Title:

### Using the Newcastle Model to Understand and Manage Behaviours that

#### Challenge in Dementia: a Case Study

Authors:

1) Nils Rickardsson, NHS Lothian, Edinburgh, UK & University of Edinburgh,

Edinburgh, UK

2) Dr Suzanne Crooks, NHS Lothian Older Adult Psychology Service, Edinburgh, UK

Corresponding author:

Nils Rickardsson, Trainee Clinical Psychologist, NHS Lothian. Email: rickardssonnils@gmail.com

Key words:

Newcastle model, stress and distress, dementia, challenging behaviour, behaviour

support

50-word biographical statement for each author:

Nils Rickardsson: Nils Rickardsson is a trainee Clinical Psychologist with an interest in neuropsychology and psychological approaches to difficulties associated with acquired and degenerative neurological conditions.

Dr Suzanne Crooks: Suzanne Crooks is a Clinical Psychologist specialising in systemic practice. She currently works in a Dementia outreach service and has an interest in understanding the causes of distressed behaviour, and developing effective interventions at a systemic level.

This is a peer-reviewed, version of record of the following paper: Rickardsson, N., & Crooks, S. (2021). Using the Newcastle model to understand and manage behaviors that challenge in dementia: a case study. Clinical Case Studies, 20(6), 452-467. https://doi.org/10.1177/15346501211012099

Title: Using the Newcastle Model to Understand and Manage Behaviours that Challenge in Dementia: a Case Study

#### Abstract

Behaviours that challenge (BC) are common in dementia and can have a significant impact on the wellbeing of the person with dementia, their family and staff in care homes. The Newcastle model is a biopsychosocial, person-centred, approach that aims to support care staff and family members in order to manage BC within care homes by identifying and fulfilling unmet needs of the person with dementia. After outlining its theoretical basis and practical utility, we describe a case study where the Newcastle model has been implemented to manage sexualised behaviours and verbal aggression. The patient described is a lady with dementia residing in a care home where the staff felt unable to manage increasing incidence of these BC. Information from multiple sources was collated to conceptualise the behaviours and understand them in terms of unmet needs, which was followed by a process to develop corresponding practical strategies together with care staff and family. Following successful implementation of the Newcastle model, the care staff reported a reduction in BC on standardised instruments (Cohen-Mansfield Agitation Inventory, and the Neuropsychiatric Inventory). The staff group also described increasing confidence in managing sexualised vocalisations as they had a better understanding with regards to premorbid history and personality, and an increased awareness of the impact of dementia on behaviour. Complicating factors relating to staff stress and physical health conditions in older adults are discussed, and adaptations to the model are suggested in order to maintain treatment gains in the long-term.

Using the Newcastle Model to Understand and Manage Behaviours that Challenge in Dementia: a Case Study

#### 1. Theoretical and Research Basis for Treatment

Dementia prevalence rates in the United Kingdom are estimated to 7%, 20% and 32% in people over the age of 65, 85 and 95, respectively (Alzheimer's Society, 2014). Dementia is the strongest determinant for entry into residential care for people over 65, and between 60-80% of all people living in care homes are estimated to have a form of dementia (Alzheimer's Society, 2007; Thornton & Offord, 2015). Thus, dementia represents a large challenge not only for individuals and their families, but also for health and social care services. Nation-wide strategies and guidelines have been set out to meet these challenges and improve the experiences of people with dementia in care homes (e.g. Department of Health, 2009; Scottish Government, 2017). Polypharmacy is a widespread issue in residential care, and behavioural problems are by far the most common reason for antipsychotic medication being prescribed to people with dementia (Jokanovic et al., 2015). As a result of an increased recognition of the severity of side-effects from psychotropic medication there has been a several national programmes designed to reduce the prescribing rates of antipsychotic medication for this population (Banerjee, 2009; Thomas, 2020). Clinical guidelines now recommend non-pharmacological interventions as a first-line approach for Behaviour that Challenges (BC) in dementia (AGS/AAGP, 2003; Brechin, Murphy, James, & Codner, 2013; NICE, 2018).

BC can be defined as any behaviour that has a negative impact on the wellbeing of individuals due to the distress it causes the person or their surroundings. BC in the context of dementia has historically been referred to as Behavioural and Psychological Symptoms of Dementia (BPSD). However, the term BPSD has been criticised as it implies that problematic behaviours and distress are linked directly to the dementing process, and thus, are unavoidable and not treatable (James & Jackman, 2017).

BC is common in dementia, and tend to present more frequently and severely in the later stage of the illness progression (Lyketsos et al., 2002; Thompson et al., 2010). Most BC resolve on their own or from the intervention of carers or family members. However, more complex and chronic difficulties require input from specialist services. James and Jackman (2017) provide a list of common BC in dementia, in which behaviours are categorised into 'aggressive forms' and 'non-aggressive' forms. A sample from this list is presented in Table 1. Similarly, Cohen-Mansfield (2000; 2013) proposes sub-types of BCs, namely: physically aggressive behaviours (e.g. hitting, spitting); physically non-aggressive behaviours (e.g. wandering, smearing); verbally aggressive behaviours (e.g. swearing, screaming); and verbal non-aggressive behaviours (e.g. repetitious questioning).

#### <Table 1. here>

Compared to other BCs, Sexual Inappropriate Behaviour (SIB) has received significantly less attention in research and in practice and there is, therefore, a lack of evidence-based interventions for these difficulties (Thornton & Offord, 2015). SIBs are behaviours such as sexualised language or sexual acts that are carried out within a context where the behaviour is deemed socially unacceptable (De Giorgi & Series, 2016). SIB has been reported as the most difficult type of behaviour to manage by carers, and can cause a high level of stress in family members (Higgins et al., 2004; Tsatali et al., 2011).

#### Conceptualisation and Management of BC in Dementia

There are several theoretical models to explain BC in dementia, and interventions take different forms dependent on the conceptualisation. The frequent use of antipsychotic

medication to manage BC is a result of a biological conceptualisation, and a medical treatment model, which emphasises pharmacological interventions (Taft et al., 1997). Biological theory postulates that BC stems from neurodegenerative changes in the brain, and BC is considered a symptom of dementia. The medical treatment model has come under greater scrutiny as the potential side effects of medications have become better understood, such as delirium, confusion, and increased rates of mortality (Hajjar et al., 2007; Wastesson et al., 2018). BC is now more often considered from biopsychosocial frameworks.

