Supporting distress behaviours in people with dementia in the community

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Dementia is rising in prevalence across the globe. In the UK it is estimated that there are around a million people with dementia, and that number is set to increase to 1.6 million by 2040 (Wittenberg et al, 2019) . Dementia is an umbrella term defined as a syndrome comprising a group of symptoms which include memory loss, problems with social functioning and changes to behaviour and personality (Sandilyan and Dening, 2019) . Dementia has several forms, all of which are progressive. The more common ones include Alzheimer's disease, vascular dementia, mixed dementia, dementia with Lewy bodies, and frontotemporal dementia (Sandilyan and Dening 2019). Dementia can also occur in those under 65 years of age (termed young-onset dementia) (Knight and Pepper, 2024), although it is typically thought of as a disease of older people.

Up to 80% of people with dementia will experience distress behaviours during the course of their dementia (Ismail et al, 2014). This distress can take many forms, including agitation, aggression, apathy or depression. With the rising prevalence of the syndrome and the presence of multiple conditions in people with dementia (Bunn et al, 2014), community nurses are becoming more likely to have people with dementia in their care. When distress is present, it poses significant challenges to a nurse managing care safely and effectively.

Abstract

The outward signs of distress can take many forms, including agitation, aggression, apathy, anxiety and depression and is experienced by most people with dementia at some point during the disease trajectory. Supporting people with dementia who experience distress can pose a significant challenge to community nurses who may lack the time, knowledge and skills to manage distress effectively. This article discusses distress in dementia, including the interplay between stress and distress, examines the various forms of distress and its causes. The article also presents two fictionalised case studies, drawn from the authors' clinical experience, demonstrating evidence-based approaches community nurses can use in their practice to support people with dementia who experience distress.

Keywords: community • dementia • distress • nursing

Stress and distress in people with dementia

Stress is a naturally occurring adaptation reaction in human beings in response to internal or external threats to homeostasis (Lecic-Tosevski et al, 2011). People with dementia, as with any person, are likely to experience stress at times. While people are often able to function normally with a relatively low level of stress (Lecic-Tosevski et al, 2011), as a person's dementia progresses, their stress threshold may change and their ability to manage their stress levels may become increasingly compromised (Kinnaird, 2018). Experiencing high levels of stress along with psychological and physical stressors, difficulties with communication and ability to articulate various needs could result in distress.

What is distress in dementia?

Distress reactions in dementia is a relatively new term. The terms 'challenging behaviour', or 'behaviour that challenges' were more common, but are no longer considered appropriate in dementia care as they can often imply blame or intent of the person with dementia and fail to capture the causative or underlying reason for the distress or change in behaviour. When changes in behaviour are framed as distress, there is an onus on health and care professionals to seek out the reason for that distress and develop strategies to support the person, rather than lay blame on them for their behaviour. In this approach, distress can then be defined as a change in behaviour related to, or as an attempt to communicate, an unmet need (Cohen-Mansfield et al, 2015). Distress can take many different forms, but some of the more common examples might include agitation (pacing, fidgeting or trying to leave the house), vocalisations (shouting, crying, repeating questions or phrases, or swearing) or physical aggression (hitting or grabbing during personal care interventions). These are just some examples and, as with all human behaviour, it can vary widely across the spectrum.

As a person's ability to verbally communicate becomes more compromised, a person with dementia may try to communicate their needs by means of non-verbal communication, including some behaviours such as those noted. These behaviours are at risk of being misinterpreted

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by those around them and could be perceived as an exacerbation of their dementia symptoms, leading to the person being labelled as challenging (Ellis and Astell, 2017) or resistive to care (Featherstone et al, 2019).

What causes distress in a person with dementia?

Distress can have many different causes, and often more than one causative factor may need to be considered. Table 1 lists some of the more common causes of distress that can be helpful to consider when working with someone with dementia who is distressed. However, this list should not be considered exhaustive, and it is important to consider other factors based on the history and unique circumstances of each person.

The following two fictionalised case studies which are drawn from the authors' clinical experience, will demonstrate the varied ways that distress might present in a person with dementia in community nursing practice, and discuss the interventions that might be useful in supporting them.

