

Getting our terminology right: the power of language

Language matters in dementia care and terms like “challenging behaviour” and “BPSD” have become widely questioned, but what should replace them? **Ian James** and colleagues have been exploring alternatives and report on their findings so far

For over 25 years, the term challenging behaviour (CB) has been used to describe agitation and other “distressed” behaviours associated with dementia (Stokes 2000). But such is the power of language and the importance of getting our terminology right, there has been much debate about whether we should continue to talk of “challenging behaviour”. We will discuss the results of a survey on what should replace the term, but first we will review the background to the debate.

Origins and background

Challenging behaviour was originally coined as a term in the field of learning disability, where it was used to describe problematic behaviours that caused difficulties. It drew on the work of Blunden and Allen (1987), who suggested that the term shifted the focus of attention away from individual pathology towards a caregiver and setting-focused conceptualisation that understands behaviours as challenging to carers and services.

But there have, of course, been rival terms. The term behavioural and psychological symptoms of dementia (BPSD) was conceived by a group in 1996 (Finkle *et al* 1996) and became popular in the medical literature. However, it has been criticised for its implication that all such behaviour is a direct consequence of both organic damage and the dementing process, sometimes leading to nihilistic attitudes about the inevitability of progression where “nothing can be done” to improve the lives of people with dementia.

Another change in emphasis emerged with the rise of the “needs” perspective (Algase *et al* 1996, Kolanowski 1999) in the mid to late 1990s. These authors proposed that the “problematic behaviours” are an expression of distress that arises from physical or psychological unmet needs. For example, Cohen-Mansfield (2000) suggested that behaviours often reflect an attempt by a

person to signal a need that is currently not being met (eg, to indicate hunger, to gain relief from pain or boredom, etc).

On this analysis, behaviours reflect an effort by individuals to get their needs met directly (eg, leaving a building in the belief that one must either go to work or collect children from school) or a sign of goal frustration (eg, feeling angry at being told one is not allowed to exit a building).

In all of these situations, the actions are active attempts by the individual to enhance and maintain a sense of self by seeking to manage a particular need. Therefore, it was argued that identifying and resolving the need should be the focus of treatment, a perspective that led to the emergence of the term “unmet needs” to describe this concept associated with behavioural and emotional reactions in dementia care.

In 2006, the term behaviour that challenges (BtC) first appeared in the National Institute for Health and Care Excellence (NICE) guidelines on dementia. This name incorporated clinical and social constructs, shifting the focus again away from people with dementia towards caregivers and requiring them to find solutions to the problematic behaviours.

BtC has been defined as “actions that detract from the wellbeing of individuals due to the physical or psychological distress they cause within the settings they are performed” (James 2011, p12). More recently this definition was refined as:

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An expression of distress by the person living with dementia (or others in the environment) that arises from unmet health or psychosocial need(s). The behaviours often reflect attempts by the person living with dementia to maintain a sense of control, dignity and wellbeing, and/or to ease discomfort or distress (BPS 2018).

The term BtC, however, has not been widely used outside the UK, and in 2018 the updated NICE guidance replaced it with “non-cognitive symptoms”. NICE now specifies the actual symptoms as “agitation, aggression, distress and psychosis”, but the lack of a distinction between the constructs of agitation, aggression and distress is highly problematic, and is reminiscent of problems we observed when using the term BPSD. ►

A change in emphasis came with the rise of the “needs” perspective, proposing that “problematic behaviours” are an expression of distress that arises from physical or psychological unmet needs