Biopsychosocial frameworks of BC include a behavioural model, the Progressively Lowered Stress Threshold (PLST) model, and the unmet needs model. The behavioural model is based in learning theory, and suggests that BC can be understood by analysing its antecedents and consequences (Buchanan, 2006; Fisher et al., 2007). Antecedents are stimuli or situations which trigger a behaviour, whilst consequences act to reinforce and maintain the behaviour. The PLST model proposes that BCs are stress responses, and manifestations of an over-reaction to stimuli and situations (Hall & Buckwalter, 1987; M. Smith et al., 2004). This over-reaction is due to a progressively greater vulnerability, and a lowered stress threshold, which is considered part of the dementia process. The unmet needs model explains BC as a response to unmet needs (e.g. attachment, identity, comfort) that the person with dementia is not able to effectively communicate, or successfully identify, due to impaired functioning (Cohen-Mansfield, 2000b, 2008). The model posits that by identifying and meeting this need, the BC will reduce, and the individual's wellbeing will improve.

#### The Newcastle Model to Understand and Manage BC in Dementia

The Newcastle model is a clinical model for BC in dementia, developed by the Newcastle Challenging Behaviour Team, led by Ian James (James & Jackman, 2017). It is an idiosyncratic formulation-driven approach, which reflects Kitwood's person-centred conceptualisation of dementia (Kitwood, 1997). The Newcastle model incorporates aspects of above-mentioned biopsychosocial theories of BC, particularly the unmet needs model by Cohen-Mansfield (2000a). The model is also incorporating theory from cognitive therapy (Beck, 1976).

The Newcastle model was developed specifically for BC in dementia within a care home setting. Clinicians work in small specialist behaviour support teams consisting of psychologists and nurses. Each clinician manages a small caseload of patients from various care homes (Jackman, 2020). Referrals come from care homes regarding specific residents and for a particular behaviour of concern. The focus on individual patients is distinctive to programmes such as the Staff Training in Assisted Residences (STAR), in which clinicians provide wider training to carers and staff teams on how to implement a behavioural approach (Teri et al., 2005). Moreover, compared to other formulation-led interventions, the Newcastle model is unique in that it is provided to dementia care homes by an external specialist team (Holle et al., 2017).

James and Jackman (2017) provide a detailed structure of the Newcastle model. Running over approximately 8 to 12 weeks, the approach includes comprehensive assessment of the BC including information gathered from staff, family and structural assessment measures (Jackman, 2020). From the assessment, a biopsychosocial formulation is developed collaboratively between the clinician, the involved care home staff members and family as part of an Information Sharing Session (ISS). Following the formulation stage, the specific care staff and family members implement the person- and formulation-specific intervention strategies with the support of the clinician from the Behaviour Support Team. During the end phase, the clinician is monitoring progress, providing further support to care home staff and tweaks strategies as necessary.

The Newcastle model is the most widely-used formulation for BC in dementia amongst clinicians in the UK (James et al., 2020). Other formulation-led approaches exist,

4

which are similar in their non-pharmacological and person-specific emphasis (e.g. Kales, Gitlin, & Lyketsos, 2014; Karlin, Visnic, McGee, & Teri, 2014).

There are certain unique aspects of the Newcastle model, such as the ISS. The ISS is arranged by the clinician following the assessment stage with both care staff and family members attending. The ISS offers an opportunity for all involved parties to discuss their understanding of the BC (Jackman, 2013). During this session, the clinician outlines the Newcastle model but then allow the care staff and family members to develop their own hypotheses regarding unmet needs, and how to meet these with strategies. The clinician's role is to facilitate discussion around the biopsychosocial factors rather than direct or inform staff, which promotes collaboration and ownership of the intervention (Jackman, Wood-Mitchell, & James, 2014). As such, facilitation of information and knowledge between systems of care is a key aspect of the ISS, and the Newcastle model.

Collaboration with care staff is an integral part of the Newcastle model, and the clinician adopts an informal and genuinely curious stance towards assessment, formulation and intervention. The Newcastle model is sometimes referred to as the 'Columbo approach', which highlights the investigative role of the clinician, but also the mindset adopted in order to facilitate true collaboration and ownership. Clinicians utilise frameworks such as Listen, Clarify, Agree, Plan and Support (LCAPS), which is outlined in James and Jackman (2017). The LCAPS underpins the collaborative style of the Newcastle model, and helps assist care staff to make important links between variables in the formulation and to discover possible ways forward.

Moreover, clinicians using the Newcastle model are not evaluating the intervention solely in terms of a reduction in the observed behaviour. Adopting a more socialconstructivist view, a change in care staff culture and perceptions, or families' beliefs, is seen as just as important in terms of having an impact on the wellbeing of the person with dementia. This view is in contrast to traditional behavioural interventions where a positivistic stance on goal setting and evaluation relies more on observable reductions in the targeted behaviour.

From a social-constructivist interpretation, a behaviour is not regarded as intrinsically problematic (Taft et al., 1997). This analysis could be particularly suitable for SIBs, which are reported to be the most difficult behaviours by carers and families, often because they are not in keeping with the premorbid personality of the person with dementia (Tsatali et al., 2011). As such, the behaviour is primarily distressing for people around the person with dementia. In order not to pathologise sexuality, it is crucial to recognise the impact of social and cultural norms on the perception of SIB.

Figure 1 shows a diagram of the Newcastle formulation illustrating how the model accounts for biological (medication, physical health, cognitive impairment), psychological (personality, mental health) and social (environment, history) factors. As seen in Figure 1, medication and physical health are part of the formulation, and this reflects the prevalence of long-term health conditions, incontinence, pain and infections, which can all be underlying factors in BC (Sampson et al., 2009).

