

Language paradigms when behaviour changes with dementia: #BanBPSD

1 | BPSD: A BACKGROUND

The term behavioural and psychological symptoms of dementia (BPSD) first arose following a meeting of the International Psychogeriatric Association (IPA) in 1996. The primary purposes of the meeting were to review current understandings of “behavioural disturbances” of dementia, as they were then described, and to reach consensus on four key areas, namely, definition of symptoms, causes of symptoms, definitions of clinical symptoms, and research directions.¹ While behavioural symptoms associated with dementia have been documented since the condition was first recognised, it was not until the 1980s that a dedicated focus on the behavioural symptoms associated with dementia clearly emerged.¹

A key motivation for the development of a new term in the 1990s was a desire to better understand the lived experience of people with dementia and their carers: why they behaved the way they did and what was the impact of their behaviour. It was also an attempt to counter criticism at the time of prevailing terminology such as *challenging behaviours*. Researchers and clinicians alike had been aware that BPSD are associated with premature admission to residential care, increased hospitalisation, distress for carers, and reduced functional ability for the person with dementia.² It was hoped that a new focus on understanding behaviours would facilitate improvements in both care and quality of life for people with dementia and their carers.

This is, at least in part, what has since occurred. Since the mid-1990s, there have been numerous studies aimed at improving care for people with dementia. Initially, there was a tendency for research to focus on listing and categorising different types of BPSD and to review different treatments or responses against these categories. However, it is now accepted that people experience dementia in a personal way and that BPSD vary greatly among individuals according to a broad range of psychosocial factors, such as life history and culture.¹ It is also acknowledged that any “intervention” for people with BPSD must be tailored to their individual needs and situation.³

While most “treatments” for behavioural and psychological disturbances have focussed on the use of psychotropic medications, there has been a growing interest in non-pharmacological interventions for people living with dementia, beginning in the 1980s^{3,4} and expanding over subsequent decades. Today, guidelines authored by medical organisations and expert groups recommend psychosocial approaches

as the first line of “treatment” for BPSD.^{5,6} This growing emphasis upon non-pharmacological responses to BPSD is particularly important, given the side effects linked to many psychotropic medications, including an increased risk of falls, stroke and death, and their small effect sizes. However, it is accepted that pharmacological intervention may be required in response to specific incidents, such as those involving severe physical aggression.¹

The term BPSD has filtered down to aged care and other generalist settings where, in recent years, some have begun to question its appropriateness. These critics have argued that in practice, the widespread use of this term can lead people to ignore the underlying causes or needs of a person's behaviour, create the perception that behaviours are inevitable, and pathologise behaviour and emotion.⁷ In community and residential care settings alike, various alternative expressions to describe the behaviours of people living with dementia have been proposed. These include such terms as “problem behaviours,” “challenging behaviours,” and later, “behaviours of concern,” which evolved as an attempt to divert the focus onto identifying what specifically was of actual concern, and to whom. Due to the stigma attached to these terms, the Dementia Australia *Dementia Language Guidelines*⁸ recommend that none of these be used. In their place, the following alternatives were proposed: “changed behaviours” and “expressions of unmet need.” Others have recommended “responsive behaviours.”^{7,9} Interestingly, Dementia Australia maintains support for the use of BPSD in a clinical context.

2 | THE INFLUENCE OF KITWOOD

Around the same time that the IPA was reaching consensus on the term BPSD, respected psycho-gerontologist Tom Kitwood was articulating a distinct approach to the understanding of dementia behaviours. Kitwood argued that many of the behaviours characterised as BPSD were actually valid responses to inappropriate external circumstances and relational approaches.¹⁰ In so doing, he advocated for a greater focus on the behaviours of family members and care staff who interact with people living with dementia. Kitwood believed that people with dementia in care environments often experience “ill-being” as a result of what he termed, “malignant social psychology.” Kitwood argued that this included a range of behaviours such as

deception, intimidation, and stigmatisation, that taken together, amount to treating people with dementia as less than human.¹¹ As a counter to “malignant social psychology,” Kitwood called for an increase in “positive person work,” which includes approaches like recognition, negotiation, and collaboration and serves to increase a person's well-being—ideas which remain influential today.

