Loaded meanings: the narrative of behaviour

Holly Markwell offers a valuable perspective on the debate about language choice and its role in the perception and portrayal of dementia and behaviour.

Regular readers of this journal will be familiar with the ongoing, and at times intense, debate about language choices and how they affect people who are living with dementia. This is particularly so of the language employed to describe or define behaviour.

The fact that language is debated in this way should not be seen in a negative light – it can be framed as a sign of a growing awareness in how we think about dementia and the impact of language. We may be far from reaching a consensus on terms like behavioural and psychological symptoms of dementia (BPSD), but we must engage with people who are living with the condition to understand it from the lived experience. The debate is also an opportunity to reflect on the narrative we thicken or thin via our language choices: the problem-based narrative of deficit and loss or the narrative of hope, individuality and finding strengths at all points on the trajectory of dementia.

Common ground
In any contentious situation it is worth acknowledging common ground. There is widespread recognition that language is both powerful and ever-evolving and that stigma impacts real people with real lives. Our language choices are a potentially helpful component in the armoury to counteract stigma in every conversation we have: with people with dementia, colleagues, family, in progress notes and handovers. Too often we underestimate the power of the narrative in which we engage. When our narrative is rich in strengths and positive associations we encourage the people around us to have hope that people with dementia are valued and can live lives worth living.

This article is not intended to provide definitive answers to the contested language but it attempts to provide a useful perspective and contribution to the discussion. I will also offer some background and framing of the discussion about the perceptions and portrayal of dementia and behaviour and consider the context of language choice.

The issue has been a topic of much discussion and reflection in the Dementia Training Study Centres (DTSC) / Dementia Behaviour Advisory Services (DBMAS) regular collaborative working group meetings. To further reflect on the impact of language, we were privileged to have dementia advocate Christine Bryden, who is living with dementia, provide the DBMAS Leadership Group with her perspective on the issue (see box p15) at our national meeting earlier this year.

Why do our language choices matter?
The stigma associated with dementia has been extensively written about and discussed by people living with a cognitive disability, family members, academics, care professionals and peak bodies. The language we choose to represent people with dementia and their experience of the world can serve to add to stigma or help to support wider efforts to reduce stigma.

Our language choices are just one element in the effort to improve both the practice of dementia care and inclusivity of people with dementia in the community. As Dyer writes (1993 p1)

"...representations here and now have real consequences for real people, not just in the way they are treated... but in terms of the way representations delimit and enable what people can be in any given society". Efforts to change the language we use around dementia and behaviour represent attempts to establish a stronger foothold for cultural change and a greater awareness and acknowledgment respectfully of the lived experience of people with dementia.

This acknowledgment is being driven by a growing activism and advocacy movement by and for people living with dementia who are working for greater autonomy and quality of life. A growing awareness of dementia in a disability rights framework means that the phrase 'nothing about us, without us' rings ever louder and clearer.

The principle that people with dementia need to be included in discussions and decisions which affect them is one of the core beliefs of Dementia Alliance International (DAI), an independent self-advocacy organisation of people with dementia in partnership with Alzheimer’s Disease International (ADI). At the opening address of the World Health Organisation’s Ministerial Conference on Global Action Against Dementia in 2015, the DAI advocated that the UN Convention on the Rights of Persons with Disabilities must include people living with dementia (ADI 2015).

With a wider adoption of a disability rights perspective, not only will the language we use be evaluated for its capacity to help break down ‘us’ and ‘them’ thinking and acting, but our record of engagement and inclusion of people with a cognitive impairment will be noteworthy.

At the same time, the language we use around behaviour across care settings must also serve to create clarity and prompt health care practitioners to respond appropriately to any expression of distress by a person with dementia.
BPSD

The case for using this term

"Using BPSD leads people to see a person's response to a situation as a symptom demanding intervention ie, seeking the underlying cause/need" (Winbolt M 2015 PowerPoint presentation on BPSD).

People expressing their needs or preferences in strongly assertive or 'unusual' ways may be labelled as manipulative or deliberately disruptive. The term BPSD focuses on dementia to avoid the person being blamed.

The case against

"Not using BPSD leads people to see a person's response to a situation as 'normal human response' demanding intervention; seeking the underlying cause/need" (Winbolt M 2015, PowerPoint presentation on BPSD).