The formulation has a strong emphasis on the combined influence of historical and present factors. A comprehensive life-history and description of the premorbid personality of the person with dementia can provide information about underlying causes to the BC, and how the behaviour can be understood in the present context. In fact, the formulation used in the Newcastle model tends to focus more on biographical factors compared to other biopsychosocial frameworks. For example, Kunik's mutable and immutable variables model has a stronger emphasis on present and adaptable determinants (e.g. Kunik et al., 2003).

Further, the Newcastle model is incorporating aspects from cognitive theory (Beck, 1976) into the formulation, which is another unique feature of the model. As seen in Figure 1,

observations of the BC are included in the formulation in terms of vocalisations and appearance, which are understood as representations of thoughts (vocalisations) and feelings (appearance) of the person with dementia. Thoughts and feelings, in the context of the biography and additional biopsychosocial factors, provide information to better understand unmet needs (James, 2015).

<Figure 1. here>

The evidence for individual formulation-based approaches is promising, but more research is needed (Holle et al., 2017). There is evidence for the clinical utility of the Newcastle model in order to manage BC in dementia (Fossey & James, 2007; James, 2010; James & Jackman, 2017; Kennedy & MacKenzie, 2007; Smith & MacKenzie, 2011). The approach has been used in a large randomised controlled trial conducted over multiple sites, resulting in significant reductions in antipsychotic medication within the participating care homes (Fossey et al., 2006). Similarly, there is evidence for the underpinning principles of the model (James & Fossey, 2013).

In summary, the Newcastle model utilises established theoretical frameworks whilst offering an innovative and flexible clinical approach to manage BC. More clinical evidence is needed for SIB, and the Newcastle model could be advantageous for these presentations due to its focus on understanding the unmet need in the context of biographical variables and by adopting a more social-constructivist view of BC.

#### 2. Case Introduction

The present case conceptualisation describes the implementation of the Newcastle model to manage verbal agitation, aggression and sexual vocalisations in a patient with dementia who lives in a care home setting. All names, and some information, have been changed to ensure anonymity. The patient, referred to here as "Susan", is a lady in her late 80s who was referred to the Behaviour Support Service by her General Practitioner (GP). The Behaviour Support Service is a specialist service in Scotland which works exclusively with BC in dementia in care homes using the Newcastle model.

The brief referral described frequent and persistent rudeness and bad language, and occasional verbal aggression. It was detailed that Susan can be very impatient with other residents, particularly when needing the toilet. The care home staff team had contacted the GP as they felt they required additional support in managing this behaviour and were grateful for any input.

#### **3. Presenting Complaints**

Care home staff reported two BCs. The first BC was described as a Sexually Inappropriate Behaviour (SIB). The SIB involved sexual comments towards staff (e.g. "I'd rather have you then the medication"), whistling at and, at times, pinching staff on their bottoms. During these situations, staff had described Susan's appearance as restless and amused. There were no obvious triggers identified.

The second BC described was that Susan could become verbally agitated and aggressive including swearing and shouting abusive comments (e.g. "f\*\*k off" or "you can't tell me what to do"). The care staff's accounts described Susan as impatient, frustrated or angry during these episodes. The verbal aggression was mainly targeted towards staff, but there had been incidents where other residents had been verbally abused. This BC was often triggered by being challenged, or when Susan needed to go to the toilet.

The staff team's general approach to manage these two types of behaviours was to verbally inform Susan that her behaviour was inappropriate and not acceptable. Susan was directly challenged with regards to swearing, and if her agitation escalated she could be redirected to another area of the care home.

#### 4. History

To gather more details about Susan's history and pre-morbid personality an interview was carried out with her daughter, referred to here as "Carol". Carol explained that Susan grew up in a small town and her childhood was described as free and independent. Susan's mother had met a new partner after Susan's biological father had died, but Susan never accepted or got along with her step-father even as an adult. Susan had a successful career working her way up to become a manager and was highly regarded in her line of work. When Carol was around ten years old her father had an affair and Susan left her husband the same day she found out, taking the three children with her. Susan never showed any emotions about the divorce in front of her children and she never had any partner after this.

In addition to having a strong and independent personality, Carol also described her mother as a creative and social person who loved to sing and play music, such as the piano, especially at social gatherings. On occasions, Carol still notices Susan's social personality, and her Mother sometimes asks if they 'can have a laugh' in the care home. Susan has always loved to listen to classical and folk music and as a Sunday school teacher she often practiced church songs with her children at home. Church had always been a big part of Susan's life, and Carol said her Mother regarded swearing as a sign of a lack of education. Moreover, Susan never liked to be in the wrong or to be criticised, and she had always disliked authority. Carol said the dislike of criticism probably originated from frequently being criticised by her step-father.

#### 5. Assessment

The assessment took place over the first two weeks of the intervention and included a telephone screening, semi-structured interviews with care home staff, Susan's daughter and Susan. In addition to these interviews, Antecedent Behaviour Consequence (ABC) charts were completed by the care home staff team over a period of two weeks, and subsequently

9

summarised by the Behaviour Support Service. The assessment process followed the Newcastle model and the information gathered is synthesised and presented below to reflect the model.

#### **ABC Charts and Functional Analysis**

From the assessment, a functional analysis was carried out to summarise all information from the ABC charts about details such as appearance and vocalisations. This analysis indicated that the charts corroborated information from the interviews, which was again reiterated by quantitative data from standardised measures. It also became clear that Susan's verbal aggression appeared to be triggered, or escalated, by being verbally challenged or reprimanded with regards to her inappropriate language.

#### **Physical Health**

In terms of physical health, Susan suffers from diabetes, osteoarthritis and she had recently been struggling with constipation and diverticulosis - a gastrointestinal disease causing discomfort and abdominal pain. Additionally, her records indicated that Susan had suffered from frequent and persistent Urinary Tract Infections (UTIs) over the past year which had been treated with antibiotics. The urine sample screening, requested to be carried out, came back clear from infection. Staff also administered brief pain scales, which together with their verbal accounts did not indicate significant pain.

#### Medication

Susan was prescribed regular analgesia, laxatives, one antidepressant medication, Pregabalin, and Galantamine. It was noted that her medication was reviewed regularly and recently by her GP.

