Investigating the causes of behaviours that challenge in people with dementia

Using a case study, John Keady and Lesley Jones show how a person-centred approach can reveal the individual behind the behaviour and help to tailor subsequent interventions.

Summary

Nurses are the main providers of care to older people and to people with dementia in a variety of settings, including acute hospitals.

Behaviours that challenge in people with dementia, such as agitation, aggression and ‘resistiveness’, can best be understood as a form of communication based on a person’s perceived and/or actual unmet need(s).

This article explores ways of understanding behaviours that challenge and contains a composite case study of ‘Frank’, a person with severe dementia who has been admitted to an NHS inpatient mental health assessment ward.

A three-step approach to investigate, formulate and personalise a range of interventions is shared (clue finding; motive identifying; and formulating, applying and evaluating interventions) together with ways of intervening in behaviours that challenge.

Keywords

Behaviours that challenge, dementia, intervention

ADVANCING AGE is the most significant risk factor in the development of dementia (Burns and Iliffe 2009), with Alzheimer’s disease the most prevalent form of dementia in younger and older people (Harvey et al 2003, Alzheimer’s Society 2007). Older people are the greatest consumers of health and social care services and are most likely to be admitted to acute hospitals for medical treatment, such as after a stroke (Sampson et al 2009). Furthermore, a significant percentage of older people living in care homes are likely to have some form of dementia (Help the Aged 2007) and be prescribed inappropriate antipsychotic medication to help ‘control’ behaviours that challenge; that is, ‘aggression’ and ‘wandering’ (Banerjee 2009). Nurses are the main providers of care to these patients.

In NHS mental health services people with dementia can be admitted for inpatient assessment because of complex patterns of presentation, high levels of risk and/or uncertainty with the meaning of exhibited behaviour. There may be occasions when due to the nature and severity of this behaviour that individuals are detained under the Mental Health Act 1983 or care and treatment is delivered under the auspices of the Mental Capacity Act 2005 (see Rapaport and Manthorpe 2008).

Dementia is more than a cognitive condition and this article concerns behaviours that challenge and the nursing role in assessment and intervention. The article is transferable across different settings and locations.

Dementia: context and stages

The ICD-10 Classification of Mental and Behavioural Disorders (World Health Organization 2007) defines dementia as: ‘A syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not clouded. The impairments of cognitive function are commonly accompanied, and occasionally preceded,
by deterioration in emotional control, social behaviour, or motivation. This syndrome occurs in Alzheimer’s disease, in cerebrovascular disease, and in other conditions primarily or secondarily affecting the brain.’

Dementia is often labelled as a progressive condition in that the signs and symptoms will change in severity and complexity over time; indeed, in England, the National Dementia Strategy (Department of Health 2009) labelled dementia as a terminal condition with life expectancy from diagnosis to death being around 4.5 years (Xie et al 2008). Dementia is usually separated into three stages; namely, mild, moderate and severe (see Box 1).

While behaviours that challenge can occur in any of the three stages of dementia (Box 1), it is usually in the moderate to early severe stages that people with dementia exhibit behaviours that cause significant stress and upset to carers and which may lead to the person being admitted to a care home (Andrén and Elmståhl 2008), respite care or to an NHS inpatient dementia assessment unit for further investigation.

**Behaviours that challenge**

In England and Wales the National Institute for Health and Clinical Excellence (NICE) and the Social Care Institute for Excellence (SCIE) guideline (2006) Dementia: Supporting People with Dementia and their Carers in Health and Social care promoted a biopsychosocial model of dementia. In other words, the interplay between neurobiology, psychology and the social environment provides the most holistic way of understanding the lived experience of dementia and the effect it has on carers and the person’s social/family networks. The NICE/SCIE (2006) guideline proposed the concept of ‘behaviours that challenge’ to instil a more person-centred language and reduce the stigma that other labels had evoked, such as ‘challenging behaviour’, ‘disruptive behaviour’ and ‘behavioural and psychological symptoms in dementia’, often shortened to BPSD.

Examples of types of behaviour that challenge are similar across published articles with restlessness, wandering, repetitive questioning, disruptive vocalisation, disinhibition, aggression, agitation and sexual inappropriateness often mentioned (Turner 2005, NICE/SCIE 2006, Dewing 2010). Furthermore, it is estimated that up to 90 per cent of people with dementia may experience one or more of these symptoms during the course of their condition (Steinberg et al 2003).