A person's expressions of distress may be dismissed by staff as being caused by dementia, thereby negating action and personal responsibility - "it's the dementia, there is nothing we can do". The term may reduce the possibility for insight into family and care professional behaviours and routines which may be a contributing factor to the person's behavioural expression/distress.

"The term BPSD can be problematic in that it can be construed that somehow these problems are inevitable or inexplicable" (Brooker D 2011, cited in Australian Journal of Dementia Care Oct/Nov 2012 1(3) p36).

The term BPSD is part of a bio-medical model and pathologising of behaviour and emotion. If you have a diagnosis of dementia, all of your actions and expressions are viewed through a 'dementia/disease lens' (Dupuis et al 2012). This does not support a person-centred approach.

Managing behaviour

The case for using this term

"Managing the behaviour" means managing the underlying contributing factors of the behaviour. The term is shorthand for saying that we need to manage the circumstances and interactions under which the behaviour occur.

"Managing" also refers to a number of processes which may be happening simultaneously within a bio-psycho-social approach including assessing, charting, educating staff, mediating between family members/staff, trialling interventions and so on.

The case against

The word 'managing' contains an implicit power imbalance between the person with the behaviour in question (who is presumed to be in need of managing) and the person (who does not have a cognitive impairment) doing the managing.

'Managing behaviour' may be misinterpreted as managing the symptoms (as opposed to the contributing factors). Some critics have suggested that 'managing/BPSD' puts the emphasis on the symptoms and that this can lead to inappropriately prescribed anti-psychotics or benzodiazepines.

'Managing' has a similar connotation to 'dealing with (a behaviour)' or 'handling'- which again implies that control needs to be exerted over another person.

The term 'manage/managing' sounds negative and impersonal. It doesn't proactively convey a sense of hope that our sights can be set beyond managing behaviour to reach for enabling well-being.

Both the terms BPSD and 'managing behaviour' may lead to an uncritical acceptance of the need to manage/control/minimise the symptoms instead of searching for the cause of the symptoms.

What language choices represent the best fit given the need both for clarity in a clinical context and the aspiration to support personhood across all sectors of our communities?

Although a number of different phrases and words have been the subject of discussion, this article will focus on the use of the following phrases and present the case for and against the use of these terms (see boxes above and next page):

- Behavioural and psychological symptoms of dementia (and the various alternatives and options); and
- Managing behaviour/behaviour management.

For a broader description of appropriate language in various contexts, please refer to the Alzheimer’s Australia Dementia language guidelines (http://bit.ly/1o1A5s5).

How important is the context of the communication?