#### **Social Environment**

Susan has frequent visits from her daughter, Carol, and her two grandchildren. Carol lives nearby and was well known by the care home staff. Staff described Susan as an active

10

person, but that her involvement in activities depends on her mood. Staff said that Susan loves music and always engages with activities that involve music.

#### **Cognition and Dementia Diagnosis**

Meetings with Susan were arranged to observe, in-person, the level of agitation and to broadly examine her cognitive functioning in areas such as orientation and memory. Susan has a diagnosis of mixed vascular/Alzheimer's dementia. She has severe memory impairment and when asked, Susan did not remember any names of her key workers or her most recent meal, nor her daughter's name. She appeared orientated to place and could state the name of the care home. From meeting with Susan there was some evidence of disinhibited behaviour but no verbal agitation.

#### **Mental Health**

Susan's daughter did not believe that Susan suffered from low mood or significant anxiety, and did not describe a history of mental health difficulties. Care home staff reported that Susan at times can be withdrawn from activities, but this appeared to be a reflection on her personality or simply a dislike of the activities on offer. It is possible that the medication Susan was prescribed was beneficial.

#### **Standardised Instruments**

Standardised instruments were used to gather quantitative information, but also to be used as pre- and post-treatment measures in order to evaluate the intervention. The below questionnaires were administered to the same member of the care home staff on the first and last visit.

# The Neuropsychiatric Inventory (NPI) (Cummings et al., 1994; Cummings, 1997).

The NPI is an informant-based questionnaire divided into 12 sub-domains, including delusions, agitation and disinhibition. It measures frequency of behaviours and the impact on

carers. The NPI has good validity, and a benefit of measuring a wide variety of domains is that it is sensitive to multiple types of dementia, not just Alzheimer's Disease (Cummings et al., 1994).

## Cohen-Mansfield Agitation Inventory (CMAI) (Cohen-Mansfield, Marx, & Rosenthal, 1989).

The CMAI is a widely used informant-based instrument designed to measure frequency of behaviours using a liker-type scale, and has been found to have excellent validity and reliability in care-home settings (Finkel, Lyons, & Anderson, 1992). The Behaviour Support Service uses a system to calculate the CMAI scores which gives a total score for frequency of BC, but also a score for each behaviour category. Higher score equals higher frequency of BC and the maximum score is 174 for total score, 66 for physically nonaggressive behaviour, 60 for physically aggressive behaviour, 24 for verbal-non aggressive behaviour and 24 for verbal aggressive behaviour.

Table 2 illustrates that the scores indicated mainly verbal aggressive and verbal nonaggressive behaviours as the main type of difficult behaviours, which was in line with their verbal reports. The total score on the CMAI was 35 out of 174, with higher scores indicates higher frequency of BCs. As such, although the verbal reports had described how staff found these behaviours difficult to manage, the frequency of BC, as reported on the standardised instruments, was relatively low.

Additionally, staff members had administered several Abbey Pain Scales, which is a brief instrument to quantify pain in patients with progressed dementia (Abbey et al., 2004). The pain scales did not indicate pain as a contributing factor to Susan's distress.

#### 6. Case Conceptualization

An initial formulation of Susan's distress was developed using the Newcastle model. To ensure anonymity, only a summary of the case-formulation diagram is presented in Figure 2. As mentioned in the introduction, a key to a successful implementation of the Newcastle model is to acknowledge and involve people and systems around the individual (Jackman, 2020). An Information Sharing Session (ISS) was arranged inviting anyone involved in the care of Susan. Key members of the care team, her daughter and two clinical psychologists from the Behaviour Support Service were present for this session. During the ISS, the key contributors were care home staff and the daughter (Jackman, Fielden, & Pearson, 2017). Several hypotheses were discussed with regards to how the identified BCs could be understood from a biopsychosocial perspective, acknowledging contributing factors and unmet needs. Moreover, the ISS provided a chance for staff to sit down with the daughter to share their knowledge and expertise about Susan and the presented problem. It was hoped this allowed staff to recognise a sense of ownership of the intervention (Janes & Shirley, 2008; Kennedy & MacKenzie, 2007). Similarly, the ISS provided staff with further information about Susan's history and personality. Below is a summary of the hypotheses that came out of the ISS for each of the two BCs.

#### Hypotheses Regarding Sexually Inappropriate comments, Whistling or Pinching Staff

Susan has always been a social person who thrives on being the centre of attention, and she still likes to 'have a laugh'. Due to her dementia, her behaviour has become increasingly disinhibited. Thus, a reduced ability to 'filter' her language in combination with her social personality can lead to inappropriate comments, and behaviour intended as a way of 'having a laugh' can be perceived as offensive by staff and other residents. Susan appears to be more distressed when staff let her know that her language is inappropriate, which can sometimes escalate into verbal aggression. Susan has always been strongly against swearing and has strong religious beliefs and so it is understandable that she feels embarrassed from being reminded of her inappropriate behaviour. In addition, Susan has never handled criticism well, and did not like her step-father who frequently criticised her, and so it is expected that Susan's distress increases when being verbally challenged by staff. Moreover, due to her impaired memory, it is unlikely Susan will learn from being 'told off' and adapt her behaviour from this. Staff at the care home felt uncomfortable by the sexual nature of Susan's comments and their need to instantly challenge this behaviour could have been exaggerated by their own anxieties.

In summary, it was thought that Susan appeared to communicate some of her premorbid personality and identity as the person who is at the centre of attention, and who is social and outgoing. Staff and family had identified an unmet need for identity that could be met using strategies focusing on social interaction and positive attention.

#### Hypotheses Regarding Verbal Aggression, Irritability and Being Impatient

Susan has a history of frequent and persistent UTIs which can cause discomfort and toileting urgency. Moreover, UTIs can cause confusion and irritability from potential delirium. Susan has also suffered from diverticulosis and although pain scales did not indicate significant pain this condition can result in intensive pressure on the bladder and bowel leading to discomfort and feelings of urgency. As a result of her dementia, Susan might find it difficult to identify and communicate these needs in an appropriately and timely manner. Susan might behave impatiently and aggressively as she is perceiving the discomfort as a sign of immediate urgency to the toilet and is afraid she will not get there in time. It was believed between staff and the daughter that Susan appears to have an unfulfilled need for physical comfort and finds it difficult to identify and communicate this effectively. In addition to this need, to challenge Susan on her language during this distress only triggered further swearing and aggression, relating to above hypothesis.