Term	Reasons for preferring the term	Reasons for disliking the term
BEEN – Behavioural and Emotional Expressions of Need	This term has recently been suggested as an alternative to “unmet need”. It offers a positive way for practitioners to consider how to “meet” unmet needs in people with dementia through observing their behavioural and emotional expressions.	This was surveyed in the north of England with 30 professionals and completed with one family carer. The carer felt that this implied the person with dementia was a “has been” and therefore lacked respect. The practitioners suggested either “Emotional or Behavioural Expressions of Need” or “Behavioural Expressions of Need” (BEN) as alternatives.
BECON – Behaviour and Emotional Communication of Need	An alternative to BEEN and BEN, with a better abbreviation of name. The term is consistent with the notion of “unmet needs” and highlights the key role of communication.	The abbreviation is potentially too long and/or complicated. In a recent survey, many participants were unable to recall the words that made up the acronym two hours after learning it.
BtC - Behaviours that challenge	BtC is a well-known and widely used term in the UK. It is easy to understand and “user friendly”. Importantly, it does not blame the person with dementia, recognising that much of the responsibility is with others and their communication with the person.	The word “behaviour” can imply that the person is “at fault”, doing it deliberately or is misbehaving. In addition, the term BtC is not used outside of the UK.
BPSD – Behavioural and Psychological Symptoms of Dementia	BPSD is a broad general term while also being clear and descriptive. It is widely used internationally, attributing behaviours to dementia as symptoms of an illness.	BPSD has received criticism for being too medical, with some people suggesting that over the years this term has led to the increased use of potentially harmful drugs with limited evidence of their efficacy. Continued use of this term might make clinicians more likely to think of psychiatric drug treatments. Furthermore, this term can be seen as judgemental and blaming, attributing behaviour to dementia alone and suggesting nothing can be done where there can be other understandable reasons for the behaviours. The term is not seen as “family friendly” and is seen as too general and meaningless when providing care.
Challenging behaviour	This term is widely known and used internationally by non-medical professionals. It was developed to move away from considering behaviours as inevitable in dementia and focuses on what can be changed. This can encourage carers to change the way the person is supported and to see “challenging” as a challenging setting as opposed to a challenging person.	The word “behaviour” can imply that the person is at fault, doing it deliberately or misbehaving. This term has been criticised for not being specific enough and implying helplessness.
Responsive behaviours	This term arose out of the survey, mentioned by some participants.	Not currently used in the literature.
Stress and distress	Stress and distress is a broad general term, perceived as “normal” human reactions which people can relate to. It evokes compassion, motivating people to help, and is family friendly. The term focusses on emotions, without blame or stigma, helping people to see behavioural changes as a way of communicating needs.	The term is perhaps not specific enough to be useful and often doesn’t convey the severity of the situation. Furthermore, recognising stress in dementia can be difficult which may create problems for practitioners. A person with dementia can be upset (withdrawn) but there are no challenges noticed by others as they are seen by some as “no trouble”.
Unmet needs	The term “unmet needs” emphasises that there is a possible reason for the behaviour and focuses on not blaming the person. The term is “user friendly”; “needs” are universal so others may be more understanding and thus be more inclined to support the person by meeting the need.	Unmet needs are not easy to measure in someone with dementia who may not be able to communicate clearly because they are upset. This can be challenging for the practitioner to know how to help and to know if their support has been helpful.

Box 1: Description of the terms

Term	Mean*	Times ranked no. 1 <small>MOST PREFERRED TERM</small>
Unmet Need	4.82	96
Behaviours that Challenge	4.75	74
BPSD	6.85	67
Stress and Distress	4.33	53
Distress	4.79	25
Distressed Behaviour	4.84	21
Managing Distress	5.83	12
Challenging Behaviour	7.99	9

*Note: Score of 1 reflects highest preference therefore lower means reflect higher rankings.

Table 1: Terminology

► A backward step

Taking an overview, the current authors consider the term non-cognitive symptoms to be a retrograde step since it returns to the pathologising of what may be perfectly understandable behavioural responses to environmental circumstances. Furthermore, this perspective frames the phenomena from the wrong end of the telescope, focusing on the end-point symptoms rather than the underlying causes of the behaviours (eg, unmet needs, restricted coping strategies, carer communication skills, etc) or the system in which they occur.

