Using the Newcastle Model to understand people whose behaviour challenges in dementia care


Abstract
National guidance for working with people whose behaviour challenges in dementia care suggests that a psychosocial approach should be the first-line intervention. However, there is little guidance for nurses about how to assess and manage behaviour that challenges in people with dementia. Nurses across specialties who work with older people might be asked to contribute to an assessment or provide advice to care home staff or families.

This article presents one psychosocial model – the Newcastle Model – that provides a framework and process in which to understand behaviour that challenges in terms of needs which are unmet, and suggests a structure in which to develop effective interventions that keep people with dementia central to their care.

Aim and intended learning outcomes
The aim of this article is to introduce nurses in all specialties working with older people with dementia to a psychosocial model that might help them understand behaviour that challenges. The model has been developed for professionals who are working with staff in care settings, but it has also been helpful for working with people living in their own homes. The model is a psychological formulation model, which means that it is based on psychological theory and, therefore, enables us to link patterns of behaviour to current situations or triggers and past experiences, with guidance from what we know about 'typical' behaviour. This provides us with more information about how we might alter our approaches or the environment with individuals' needs in mind in a way that has a positive effect on their behaviour.

After reading this article and completing the time out activities, you should be able to:
- Use holistic assessment to recognise and address the unmet needs of people with dementia.
- Use insights from the psychologically based formulation to support the individual needs of the person with dementia.

Introduction
In this article, the term ‘behaviour that challenges’ is used rather than behavioural and psychological symptoms of dementia or challenging behaviour. We use this term to ensure that these behaviours are not viewed as an inevitable symptom of dementia or as intentional, and that the challenge is often experienced by the caregiver rather than the person with dementia.

Bird and Moniz-Cook (2008) define behaviour that challenges as ‘a manifestation of distress or suffering for the person with dementia, or of distress in the carer’.

People with dementia are estimated to constitute 69% of the care home population in the UK (Alzheimer’s Society 2014), with behaviour that challenges estimated to present in between 30 and 60% of cases (Institute of Public Care 2011).
These high numbers reflect the increasing complexity of need in nursing and care home residents as those with less complex needs are enabled to live at home wherever possible. Clinical experience would also suggest that there are many people with dementia living on their own or with their families in the community with behaviour that challenges.

The experiences of people with dementia can vary but typically reported symptoms include memory loss, disorientation, lack of insight, visuospatial problems, hallucinations, delusions, word-finding difficulties and poor object or facial recognition (National Institute for Health and Care Excellence 2006). People’s thought processes are muddled or slowed down. This can be a time of great frustration, worry, sadness and fear (Bryden 2005). In the context of these problems, people can feel lost and find everyday demands overwhelming. Help offered might be interpreted as threatening and, not surprisingly, people’s behavioural responses might seem at odds with the environment. For example, someone who has a dressing apraxia (is no longer able to recognise the order and function of clothing), but lacks insight, might feel threatened by a care worker escorting them to their room to remove clothing. Their perception of being under threat might cause them to shout or hit out.

Understanding the person with dementia’s experience is central to person-centred care. Kitwood (1997) suggested that several factors influence the wellbeing and experience of the person with dementia. He expressed these factors in the equation:

Dementia = Biography + Personality
+ Physical Health
+ Neurological Impairment
+ Social Psychology

In other words, the person’s experience of dementia is not solely influenced by neurological impairment (severity of brain damage), but by a combination of factors. Kitwood (1997) emphasised the uniqueness of every individual’s experience of dementia. His term ‘social psychology’ refers to the social environment of the person with dementia, specifically the interactions between the person with dementia and those caring for them.

Kitwood’s (1997) equation is helpful in improving our understanding of why behaviour that challenges might occur. It came at a time when there was little that could be done to alter the biological course or progression of the condition. In this way, it gives a more optimistic message that we can have a positive effect on a person’s experience through improving their social environment, understanding the importance of their histories and ensuring they are physically well.

Now do time out 1.

### Understanding another’s behaviour

Imagine that you believe you are 21 years old and you live with your husband and have an eight-month-old baby. You wake from a doze to find that you are in a strange house sitting with an older man with the TV on. You ask the man politely where your husband is. He becomes upset and says, ‘Can’t you even recognise me now? It’s me. I am your husband.’

- How do you feel? What would you do (how would you behave)?
- You get up to leave to find out for yourself where your husband and baby are. The man tries to stop you by locking the front door.
- How do you feel? What would you do?
- The man holds you firmly by the wrists and pulls you back into the living room.
- How do you feel? What would you do?
- At any time, do you think your behaviour might be seen as ‘challenging’ by someone who does not see the world as you do?