<Figure 2. here>

#### 7. Course of Treatment and Assessment of Progress

#### Infections

Infections can cause delirium, confusion and discomfort. As Susan had a history of frequent urinary tract infections, strategies were developed to prevent and manage infections in order to avoid distress and agitation. For example, it was agreed that staff would closely monitor for future infections and carry out urine sample screenings promptly if they noticed a rapid increase in distressed behaviour. Similarly, to prevent infections fluids would be encouraged and staff would be extra thorough with personal care.

#### Strategies to Meet the Need for Comfort

Several strategies were agreed to ensure Susan's need for comfort was being met. It is important that psychosocial input should be both preventative as well as reactive (James, 2015). In terms of preventative strategies, blankets were known to provide comfort and reduce stress for Susan. Staff decided to more frequently check if Susan needed to go to the bathroom in order to reduce urgency in the first place. They would also check her trousers to ensure they are not causing unnecessary pressure on her bowel and bladder. Staff also suggested using one particular toilet as this was closer to the lounge. In terms of reactive measures, staff agreed to not challenge Susan if she became upset and verbally aggressive. Instead, they would try to validate her emotions and turn the conversations to topics she enjoys, such as textile or music.

#### Strategies to Meet the Need for Identity and Positive Attention

Susan likes to interact with people and she has an interest in singing and to listen to music. Staff would introduce and trial "playlist for life", an intervention where a playlist is created for the person with dementia and staff listens to the music together with the person. Carol agreed to provide the staff team with particular songs. Jokes and positivity were

suggested as a mean to provide more positive attention. Staff and the daughter agreed to work together to create a "life story" book with photos, memories and textiles for texture that Susan could use either on her own or together with staff. Similarly, a poetry book was suggested, where Susan could write down things she later could re-cite. Staff would continue to prompt and encourage Susan to use both the life story and poetry book, considering it would be difficult for her to initiate this.

#### **Additional Processes Part of the Intervention**

Discussions and psychoeducation with regards to disinhibited behaviour in dementia was provided to staff and family in order to normalise this. Similarly, Susan's memory impairment was discussed in relation to how much she will retain from being verbally reprimanded. Socratic questioning was used during the assessment and formulation session to allow members of the staff team to evaluate the strategy of directly challenging Susan's language. Staff started to realise that their current strategy was actually worsening Susan's distress, and they decided to trial another approach, in which they tried to ignore the words initially. If the sexual language escalated, staff would apologise to other residents and use the poetry book or any other activity to re-engage Susan in distraction.

#### **Progress and Outcome**

The above-mentioned strategies were summarised into a personalised care plan and presented to the care home staff and the daughter. As recommended, this care plan was a concise summary to ensure staff engaged with it without feeling overwhelmed with information (James and Jackman, 2017). Following the delivery of the care plan to the care home, weekly phone calls or visits were arranged to monitor progress and to adjust any strategies during this trial period.

Preventative strategies were successfully implemented. For example, Carol had bought a poetry book, which she reported had been positively received by Susan. This was reiterated by care staff, who said Susan always carried the poetry book with her and often cited her own poems, and carers prompted her to use the book as they were aware of her memory difficulties. Reactive strategies, such as responding to inappropriate language using re-engagement with humour instead of verbally challenging Susan, has led to fewer incidents where inappropriate comments would escalate into verbal aggression and agitation.

As indicated by data in Table 2, staff reported an overall reduction in observed BC over the course of the involvement of the Behavioural Support Service. Likewise, they reported a reduction in the disruptiveness of these behaviours as seen on the NPI column in Table 2. Interestingly, and in accordance with staff verbal accounts, the verbal-aggression subscale of the CMAI indicated only a slight pre- to post-intervention reduction in the frequency of this behaviour. One carer described that Susan continued to sometimes vocalise inappropriate comments but that the staff team now felt more comfortable and able to manage this type of behaviour.

#### <Table 2 here>

Changes were also reported in the staff group. Following psychoeducation about the concept of disinhibition, staff and Carol started to re-phrase this as "Susan has lost the ability to filter conversations and the ability of stopping herself saying these things". This re-phrasing appeared to have created a more emphatic narrative to Susan's behaviour. Similarly, it became clear that the staff group had appreciated the information regarding Susan's personal history. The staff team admitted that they had very limited previous knowledge regarding 'who Susan really was'. This information had somewhat shifted their perspective from seeing the behaviour as being part of her personality to instead view it in the context of dementia. Again, the staff group's 'narrative' of the problem had potentially changed.

#### 8. Complicating Factors

There were a few complicating factors that had to be acknowledged during the intervention and on reflection. Firstly, most BC in the context of dementia occur co-morbidly with various long-term physical health problems and medical conditions (Bunn et al., 2014). In the case of Susan, she suffered from osteoarthritis, which appeared to be well managed with medication. In addition, she was diagnosed with diverticulosis, a disease causing discomfort. Together, these long-term physical health conditions were incorporated into the formulation, and the care plan, as possible contributing factors to her distress.

Secondly, it was known that Susan had a history of frequent and persistent urinary tract infections (UTIs). Infections can cause delirium, confusion and discomfort, and psychosocial interventions will have little to no effect if the underlying cause is biological as this requires antibiotics (Krishnamoorthy & Anderson, 2011). It was therefore essential that UTIs were screened for and ruled out before any further assessment was undertaken.

Lastly, Susan experienced significant cognitive impairment as a result of progression of the dementia process. Cognitive impairment, in Susan's case particularly autobiographical recall and impaired learning, often results in the individual with dementia having limited capacity and volition to change their own behaviour. For example, in Susan's case she had to be frequently reminded of the poetry book she had been given as a strategy to meet the need of identity.

