Keywords Dementia/Distressed behaviour/Communication

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In this article...

- Why people are more likely to communicate their needs non-verbally as dementia progresses
- How behavioural and psychological symptoms of dementia are often a communication of need
- Why it is important to rule out any physical causes for a person's behaviour

Dementia 6: understanding distressed behaviours in people with dementia

Key points

Distressed behaviour can be how a person with dementia communicates an unmet need

Changes in behaviour can be an indication of delirium – this is important as people living with dementia are at high risk of developing delirium

Person-centred, non-pharmacological interventions are effective ways of managing distressed behaviour

Antipsychotic medication should be a last resort that is only considered if a person is experiencing severe distress or at risk of harming themselves or others

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Abstract The term 'behavioural and psychological symptoms of dementia' refers to a range of neuropsychiatric disturbances, such as agitation, aggression, depression, apathy, psychosis, wandering, repetitive questioning and sleep problems. More often than not, these behaviours are a sign of distress and an attempt by the person living with dementia to communicate an unmet need. This article, the sixth in a series on dementia, suggests some of the possible causes of distressed behaviour. Using a fictitious scenario, it demonstrates how early and accurate identification of the possible causes of distressed behaviour can dramatically improve outcomes for people living with dementia.

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In 2016, there were 11.8 million people aged ≥65 years in the UK, representing 18% of the total population. It is estimated that, by 2066, this number will increase by a further 8.6 million, taking the total number in this group to 20.4 million people, equating to 26% of the total population (Office for National Statistics (ONS), 2018). The risk of developing dementia increases significantly with age (Livingston et al, 2020) so, as the population ages, the number of people living with dementia is also set to rise. That said, it is important to acknowledge that dementia is neither a normal nor an inevitable part of ageing (Qiu and Fratiglioni, 2018).

Dementia is an umbrella term to describe a group of symptoms characterised by:

- Memory impairment;
- Behavioural changes;
- Loss of cognitive and social functioning caused by neurodegenerative disorders (Qiu and Fratiglioni, 2018).

There are >200 subtypes of dementia, with the most common types being:

- Alzheimer's disease;
- Vascular dementia;
- Lewy body dementia;
- Mixed dementia (usually a combination of Alzheimer's disease and vascular dementia);
- Frontotemporal dementia (Sandilyan and Dening, 2019).

Of the 944,000 older people who are estimated to be living with dementia in the UK, it is proposed that 593,200 are living with advanced symptoms (Wittenberg et al, 2019). As dementia progresses to the advanced or severe stages of disease, those affected experience significant cognitive and physical impairment (Moyle and O'Dwyer, 2012), and are likely to:

- Be urinary and faecally incontinent;
- Be unable to verbally communicate;
- Need support with all of their activities of daily living (Kupeli et al, 2018).

Unmet needs

As the ability to verbally communicate becomes more difficult, people living with advanced dementia may try and communicate their needs by means of non-verbal communication. However, this may not be acknowledged by carers or may be misinterpreted as the person affected being "challenging" (Ellis and Astell, 2017) or "resistive to care" (Featherstone et al, 2019).

The manifestation of distressed behaviours may be the person's only way of indicating an unmet need (Cohen-Mansfield et al, 2015), and a signal that they are experiencing discomfort in the absence of being able to convey this verbally (James and Jackman, 2017). The Unmet Needs Model (Cohen-Mansfield et al, 2015) suggests that identifying the unmet need and resolving it should be the primary focus of those caring for people who are living with dementia; this will be considered later in this article.

Behavioural and psychological symptoms of dementia (BPSD)

The term 'behavioural and psychological symptoms of dementia' (BPSD) refers to a range of neuropsychiatric disturbances such as agitation, aggression, depression, apathy, psychosis, wandering, repetitive questioning and sleep problems (Kales et al, 2015). It has been suggested that nearly every person living with dementia will experience at least one of these symptoms over the life course of their condition (Mukherjee et al, 2018; Feast et al, 2016; Kales et al, 2015).

BPSD negatively affect outcomes for the person living with dementia, their carers, and the wider health and social care system by causing:

- Increased distress;
- Increased use of medication;
- Prolonged hospital admissions (Feast et al, 2016).

