Themes were checked again against the raw data to ensure they represented participant's responses and were authentic and trustworthy before being named. Finally, a narrative was created to ensure a meaningful 'fit', with clear distinctions between themes. Rather than attempting to fit the material into a preexisting coding frame, the analysis was inductively driven where the data were examined and reexamined to extract emerging themes. It was not possible to check themes with respondents as participation was anonymous. The authors were not without a prior theoretical understanding in the analysis, having conducted similar language surveys with other key stakeholders [4, 6]. Therefore a new researcher (Dunning) joined the team and played a significant role in the data analysis to help ensure themes were grounded in the data and to support team reflexivity.

Results

Description of survey participants

A total of 229 carers (90.4% female) completed the survey across the two formats (192 online and 37 paper-based). The overall average age of participants was 60 years ($SD = 11.9$), with a slightly younger demographic returning the online survey [average age 58.8 years ($SD = 11.2$)] than the paper version [average age 66.2 years ($SD = 13.9$)]. The majority of participants were from the UK, with 75.5% from England (Table 1).

Participant preferences

The top three preferred terms were BEEN (23.3%, $N = 53$); 'unmet needs' (17.6%, $N = 40$) and 'stress and distress' (17.2%, $N = 39$). The two least preferred terms were CB (53.1%, $N = 119$) and RRACC (21.9%, $N = 49$). Most participants had heard of the term CB (87.8%, $N = 201$), and many had heard of stress and distress' (62.4%, $N = 143$) and 'behaviours that challenge' (57.2%, $N = 131$). Eighteen participants had not heard of any of the terms, 12 were either unsure or did not select a preferred term, and 2 were either unsure or did not select a least preferred term (Figure 1).

Subtracting '"least preferred" from "preferred" scores for each of the top three items, demonstrates a preference for the terms behavioural and emotional expressions of need'—BEEN (53–2 = **51**); unmet needs (40–7 = **33**); stress and distress (39–7 = **32**) (Table 2).

Gender

Respondents were 22 males and 207 females. The top two terms for males were BEEN (27.3%) and 'Behaviours that Challenge' (18.2%). The top two terms for females were BEEN) (22.7%) and 'Unmet needs' (18.8%). There were no significant differences between gender and preferred terms, χ^2 (7, $N = 227$) = 6.64, $P = 0.47$ or gender and least preferred terms, χ^2 (7, $N = 224$) = 7.59, $P = 0.37$.

Table 1. Participant demographic characteristics

Demographic	Description	N (%)
Gender ($N = 229$)	Female:	207 (90.4%)
	Male:	22 (9.6%)
Age ($N = 229$)	Age range:	23–89 years
	Average age:	60.03 years
	Standard deviation	11.9
Time since care recipient diagnosis of dementia ($N = 222$)	Range:	0.17–20 years
	Average:	5.8 years
Care recipient's diagnosis ($N = 142$)	Alzheimer's disease	53 (37.3%)
	EOAD	2 (1.4%)
	FTD	11 (7.7%)
	LBD	3 (2.1%)
	Logopenic aphasia	1 (0.7%)
	Mixed – Alzheimer's and FTD	1 (0.7%)
	Mixed – Alzheimer's and LBD	1 (0.7%)
	Mixed – Alzheimer's and Parkinson's	1 (0.7%)
	Mixed – Alzheimer's and vascular	27 (19%)
	Mixed – PCA and vascular	1 (0.7%)
	Parkinson's-related dementia	3 (2.1%)
	PCA	4 (2.8%)
	Vascular	34 (23.9%)
Geographical location ($N = 229$)	UK	199 (86.9%)
	North America	17 (7.4%)
	Europe	8 (3.5%)
	Australia	3 (1.3%)
	Middle East	1 (0.4%)
	East Asia	1 (0.4%)

EOAD = early onset Alzheimer's disease; FTD = frontal temporal dementia; LBD = Lewy body dementia; PCA = posterior cortical atrophy.