#### 9. Access and Barriers to Care

There were no financial barriers to care. The treatment presented in this case study was provided by a specialist service which is part of the National Health Service (United Kingdom). The National Health Service offers publicly funded medical care. In terms of access to care, the present case took place in a care home located within a city in the United Kingdom. However, specialist services, such as the BSS, are less common in rural areas, and

18

access to specialist advice on BC in the context of dementia is not always available to care home staff or nursing staff in hospitals (Alzheimer's Society, 2007; Krishnamoorthy & Anderson, 2011).

#### **10. Follow-Up**

As part of the Newcastle model, the weeks following the delivery of the care plan involves contact with the care home and the family to provide ongoing evaluation and adjustment of implemented strategies. Meetings were arranged at the care home and over the telephone, at which the intervention progress was discussed and the staff group had opportunities to voice their experience of implementing the strategies. In addition to monitoring progress and outcome, research has shown that continued staff support is linked to better long-term outcomes and staff confidence (Featherstone et al., 2004; Fossey et al., 2006). Following this period, a final visit is carried out to the care home where posttreatment assessment measures are completed and a post-intervention interview is held with care staff. Continued direct and indirect benefits were reported. Susan continued to be more occupied with meaningful tasks, and staff had adjusted their response to her sexual inappropriate comments. Staff reported an increased confidence in their knowledge about Susan, and felt more capable managing any BC that occurred. Susan could still became verbally agitated at times, but the care staff now interpreted this vocalisation as a way of communicating discomfort or distress, and they now had several strategies to manage these incidents.

Unfortunately, there were no additional long-term follow-up assessment with standardised instruments. The present case study was carried out in a clinical practice context and therefore followed the model structure. This is a limitation to the present case as it makes it impossible to provide an evaluation of the Newcastle model from a long-term perspective in this particular case.

#### **11. Treatment Implications of the Case**

There are some important implications from the present case. The Newcastle model is the most common approach in managing BC in dementia in the UK (James et al., 2020). The present case report indicates that the Newcastle model has utility in managing verbal aggression and sexual comments in the context of dementia within a care home setting. The Newcastle model is a flexible approach, grounded in theoretical conceptualisations of dementia and BC. The Newcastle model offers a relatively brief intervention which should be considered as one of the biopsychosocial first-line treatments to BC in dementia, as this is recommended prior to medication (Banerjee, 2009).

The present case has also demonstrated that the main changes were not only observed in quantitative reductions of the BC. In Susan's case, the behaviour had become less 'challenging' as the care staff knew more about her history, personality and about the concept of disinhibition in dementia. This could be argued as an example of the social-constructivist view, where context and culture plays a key role, and the behaviour in itself is not the only 'story' (Taft et al., 1997). Similarly, it emphasises the importance of a collaborative and systemic approach where care staff and family members are regarded as active participants, and not simply sources of information. Thus, the present case has also shown that the Newcastle model is a collaborative approach between clinicians and systems of care around the individual with dementia (Jackman, 2020). In the present case, the care staff's responses and understanding appeared to be the largest change.

Additionally, the present case study introduces questions about the role of care staff, and their own anxieties and stress levels. For example, members of the staff group explicitly stated that they did not know much about the person they cared for, Susan. Working with dementia, and BC, in care homes has been associated with stress, lower job satisfaction and 'compassion fatigue' (Dougherty et al., 1992; Everitt et al., 1991; Peate, 2014). Stress and low staff morale amongst care staff can lead to a depersonalisation of patients (Bredin et al., 1995). In fact, Kitwood (1997) regarded this as a barrier for organisational change towards a person-centred dementia care system. Taken together, the findings from the present case study shows that when care staff are given time to focus on an individual patient and their history, the staff group's perceptions alter and they are able to manage difficult behaviours, and potentially feel less anxious at work.

#### 12. Recommendations to Clinicians and Students

The Newcastle model could be recommended as a helpful, brief and easy to implement approach to manage verbal aggressions and sexual comments amongst people with dementia in care homes. It will be important to produce reports of the implementation of the Newcastle model to other types of BCs. BC is heterogeneous concept and although the Newcastle model is idiosyncratic and flexible, it should also not be considered a one-sizefits-all, as this is one of the main criticisms of antipsychotic medication in the treatment of BC. Further studies evaluating the Newcastle model do not necessarily require randomised controlled trials in the first instance, but small N designs or case reports could further delineate ecological validity and utility, in which results such as the reported changes in staff perception can be acknowledged.

For clinicians, a recommendation from this case report is the importance of collecting a personal history and pre-morbid personality, and to share this with individuals involved in the care of the patient, as outlined in the Newcastle model (James & Jackman, 2017). The staff group in the present case voiced their lack of knowledge regarding Susan's personality and history, and providing this information appeared to have helped develop and maintain an emphatic approach in their future care of her.

The final recommendations would be with regards to long-term follow-ups and measurements. The Newcastle model is a brief model, but an improvement would be to

extend it by a follow up appointment three, six or twelve months post-intervention. As staff perceptions have been outlined as a key change in this case, it will be essential for future studies to measure these using questionnaires, in order to collect and present quantitative data supporting the claims in the present case study.

#### References

- American Geriatrics Society and American Association for Geriatric Psychiatry. (2003).
  Consensus statement on improving the Quality of Mental Health Care in U.S. Nursing
  Homes: Management of depression and behavioral symptoms associated with dementia. *Journal of the American Geriatrics Society*, 51(9), 1287–1298.
- Alzheimer's Society. (2007). *Home from Home: a report highlighting opportunities for improving standards of dementia care in care homes.*

Alzheimer's Society. (2014). Dementia UK: Update.

- Banerjee, S. (2009). The use of antipsychotic medication for people with dementia: Time for action. *Department of Health*, 60.
- Beck, A. T. (1976). *Cognitive therapy and the emotional disorders*. International Universities Press.
- Brechin, D., Murphy, G., James, I. A., & Codner, J. (2013). Alternatives to antipsychotic medication: psychological approaches in managing psychological and behavioural distress in people with dementia.
- Bredin, K., Kitwood, T., & Wattis, J. (1995). Decline in quality of life for patients with severe dementia following a ward merger. *International Journal of Geriatric Psychiatry*, 10(11), 967–973.
- Buchanan, J. A. (2006). A review of behavioral treatments for persons with dementia. *The Behavior Analyst Today*, 7(4), 521–537.