3 | THE #BanBPSD CAMPAIGN

Pursuing similar objectives, a movement has emerged on social media comprising campaigners around the world calling for change in dementia care policy and practice, criticising what they call the “behavioural paradigm.”¹² The #BanBPSD movement has existed in various forms for some time; however, it has gained momentum and increasing support in recent years. While the movement is made up of disparate members, a number of campaigners agreed to and co-signed an open letter to the *Australian Journal of Dementia Care*, published in the August/September 2018 edition.¹³ Signatories included health care professionals, authors, advocates, academics, and care partners. Kate Swaffer, an Australian author and PhD candidate who is living with dementia, has highlighted the movement on her blog with a focus on #BanBPSD throughout September 2018 under the broad title, “Rethinking Dementia: Normal Human Responses.”¹⁴

At the heart of the #BanBPSD movement's various messages is opposition to and action on chemical restraint by way of overmedication, systematic prejudicial labelling, and “human rights breaches.” While the campaigners recognise that the original intent behind the term BPSD was to improve care,¹³ they suggest that once someone has been labelled as exhibiting BPSD, they are more likely to be overmedicated and less likely to be afforded understanding or consideration of the root cause of their experience.¹⁵ The group's open letter goes so far as to say that as a result of the “BPSD paradigm, physicians can and do prescribe medications for “behaviours of concern” that generally are a result of a person's responses to unmet needs, or the challenges of living with changing cognition within environments that reflect an inadequate understanding of, and accommodation for, those changes.¹³

Among campaigners, there is a strong emphasis on characterising behaviours that have traditionally been labelled “BPSD,” as normal human expressions in response to unmet needs. Leah Bisiani, an Australian registered nurse and dementia consultant, builds on the work of Kitwood to claim that the essential needs of people with dementia are being ignored and the so-called BPSD they display are a “response to feeling devalued” and expressions of frustration are due to an inability to verbalise those needs effectively.¹² Dr Allen Power, a US geriatrician and author, suggests that the label of BPSD relegates the cause for people's expression to brain disease, ignoring relational, environmental, and historical factors and causes.¹⁶ Movement contributor Sonya Barsness, a fellow US gerontologist and consultant, has taken issue with describing behaviours as symptoms, saying this term “medicalises” expressions and frames them as “abnormal.”¹³ Another campaigner living with dementia in the United

Kingdom, Howard Gordon has highlighted a number of potential causes of behaviour in dementia including physiological (UTI, constipation, pain, hunger), emotional (fear, apathy, boredom, loneliness), environmental (temperature, noise, lack of meaningful activities), and those due to organic brain changes (not recognising people/places, regressing to a different time).¹⁷

Rather than using the term BPSD, the movement recommends moving to a more “progressive and expansive view of the person who lives with a diagnosis of dementia.”¹³ The movement advocates an approach that removes all forms of restraint (both physical and chemical) by acknowledging that all people have the right to “freedom of expression.” In addition, they argue that care should be provided based on a person's remaining strengths and should take the form of rehabilitative support for acquired cognitive disabilities.¹³

Bisiani stresses the importance of seeking to understand what it is that a person with dementia is trying to communicate, as well as why and how specific issues can be resolved in partnership with family or professional carers.¹² Bisiani states that when care partners understand the origins of a person's stress-related response, they are able to remove triggers and address the root causes of a specific behaviour.¹² Moreover, care partners are able to minimise or avert behavioural expressions (and the associated negativity) by understanding a person's cognitive boundaries, respecting preferences, and providing care in a way that “least exhausts their capabilities.”¹²

4 | IMPORTANT ISSUES RAISED BY THE #BanBPSD CAMPAIGN

The #BanBPSD campaign has done much to highlight a number of serious issues in the care provided to people living with dementia. Chief among these is the issue of systematic labelling, particularly in aged care environments. When a person with dementia is labelled with terms like “wanderer”, “screamer”, “hitter” or “sundowner,” this can have a tangible negative impact on the way other people interact with them. A major issue identified by Dupuis et al¹⁸ is that when people with dementia are reduced to a pejorative label, they are more likely to be perceived as a “burden” or “problem” that must be managed or controlled. At the same time, it is less likely that others, including aged care staff, will seek to understand a person with dementia who has been labelled. In this sense, labels and preconceived ideas about dementia that are applied without a personal context can truly be “fatalistic and destructive.”¹⁸

Another valid concern highlighted by the #BanBPSD campaign is that not all behaviours displayed by a person living with dementia (including those behaviours others find challenging) are the direct result of changes in the brain. This argument is, in part, evidenced by the rich data set emerging from the national Dementia Support Australia (DSA) service.* An unpublished analysis of all completed DSA cases between January and July 2018 (n = 3566) found over

*Dementia Support Australia (DSA) is run by HammondCare's Dementia Centre and is funded by the Commonwealth Government to deliver the national Dementia Behaviour Management Advisory Service (DBMAS) and Severe Behaviours Response Teams (SBRT) programmes.