Table 2. Overview of preferences for terminology

Term	Preferred term	Least preferred	Overall Like score (preferred minus least preferred)
BEEN	53	2	51
Unmet need	40	7	33
Stress and distress	39	7	32
BPSD	36	23	13
BtC	19	15	4
RRAC	16	49	−33
Challenging behaviour	12	119	−107

Age

Participant ages were divided into two groups, aged 59 and below ($N = 110$) and aged 60 and above ($N = 119$). This cut-point was based on the average age for the survey of 60 years ($SD = 11.9$). BEEN was the top term for both age groups. There were no significant differences between age and preferred terms, χ^2 (7, $N = 227) = 3.99$, $P = 0.78$, or between age and least preferred terms, χ^2 (7, $N = 224) = 7.85$, $P = 0.35$.

Survey format

About 192 participants completed the survey online and 37 completed the paper-based version. A significant association between survey format (online versus paper-based) and preferred terms $\chi^2(7,\ N = 227) = 36.28$, $P < 0.001$, $\varphi_c = 0.38$) was noted where participants using the two versions differed in their choices for their preferred terms. For the online survey, the preferred term was BEEN and for the paper-based version, the preferred term was 'stress and distress'. Although there were significant differences between online and paper-based survey participants in their choices for disliked terms $\chi^2(7,\ N = 224) = 19.21$, $P = 0.008$, $\varphi c = 0.35$, the term CB was still most frequently chosen as the least preferred term by both types of survey participant.

Qualitative data

None of the terms were either entirely preferred or least preferred. However, when analysing the reasons carers gave for choosing their preferred (or least preferred) terms, some clear themes were evident (Table 3).

Theme 1: Terms that are easy to understand

When discussing a preferred term, many stressed the importance of a term that they felt they could understand.

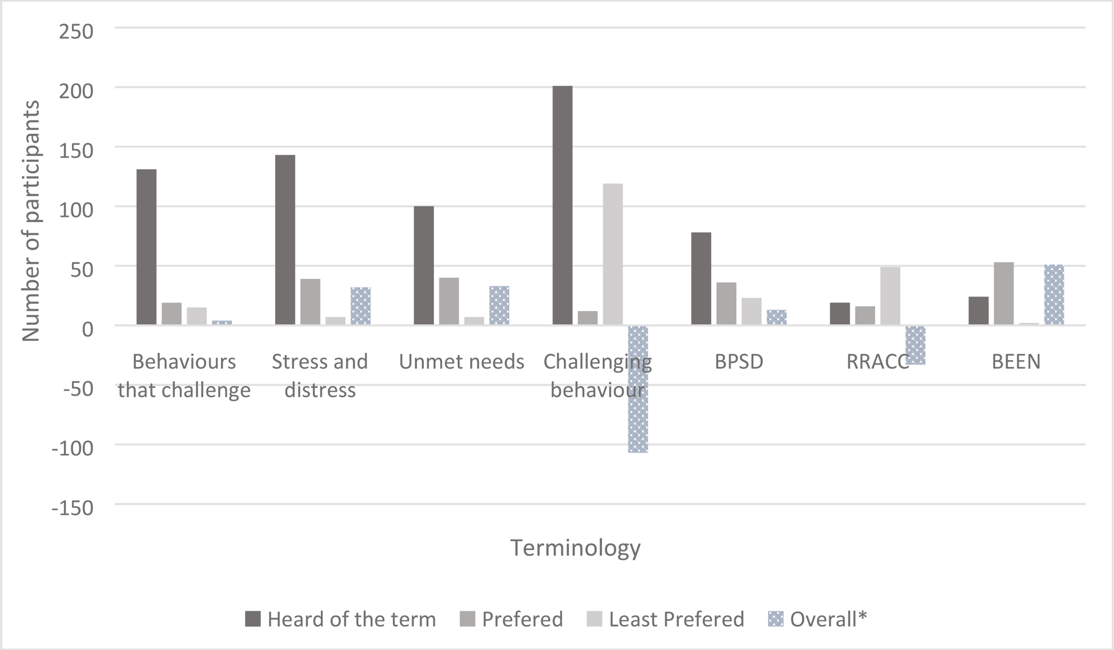

Figure 1. Participants familiarity with terms, preferences and least preferred terms. †*Survey respondents could choose more than one term.* **Overall = preferred—least preferred.*