Bunn, F., Burn, A. M., Goodman, C., Rait, G., Norton, S., Robinson, L., Schoeman, J., &

Brayne, C. (2014). Comorbidity and dementia: A scoping review of the literature. *BMC Medicine*, *12*(1).

- Cohen-Mansfield, J. (2000a). Nonpharmacological Management of Behavioral Problems in Persons with Dementia: The TREA Model. *Alzheimer's Care Today*, *1*(4), 22.
- Cohen-Mansfield, J. (2000b). Theoretical Frameworks for Behavioral Problems in Dementia. *Alzheimer's Care Today*, 1(4), 8.
- Cohen-Mansfield, J. (2008). The Language of Behaviour. In M. Downs & B. Bowers (Eds.), *Excellence in Dementia Care: Research into Practice*. Open University Press/McGraw Hill Education.
- Cohen-Mansfield, J. (2013). Nonpharmacologic treatment of behavioral disorders in dementia. *Current Treatment Options in Neurology*, *15*(6), 765–785.
- De Giorgi, R., & Series, H. (2016). Treatment of Inappropriate Sexual Behavior in Dementia. In *Current Treatment Options in Neurology* (Vol. 18, Issue 9).

Department of Health. (2009). Living well with dementia: A National Dementia Strategy.

- Dougherty, L. M., Bolger, J. P., Preston, D. G., Jones, S. S., & Payne, H. C. (1992). Effects of Exposure to Aggressive Behavior on Job Satisfaction of Health Care Staff. *The Journal of Applied Gerontology*, 11(2), 160–172.
- Everitt, D. E., Fields, D. R., Soumerai, S. S., & Avorn, J. (1991). Resident Behavior and Staff
  Distress in the Nursing Home. *Journal of the American Geriatrics Society*, 39(8), 792–798.

Featherstone, K., James, I. A., Powell, I., Milne, D., & Maddison, C. (2004). A Controlled

Evaluation of a Training Course for Staff Who Work with People with Dementia. *Dementia*, *3*(2), 181–194.

- Fisher, J. E., Drossel, C., Yury, C., & Cherup, S. (2007). A contextual model of restraint-free care for persons with dementia. In *Functional Analysis in Clinical Treatment* (pp. 211– 237).
- Fossey, J., Ballard, C., Juszczak, E., James, I., Alder, N., Jacoby, R., & Howard, R. (2006). Effect of enhanced psychosocial care on antipsychotic use in nursing home residents with severe dementia: Cluster randomised trial. In *British Medical Journal* (Vol. 332, Issue 7544, pp. 756–758).
- Fossey, J., & James, I. A. (2007). Evidence-based Approaches for Improving Dementia Care in Care Homes.
- Hajjar, E. R., Cafiero, A. C., & Hanlon, J. T. (2007). Polypharmacy in elderly patients. *American Journal Geriatric Pharmacotherapy*, 5(4), 345–351.
- Hall, G. R., & Buckwalter, K. C. (1987). Progressively lowered stress threshold: a conceptual model for care of adults with Alzheimer's disease. *Archives of Psychiatric Nursing*, *1*(6), 399–406.
- Higgins, A., Barker, P., & Begley, C. M. (2004). Hypersexuality and dementia: dealing with inappropriate sexual expression. In *British journal of nursing (Mark Allen Publishing)* (Vol. 13, Issue 22, pp. 1330–1334).
- Holle, D., Halek, M., Holle, B., & Pinkert, C. (2017). Individualized formulation-led interventions for analyzing and managing challenging behavior of people with dementia–an integrative review. In *Aging and Mental Health* (Vol. 21, Issue 12, pp.

1229–1247).

- Jackman, L. (2013). When, how and why does indirect formulation work? Proposing a "shared formulation" framework. *Clinical Psychology Forum*, *245*, 25–31.
- Jackman, L. (2020). Extending the Newcastle Model: how therapeutic communication can reduce distress in people with dementia. *Nursing Older People*, *32*(2), 33–41.
- Jackman, L., Wood-Mitchell, A., & James, I. A. (2014). Micro-skills of group formulations in care settings. *Dementia*, *13*(1), 23–32.
- James, I. A. (2010). The treatment of challenging behavior in care facilities: Ellen. In Casebook of clinical geropsychology: International perspectives on practice (pp. 135– 153). Oxford University Press.
- James, I. A. (2015). The use of CBT in dementia care: A rationale for Communication and Interaction Therapy (CAIT) and therapeutic lies. *Cognitive Behaviour Therapist*, 8.
- James, I. A., & Fossey, J. (2013). Nonpharmacological interventions in care homes. Oxford Textbook of Old Age Psychiatry (2nd Ed.)., March, 269–281.
- James, I. A., & Jackman, L. (2017). Understanding behaviour in dementia that challenges: A guide to assessment and treatment, Second Edition. PA: Jessica Kingsley.
- James, I. A., Mahesh, M., Duffy, F., Reichelt, K., & Moniz-Cook, E. (2020). UK clinicians' views on the use of formulations for the management of BPSD: a multidisciplinary survey. *Aging & Mental Health*, 1–8.
- Jokanovic, N., Tan, E. C. K., Dooley, M. J., Kirkpatrick, C. M., & Bell, J. S. (2015). Prevalence and Factors Associated With Polypharmacy in Long-Term Care Facilities: A

Systematic Review. In *Journal of the American Medical Directors Association* (Vol. 16, Issue 6, pp. 535.e1-535.e12).