50 different factors (across biological, psychological, social, and environmental domains) that contributed to the behaviours of clients referred to the program. Many of the potential causes raised by Howard Gordon in his blog, such as constipation, pain, boredom, loneliness, and noise, were among the contributing factors identified by DSA. From the DSA data set, the three most common contributing factors were not directly linked to cognitive impairment. They were pain (47% of cases), carer approach (34% of cases), and over- or under-stimulation (27% of cases). However, each case had an average of five identified contributing factors, further highlighting the complex nature of behaviours among people living with dementia. It is thus clear that even when the physiological brain changes of dementia do contribute to behaviours, usually a range of other environmental, psychological, social, and biological factors are also involved. It remains essential to bear in mind, that behaviours triggered by non-cognitive impairment related factors (such as pain) are still mediated by the person with dementia's lived experience of cognitive impairment.

The #BanBPSD movement's desire to address over-medication and chemical restraint is valid and worthwhile. Antipsychotics continue to be commonly prescribed in aged care homes, despite widespread concerns about this overmedication.⁶ This is particularly frustrating because there is evidence to suggest that high prescribing rates for antipsychotics are not inevitable. An Australian study, for example, found that residents in those aged care homes adopting a distinct home-like model of care were prescribed fewer potentially inappropriate medications, including psychotropic agents.¹⁹ Simultaneously, the *RedUse* program has seen the rates of regular antipsychotic prescription in 150 Australian aged care homes decline by 13%, while the rates of regular benzodiazepine prescription reduced by 21%.⁶

5 | CONCERNS WITH THE #BanBPSD CAMPAIGN

While the #BanBPSD campaign raises a number of critical concerns that demand positive action in aged care policy and practice, the campaign serves also to undermine other perspectives. A key voice among these perspectives is that of family carers who have intimate knowledge of the person with dementia. At times the #BanBPSD campaign fails to understand and accommodate the needs and rights of those closest to the person.

Although the way a person with dementia behaves may be quite normal for that person in the light of their experience, it can seem far from normal to their family. When challenging the paradigm for living and working alongside the person with dementia, it is important to understand, include, and work with families, rather than alienate them. Given the substantial evidence suggesting that interventions aimed at family carers can be highly effective,^{5,20} it is vitally important that these voices are heard and validated.

Another concern with the #BanBPSD campaign is that it does little to acknowledge the degenerative nature of dementia, the progression of cognitive decline and the breadth of experience among people living with dementia. The campaigners rarely acknowledge that a small

proportion of people with dementia behave in a way that places both themselves and others at serious risk.² Even within an ideal environmental and social setting, this small number of people will require specialist support and attention due to behavioural changes, and such support may appropriately involve the use of psychotropic medication. This is the reality that confronts medical specialists and service providers supporting people with significant behavioural changes on a routine basis. It is also a reality that confronts their families. That is not to say that these people are "problematic" or that they will continue to need intensive support indefinitely. Nor does it mean that there is no benefit to be gained in seeking to understand the person's unique needs and circumstances. In fact, this is what these people require most.

Deconstruction of the term behavioural and psychological symptoms of dementia reveals another issue. While many of the behaviours such as "agitation" or "wandering" may reflect environmental, interpersonal, or other psychosocial causes or pain, delusions, or hallucinations usually arise from changes to brain pathophysiology resulting from the dementia or a superimposed delirium although they may be exacerbated by psychological and environmental factors. Terms such as "responsive behaviours" or "unmet needs" fail to adequately explain their origin.

Any attempt to de-pathologise dementia must not ignore the realities of the lived experiences of people with dementia—and those around them—who experience severe changes in behaviour. That is, behavioural and psychological changes in dementia can cause severe distress to people living with dementia and to those around them. It is essential that in attempting to de-pathologise dementia, that such changes are not discounted as normal nor desirable to normalise. While removing labelling and stigma is necessary, it is equally important that the severity of the most extreme behavioural changes in people living with dementia is neither obscured nor ignored.