By completing time out 1 you will recognise the importance of putting yourself in the shoes of the person with dementia, to understand the way they behave. When we understand how the person perceives his or her environment, many behaviours perceived to be challenging are functional and normal.

### Working with behaviour that challenges

There has been a growth in the number of specialist teams working with staff in care homes to help them understand and respond appropriately to people with behaviour that challenges. Clinicians in these teams are predominantly nurses, occupational therapists and psychologists. Many of them use psychological formulation (Box 1, page 34) to help explain why behaviour occurs. Formulation models are used by clinical psychologists and other professionals with further specialist training, and are based on theoretical models about human behaviour. The importance of using a formulation model is that it provides a hypothesis about why and when a specified behaviour might occur, giving increased opportunities to devise interventions we would predict would target behavioural change.

The Newcastle Model has a growing evidence base that is being used nationally and internationally (James 2011). The Newcastle Model was known as...
the ‘Columbo approach’ (James et al 2006) to working with behaviour that challenges, named after the fictional American detective TV series and reflecting the curious stance of the clinician undertaking the assessment and intervention. It was later called the Newcastle Model after its city of origin and the team developing the approach led by Ian James. The Newcastle Model and its theoretical background have been described extensively elsewhere (James 2011) and a summary only is provided in this article. Its main premises are that behaviour is understandable if we use information about the person to hypothesise what their beliefs about the situation might be, and that behaviour that challenges is a poorly communicated expression of need (Cohen-Mansfield 2000, 2001).

The Newcastle Model
The Newcastle Model (James 2011) incorporates a framework and a process. The framework is shown in Figure 1. The boxes at the top of the figure indicate

### Box 1 Psychological formulation

Formulation has been described by Johnstone and Dallos (2006). Psychological formulations:
- Summarise the service user’s core problems.
- Suggest how the service user’s difficulties may relate to one another, by drawing on psychological theories and principles.
- Aim to explain, on the basis of psychological theory, the development and maintenance of the service user’s difficulties, at this time and in these situations.
- Indicate a plan of intervention that is based on the psychological processes and principles already identified.
- Are open to revision and reformulation.

### Time out 2

Think about someone with dementia you have worked with whose behaviour has been challenging.
- How much did you know about them?
- Could you have completed the Newcastle Model framework?
- What information was missing?

Time out 2 highlights the importance of obtaining a comprehensive history. It is difficult to care for someone without it. We need to be able to view their behaviour or distress in the context of their past life experiences and beliefs. Further, nurses using the Newcastle Model as an assessment framework should always be mindful of what it is about the information they have that is relevant. For example, we may know that a man we are working with was the eldest in a family of ten. We might begin to hypothesise what that means for behaviour that caregivers might report as challenging – if he is said to be ‘interfering’ with other residents could we see that as trying to care for others as he might have done for siblings? Could refusing food be related to perceiving there is not enough for everyone? Does he believe he should still be working to keep money coming in to help the family?

The boxes at the bottom of Figure 1 are to gather information about what is happening for the person at the moment they are challenging. The information to
complete them is not always available. We might not know for sure someone's thoughts about a situation. Sometimes we have to listen to what people say closely to understand their interpretations, and we can judge feelings from the person's non-verbal communication. However, we can also fill in the gaps with what we know about human behaviour. For example, we know that angry feelings and behaviour generally emerge from thoughts of being misunderstood or cheated; and that avoidance or bad temper can be the result of high levels of anxiety (fight or flight).

Now do time out 3.

3 Thoughts, feelings and behaviour

Try to fill in the gaps to understand the thoughts, feelings and behaviour of a person in a moment of distress.

Example 1. A female resident is being taken to the bathroom by a male healthcare assistant. She shouts 'Get off! Don't you bloody dare!'

- What might she think is going to happen?
- How might she feel about that? What is she likely to do?

Example 2. A male resident is at risk of falling. He does not know this and wants to go for a wander to get his circulation moving. A nurse repeatedly advises him to sit down.

- What might he think? What kind of feelings might he have? How might he react?
- Would the behaviour of these two people seem reasonable given what they might be thinking is happening? Might you have done the same in the circumstances? Would their behaviour be called challenging?

In time out 3 we use links made in cognitive-behavioural formulation frameworks, for example, Padesky and Mooney (1990), to help us make sense of someone's behaviour in that moment. Cognitive-behavioural formulation frameworks suggest that behaviour is the result of our beliefs and feelings about a situation. This helps us to see that behaviour is generally understandable if we take into account the thoughts (beliefs) people might have. This increases the chances of us being able to use our hypotheses to predict future patterns.