The context in which the communication is taking place is an important part of the overall picture. To varying degrees, people contextualise their language choices across a number of different continua: the level of formality in the setting, how familiar the other parties are with the topic, the
<table>
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<tr>
<th>Options</th>
<th>The case for using this term</th>
<th>The case against</th>
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<tr>
<td>Changed behaviours</td>
<td>This is listed as a preferred term in the Alzheimer’s Australia Dementia language guidelines (AA guidelines). Neutral term suitable for general use.</td>
<td>Not that well known. Requires some explanation so that the guiding principles are understood.</td>
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| Responsive behaviour (RB)                   | The term originates from the Murrey Alzheimer Research and Education Program (MAREP) (University of Waterloo, Canada) and was created in consultation with people living with dementia. It has been adopted by the Ontario Government and the newly formed BSO (Behavioural Supports Ontario). The term RB rests on the following principles: *All personal expressions (words, gestures, actions) have meaning.*  
*Personal expressions are an important means of communicating meanings, needs, and concerns.*  
*Care partners require a multidimensional lens that seeks understanding of others' expressions.*  
*Rather than the current focus on pathology/disease as the root cause of all actions, words, or gestures, a multidimensional lens/approach helps partners in care develop a broader and more comprehensive understanding of what the person with dementia is subjectively experiencing, which personal expressions they are communicating, and how best to offer compassionate support.* (University of Waterloo MAREP 2012). |                                                                                                                                                                |
| Behaviours of concern                       |                                                                                                                                                                                                                             | A term which the AA guidelines indicate should not be used. Authoritarian in tone.                                                                     |
| Challenging behaviours                      |                                                                                                                                                                                                                             | A term which the AA guidelines indicates should not be used. Implication is that the person is being deliberately or willfully challenging. Confrontational in tone. |
| Expressions of unmet needs Behavioural expression of need | Encourages further investigation of what the need might be. Care teams with a genuine understanding of the Need-Driven Behaviour Model (Agapea et al 1996) may be well placed to take into account the role of both background factors (eg. the person’s history, personality, neurological, cognitive and health status) and current or proximal factors (eg. emotional states, physical needs, and the physical and social environment) in the genesis of behavioural expressions. Behaviour is conceptualised as the most coherent response the person is able to make, at any given time, given their unique set of background and proximal factors (Beatle E, personal communication, 2016). I suggest that this paves the way to support a strengths-based approach. | The term ‘unmet needs’ is often used very loosely. I have seen numerous instances in which RACF progress notes are written up as a ‘behaviour not related to an unmet need’ – a fuzzy phrase and a judgment that is not possible for one person to definitively determine for another person. |
| Behavioural expression of distress          | A general term which may be acceptable if it does relate to observable signs of distress. It may be used more specifically (behavioural expression of pain/boredom/loneliness etc) but this assumes that we have been able to identify a major contributing factor. Behaviour is often more likely to be multifactorial in nature. |                                                                                                                                                                |
| Distressed behaviour                        | Similar to above term – it may be appropriate to use if it is accurate.                                                                                                                                                     | The term is being questioned by people living with dementia, industry representatives and advocates (with or without lived experience). For example, see Kate Swaffer’s article *The power of language* (Australian Journal of Dementia Care Feb/March 2015 4(1) [http://journal/dementiacare.com/the-power-of-language/]). BPSP carries a risk of “diagnostic overshadowing” where “…all actions and expressions are attributed to the labelled condition” (Downs et al 2006 p240, cited in: Dupuis et al 2012 p170). BPSP is a disease or biomedical framing which normalises behaviour as part of the disease process. See above for a description of the potential negative impact of this term. |
| Behavioural and psychological symptoms of dementia (BPSP) | Widely used and accepted in research and medical contexts. The term was created in 1996, at the International Psychogeriatric Association (IPA) Consensus Conference on Behavioural Disturbances of Dementia. BPSP is defined as: symptoms of disturbed perception, thought content, mood or behaviour that frequently occur in patients with dementia. (Firth & Burns 1999 cited in IPA BPSP educational pack, revised in 2003). BPSP is included in the AA guidelines. | Though uncommon, there may be instances in which the person’s behaviour may not indicate or cause distress for the person themselves – but may cause distress for other people. |
| Behavioural and psychological indicators of distress in dementia | Dementia is recognised as part of the person’s experience but not necessarily as the ‘cause’ of behaviour.                                                                                                                                 | The term is not in common usage.                                                                               |
| Behavioural and psychological changes in dementia | Serves to emphasise that dementia is a part of the picture and that the changes the person is experiencing are related to neurological impairment but are not attributed to dementia per se. Seeks to recognise change as an inherent part of the experience of living with dementia (both for the person and their family). |                                                                                                                                                                |
roles and perceived status of each party to the communication, and so on. In many ways, these contextual elements will guide the choice of language. Choice of language will also depend on the cultural appropriateness of the terminology used and whether or not the phrase or term will be translated into a different language.

While context is important, we should avoid wherever possible the creation of any circumstances which lead to divisions between people due to terms being considered appropriate for some situations and not for others. Instead, there is value in a shared language around behaviour and dementia. A shared understanding is important because:

- No single group (researchers, medical staff, etc) is necessarily immune from the way in which the portrayal of behaviour and people with dementia impacts on perception/thinking and actions.
- Behaviour is complex, multifactorial, and invariably changes over time – diagnostic categories of behaviours are not typically discrete or clearly delineated.
- Family or friends who are supporting a person with dementia will vary considerably in their level of knowledge and understanding of the changes they and the person are experiencing.
- Responding to a person who communicates their distress via behaviour is the responsibility of a range of care staff with varying levels of skills and knowledge (from workers with a Certificate III level qualification to clinicians and consultants across multiple disciplines).
- A shared understanding must be inclusive of people living with a dementia.
- Although the meaning of the language we use will need to be supplemented by descriptions, aiming for inclusivity and accessibility in our language will parallel wider efforts to promote person-centred approaches, inclusivity and the rights of people with a cognitive disability.

What questions will help guide our choice of language?