These, in turn, have a negative impact on health outcomes and costs (Feast et al, 2016). BPSD are also often associated with an increased likelihood of transition to residential care (van der Linde et al, 2016).

There is no single cause of BPSD. Instead, a biopsychosocial model has been proposed that attributes neuropsychiatric symptoms not only to the pathology of the condition, but also to interactions between an individual's physical, psychological and socioenvironmental factors (Steele et al, 2022; Cullum and Taye, 2020). Consequently, there is a need for nurses and other health and social care staff to:

- Have an increased awareness of contributing factors;
- Be able to consider the often complex and multifactorial reasons why someone living with dementia might demonstrate distressed behaviours.

Box 1 shows some possible causes.

"The manifestation of distressed behaviours may be the person's only way of indicating an unmet need"

Delirium

It is also vital for health and social care staff, including nurses, to have an increased awareness of the relationship between dementia and delirium. Dementia is the strongest risk factor for developing hypoactive and hyperactive delirium (Jackson et al, 2017; Ahmed et al, 2014). In fact, delirium is 10 times more common in people living with dementia than in people without dementia (British Geriatrics Society (BGS), 2020). If a person with dementia experiences a sudden change in behaviour, it is important that they have a physical examination and medication review and, if necessary, a blood test and urinalysis to identify or rule out delirium as a cause for any behavioural changes (Cullum and Taye, 2020).

An improved awareness of delirium, and some of the possible causative factors, can promote opportunities to reduce the risk of a person living with dementia developing delirium and any subsequent distressed behaviours associated with the condition. The BGS's (2020) PINCH ME mnemonic (Box 2) is a useful aide memoire when considering possible causes of delirium.

Box 1. Some possible causes of distressed behaviour

Physical causes

- Acute medical problem – for example, delirium
- Sleep deprivation
- Pain
- Infection
- Dehydration
- Constipation/urinary retention
- Medication
- Sensory impairment
- Continence issues

Psychological causes

- Fear
- Boredom
- Depression
- Psychosis/hallucinations
- Anxiety
- Social isolation
- Loneliness
- History of trauma
- Grief/loss
- Lifelong habits and personality

Environmental and psychosocial causes

- Relationships
- Transitions of care
- Disorientation
- Neglect/abuse
- Unfamiliar people
- Too noisy/quiet
- Too much/not enough stimulus
- Too hot/cold

Sources: Adapted from British Geriatrics Society (2020), Cullum and Taye (2020) and Cohen-Mansfield et al (2015)

Biopsychosocial approach

The Unmet Needs Model posits that distressed behaviour results from unmet needs as a consequence of the person being unable to communicate those needs and meet them themselves. To fully appreciate the meaning behind a person's behaviour, it is paramount to try to understand the behaviour from the perspective of the person living with dementia and not immediately interpret the behaviour as a feature of advancing dementia (Cullum and Taye, 2020).