Table 3. Descriptions of themes and example quotations

Theme	Description of theme	Example of participant responses for preferred terms	Example of participant responses for least preferred terms
Easily understood	Preferred terms that were easy to understand and to use. Participants' disliked terms that they felt were clinical jargon. Vague terms were disliked due to concerns that could be easily misunderstood.	'*simple and clear*' (referring to Stress and Distress) *'clear and describes what it is'* (referring to Behaviours that Challenge).	'*jargonised and potentially pejorative and exclusive*' (referring to RRACC) '*too clinical, a fancy term used by medics'* (referring to BPSD).
Person-Centred and Hopeful	Preferred terms recognised that each person with dementia is unique. Terms that made a distinction between the person and the dementia were seen to incite empathy and give hope that something could be done. In contrast, terms were disliked when they seemed to imply the person was at fault. Concerns were expressed that some terms were blaming and stigmatising. Participants' expressed concern that some terms implied that nothing could be done.	'*because it is an unmet need and I find this a less accusatory term'* (referring to Unmet Needs) '*To me it seems the most positive and respectful way of dealing with someone with dementia*' (referring to RRACC	'*negative and stereotyping as well as demeaning to the person. Promotes stigma*' (referring to BPSD) '*it is somehow a hopeless term*' (referring to Challenging Behaviour)
Acknowledging the role of the carer	There was a preference for terms that acknowledged the role of the carer, the impact that behaviours may have on them and their role in responding the behaviours.	'*both the person and the carer may have such symptoms!*' (referring to Stress and Distress) *'I really like that it acknowledges that people with dementia. . . are expressing a need.. forces me to try and understand what the need is and how do I respond. . .'* (referring to BEEN)	*'Challenging to who? Whether we have dementia or not we all behave in challenging ways sometimes'* (referring to Challenging behaviour) *'Who is being challenged? The carer or the person with dementia?'* (referring to Challenging behaviour)

Throughout the responses, there was an active dislike for terms that they felt were jargon and a preference for more familiar, usable language. Carers preferred terms that they felt were broad and encapsulated their experiences. In addition, there was a preference for terms that were felt to be more simplistic; often then interpreted as being clearer. Preference was also given to themes that were felt to be accurate. In comparison, least preferred terms were perceived as being vague or misleading; often referenced together.

Theme 2: Terms that are felt to be person-centred and positive

On the whole, carers preferred terms that they perceived to be person-centred. Terms that were felt to be blaming were often least preferred. There was also a preference for terms that were perceived to incite empathy and that made a distinction between dementia and person. Some terms were not seen to encourage understanding or further investigation and were disliked due to this. Carers preferred terms that they perceived as being positive. Conversely, they expressed dislike for terms that they felt were negative. There was also a non-preference for terms that were felt to imply suffering.

Theme 3: Terms that acknowledge their active role as the carer

Finally, carers preferred for terms which acknowledged their experiences i.e. the role of the carer and the impact that behaviours may have on them. Carers questioned some terms for being ambiguous about who was being challenged and the context of this, such as whether the care approach was part of the problem or the solution.

Discussion

This study examined the views of family carers about language used to describe behavioural changes associated with dementia. It complements findings of recent work with professionals and people with dementia [4–6]. To our knowledge this is the first large scale study to explore family perceptions on this topic, which adds to the findings of two recent qualitative explorations from the US and Australia [7, 8]. A good number of family carers engaged with this survey, suggesting that 'words do matter' [25]. Overall carers preferred positively construed, easily understood, person-centred terms that attributed changes in behaviour to unmet need, and those which acknowledged the carers' role in management of the interpersonal care environment. The findings suggest that the terms CB, BtCs and 'BPSD' should be avoided.