Information about what is happening in the moment that the challenge occurs is usually collected by keeping behaviour charts over a week or longer if the behaviour is infrequent. Although the usual Antecedent, Behaviour, Consequence (ABC) charts can be useful, the Newcastle Model benefits from more detailed information being gathered about what the person might be saying at the time of the incident, and how they might look. This information can provide valuable insights into their perceptions about what was happening and their emotional state at the time. A sample behaviour chart can be found in James (2011). The detection of patterns is also useful in identifying situations in which behaviour that challenges might occur. Charts should identify who was present, the time of day and what was going on around the person at the time of the challenge.

The Newcastle Model framework is the template specialist clinicians will use to help nursing and care staff make connections between the person's experience and their behaviour. The information is often presented to staff on a flip chart as part of a ‘formulation-sharing session’ (Jackman 2013), where the facilitator will work with staff to devise care plans. The care plans emerge from understanding the person's behaviour in terms of a need being expressed.

Understanding behaviour as a communication of need

The formulation framework in Figure 1 helps us to understand why the person might find a particular situation difficult and so why they might behave in a particular way. A useful way to connect this with care planning is to use Cohen-Mansfield’s (2001) work, which describes three ways in which a person’s needs might be expressed as behaviour that challenges:

- The person might behave in a way that is intended to fulfil a need, for example, taking food from someone's plate might be a need for food, or for security.
- The person's behaviour might be a communication of need, for example, shouting ‘nurse’ or ‘help’ repeatedly.
- The person's behaviour might be the result of frustration when a need is not met, for example, they think they need to leave the building to go to work but are stopped by staff.

Now do time out 4.

4 Unmet needs

Behaviour that challenges can be an expression of unmet need. What ‘unmet needs’ might these behaviours correspond with?

- Following a member of staff around all day.
- Barricading bedroom door from inside.
- Walking up and down corridors.
- Hiding food in pockets.

In your response to time out 4, you might have hypothesised that following staff around might correspond to a need for company or for safety. Walking
Continuing professional development

the corridors might reflect a need for exercise or activity or to find something or someone. It is easier to identify people’s needs when you have built up knowledge of them from a formulation.

The more you know about a person the easier it is to understand behaviour that challenges. However, the memory deficits associated with dementia mean that people with this condition may forget or misremember events in their own histories. If family members or friends are not available to add to our information, we sometimes have to infer information from wider knowledge of human experience and need. Just as we used a basic cognitive-behavioural framework to fill in the gaps about the moment-to-moment thinking of someone who appears to be anxious, we can begin to hypothesise about people’s needs using theoretical frameworks. If you do not know the person well, and there is not much information to go on, Maslow’s (1954) hierarchy (Figure 2) can be used to think about universal human needs.

We should not imagine that the general needs of people with dementia are any different to our own. A helpful exercise is to think ‘How would I react if it were me? What would my needs be?’ We have found that the activity in time out 5 is an effective warm-up to use with nurses and care workers at the start of a shared-formulation session to highlight the needs-led approach.

Now do time out 5.

5 Identifying needs

When you woke up this morning, what were the first things you needed – a drink, the toilet? Write a list. Now, imagine you have just woken up and you are in a nursing home. What would your needs be first thing in the morning? Once your basic needs were met, what other needs do you have? Would care settings be able to cater for you? How would a care home meet your need for love and belonging or status?

(Adapted from Jackman and Young 2013)

A short case study (Box 2) is now presented to illustrate the benefit of using this framework to develop person-centred care plans.

When we consider the assessment information included in the Newcastle Model, we can identify some potential unmet needs in Jean’s story. For example, we know that people with dementia who experience pain are not always able to communicate this and may ‘tell’ us through their facial expressions like grimaces, or behaviour that others might find challenging like continuous walking or hitting out during personal care (Ahn and Horgas 2013). So, does Jean need more pain relief? Does she need hearing and sight aids? You will spot other potential unmet needs too. When we consider other areas in Maslow’s hierarchy, we can see that Jean’s behaviour suggests she does not feel safe and secure in her environment. She feels threatened by staff because she perceives them to be social workers or police with whom she has had negative experiences. She is living in the same environment as ex-neighbours and what seemed to be paranoia initially might be an actual experience of being talked about by visiting families and other residents. She is terrified that her things will be taken away from her because this happened so often when she was younger.