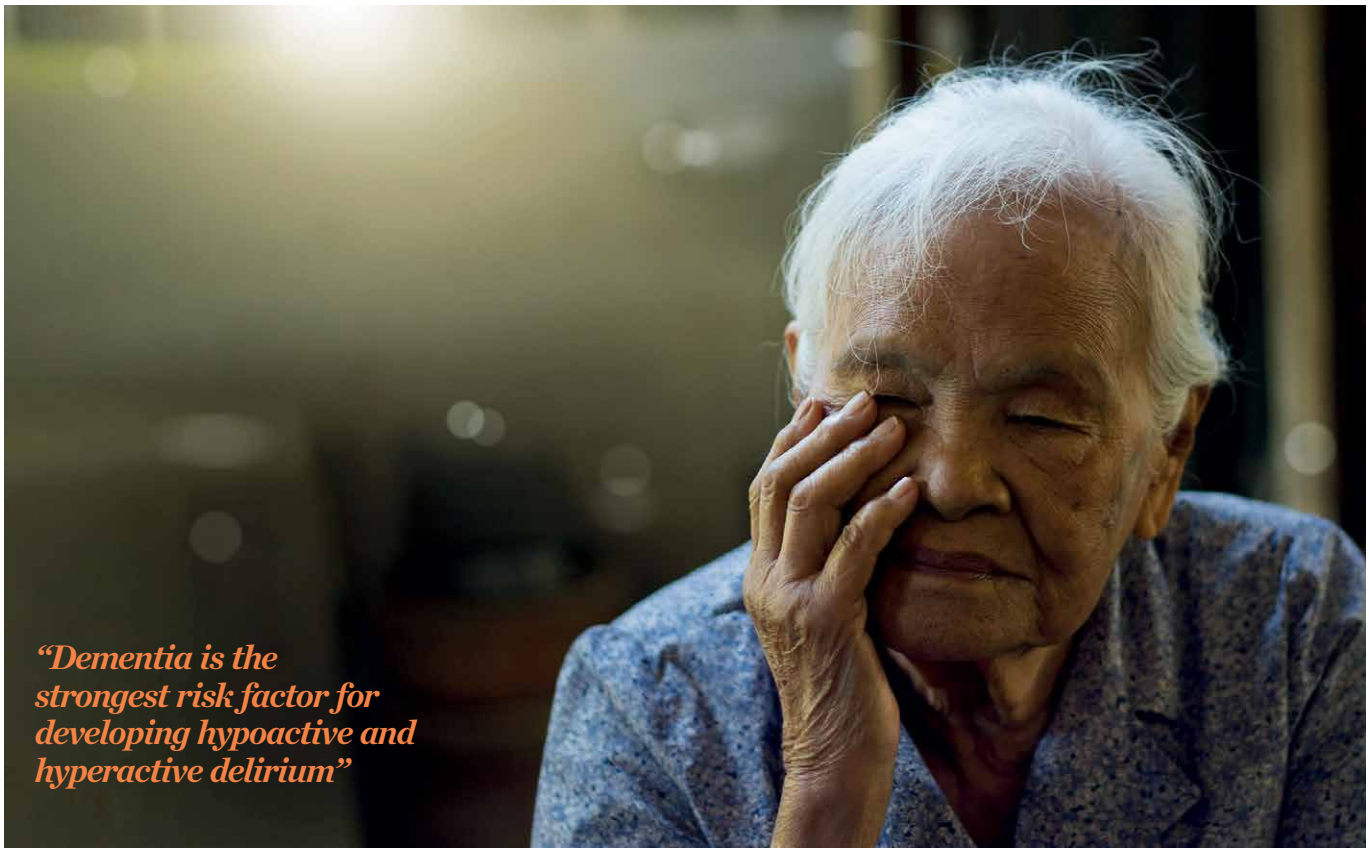
However, due to the plethora of needs that may remain unmet, it can be hard to decipher what the person might be trying to communicate, so it is important to get to know, and see, the person beyond the dementia diagnosis. Getting to know the person's family and medical history, their background, what is normal for them, their pre-morbid personality, any sensory impairment issues and social situation may enable improved understanding of what they might be trying to communicate and what might be of importance to them (Cohen-Mansfield et al, 2015). This is not only key in managing distressed behaviour, but also in providing person-centred care in dementia overall.

Box 2. PINCH ME mnemonic

Physical causes

- **P** – pain
- **I** – infection
- **N** – nutrition
- **C** – constipation
- **H** – hydration
- **M** – medication
- **E** – environment

Source: British Geriatrics Society (2020)



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Despite the endeavours of staff and others who know and care for the person, patterns of behaviour may still not be obvious, so it can be helpful to observe and record behaviour. Using the ABC approach (Box 3) to generate an ABC chart is a common method adopted by generalists. The purpose of the ABC approach is to observe and record the antecedents, behaviour and consequences of distressed behaviour to see whether any pattern or triggers can be identified (Smith, 2006). This can inform care planning and interventions to reduce incidence of the behaviour of concern, and help to alleviate the distress experienced by the person living with dementia.

If a potential cause or trigger is identified, in keeping with the biopsychosocial model of BPSD, National Institute for Health and Care Excellence (NICE) (2018) guidance advises that non-pharmacological approaches should be prioritised when trying to understand and manage distressed behaviour. Such approaches are not universal, and should be person centred and informed by a thorough assessment. They can include interventions such as:

- Distraction and behavioural management techniques;
- Music therapy;
- Massage and touch therapy;
- Cognitive stimulation;
- Reminiscence therapy;
- Validation therapy (Abraha et al, 2017).