Case studies can be both educational and informative and offer a simulation of practice examples where clinicians can identify themselves in or recall similar scenarios that they witnessed or experienced (Seshan et al, 2021). Similarly, reviewing case studies can offer ideas on how to improve clinical practice and patient outcomes, as well as generating a deeper and multifaceted understanding of complexities encountered in a real-life clinical context.

Table 1. Factors that may impact on distress

Physical factors	Psychological factors	Environmental factors	Social factors
Delirium	Fear	Disorientation	Relationships
Insomnia	Boredom	Noise levels	Care transitions
Pain	Depression	Light levels	Isolation
Infection	Anxiety	Stimulation	Being with unfamiliar people
Dehydration	Loneliness	Temperature	Carer stress
Constipation	History of trauma	Being in new or unfamiliar places	
Medication side effects	Grief/loss		

Adapted from Aldridge and Dening (2023)

Case study 1

A nurse visited Kayleigh, who lived with Alzheimer's disease and had difficulty with communication and the ability to care for herself. She had carers to support her with her needs as she did not live with family. The community nurse had been asked to visit Kayleigh to attend to a wound on her shin, sustained during a fall.

Kayleigh had a diagnosis of Alzheimer's disease, which moderately impacted her ability to communicate and care for herself. She lived alone and had carers that came in three times a day to support her care needs. She was able to communicate verbally but the content of what she said could be confused and sometimes hard to follow. Despite this, she was generally in good spirits when the nurse visited her and had been amenable to all the care offered. When the nurse visited, Kayleigh did not answer the door as usual and the nurse had to use the key safe. Kayleigh was sitting in her chair looking very anxious and worried, and when greeted, she did not answer, which was unusual for her. When the nurse tried to lift her trouser leg to assess her wound, Kayleigh shouted at her to stop and started kicking her leg out.

Something has clearly changed for Kayleigh since the nurse's last visit to see her, as evidenced by this new distressed behaviour. When distress is seen as an attempt to communicate an unmet need, healthcare professionals need to work out what that need is. When there is a sudden change in a person with dementia, as with Kayleigh, the first consideration should always be whether there may be a delirium present (Harrison Dening and Moore, 2023). Since dementia presents the biggest risk factor for developing a hyperactive delirium (characterised by agitation and distress) (Ahmed et al, 2014; Jackson et al, 2017) it is important for community nurses to be aware of the association between dementia and delirium. In Kayleigh's case, this could be due to an infection in the wound or pain. It is important to carry out or arrange for a physical examination if delirium is suspected which may include a review of medication, blood test or urinalysis (Aldridge and Dening, 2023). Delirium can often be the cause of a sudden change, but if this is ruled out, other factors may need to be considered.

Knowing that Kayleigh has carers who visit regularly, her care record may be a good place to start. In this case, the community nurse identified that she might have missed her morning visit with her carer. Kayleigh was likely to be hungry because no one had been present to help her with her breakfast, and the house was cold because the carer usually turned the heating on in the morning. With this knowledge, the nurse responded to Kayleigh's unmet needs (for food and a warm environment so that she felt happy to have her leg exposed) before she attempted to change the dressing of Kayleigh's wound. *Table 2* has further advice for responding to distress during a nursing intervention.

Case study 2

A nurse visited Rohan, who had type 2 diabetes to administer his insulin injections. He had also been diagnosed with vascular dementia recently and was cared for by his wife Meera.

When the nurse arrived, Meera unlocked the front door and appeared very worried. Rohan appeared from behind her, demanded to be let out of the house and said that he was being kept prisoner. He did not appear to know who Meera was or that he was in his own home. Meera struggled to calm Rohan down and disclosed to the nurse that he had pushed her into the wall when she tried to stop him leaving the house earlier.