There are a number of possible options for a set of guiding questions or principles which will serve to evaluate language and how people with dementia and changed behaviour are portrayed. The first four sets of questions are based on the VIPS model of person-centred care (Brooker 2007).

- Does our choice of language convey to the listener the value of the person who is living with dementia, regardless of the person’s actions, mood or level of cognitive disability?
- Does our choice of language convey a sense that the person’s behaviour and/or psychological states are complex and changing with a diverse set of contributing factors unique to the person and their circumstances?
- What is the perspective of people who have a cognitive disability on the language choices being made? What might be the perspective of the person who is attempting to make sense of their world with their remaining abilities?
- What impact might the language have on the social environment experienced by a person with dementia? Are there any unintended consequences to our choice of words?

The following principles are a selection from a report by Alzheimer Europe 2013 titled The ethical issues linked to the perceptions and portrayal of dementia and people with dementia. This report provides an extensive and thought-provoking reflection on the implications for well-being and the connection to how dementia and people with dementia are perceived and portrayed. The statements below are a valuable guide to growing our awareness of the narratives we create about dementia:

- Avoid reducing people to numbers, objects, medical cases and problems.
- Avoid portraying people with dementia as ‘other’, fundamentally different or inhuman.
- Reflect on ways to capture the dignity, personhood, individuality and citizenship of the people you are portraying.
- Make an effort to talk to people with dementia and to obtain their feedback with regard to the issues you intend to portray or report.
- Consider not only the message you wish to communicate but also the different possible ways it might be interpreted.
- Question your own assumptions about dementia. Choose your words, metaphors and images carefully.
- Consider what the words you use when talking about dementia or people with dementia imply and whether you personally agree with those
implicit assumptions.

- When communicating for a particular reason to a particular audience (ie strategically), reflect on how people with dementia might feel about your portrayal.
- Reflect on how people with dementia are portrayed by others, what kinds of messages are being communicated and possible reasons for trying to convey a particular perspective.
- Be prepared to challenge the way dementia is portrayed if you feel that it is inaccurate, disrespectful or misleading.

In summary

How well the terms or words we use compare against such a list of principles will be a matter of individual interpretation. Only a process of reflection will allow us to challenge ourselves to question our assumptions and beliefs. It is through discussion and reflection that change occurs and what may have seemed unthinkable in years past can become acceptable in the here and now.

What we can be sure of is the debate is not going to dissipate of its own accord. Language will always evolve, even if agreement is reached in the short term. However, genuine dialogue and inclusion with people with a cognitive disability on this and other issues is a positive and proactive approach.

The terms ‘responsive behaviour’, ‘changed behaviour’, ‘distressed behaviour’ and ‘behavioural expression of distress’ are options which may be appropriate according to the situation that is being portrayed or discussed.

‘Responsive behaviour’ may help to convey a sense of agency and meaningfulness on the part of the person with dementia, but it will usually need some explanation so that the term is understood.

The term BPDS is still the language of research, which must rely on clarity of terminology for ‘good’ science to occur. But we are right to question its use and reflect on the impact of this term. What alternative might serve researchers and at the same time not create the potential for further stigma or loss of hope? Does ‘behavioural and psychological changes in dementia’ serve as a useful middle ground at this point in the debate?

‘Changes in behaviour’ or ‘behavioural changes’ are plain English terms and widely accessible. The words ‘behavioural and psychological changes’ may help to minimise the ‘disease lens’ or biomedical framing of behaviour.

H owsoever this is resolved, health professionals who are responsible for responding to distress in a person with dementia must encourage the understanding in both care staff and family carers that a person with changes in mood and behaviour is working to interpret the world around them at the same time as experiencing things like:

- altered perceptions of both time and space
- lower tolerance to stress
- the experience of being a recipient of care (where this is relevant)
- communication changes/losses, and in situations where distress is evident
- a range of emotions from frustration, boredom and uncertainty through to anxiety, fear, anger and grief.

The notion that the person is making the best sense of the world that they currently find themselves in and using remaining skills is a strengths-based approach. Further efforts to convey this to care staff alongside a model of person-centred care, such as the ViP Model (Brooker 2006) may help to thicken the narrative of hope, enablement and engagement.

To be genuinely person-centred we need to engage in self-reflective practice to question which narrative we may be strengthening and engage with people with the lived experience to expose and eradicte the stigma of dementia.

Footnote

Other guidelines on language and dementia (not previously referred to in this article) are:


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References