The presentation of behaviours that challenge can be a cause of stress for individuals and their carers, reduce individuals’ quality of life and be a reason for admission to institutionalised care (Moniz-Cook et al 2000, Gilley et al 2004).

**Nursing interventions**

The NICE/SCIE (2006) clinical practice guideline on dementia acknowledges the importance of recognising behaviours that challenge and advocates that people with dementia who develop these should be offered a comprehensive assessment at the earliest possible opportunity.

This should establish likely factors that may generate, improve or aggravate such behaviour. Areas for assessment are identified as:

- Physical health.
- Depression.
- Pain.
- Side effects of medication.
- Individual biography.
- Psychosocial factors.
- Environmental factors.

Behavioural and functional analysis is also recommended (Dwyer-Moore and Dixon 2007), with non-pharmacological interventions suggested as the first line approach in the management of behaviours that challenge (NICE/SCIE 2006).

Pharmacological interventions should only be the first approach if the individual is severely distressed, or if there is immediate harm to the person or others.

Examples of non-pharmacological interventions include reminiscence therapy, reality orientation, aromatherapy, music therapy and multi-sensory stimulation, although the evidence base for these interventions remains sketchy and in development.
The person with dementia’s behaviour may be an attempt to communicate a need or be as a direct result of an unmet need

James et al (2008) report that these types of interventions are aimed at promoting a sense of wellbeing for the individual which, it is anticipated, will reduce incidence of ‘problematic’ behaviour.

However, while these are worthy aims, such approaches do not attempt to address the underlying cause of the behaviour. In an attempt to rectify this, a number of conceptual and practice-based models that examine and assess behaviours that challenge have been developed, using a needs-led approach and multiple pathways to assessment (Cohen-Mansfield 2000, James et al 2007, Bird and Moniz-Cook 2008).

The needs-led models, all similar in construct, use two types of information: background information on the person’s biography, physical health, personality, mental health status, and an in-depth description of the behaviours that challenge. Underpinning this approach is the belief that behaviours that challenge are usually manifestations of an individual’s needs or unmet needs, fuelled by impaired ability to express desires and wants (Stokes 2000, Cohen-Mansfield 2008, James et al 2006, 2007, 2008).

The person with dementia’s behaviour may be an attempt to meet a need, communicate a need or be as a direct result of an unmet need (Cohen-Mansfield 2008). Needs-led approaches keep the person firmly at the centre of the assessment and intervention process, as opposed to the more traditional bio-medical model which maintains that dementia is the sole reason for the behaviour.

Such an approach to understanding the meaning of behaviour and communication is applicable in whatever the setting the person with dementia is living, including the community (Pugh and Keady 2003). Frank’s case study illustrates this.

Frank: a case study

Frank is an 86-year-old man who has a diagnosis of Alzheimer’s disease. He is now believed to be in the severe stage of the condition (Box 1). Frank lives in a care home and has been admitted to an NHS mental health, dementia-specific, inpatient assessment ward due to his agitated and aggressive behaviour in the care home.


James et al (2006) liken their needs-led model to a ‘Columbo approach’ in which painstaking detective work is necessary to assemble possible explanations for the presented picture.

Collecting information

This first step is all about trying to understand why a person is demonstrating the behaviour and what may have happened to trigger it.

Nursing staff collected and collated background information about Frank, covering his life story, personality and coping mechanisms, preferred living environment, current and past medication, and mental and physical health, including pain.

In order to start piecing together the clues, a number of approaches were used, including talking with Frank, gaining a collateral history from his nearest relative and residential care staff, examining medical and care records, reviewing medication and obtaining a history from his GP. In addition, detailed reports were collected about when Frank had become agitated and aggressive.

To assist with this process observed behaviour charts were implemented to allow staff to record the behaviour in a consistent way under a number of headings, such as when the agitation and aggression occurred, frequency, time of day or night, duration, location, perceived purpose, impact, precipitating factors and any other contextual issues.

The information was then collated to present in a case review.

Case review

A case review was attended by all members of the multidisciplinary team, relatives and carers. The aim of a case review is to present and discuss the ‘clues’: information obtained from observed behaviour, background information to enable possible reasons for the behaviour to be suggested and explored and ‘motives’ to be identified. A case review helps to identify what the individual may be trying to communicate and what their needs and/or unmet needs may be. From this vantage point multidisciplinary interventions are then identified and care plans implemented and reviewed at regular intervals.