Box 2 Jean’s story

Jean is a 76-year-old widow who lives in a care home. She has been referred to a specialist team by her GP after staff expressed concerns about her behaviour. The staff tell the team member that Jean is ‘targeting other frail residents, and stealing their belongings’. They explain that Jean has a vascular dementia that is well progressed. She often expresses paranoid thoughts about people talking about her. She sometimes becomes aggressive at mealtimes or visiting times.

The team member gathers information using the Newcastle Model framework (Figure 3, page 37).
So, already, we have identified a number of needs that we can devise care plans to meet:

- Pain relief.
- Support with hearing and sight.
- Safety from gossip, and from having things taken from her.

We could continue to think through the elements of Maslow’s hierarchy to identify increasingly complex needs such as the need to feel she belongs in her environment, and to have some feeling of self-worth.

Identifying unmet needs allows us to be creative in our thinking about how best to help someone. It also takes emphasis away from their behaviour as being something they are doing to affect others, to being something they are doing to satisfy universal human needs. In Jean’s case, we addressed her needs by prescribing pain relief as a regular dose, supplying new glasses (she would not tolerate a hearing aid), and by distracting her when visitors were around by helping her do tasks that were within her capability (to preserve her self-esteem) and which gave her opportunities to develop good relationships with staff. Finally, Jean was given a large bag to hang on her walking frame with items she recognised as belonging to her. She was redirected to

**Figure 3: Information about Jean gathered using the Newcastle Model framework**

<table>
<thead>
<tr>
<th>Life history and experience</th>
<th>Personality</th>
<th>Cognitive impairment</th>
</tr>
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<tbody>
<tr>
<td>Jean was never well off. She had four children and her husband was regularly in prison. He had been convicted of raping and molesting a number of local women. Jean and her children had needed to move several times because of accusations from neighbours. Jean used to buy things on credit and then have them taken from her when she could not keep up payments.</td>
<td>Anxious, always worried about what people thought. Coped by moving a lot. Loving mother. Cared for a number of older relatives.</td>
<td>Jean has vascular dementia. Some of her behaviour seems impulsive and she often repeats tasks over and over unless she is distracted. She has problems recognising she is in care and mistakes members of staff for police officers or social workers.</td>
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</tbody>
</table>

**Mental health**

Jean does not have a history of mental health problems. Now she often seems to be either anxious or angry.

**Physical health**

Jean has diabetes with volatile blood sugars. She needs a frame to mobilise but sometimes forgets to use it. Jean has poor sight and hearing.

**Trigger situation**

1. Residents’ families visiting.
2. Residents picking up ornaments in the communal area.

**Thoughts (what Jean says)**

1. They’re talking about me (‘Mind your own business! Leave me alone!’)
2. They’re taking my stuff (‘Get off my stuff! Put it back’)

**Feelings (taken from how we might feel and how Jean appears)**

1. Anger, shame.
2. Anxiety, anger.

**Behaviour (what Jean does)**

1. Shouts at visitors, goes to strike people she mistakes for old neighbours or social workers.
2. Grabs items from other residents.

**Medication**

Jean does not take much medication. She is prescribed paracetamol when required for pain but does not ask for it.

**Social environment**

Jean’s care home is close by the neighbourhood where she brought her family up. It is a spartan environment with little to pick up and fiddle with.
this bag each time she approached another resident to take things from them. In the process of thinking about what needs Jean’s behaviour is expressing, we have naturally moved away from the labels that were applied to her behaviour before. It is difficult to hold negative ideas in mind at the same time as being actively curious about why behaviour might occur. The case study in time out 6 provides some further examples of this.

Now do time out 6.

### Labels reconsidered

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<th>Time out</th>
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Care home staff have labelled Mrs Smith as a ‘nasty’ woman. She was described as a ‘liar’ and ‘manipulative’ because she buzzed continuously for staff, and when they attended seemed to make up reasons for calling them. She sometimes told attending staff that she had been buzzing for hours and was being ignored. She even told this to a Care Quality Commission inspector.

Through a formulation session, it was identified that she was anxious and had a short memory span. She did not have a clock in her room and it was a long way off the normal route for nurses, meaning that she might not see people for long periods.

What needs might Mrs Smith be expressing by buzzing for staff and accusing them of not attending?

When you have identified her needs, do the previous labels still apply to her personality?

### Person-centred risk care planning

The Newcastle Model is an excellent framework with which to gather the right information to be able to identify why some situations are triggers for certain people but not others. It helps make sense of what people are doing – it contextualises their behaviour in the thoughts and feelings that might be raised for them in the trigger situation.

