

Dementia Gateway: Difficult situations

Key messages

- Difficult situations for the person with dementia or those caring for them are often triggered by behaviours in people with dementia such as agitation and aggression, refusing help or problems going to the toilet; attitudes and responses from others to people with dementia; and factors to do with the person with dementia's surroundings.
- There are very few good-quality studies on difficult situations in people with dementia, which means that findings about interventions are often inconclusive.
- Where communication is difficult, interventions may not always identify and assess the cause or causes of a behavioural or psychological difficulty, such as pain,^{1,2} and the focus is on dealing with the behaviour instead.^{4,5}
- Behavioural and emotional disturbances can have a more profound impact on the person with dementia and those around them than cognitive (thinking, reasoning, memory) problems,² so it is important for the person with dementia and people around them that they are addressed.
- Aggression can cause injury to the person with dementia and to other people. It can lead to higher care costs, a greater risk of being placed into institutional care and a greater risk of the use of physical restraints.¹
- Overprescribing in care homes has been identified as a major problem.⁶ Medication should not be seen as a first resort to managing difficult situations except where there is extreme risk of harm.^{6,7}

Introduction

This summary highlights key messages from research on the topic of difficult situations and dementia. It is not intended to be a comprehensive review of the literature on this topic. The material on which this summary is based was identified through focused searching of the literature published from 2008 to 2012. Some material pre-dating 2008 is referred to where necessary. No material contains the direct views of people with dementia.

What is the issue?

Introduction

Difficult situations may occur for the person with dementia or those caring for them – or both parties. A variety of things can trigger such events, including: behaviours in people with dementia such as agitation and aggression, refusing help or problems going to the toilet; attitudes and responses from others to people with dementia; and factors to do with the person with dementia's surroundings.

The research literature often refers to behavioural and psychological symptoms of dementia (BPSD), which are a group of symptoms common in people with Alzheimer's disease and related dementias, and especially common in care homes.^{2,3} However, this kind of language is unhelpful and misleading as the behaviours are rarely symptoms of dementia, but instead are generally reactions to some kind of stressful or threatening situation. It is better to avoid the term 'symptom' in this context and describe the

subject in terms of reactions, responses, signs of distress or other suitable alternatives.

Behavioural reactions may include restlessness, physical aggression, agitation, wandering, sexual disinhibition, repeated questioning, screaming and cursing, while psychological responses may include anxiety, depressive mood, withdrawal, hallucinations, delusions and psychosis.^{2,4,6,16} Understanding the causes of behavioural and psychological signs of distress has only recently become a focus of dementia research, but researchers agree that these responses are caused by a complex combination of biological, environmental and social factors.⁴

Compared with cognitive (thinking, reasoning, memory) symptoms, behavioural and psychological disturbances can have a more profound impact on people with dementia and on those around them.² This leads to difficult situations and encounters with others in various care settings and environments.

Responding to behavioural and psychological signs of distress – the unmet needs model

The 'unmet needs' model presents a helpful framework for understanding behavioural disturbances in people with dementia. This model proposes that agitation and aggression, for example, happen because of a person's unmet physical, psychological or social needs.^{1,8,9} A key part of any intervention is to recognise and respond appropriately to unmet needs,¹ but where communication is difficult, interventions may not always identify and assess the cause or causes of a disturbance.^{1,2} For instance, it may be that a person is suffering from pain or discomfort (an unmet need)

caused by an infection but has difficulty communicating this to staff, so this becomes overlooked and the focus is on dealing with the aggressive behaviour instead.^{4,5} Adopting a person-centred approach that takes account of the person and any recent changes in their behaviour is important to understanding why they behave the way they do.

The status of research

The research that this summary draws from includes reviews of clinical studies of interventions.^{1,3,6,10,11} But overall, there have not been many intervention studies and these have been limited in terms of how they were designed, the methods that were used and how the results were analysed and reported. This makes it harder to draw firm conclusions about different approaches designed to manage difficult situations in people with dementia.

There is a scarcity of controlled studies for psychological interventions. Tailored music therapy, bright light treatment and specific behaviour interventions have been found to improve some behavioural problems in dementia, but more evidence is needed in this area.¹² The research evidence on the use of medications is also modest⁶ and there is little on which to base recommendations.⁵ One clinical review concludes that antipsychotic drugs show minimal benefit for the treatment of behavioural and psychological problems in people with dementia,⁶ while some medication may cause agitation.^{8,10}

The quality of research about treatments for agitation based on research evidence is weak and proper

conclusions cannot be drawn.⁸ What evidence there is concludes that things such as isolation and lack of stimulation in the person's surroundings can increase verbal agitation, but there are not enough studies looking at whether interventions providing social interaction and stimulation of the senses can reduce verbal agitation.¹³

There is a distinct and noticeable absence of the views of people with dementia. The views of carers and health and social care staff are also absent, although vaguely referred to in the written research narratives.