It must also be acknowledged that cognitive decline due to dementia is also a contributing factor to a number of behaviours. For example, memory impairment was assessed to be a contributing factor in 27% of DSA cases closed between January and July 2018, while communication difficulties contributed to 18% and frontal lobe/executive impairment contributed to 13%. Even when the factors contributing to behaviour are primarily environmental or social, the way they are expressed is influenced by the changes in their brain. This is supported by studies showing that certain behavioural responses are more strongly associated with specific types of dementia. For instance, depression is more common in vascular dementia, while hallucinations are seen more often in Lewy body dementia than Alzheimer's disease.⁵ While it is important to acknowledge the broader factors that contribute to behaviours, it is equally necessary to acknowledge the way a person's changing brain affects their behaviour.

6 | A WAY FORWARD

The campaign against the so-called "BPSD paradigm" has shone a valuable light on a number of significant issues with care provided to those living with dementia. These include the negative impacts of

systematic labelling, the need to acknowledge the broad range of factors that contribute to behaviours, and the consistent inappropriate use of medication, particularly for people living in residential aged care. A consistent theme among these concerns is the damage caused by an inadequate effort to understand the person with dementia; to understand why they behave the way they do; to understand the personal and cultural history; and to understand the environmental, social, and biological adjustments that can be made to ease distress and promote quality of life.

In order to improve the way that caring professionals and society as a whole think and talk about dementia, we must place this type of “understanding” and focus on working together at the forefront of our minds. Thus, irrespective of the term that is used to describe a person's behaviour, we recommend including the verb “to understand” when talking about a person's behaviour (e.g., “understanding changed behaviours as a result of dementia”). Such use highlights the need to address and respond to each person on an individual basis, and to understand them holistically. In so doing, the onus is redirected from the person with dementia to justify their behaviour and instead, calls on family and professional carers to explore and understand the causes of the person's behaviour and to work with them to address these.

With a focus on understanding the person and their behaviour, it may be reasonable to continue using the phrase behavioural and psychological symptoms of dementia in specialist clinical and research settings. While there have been some objections to using the word “symptoms,” when used with care and in an effort to understand this person, the risks associated with this word are lessened. It is worth emphasising that a symptom, by definition, is not a diagnosis, but a response that is produced when distress is experienced. It is the cause of that distress, rather than the treatment of the resulting symptom, which must be addressed. In non-specialist settings such as primary care and aged care environments, it remains more appropriate to use a more accessible term. It is crucial that the term selected does not stigmatise and must also be accurate and meaningful.

Some have advocated for the expression “responsive behaviour” as an acceptable alternative. However, even those who broadly support the term acknowledge that it requires significant explanation to be understood properly.⁷ This is problematic in that as the phrase is so vague that it becomes devoid of real meaning. Further, as shown by data from Dementia Support Australia, not all behaviours are responsive, even after optimal psychosocial and psychopharmacological interventions.

For these reasons, we recommend using the expression “behaviours and psychological symptoms of dementia.” This term is neutral and has broad acceptance among people with dementia and their carers.⁷ It explains that the person living with dementia is behaving differently to how they did previously and also acknowledges the changes and challenges experienced by family carers and care staff in relating to the person with dementia without labelling or being pejorative. Importantly, it also acknowledges that what is considered “normal” for the person with dementia has changed and continues to evolve.

Finally, and perhaps most importantly, umbrella terms like “BPSD” and changed behaviours should never be used to describe the specific

behaviour or symptom presented by an individual. Instead, each behaviour should be named neutrally while the impact of that behaviour should be described in a clear and objective manner.

One point of caution, however, is to remember that regardless of the term adopted in an attempt to decrease stigma and increase understanding that term will, through common usage, eventually become pejorative and stigmatising in its own right. Such a caution reveals the value in continuing a robust discourse in relation to how we understand and discuss behaviours associated with dementia.

Future research examining the views of people with early dementia (as well as their care partners and care providers) may prove valuable in clarifying their preferences with regards to terminology and advance planning should they develop BPSD.

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CONFLICT OF INTEREST

The authors have no conflicts of interest to declare.

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