Box 3. **ABC approach**

Antecedent
A is for antecedent – the events or factors that *precede* the behavioural symptom and contribute to its occurrence. Antecedents are also called 'triggers' because they 'set off' behaviours.

Behaviour
B is for the specific behavioural symptom that is of concern and is ascertained by looking at *one* behavioural symptom at a time in the problem-solving and care-planning process.

Consequences
C is for consequences – the things that happen *after* the behaviour occurs. That includes *all* the reactions and responses to the person, including those by others, such as fellow patients or residents, family, staff, etc.

Source: Adapted from Smith (2006)

Antipsychotic medications

There are some occasions when it may be appropriate to consider the use of neuroleptic medications – also known as antipsychotic medications – which can be used to treat some of the more distressing BPSD, in incidences when the person is:

- At risk of harming themselves or others;
- Experiencing agitation, hallucinations or delusions that cause them severe distress (NICE, 2018).

Antipsychotics have only very limited, short-term benefits in treating perceived psychiatric symptoms in people living with dementia and non-pharmacological interventions should be the first line of treatment. Antipsychotic medication significantly increases the risk of serious side-effects, including stroke, accelerated decline and death, and are only

Table 1. **Extract from Bob's ABC chart**

Date and time	Antecedent	Behaviour	Consequences	Any other comments	Initials
02/02/22 08:30	Bob sat at breakfast table pushing food around plate; staff encouraged him to eat	Bob pushed plate across table aggressively. It landed on the floor and broke	Bob paced up and down the hall, declined support and looked increasing agitated	Ate or drank very little	AA
02/02/22 10:30	Staff concerned as they hadn't seen Bob for a while so looked for him. Found him sat on toilet	Bob verbally aggressive, swore at staff to leave and threatened to hit member of staff	Staff left toilet and monitored at a safe distance. Bob left toilet five minutes later, looking agitated	Threats to harm very out of character	BB
02/02/22 12:30	Went to find Bob for lunch	Found Bob laying curled up on bed. He refused lunch and was verbally aggressive	Staff tried to encourage Bob to come and have something to eat. He agreed. Looked really uncomfortable mobilising	Bob offered pro re nata pain relief. Pain chart started	CC
03/02/2020 03.30	Bob not in bed when staff did 3.30am care round	Found Bob sitting on toilet in foyer area. Looked very uncomfortable, refused to leave bathroom. Verbally aggressive to staff	Left Bob and checked on him 15 minutes later. Still on toilet, refusing to leave. Bob went back to bed 40 minutes later		DD

ABC = antecedent, behaviour, consequences.

recommended for short-term treatment of psychiatric symptoms associated with serious distress or risk (NICE, 2018). As such, before starting antipsychotic medication, the possible risks versus the benefits of the medication should be discussed with the person, along with their family members or carers (as appropriate) (NICE, 2018; Ballard and Howard, 2006).

If antipsychotic medications are prescribed, they should be reviewed every six weeks to see if they are still needed (NICE, 2018); this may not be by the initiating clinician. If the medication was started in secondary services and the person living with dementia is subsequently discharged with no planned follow-up, the responsibility for review will fall to the clinician prescribing the medication; in many cases – subject to local arrangements and shared care protocols – this is likely to be the GP.

Treatment should be stopped if there is no clear benefit to the person and after discussion with the person and their family members or carers. It should be recognised that for people with Lewy body dementia or Parkinson's disease dementia, the use of antipsychotic medication can be harmful, worsening motor features and causing severe antipsychotic sensitivity reactions (NICE, 2018).

"If a person with dementia experiences a sudden change in behaviour it is important that they have a physical examination and medication review"

'Sliding doors' scenarios

Using fictitious scenarios, we can show how an accurate, timely assessment, alongside appropriate management of the underlying cause of distressed behaviour, can positively affect the outcomes for a person living with dementia.

Scenario 1

Bob is an 85-year-old man living in a care home. He has a diagnosis of vascular dementia. Over recent weeks he has become increasingly agitated, pacing the building, refusing personal care, and being verbally and physically aggressive to care staff when attempts are made to do this. Staff have tried several approaches to encourage him to accept personal care, with minimal success. Bob's symptoms are attributed to a progression of vascular dementia, so the GP prescribes an antipsychotic medication to try to reduce the incidence of the aggressive behaviours and allow personal care to be delivered.