Only three terms were found to be somewhat acceptable i.e. 'unmet need', 'stress and distress' and the most acceptable was the newest concept BEEN', that relatively few carers had previously heard. The implication of 'has been' was seen by some as a lack of respect for the person with dementia [5], but perhaps reflects problems associated with acronyms and abbreviations. Given that relatively few carers had heard of some of these terms, it is difficult to conclude as to whether a preferred language would be widely understood. Even the most preferred term was selected by only 23.3% of respondents and differences in preferences between online and paper-based respondents also raise questions about potential response bias, suggesting that views many not be representative of all family carers. Therefore, on the basis of our findings of the views of a large group of family carers, it is not possible to recommend a specific preferred term from this study. However, by comparing the responses of carers, with those of people with dementia [6] and professionals [4, 5], some clear consensus emerges. Firstly, the terms 'unmet need' and words associated with 'stress and distress' are broadly acceptable across the three stakeholder groups. Secondly, people with dementia and carers have a strong dislike for the terms CB and 'BPSD', despite the latter being popular with some professionals. BtC does not appear to be a viable alternative to CB, with almost as many carers disliking it as preferring it. As with BPSD, only professionals' consider BtC as an option. Qualitative data indicate that all three stakeholder groups look for ease of use in any terminology. There is general agreement that terminology should not lead to interpretations that are 'blaming' or result in risky consequences for the person with dementia [16]. Carers and people with dementia emphasise the importance of terms that: do not detract from the 'personhood' of people with dementia; are personally relevant to both the person and carer and acknowledge the important role of the latter. Carers preference for terms that recognise their own concerns is consistent with studies suggesting that family carers often ignore or delay seeking professional help due to feelings of distress, isolation or embarrassment [26] until a crisis point is reached [27]. A review of qualitative studies notes that family carers can also feel that their concerns about changes in behaviour are dismissed [28].

This study is not without limitations. Our methodology, which drew on terms from a professional consultation and then extracted the top five preferred from an associated large survey (Appendix 1) [4] excluded other terms such as 'distress'. The initial consultation conducted in the UK did not capture the term 'responsive behaviour' which originated in Canada but is not widely used and requires explanation [29]. The term 'stress and distress' is widely used in Scotland, within all official Scottish documentation. This might explain preference for the term since 5.7% of carers that responded were from Scotland. In the context of caring in dementia, this was a relatively young sample (average age 60 years), perhaps due to our online recruitment strategy. We did not collect data on the nature of the relationship between the carer and their relative. Our relatively young sample may reflect that a high proportion of carers were adult children. We did not collect data on the age of the care recipient and future research could explore whether the views of carers of those with younger onset dementia reflect the views of those caring for an older cohort of people with dementia The sample was largely female reflecting the trend in family caring and although no gender differences about terms were found, future studies could purposively recruit male carers given limited research with this group [30, 31] Although our study recruited an international sample, the majority were from the UK (Table 1), and we did not collect data on ethnicity. Finally, we did not ask about the respondents' experiences of changes in behaviour associated with dementia so respondents may not have experienced changed behaviour in their relative. This is unlikely in a sample as large as ours, since changed behaviour is seen in mild dementia and many of these are hidden from services [33].

Two recent qualitative studies [7, 8] concur with our findings with a large group of family carers to note that: effective communication between professionals and families is essential for provision of good care; and encounters should ideally involve both the person and their family [34]. The manner in which clinicians use language, can have a significant impact on carers' understanding and consequent decision-making about interventions [35]. This is significant in the context of changes in behaviour, since carers often act as proxy decision makers, which may involve the prescription of antipsychotic medications.

This study confirms findings of a recent qualitative study suggesting that there is a distinction between the language that health professionals might use when communicating with other professionals (where jargon, acronyms and abbreviations might aid communication), and that which they use when communicating with patients and carers [7]. In developing guidelines about terminology, Australian groups now conclude that the following terminology is acceptable for talking about 'BPSD' i.e. changed behaviour(s); expressions of unmet need; BPSD of dementia (in a clinical context) [36]. Our study demonstrates that many family caregivers are familiar with a range of 'clinical terminology', so there is perhaps not such a clear distinction in reality, although concern about respect for the person with dementia remains important to many. This raises the question of how clinical discourses can be changed and how we can ensure that language is aligned to the values we wish to promote. Here we can learn from other fields such as oncology, about the need to intentionally address language in training future professionals [37].