- Kales, H. C., Gitlin, L. N., & Lyketsos, C. G. (2014). The time is now to address behavioral symptoms of dementia. *Generations*, 38(3), 86–95.
- Karlin, B. E., Visnic, S., McGee, J. S., & Teri, L. (2014). Results from the multisite implementation of STAR-VA: A multicomponent psychosocial intervention for managing challenging dementia-related behaviors of veterans. *Psychological Services*, *11*(2), 200–208.
- Kennedy, E., & MacKenzie, L. (2007). Challenging behaviour. Understanding Thomas: needs born of fear and frustration. *Journal of Dementia Care*, *15*(6), 20–24.
- Kitwood, T. (1997). Dementia reconsidered: The person comes first. Open University Press.
- Krishnamoorthy, A., & Anderson, D. (2011). Managing challenging behaviour in older adults with dementia. In *Progress in Neurology and Psychiatry* (Vol. 15, Issue 3, pp. 20–26).
- Kunik, M. E., Lees, E., Snow, A. L., Cody, M., Rapp, C. G., Molinari, V. A., & Beck, C. K. (2003). Disruptive behavior in dementia: A qualitative study to promote understanding and improve treatment. *Alzheimer's Care Today*, 4(2), 125–136.
- Lyketsos, C. G., Lopez, O., Jones, B., Fitzpatrick, A. L., Breitner, J., & Dekosky, S. (2002).
  Prevalence of neuropsychiatric symptoms in dementia and mild cognitive impairment:
  Results from the cardiovascular health study. *Journal of the American Medical Association*, 288(12), 1475–1483.
- National Institute for Health and Care Excellence. (2018). *Dementia: Assessment, management and support for people living with dementia and their carers (NG97).*

- Peate, I. (2014). Compassion fatigue: The toll of emotional labour. In *British Journal of Nursing* (Vol. 23, Issue 5, p. 251).
- Sampson, E. L., Blanchard, M. R., Jones, L., Tookman, A., & King, M. (2009). Dementia in the acute hospital: Prospective cohort study of prevalence and mortality. *British Journal* of Psychiatry, 195(1), 61–66.

Scottish Government. (2017). Scotland's National Dementia Strategy 2017-2020.

- Smith, K. T., & MacKenzie, A. (2011). Dementia: Complex case work. In Mental health and later life: Delivering an holistic model for practice (pp. 137–152). Routledge/Taylor & Francis Group.
- Smith, M., Gerdner, L. A., Hall, G. R., & Buckwalter, K. C. (2004). History, development, and future of the progressively lowered stress threshold: A conceptual model for dementia care. In *Journal of the American Geriatrics Society* (Vol. 52, Issue 10, pp. 1755–1760).
- Taft, L. B., Fazio, S., Seman, D., & Stansell, J. (1997). A psychosocial model of dementia care: Theoretical and empirical support. *Archives of Psychiatric Nursing*, *11*(1), 13–20.
- Teri, L., Huda, P., Gibbons, L., Young, H., & Van Leynseele, J. (2005). STAR: A dementiaspecific training program for staff in assisted living residences. *Gerontologist*, 45(5), 686–693.
- Thomas, R. (2020). Watch out for the trend: mental health matters. *Health Service Journal*, *22nd June*.
- Thompson, C., Brodaty, H., Trollor, J., & Sachdev, P. (2010). Behavioral and psychological symptoms associated with dementia subtype and severity. *International*

*Psychogeriatrics*, *22*(2), 300–305.

- Thornton, H., & Offord, R. (2015). Non-pharmacological management of sexual behaviours that challenge in dementia. *Reviews in Clinical Gerontology*, *25*(3), 194–201.
- Tsatali, M. S., Tsolaki, M. N., Christodoulou, T. P., & Papaliagkas, V. T. (2011). The complex nature of inappropriate sexual behaviors in patients with dementia: Can we put it into a frame? In *Sexuality and Disability* (Vol. 29, Issue 2, pp. 143–156).
- Wastesson, J. W., Morin, L., Tan, E. C. K., & Johnell, K. (2018). An update on the clinical consequences of polypharmacy in older adults: a narrative review. In *Expert Opinion on Drug Safety* (Vol. 17, Issue 12, pp. 1185–1196).

### Tables and Figures

Table 1. Common Behaviours tha	Challenge (BC) from	a James and Jackman (2017)
--------------------------------	---------------------	----------------------------

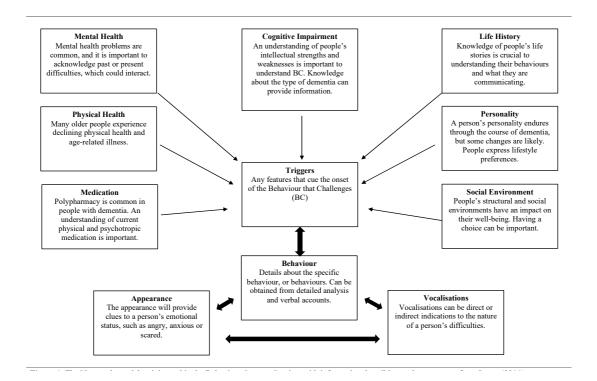
Aggressive forms of BC	Non- aggressive forms of BC	
Hitting, Kicking,	Repetitive questions, Pacing,	
Grabbing, Pushing,	Urinating in inappropriate places,	
Biting, Spitting,	Following others, Hoarding, Smearing,	
Swearing, Screaming,	Agitation, Excessive eating/drinking,	
Verbal sexual advances	Apathy	

Measure		Pre	Post	Change			
NPI							
	Total frequency/severity	31	18	-13			
	Total disruptiveness	9	7	-2			
CMA	I						
	Total frequency	35	24	-11			
	Physical non-aggressive beh.	8	5	-3			
	Physical aggressive beh.	3	1	-2			
	Verbal non-aggressive beh.	10	9	-1			
	Verbal aggressive beh.	14	9	-5			
	Passive beh.	8	6	-2			

#### **Table 2.** Changes in outcome measures from pre- to post-intervention

*Note*. NPI = The Neuropsychiatric Inventory, CMAI = Cohen-Mansfield Agitation Inventory

**Figure 1.** The Newcastle Model as it is used in the Behaviour Support Service, with information describing each component from James and Jackman (2017).



**Figure 2.** The Newcastle Model with information gathered from the assessment of Susan's difficulties (some details have been redacted to ensure anonymity).