A better appreciation of the causes would potentially assist in more precise targeting of treatments. We note that this was considered in an Australian government initiative, which emphasised the “caregiving context” through the use of the term behaviours of concern (BOC) (Wallace *et al* 2012), although the 2016 Australian clinical guidelines for dementia rather inconsistently chose to use the term BPSD.

In a recent online UK survey on this topic 376 professionals working in dementia care across the country rated 14 alternative terms for the behavioural phenomena. Participants were asked to rank the terms in order of preference and give reasons for their choices. The highest ranked terms were “unmet needs” and “stress and distress” (see table 1 (Wolverson *et al* 2019)).

“Unmet needs” was endorsed most frequently as the most preferred term by the most participants (96 participants, 25.4%), but “stress and distress” had the

best mean rating. Hence, the quantitative findings were somewhat equivocal. When considering whether there were any geographical preferences on ratings, the analysis showed the term stress and distress was favoured most frequently by participants from Scotland, where the term is used nationally in much of the documentation.

A thematic analysis of the statements about participants’ preferences revealed six key themes: the term should be user-friendly; have broad rather than narrow applicability; link to features beyond merely behaviour, including the environment; be neither derogatory nor blaming; emphasise the potential for change; and reflect the role of emotions and its link with communication (Wolverson *et al* 2019).

Review of themes and data

A review of the themes and the quantitative data took place in Belfast in September 2019 at a meeting funded by the British Psychological Society Division of Clinical Psychology (DCP). The intention was to decide what term to use in the emerging literature and subsequent DCP guidelines on behaviours that challenge.

Noting the lack of consensus among survey participants, the meeting proposed a new term which drew heavily on the themes outlined in the paper by Wolverson *et al* (2019). This was “behavioural and emotional expressions of need”, which were described as:

...manifestations of people’s unmet needs that are expressed either behaviourally

(actions/inactions) or emotionally (anger, fear, depression). Their impact is based on the interpretation of others (caregivers).

The outward signs of “behavioural and emotional expressions of need” are behaviours and feelings, although needs are the “engine room”. When a person with dementia neither believes nor senses that a fundamental need is being met, a caregiver will observe the outward behavioural signs such as excessive walking, shouting out, and exit seeking, which can be observed through facial movements.

A series of focus groups, involving 24 practitioners, were held to further assess the value of this term. It was viewed very positively, but there were concerns over the length of the term which meant that it would almost certainly be shortened to the acronym BEEN. Some people thought such an abbreviation was too close to the term “has been” and carried an unwanted implication of decline.

Exploration of the pros and cons of BEEN led to alternatives such as “emotional and behavioural expressions of needs” (EBEN) and “behavioural and emotional communications of need” (BECON). The acronyms were felt to be more acceptable and the term BECON, in particular, was more in line with the findings of the Wolverson *et al* survey, where positive communication with the person with dementia was seen as the

The term “behavioural and emotional expressions of need” was viewed very positively in the focus groups, but some people thought the acronym BEEN was too close to the term “has been” and carried an unwanted implication of decline