Research on matters such as sexual expression and problems using the toilet in people with dementia is almost non-existent. The Gateway content on these issues has been guided by the principles of dignity, respect and person-centred care; and by knowledge from professional and lay carers supporting people with dementia.

The most common signs of distress in people with dementia

Of people with dementia, it is estimated that between 70 and 90 per cent have behavioural and psychological signs of distress,⁴ with agitation, psychosis and mood disorders being the more common.¹⁴ Agitation is the most common of these three¹⁰ and is more likely to happen in the latter stages of dementia.⁴

Agitation

There is no agreement about what agitation in people with dementia is but definitions include a

range of behaviours such as general restlessness, cursing, complaining, pacing, dressing inappropriately and screaming.⁸ It is not clear why agitation happens, but it is thought to be a result of a combination of factors, including structural and chemical changes in the brain, genetics, physical disease, psychological factors, environmental factors, a response to unmet needs and pain that is left untreated.³ In care homes, pain that is not diagnosed or treated may lead to an increase in agitation and distressing behaviour in residents.³ Agitation can also affect other people, for example in health settings such as hospitals it can be emotionally draining for nurses and cause problems for other patients.⁸

The challenge of measuring agitation

Problems with the definition of agitation in turn affect how to assess and measure agitation⁸ and this has led to many different measures being in operation, such as the Cohen-Mansfield Agitation Inventory (CMAI).¹⁴ It has been stressed that directly observing residents is costly and time consuming and that less direct measures such as reports from carers are quicker, although these may be biased.^{8,14}

Approaches to managing agitation

Interventions for agitation can be divided according to whether they target the causes or the behaviour.⁸ There are a variety of approaches, which include: medication/antipsychotic drugs; physical restraint; treatment that is focused on the person's emotions; therapies that focus on the person's senses, such as aromatherapy and hand massage; pet therapy; changes to the way care homes, hospitals and so on

are run; and changes to the person's surroundings.⁸ Interventions might also be classified according to whether they see the person on a one-to-one basis or whether they see people in groups.⁸

Potential for psychosocial approaches to manage agitation

Interventions that are psychosocial in nature (that is, they look at the person's psychological and social needs) may be beneficial,⁷ but sound evidence to support this is limited.³ For example, one study has shown that only sensory interventions (aromatherapy, thermal bath, calming music and hand massage) were moderately effective in reducing agitation. But the findings cannot be supported fully because of weaknesses in the way the study was designed.¹⁰

Another example of a psychosocial intervention is multi-sensory rooms.

These rooms are equipped with coloured, moving lights, tactile and other stimuli and people are exposed to these to reduce their agitation. The rooms seem to offer a viable option and the evidence about how effective they are appears to be relatively sound, but there is no agreement as to how this approach should be delivered.⁸

Effect of pain treatment on agitation

In a systematic review about the effect of pain treatment on agitation, only three relevant studies were found, and these say that pain management does not reduce agitation in care home residents.³ However, another study says that it does.¹⁵ Because there are so few studies on pain management in

people with dementia, there needs to be more 'randomised controlled trials' (research testing interventions between one population group and another) with a significant number of people in the trials.³

Verbal agitation – potential risk factors

Verbal agitation describes things like expressing oneself repeatedly, demands for continuous attention, frequent complaints, muttering, moaning, screaming or even threats, and can be disruptive or distressing to other people.¹³ Verbal agitation may be a result of physical or psychological discomfort, for instance a direct link has been found between verbal agitation and pain, and between verbal agitation and depression.¹⁶ There is also a risk for verbal agitation when people with dementia are isolated or alone, not engaged in activities and in an environment that offers no scope for stimulation.¹³

Screaming is often associated with agitated behaviour but the reasons behind this behaviour are still not clear. However, factors that have been associated with increased screaming in care home residents include being alone, restrained or in the bathroom.¹¹

Managing verbal agitation

Without proper management, verbal agitation can become a chronic problem that happens several times an hour and consumes a good deal of the day of a person with dementia.^{13,16} This behaviour has a considerable effect on a person with dementia, their family and care staff, and can influence the quality of care that is provided in care homes.¹³ It has been

recommended that, because medication has side-effects and it is not very effective, approaches that look at the person's psychological and social needs should be the favoured first option for managing such symptoms.^{2,7,13}