Conclusions

It is important that professionals take time to explore carers' understandings and language preferences, since they are typically the agents of change, often acting as proxy decisionmakers when distressing interpersonal situations occur within this paradigm. This study suggests that well-known terms that have been used routinely for many years are unpopular. Instead, carers prefer 'person-centred' terms that attribute changes in behaviour to unmet needs that are easily understood and which acknowledge their role and distress. Given the tendency for language that is used to describe a stigmatised condition to itself become stigmatised over time, it is important that we continue to review the language we use in this area and that we regularly seek the views of people with dementia and carers on how they experience this language.

Supplementary data: Supplementary data mentioned in the text are available to subscribers in *Age and Ageing* online.

Acknowledgements: We thank all participants who took the time to complete the survey and share their expertise. We also thank Dr Sarah Kate Smith, Wendy Mitchell, June Cooke, Kate Swaffer and colleagues at Alzheimer Europe (Diane Gove and Ana Diaz), for their support with recruitment. We particularly thank Ian James for reviewing our analyses and contributing to the results section.

Declaration of Conflicts of Interest: None.

Funding: Recruitment and development for this study was part funded by the NIHR Yorkshire and Humber Clinical Research Network.

References

1. Barsness S *et al.* Rethinking dementia care. Aust J Dement Care 2018; 7: 8.
2. Macfarlane S, Atee M, Morris T, Cunningham C. When responsive and reactive meet organic? Treatment implications of language use in the era of #BanBPSD. Int J Geriatr Psychiatry 2021; 36: 1299–303. https://doi.org/10.1002/gps.5545. AQ7
3. Cunningham C, Macfarlane S, Brodaty H. Language paradigms when behaviour changes with dementia:# BanBPSD. Int J Geriatr Psychiatry 2019; 34: 1109–13.
4. Wolverson E, Birtles H, Moniz-Cook E *et al.* Naming and framing the behavioural and psychological symptoms of dementia (BPSD) paradigm: professional stakeholder perspectives. OBM Geriatrics 2019; 3: 1–19.
5. James I, Duffy F, Moniz-Cook E. Getting our terminology right: the power of language. J Dement Care 2021; 29: 24–7.
6. Wolverson E, Dunn R, Moniz-Cook E, Gove D, Diaz-Ponce A. The language of behaviour changes in dementia: a mixed methods survey exploring the perspectives of people with dementia. J Adv Nurs 2021; 77: 1992–2001.
7. Gilmore-Bykovskyi A, Mullen S, Block L, Jacobs A, Werner NE. Nomenclature used by family caregivers to describe and characterize neuropsychiatric symptoms. Gerontologist 2020; 60: 896–904.
8. Burley CV, Casey AN, Chenoweth L, Brodaty H. Reconceptualising Behavioral and psychological symptoms of dementia: views of people living with dementia and families/care partners. Front Psych 2021; 12: 1413.
9. Algase DL, Beck C, Kolanowski A *et al.* Need-driven dementia-compromised behavior: an alternative view of disruptive behavior. Am J Alzheimers Dis 1996; 11: 10–9.
10. Finkel SI, Costa e Silva J, Cohen G, Miller S, Sartorius N. Behavioral and psychological signs and symptoms of dementia: a consensus statement on current knowledge and implications for research and treatment. Int Psychogeriatr 1997; 8: 497–500. AQ8
11. Stokes G. Challenging Behaviour in Dementia: A Person-Centred Approach. Taylor & Francis, 2017.

12. National Institute for Health and Care Excellence. Dementia: A NICE-SCIE Guideline on Supporting People With Dementia and Their Carers in Health and Social Care. Leicester (UK): British Psychological Society, 2007.

13. Crowther GJ, Brennan CA, Hall KLA, Flinders AJ, Bennett MI. The development and feasibility testing of the distress recognition tool. Qual Ageing Old Adults 2019; 21: 39–52.

14. Swaffer K. We need to ban BPSD before its too late. kateswaffer.com, 2019.

15. Macaulay, S The broken lens of BPSD: why we need to rethink the way we label the behaviour of people who live with Alzheimer's disease. 2017. http://myalzheimersstory.com/2017/11/15/the-broken-lens-of-bpsd-why-we-need-to-rethink-the-way-we-label-the-behaviour-of-people-who-live-with-alzheimers-disease/#_ftn10.