It was recorded during observations and observed behaviour charts that:
Frank was aggressive when getting up in the morning and when staff tried to assist with personal hygiene needs. There had been incidents of what had been perceived as ‘unprovoked aggression’ when he was approached by staff and had hit out at them. He became agitated at meal times and when engaging in occupational therapy activities.

The background information gave a greater insight into Frank's life. Obtaining a collateral history enabled a picture of Frank ‘the person’ to be built. His niece, who gave the history, informed staff that 'his life was his wife and his work' and that he had previously worked as an architect.

Frank’s wife passed away 15 years ago and they had had no children. He did not like crowds or loud noise and his previous hobbies were classical music and bird watching.

Frank had always taken pride in his appearance preferring to wear a jacket and tie, even when relaxing at home. From the history a picture emerged of a proud, private, independent and professional man. Information from Frank’s GP records revealed a previous history of osteoarthritis. A review of medication indicated that he received medication for constipation and hypertension.

Details on the observed behaviour charts suggested that when Frank 'hit out' at staff they had approached him from his right side; a subsequent eye examination revealed that Frank’s peripheral vision on the right was very poor.

Due to the advanced stage of Frank’s Alzheimer’s disease he was not able to give any reasons for his behaviour, nor did he seem able to recall the incidents afterwards. However, he did appear to enjoy one-to-one encounters and company.

**Motives** From the case presentation it became possible to suggest 'motives' for Frank’s actions and behaviours. These suggested that:

- If Frank had osteoarthritis he may be in pain in the morning and this could be a reason for his aggression at that time.
- Frank was previously a very private and independent man who may have misidentified staff attempts to help as a personal attack, striking out to defend himself.
- His agitation at busy and noisy meal times could be due to his dislike of noise and crowds.
- Frank’s agitation during occupational therapy activities were correlated to group activities, such as bowling and art work.

**Interventions** These were formulated and a care plan developed and implemented. Interventions included:

- A trial of analgesia, ensuring that the morning dose was administered before Frank got up in the morning.
- Giving clear communication when assisting Frank with personal interventions, ensuring he did not feel rushed and enabling him to participate in the process as much as possible.
- Ensuring Frank had a selection of clothes which were familiar to him, for example, jackets, shirts, ties - as opposed to the selection of t-shirts and jumpers that were brought in with him on admission.
- Offering Frank the opportunity to have his meals in a quieter area of the ward.
- Offering Frank activities which were on a one-to-one basis and more in keeping with his previous hobbies and interests.
- Always ensuring that staff approached Frank from the front and not his right side, allowing him to see the person ahead and not taking him by surprise.

These interventions were put into a care plan and all staff were made aware of its contents.

**Findings** After a month the plan was reviewed and staff gave their feedback. There was a significant reduction in incidents of aggression or agitation. Staff reported that Frank appeared happier and more content and they felt that they were more aware of ‘Frank the person’ and were able to deliver much more person-centred care, support and interventions.

Being involved in the whole process gave staff a greater understanding of Frank and the rationale behind the interventions, which increased consistency of care in the team.

**Conclusion** Although the term ‘behaviours that challenge’ encompasses a wide and varied range of behaviour, research and practice suggest that it is the degree and/or intensity of behaviour displayed that results in it being labelled as challenging. Behaviours that challenge are therefore subjective and will be influenced by beliefs and experiences (Bird and Moniz-Cook 2008). Behaviour will also be labelled as challenging if it is viewed as 'unreasonable' and challenges the norms and roles of the context.

**Being involved in the whole process gave staff a greater understanding of Frank and the rationale behind the interventions**
in which it occurs. As the case study of Frank suggests, it is important not to label the person as challenging and to systematically work through steps to piece together the different aspects of a person’s life for solutions.

Interventions can then be implemented and tailored based on the premise that the behaviours that challenge are expressions of unmet need and attempts at communication, and not the person being ‘difficult’ or ‘demanding’ (Davisson et al 2007).

The ultimate aim of any intervention is to enhance the person’s quality of life and alleviate suffering; the very essence of nursing practice.

Find out more

John Keady, supported by the contribution of Lesley Jones, will give a presentation on aggression and challenging behaviour on the ward at the British Geriatrics Society’s multidisciplinary day for specialists caring for older people on November 5 in Brighton. Nursing Older People is a media partner for the event. Nursing strands also include achieving quality care, alcohol, epilepsy and care homes. For further information visit www.bgs.org.uk

Online archive

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References