Aggression

Saying what behaviour is an act of aggression can be difficult because it depends on your own views and understandings.⁹ However, aggressive behaviour can be divided into physical aggression (such as hitting, shoving and kicking) and verbal aggression (such as threats of violence to other people).^{1,9} Around 40 per cent of people with dementia will have aggressive behaviour.¹

Aggression can cause injury to the person with dementia and to people around them; and it can lead to higher care costs, a greater risk of being placed into institutional care and a higher risk that physical restraints will be used.¹

Treating aggressive behaviour with antipsychotic drugs

In clinical settings such as hospitals, aggression is all too often treated with antipsychotic drugs, but these have very little effect.¹ Also, some medication can have side-effects^{6,9,17} like a worsening of cognitive (thinking, reasoning, memory) abilities, urinary tract infection and a way of walking that is unusual and uncontrollable.¹⁰ Medication has also been linked to an increased risk of death.^{1,6,17} This is one reason why there has been more of a focus on alternative non-drug approaches as potentially they have lower risks for the person.¹⁰

Using non-drug approaches for treating aggressive behaviour

Approaches that do not use medication are usually not specific to aggressive behaviour and more broadly target other behavioural symptoms too.¹ Despite the wide range of these approaches, some common themes have been identified, especially the following: interventions that use pleasant events improve both mood and behavioural disturbances; environmental interventions such as aromatherapy or light therapy reduce behavioural disturbances, including aggression; most interventions target people who have emerging or established behavioural problems; and interventions in the community that focus on prevention are underdeveloped.¹

Medication

One major problem with drug treatment is their side-effects,^{2,6,8,10,13} particularly with prolonged use, and where there is little evidence of benefit to support drug use.⁵ And when several drugs are prescribed at the same time, there is a danger of 'over-medication', which can reduce the person's quality of life, affect how they move about and increase the rate of cognitive (thinking, reasoning, memory) decline.² The newer 'atypical' antipsychotic drugs, which became available from the 1990s,⁶ also have side-effects.⁹ Research in 2001 concluded that up to 40 per cent of residents of care homes may be taking antipsychotic medication¹⁸ and overprescribing in care homes was still identified as a major problem several years later.⁶ One consultant old-age psychiatrist has suggested that when the use of medication is

unavoidable, certain principles must be followed: low doses should be used initially and time should be allowed for any effect to occur; side-effects should be monitored; agreement should be sought; and the drug should be used for as short a time as possible.⁵

Carer burden

A person with dementia's behavioural and psychological problems can have a negative effect on relationships between them and those they come into contact with, for example when delusional beliefs lead the person with dementia to accuse their carer of stealing.²

A carer may cut down on the number of times they go outside the home with the person they care for because of a fear that strangers do not understand dementia, and a concern that the cared-for person's disinhibited behaviour will cause distress or embarrassment.²

Safety may be an issue for both the person with dementia and their carer, for example where physical aggression leads to violence, or where constant pacing by the person with dementia leads to an injury or a fall.²

Coping at home can be hugely challenging and stressful for family carers, with major negative effects^{2,4,6} and the need for health and social care support eventually becomes unavoidable. Sometimes despite this support, carers cannot manage and this is when a move into residential care becomes the only feasible option.^{2,4}

Implications from the research

Behavioural and psychological responses among people with dementia that people find challenging or unsettling are almost universal, causing strain and anxiety for people with dementia, their families and those who care for them.²

There are a wide range of factors that can cause unexpected or distressing behavioural and psychological responses in a person with dementia, including their surroundings, structural and chemical changes in the brain due to dementia, and untreated pain.⁴ It is therefore important to take an approach that looks at the whole person and explore what might be at the root of a change in behaviour, rather than immediately looking to treat the symptom.

Raising awareness in care staff, together with proper training and person-centred approaches to managing behavioural and psychological problems, can bring about a considerable improvement in the lives of people with dementia and be of benefit to staff too.² Medication should not be seen as a first resort except where there is extreme risk of harm.^{6,7} It is important that all possible measures and means are explored beforehand,² including the use of interventions that look at psychological and social needs,⁷ for which there is a good deal of support,² and growing evidence about the potential benefits.⁶

There is a need to carry out more systematic studies where the design of the studies allows for more people to participate and there is scope to measure various interventions in sufficient detail. One problem is that this subject area is plagued with the problem of how to define terms like agitation and aggression, and without standard definitions it makes the job of measuring the outcomes of interventions and making comparisons between them and a difficult one. Practice expertise in identifying and managing difficult behaviour may be a more fruitful approach at the moment.