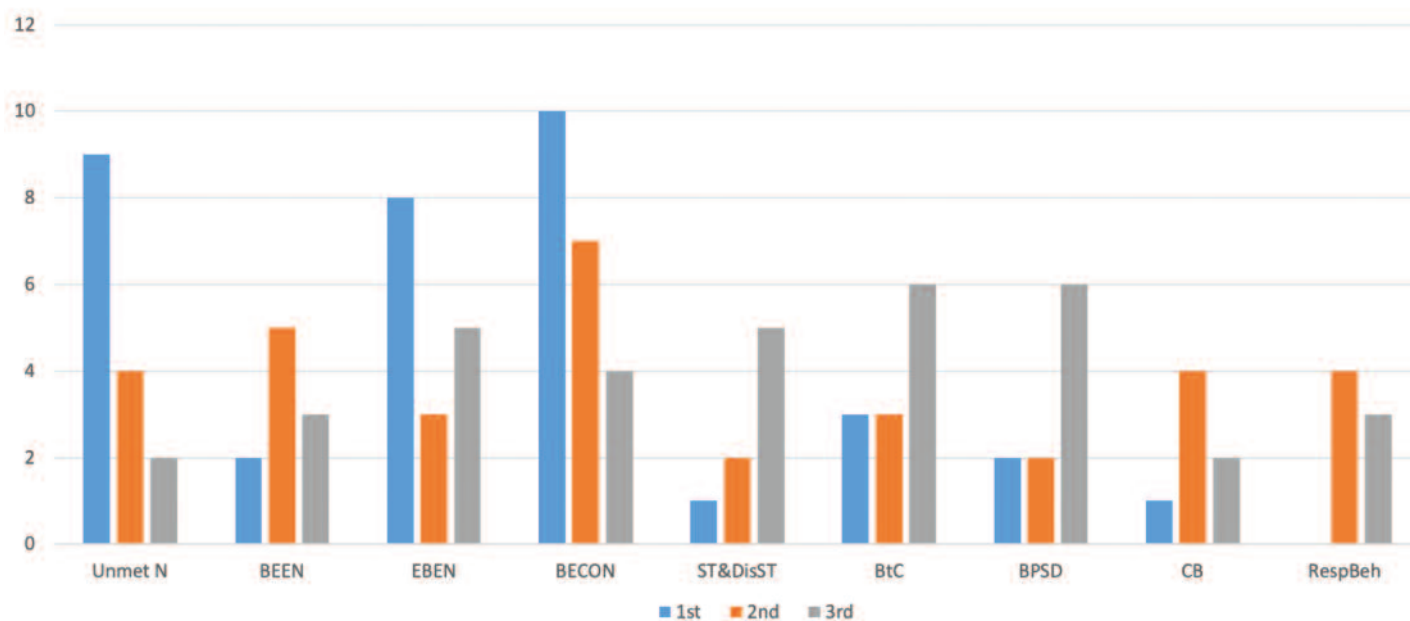


Figure 1: Terminology results (top three choices)

way forward in refining language associated with dementia.

Staff opinions

Following the focus groups, opinions were sought from staff in the Northumberland Older People's Community Treatment Team during a training session on dementia run by the first author. Descriptions of the terms were circulated and participants were asked to rank their three top preferences, giving reasons for their choices. Results from the survey of 35 clinicians are presented in Figure 1. Each of the terms is described in Box 1.

These show that the family of names associated with BEEN were favoured, with the next most popular term being "unmet need". But when the results of the survey were fed back to participants at the end of the training session, although they endorsed BECON as their top term, a mere two hours after completing the survey many were no longer able to state the words that made-up the acronym, ie, behavioural and emotional communications of need.

This was clearly an obstacle to using the term, and by the end of the discussions many participants were in favour of the shorter alternative Behavioural Expressions of Need (BEN). It was thought to be short enough not to require an acronym but, if it did, the term "BEN" was acceptable.

The potential of acronyms to detract from meaningful communication has been highlighted as hindering good support in an international mixed

methods survey, conducted between November 2019 and March 2020 and involving 53 people with dementia. People with dementia also disliked terms that emphasised the word "behaviour" and its potential for undermining their dignity. The authors conclude that "given the concerns expressed by people with dementia about this topic, clinicians need to take the time to explore an individual's preferences and understandings and to share their own meanings and understandings" (Wolverson *et al* 2021).

There is clearly a need to improve the way we speak about how people's behaviours are perceived to change following a diagnosis of dementia. In our view any terminology should reflect a need to be met by others rather than a problem to be managed. The first author would welcome contact from clinicians and researchers who wish to join a final Delphi survey on this topic. ■

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