After the antipsychotic medication is started, Bob becomes calmer and staff are able to deliver personal care. However, he also becomes less mobile, apathetic, loses a significant amount of weight and, subsequently, collapses when trying to get up from the toilet. He is admitted to hospital and it is noted that he has constipation. Bob develops a hypoactive delirium; his health rapidly declines, and he dies in hospital two weeks later after developing a chest infection.

Scenario 2

Bob is an 85-year-old man who lives in a care home. He has a diagnosis of vascular dementia and, over the past couple of weeks, has become increasingly agitated, pacing the building and, at times, being verbally aggressive towards care staff. Staff are concerned as this is out of character for him.

Bob struggles with verbal communication so staff attempt to interpret this change in behaviour, but cannot note anything obvious. They start observations and document them on an ABC chart (Table 1), and also consider whether Bob is showing signs of delirium. Staff notice a pattern to Bob's behaviour: he is most distressed after eating, is eating less but going to the bathroom more than usual, and has been

seen rubbing his stomach. The staff suspect Bob is constipated, which is confirmed by the GP. Bob is usually independent with toileting, so staff had not been aware until the emergence of his distressed behaviours.

The doctor prescribes treatment to resolve the constipation and manage Bob's immediate discomfort: an ongoing dose of a mild laxative is prescribed, and a diet of high fibre and increased fluid intake is recommended. The staff offer Bob lots of reassurance and, when he is distressed, they try to distract him by playing his favourite music and using reminiscence techniques to stimulate positive conversations with him. Bob's distress lessens over the next few days as the constipation resolves, he regains his appetite and engages in his regular activities in the care home once again.

Case discussion

It is clear that in both scenarios there was acknowledgement that Bob was distressed. However, in the first scenario, symptoms were solely attributed to his dementia – staff did not look beyond this to consider how it might affect Bob and what else might be affecting his health and wellbeing. This is not uncommon. There may often be a propensity to consider singular disease processes and attribute any changes to a primary condition, instead of considering an interaction with another condition or psychosocial factors; this is often referred to as diagnostic overshadowing (Aldridge and Harrison Dening, 2021; Voss et al, 2017).

In the second scenario, the staff looked beyond the dementia diagnosis and, rather than normalising the behaviour as a symptom of progressing disease, considered their knowledge of Bob and what was normal for him. This enabled them to identify that something was wrong much more quickly.

They examined the physical, psychological and socioenvironmental factors – as recommended by Steele et al (2022) and Cullum and Taye (2020) – and recognised there had been quite a sudden change in Bob's presentation. This led them to consider what might have changed for him and what need he was trying to express. Using the ABC chart enabled staff to see a possible link to the behaviours. If these incidents had been seen in isolation by different members of staff, the underlying cause may have been more difficult to identify and taken longer to rectify. While this may only appear to be a subtle shift, the difference in the potential outcomes is clear to see.

Useful resource

Yorkshire and the Humber Clinical Networks, London Clinical Networks (2022) *Appropriate Prescribing of Antipsychotic Medication in Dementia.* NHS.

Conclusion

Reframing the BPSD and considering them as means of communicating an unmet need, or a sign of distress, can reduce incidence of diagnostic overshadowing and promote a more person-centred approach to managing them. Most people living with dementia will experience BPSD at some point during the life course of the condition. While these behaviours can prove distressing for the person living with dementia and challenging for those who care for them, it is critical that reasons – such as unmet needs – for any changes in behaviour are swiftly identified.

Undertaking a thorough and holistic assessment – including ruling out or identifying any reversible causes, such as delirium – can significantly improve health and care outcomes for people living with dementia. **NT**

● The next, and final, article in this series will consider the palliative and end-of-life care needs of people with dementia.