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Table 2. Tips for managing distress during a nursing procedure
Take your time – tell the person what you are going to do, break the procedure into stages if possible and check regularly that they are happy for you to continue
Advise the person with dementia that they can stop the procedure until they are happy to proceed again
Find out if the person has had the procedure before. How did they cope with it and was there anything that made it easier for them?
Maintain a calm environment and demeanour and keep distractions to a minimum
Be alert to any signs of discomfort or distress, bearing in mind these may be non-verbal
If the person starts to become distressed, pause the procedure until they feel able to continue again
If the procedure cannot be completed because of distress, make sure the person is safe and comfortable before leaving. Make contact with the family carer (if appropriate), and relevant professionals (eg the GP)
Make clear records of the way the distress presented, what helped (or didn't help), and how the distress was resolved (if it was)

In some cases, distress behaviours may pose a risk to the person with dementia themselves or to others, and this may require managing that risk alongside supporting the distress. In this case, there was an immediate need to use de-escalation techniques (James et al, 2023) to calm Rohan in the moment. The validation approach can be a good framework to use when addressing such situations. The approach was first described by Feil (1993) and has been further built on by others such as Hawkes et al (2015) that developed the 'VERA' framework (*Table 3*) which acts as an 'aide memoir' for nurses who may need to respond to distress in people with dementia. An initial evaluation of its usefulness for nursing students has shown favourable results (Naughton et al, 2018) and it is well grounded in the existing theory on validation approaches.

In case study 2, the validation part of the framework (V) involved seeking reasons for Rohan's behaviour that avoided negative assumptions, but that viewed his behaviour as an expression of distress or unmet need and valued him as a person. This involved consideration of any physical factors, such as delirium, but also environmental and psychosocial factors. For example, Rohan might have been affected by Meera's own stress or there may have been other factors that lead to him feeling disoriented and confused.

The emotion part of the framework (E) involved identifying the underlying emotions that affected Rohan's behaviours such as anger, confusion, fear or a combination of different emotions. Identifying these can be helpful in empathising with patients. For example, the nurse having said: 'Rohan, I can see you are feeling really angry about being kept in the house at the moment,' showed him that the nurse understood his feelings.

Reassurance (R) follows from empathising with the person's emotions and involves offering support. For example, asking: 'How can I help you with that?' reassures the person that the nurse is there to help.

Activity (A) refers to the act of distraction. It could involve offering to make Rohan a cup of tea or suggesting a walk around the garden with him. However, in situations where this is not appropriate or possible, activity within the framework can involve reflecting on the interaction and what did and did not work.

In some cases, the person's distress may be so severe that the nurse cannot de-escalate the situation and may mean that they need to obtain support from other professionals or teams, such as the GP, mental health services or, where there is an immediate risk of harm, from emergency services.

Table 3. The VERA framework	
V	Validation
E	Emotion
R	Reassurance
A	Activity

Key points

- People with dementia can present with a number of different behaviours that can pose challenges for community nurses. By framing these behaviours as 'distress behaviours' nurses can explore the reasons for the distress and develop strategies to support the person.
- Where distress develops suddenly, it is important to consider and rule out any potential physical causes for that distress. Alongside this, a thorough and holistic assessment of the person and their physical and social environment may give clues to the cause of their distress.
- The VERA framework presents a simple and easy to use mnemonic to help community nurses respond to distress in a person-centred approach.
- It is important to be aware of, and alert to any risks posed by distress behaviours and follow local risk assessment and safeguarding processes as appropriate.
- Community nurses should also be aware of when and where to make onward referrals to other teams and services when distress behaviour requires more intensive management.

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CPD reflective questions

- Considering what you have learnt about stress and distress, can you think of a time when you were under any particular stress? How did this stress impact your behaviour?
- Think about a time when you have supported a person with dementia who was experiencing distress – consider how you might have been able to apply the VERA framework to that situation.
- Using your preferred reflective framework write a reflective piece on what you have learned from this article. You could use this as evidence towards your revalidation.

In this case study, in which Meera disclosed that Rohan had physically harmed her, and in cases where distress of the person with dementia poses a risk to another person, it is important to consider a safeguarding referral, following the local safeguarding policy and procedures.

Conclusion

People with dementia can experience distress for many different reasons. Given the growing numbers of people with dementia, it is likely that community nurses will be caring for many people with dementia who may be experiencing distress. Thus, community nurses are in a unique position to be able to use brief interventions to respond to that distress, and to know when more specialist support might be needed. This article has given an overview of some evidence-based approaches that can be used in community nursing practice. **BJCN**

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Professional commentaries

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