However, it is not always possible to avoid a person with dementia becoming distressed. We might be too late to recognise signs and act proactively, the person with dementia might have an undetected infection, or another resident’s behaviour might be implicated. There are many reasons why person-centred care plans might not solve problems for care staff.

In recognition of this, Sells and Shirley (2010) developed person-centred care plans to include ways of managing high levels of risk. The basis for the care planning format came from work in learning disability services that advocates proactive and reactive care plans.

(La Vigna and Willis 1995). Sells and Shirley (2010) describe a ‘traffic light’ approach that results in a set of three care plans:

1. ‘Green’: these are proactive. They describe ways in which to meet the person’s needs and aim to reduce the likelihood of the behaviour occurring. The care plans described for Jean would fall into this category.

2. ‘Amber’: these are aimed at spotting and changing events or environmental factors that might increase the likelihood of a behaviour that challenges to occur. They might include guidance about appropriate use of as required medication, which can often be used inappropriately after the event has occurred. In Jean’s case, ‘amber’ care plans might identify some behavioural signs of increasing distress, for example, beginning to mutter about others talking about her, or beginning to make reference to items being stolen. The care plan might involve increasing observation levels or distracting Jean with company, a snack or a drink.

3. ‘Red’: when all else has failed, how can we most effectively protect this person and those around them from harm? This might involve, in Jean’s case, asking visiting families to take relatives to their rooms and removing objects that might be thrown until Jean feels less distressed.

The behaviour of people with dementia that others find challenging can often be managed effectively without a ‘red’ care plan. In many situations, it is sufficient to gather relevant information and develop theories about behaviour and need that enable us to make changes to the way in which care is provided or the environment. However, in some cases, it is helpful to have this ‘traffic light’ framework formalised so that all parties are aware of how best to protect the interests of the person presenting the challenge and those around them.

Care planning is essential in nursing, but communication of care plans is essential if they are to be effective. The process of the Newcastle Model is designed to have as many staff as possible contribute to care planning. This means that not only are more people present to hear the outcomes of the discussions, but, because they ‘own’ the plans, they are significantly more likely to carry them out. This process takes place through the formulation-sharing session, where a group of staff caring for the person with dementia meet to hear the person’s ‘story’ related by a clinician trained in the use of formulation. The clinician makes links for the group between the person’s background, current context and behaviour. Some of the strategies and skills identified in facilitating these sessions are discussed in Jackman et al (2014). The session ends with identifying
needs and developing practical care plans that will meet those needs.

Now do time out 7.

7 Care planning for unmet needs

You have identified that one of your clients has a need to feel respected and to have some responsibility. Design two short care plans to meet these needs in a day centre setting. Discuss with a colleague and share ideas.

From time out 7, you may have established the need for your client to be addressed using her surname and title, and you might have thought about ways in which you can enhance her sense of responsibility through providing meaningful occupation.

Conclusion

This article has introduced a psychological formulation model, the Newcastle Model, as a way to organise assessment information and make links between a person’s history, context and behaviour to begin to formulate or hypothesise what events might act as triggers to behaviours that challenge, and how a person with dementia might understand and react to these events.

Importantly, we note the need to:

- Look at previous functioning and preferences using assessment areas taken from Kitwood’s (1997) equation and used in the Newcastle Model.
- Look for how past experiences might relate to trigger situations through gathering relevant information.
- Understand the thoughts and feelings of the person with dementia based on information from observations and applying our understanding of human behaviour.

Use what we know about the person to consider meeting their individual needs using Maslow’s (1954) hierarchy to support our thinking.

Manage risk through person-centred care plans aimed at meeting need, and more specific risk management plans in risky situations.

We have noted that this model is often used by specialist teams who have extra training and supervision to support their work. However, it is possible to translate some of the elements from this model into everyday practice. Many of the ideas and tools described briefly here can be found in the books and articles referenced. In particular we would recommend gathering full information about incidents of behaviour that challenges using charts that incorporate information about the person’s vocalisations and appearance at the time of an incident, and to begin to discuss together patterns to their behaviour and connections between their possible beliefs and actions. We would also advocate the use of life story work. This can either be informally by taking history as standard and asking pertinent questions about the information you receive or by engaging your organisation in formal training such as that provided by the Life Story Network (www.lifestorynetwork.org.uk).

Further information on the Newcastle Model and other aspects of working with behaviour that challenges in a person-centred framework can be found in the reference list.

Now do time out 8.

8 Reflective account

Now that you have completed the article you might like to write a reflective account. Guidelines to help you are on page 40.