References

Abraha I et al (2017) Systematic review of systematic reviews of non-pharmacological interventions to treat behavioural disturbances in older patients with dementia. The SENATOR-OnTop series. *BMJ Open;* 7: e012759.
Ahmed S et al (2014) Risk factors for incident delirium among older people in acute hospital medical units: a systematic review and meta-analysis. *Age and Ageing;* 43: 3, 326-333.
Aldridge Z, Harrison Dening K (2021) Managing comorbid conditions and dementia. *Journal of Community Nursing;* 35: 2, 54-59.
Ballard C, Howard R (2006) Neuroleptic drugs in dementia: benefits and harm. *Nature Reviews: Neuroscience;* 7: 6, 492-500.
British Geriatrics Society (2020) End of life care in frailty: delirium. *bgs.org.uk,* 12 May (accessed 20 June 2023).
Cohen-Mansfield J et al (2015) Which unmet needs contribute to behavior problems in persons with advanced dementia? *Psychiatry Research;* 228: 1, 59-64.
Cullum S, Taye T (2020) Management of dementia. In: Dening T et al (eds) *Oxford Textbook of Old Age Psychiatry.* Oxford University Press.
Ellis M, Astell A (2017) Communicating with people living with dementia who are nonverbal: the creation of Adaptive Interaction. *PLoS One;* 12: 8, e0180395.
Feast A et al (2016) Behavioural and psychological symptoms in dementia and the challenges for family carers: systematic review. *British Journal of Psychiatry;* 208: 5, 429-434.
Featherstone K et al (2019) Refusal and resistance to care by people living with dementia being cared for within acute hospital wards: an ethnographic study. *Health Services and Delivery Research;* 7: 11.
Jackson TA et al (2017) Challenges and opportunities in understanding dementia and delirium in the acute hospital. *PLoS Medicine;* 14: 3, e1002247.
James IA, Jackman L (2017) *Understanding Behaviour in Dementia that Challenges: A Guide to Assessment and Treatment.* Jessica Kingsley Publishers.
Kales HC et al (2015) Assessment and management of behavioral and psychological symptoms of dementia. *BMJ;* 350: h369.
Kupeli N et al (2018) What are the barriers to care integration for those at the advanced stages of dementia living in care homes in the UK? Health care professional perspectives. *Dementia;* 17: 2, 164-179.
Livingston G et al (2020) Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. *The Lancet;* 396: 10248, 413-446.
Moyle W, O'Dwyer S (2012) Quality of life in people living with dementia in nursing homes. *Current Opinion in Psychiatry;* 25: 6, 480-484.
Mukherjee A et al (2018) Behavioural and psychological symptoms of dementia: correlates and impact on caregiver distress. *Dementia and Geriatric Cognitive Disorders Extra;* 7: 3, 354-365.
National Institute for Health and Care Excellence (2018) *Dementia: Assessment, Management, and Support for People Living with Dementia and their Carers.* NICE.
Office for National Statistics (2018) Living longer: how our population is changing and why it matters. *ons.gov.uk,* 13 August (accessed 20June 2023).
Qiu C, Fratiglioni L (2018) Aging without dementia is achievable: current evidence from epidemiological research. *Journal of Alzheimer's Disease;* 62: 3, 933-942.
Sandilyan MB, Dening T (2019) What is dementia? In: Harrison Dening K (ed) *Evidence-based Practice in Dementia for Nurses and Nursing Students.* Jessica Kingsley Publishers.
Smith M (2006) *Back to the A-B-C's: Understanding & Responding to Behavioral Symptoms in Dementia.* John A Hartford Center of Geriatric Nursing Excellence, College of Nursing, University of Iowa.
Steele C et al (2022) Healthcare professionals' experiences of using a biopsychosocial approach to understand behavioural and psychological symptoms of dementia: a qualitative interview study. *International Journal of Older People Nursing;* 17: 2, e12427.
van der Linde RM et al (2016) Longitudinal course of behavioural and psychological symptoms of dementia: systematic review. *British Journal of Psychiatry;* 209: 5, 366-377.
Voss S et al (2017) Home or hospital for people with dementia and one or more other multimorbidities: what is the potential to reduce avoidable emergency admissions? The HOMEWARD Project Protocol. *BMJ Open;* 7: e016651.
Wittenberg R et al (2019) *Projections of Older People Living with Dementia and Costs of Dementia Care in the United Kingdom 2019-2040.* Care Policy and Evaluation Centre, London School of Economics and Political Science.