16. Harding R, Peel E. 'He was like a zombie': off-label prescription of antipsychotic drugs in dementia. Med Law Rev 2013; 21: 243–77.

17. Bird M, Moniz-Cook E. Challenging behaviour in dementia: a psychosocial approach to intervention. In: Handbook of the Clinical Psychology of Ageing, 2008; 571–94. AQ9

18. Ornstein K, Gaugler JE. The problem with "problem behaviors": a systematic review of the association between individual patient behavioral and psychological symptoms and caregiver depression and burden within the dementia patient–caregiver dyad. Int Psychogeriatr 2012; 24: 1536–52.

19. Fauth E, Gibbons A. Which behavioral and psychological symptoms of dementia are the most problematic? Variability by prevalence, intensity, distress ratings, and associations with caregiver depressive symptoms. Int J Geriatr Psychiatry 2014; 29: 263–71.

20. Beaver J, Goldberg SE, Edgley A, Harwood RH. 'Socialised care futility'in the care of older people in hospital who call out repetitively: an ethnographic study. Int J Nurs Stud 2020; 107: 103589.

AQ10 **21.** Sue VM, Ritter LA. Conducting Online Surveys. Sage, 2012.

22. McHugh ML. The Chi-square test of independence. Biochem Med 2013; 23: 143–9.

23. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol 2006; 3: 77–101.

24. Braun V, Clarke V. Successful Qualitative Research: A Practical Guide for Beginners. Sage, 2013.

25. The Dementia Empowerment and Engagment Project. Dementia words matter: guidlines on language about dementia 2014. https://www.dementiavoices.org.uk/wp-content/uploads/2015/03/DEEP-Guide-Language.pdf.

26. Oyebode JR, Bradley P, Allen JL. Relatives' experiences of frontal-variant frontotemporal dementia. Qual Health Res 2013; 23: 156–66.

27. Ducharme F, Kergoat MJ, Antoine P, Pasquier F, Coulombe R. The unique experience of spouses in early-onset dementia. Am J Alzheimers Dis Other Demen 2013; 28: 634–41.

28. Braun A, Trivedi DP, Dickinson A *et al.* Managing behavioural and psychological symptoms in community dwelling older people with dementia: 2. A systematic review of qualitative studies. Dementia 2019; 18: 2950–70.

29. Markwell H. Loaded meanings: the narrative of behaviour. Aust J Dement Care 2016; 5: 12–6.

30. Greenwood N, Smith R. Barriers and facilitators for male carers in accessing formal and informal support: a systematic review. Maturitas 2015; 82: 162–9.

31. Xiong C, Biscardi M, Astell A *et al.* Sex and gender differences in caregiving burden experienced by family caregivers of persons with dementia: a systematic review. PLoS One 2020; 15: e0231848.

32. Barnes TR, Banerjee S, Collins N, Treloar A, McIntyre SM, Paton C. Antipsychotics in dementia: prevalence and quality of antipsychotic drug prescribing in UK mental health services. Br J Psychiatry 2012; 201: 221–6.

33. Moniz-Cook E, Hart C, Woods B *et al.* Challenge demcare: management of challenging behaviour in dementia at home and in care homes–development, evaluation and implementation of an online individualised intervention for care homes; and a cohort study of specialist community mental health care for families. Prog Grants Appl Res 2017; 5: 1–290.

34. Karlsson S, Bleijlevens M, Roe B *et al.* Dementia care in European countries, from the perspective of people with dementia and their caregivers. J Adv Nurs 2015; 71: 1405–16.

35. Links A, Callon W, Wasserman C, Walsh J, Beach MC, Boss EF. Surgeon use of medical jargon with parents in the outpatient setting. Patient Educ Couns 2019; 102: 1111–8.

36. Dementia Australia. Dementia Language Guidelines 2021. https://www.dementia.org.au/sites/default/files/resources/dementia-language-guidelines.pdf.

37. Zitella LJ, Prowell TM. Words matter: use of respectful language in oncology. J Adv Pract Oncol 2021; 12: 241.

Received 22 June 2021; editorial decision 23 December 2021