References

1. Bradford, A. and Shrestha, S. (2012) 'Managing pain to prevent aggression in people with dementia: a nonpharmacologic intervention', *American Journal of Alzheimer's Disease and Other Dementias*, vol 27, no 1, pp 41–47.
2. Lowery, D. and Warner, J. (2009) 'Behavioural and psychological symptoms of dementia (BPSD): the personal and practical costs of dementia', *Journal of Integrated Care*, vol 17, no 2, pp 13–19.
3. Husebo, B.S., Ballard, C. and Aarsland, D. (2011) 'Pain treatment of agitation in patients with dementia: a systematic review', *International Journal of Geriatric Psychiatry*, vol 26, no 10, pp 1012–1018.
4. National Ageing Research Institute (2008) *Dementia resource guide* (available at [www.health.gov.au/internet/main/publishing.nsf/content/35DF1D4D4EBD8747CA257693001DEFFC/\\$File/7.%20Behavioural%20&%20psychological%20symptoms.pdf](http://www.health.gov.au/internet/main/publishing.nsf/content/35DF1D4D4EBD8747CA257693001DEFFC/$File/7.%20Behavioural%20&%20psychological%20symptoms.pdf) , accessed 8 May 2013).
5. Jackson, G.A. (2002) 'Behaviour problems and assessment in dementia', *Nursing Times.net*, vol 98, no 47, pp 32.
6. Banerjee, S. (2009) *The use of antipsychotic medication for people with dementia: Time for action*, London: Department of Health (available at <http://psychrights.org/research/digest/nlps/BanerjeeReportOnGeriatricNeurolepticUse.pdf> , accessed 8 May 2013).
7. National Institute for Health and Clinical Excellence and Social Care Institute for Excellence (2006) *Dementia: Clinical guideline*, London: National Institute for Health and Clinical Excellence and Social Care Institute for Excellence.
8. Bidewell, J.W. and Chang, E. (2010) 'Managing dementia agitation in residential aged care', *Dementia: The International Journal of Social Research and Practice*, vol 10, no 3, pp 299–315.
9. Moniz-Cook, E. and Clarke, C. (2011) 'Dementia care: coping with aggressive behaviour', *Nursing and Residential Care*, vol 13, no 2, pp 86–90.
10. Kong, E.-H., Evans, L.K. and Guevara, J.P. (2009) 'Nonpharmacological intervention for agitation in dementia: a systematic review and meta-analysis', *Aging and Mental Health*, vol 13, no 4, pp 512–520.
11. Bourbonnais, A. and Ducharme, F. (2008) 'Screaming in elderly persons with dementia', *Dementia: The International Journal of Social Research and Practice*, vol 7, no 2, pp 205–225.
12. Devanand, D.P. and Lawlor, B. A. (2000) *Treatment of behavioral and psychological symptoms of dementia*, London: Martin Dunitz.

13. Bedard, A. and Landreville, P. (2011) 'Reducing verbal agitation in people with dementia: evaluation of an intervention based on the satisfaction of basic needs', *Aging and Mental Health*, vol 15, no 7, pp 855–865.
14. Cohen-Mansfield, J. and Libin, A. (2004) 'Assessment of agitation in elderly patients with dementia: correlations between informant rating and direct observation', *International Journal of Geriatric Psychiatry*, vol 19, pp 881–891.
15. Husebo, B., Ballard, B., Sandvik, R., Nilsen, O.B. and Aarsland, D. (2011) 'Efficacy of treating pain to reduce behavioural disturbances in residents of nursing homes with dementia: cluster randomised clinical trial', *British Medical Journal*, vol 343, doi: <http://dx.doi.org/10.1136/bmj.d406> .
16. Lemay, M. and Landreville, P. (2010) 'Verbal agitation in dementia: the role of discomfort', *American Journal of Alzheimer's Disease and Other Dementias*, vol 25, no 3, pp 193–201.
17. Vasse, E., Vernooij-Dassen, M., Spijker, A., Rikkert, M.O. and Koopman, R. (2010) 'A systematic review of communication strategies for people with dementia in residential and nursing homes', *International Psychogeriatrics*, vol 22, no 2, pp 189–200.
18. Margallo-Lana, M., Swann, A., O'Brien, J., Fairbairn, A., Reichelt, K., Potkins, D., Mynt, P. and Ballard, C. (2001) 'Prevalence and pharmacological management of behavioural and psychological symptoms amongst dementia sufferers living in care environments', *International Journal of Geriatric Psychiatry*, vol 16, no 1, pp 39–44.

www.scie.org.uk/dementia/living-with-dementia/difficult-situations/index.asp