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A New Holistic Non-pharmacological Framework for Understanding and Managing Behavioural and Psychological Symptoms of Dementia

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MCQs

1. In NICE's management of BPSD the use of antipsychotics are:
 - a. Recommended for everyone with dementia
 - b. Discouraged entirely
 - c. Always preferred to the use of benzodiazepines
 - d. Used with caution due to their expense
 - e. Used with caution due to their potential for problematic side-effects

2. Formulation for BPSD is:
 - a. Always shared with the person with dementia
 - b. Used solely to direct the prescribing of medication
 - c. Most appropriate for treating the mood element of any presentation
 - d. Inappropriate for people with severe dementia
 - e. Provides a holistic perspective, examining the biopsychosocial nature of the person's presentation

3. The Stepped-care model in dementia is:
 - a. An evidenced-based exercise treatment for people with dementia
 - b. A treatment program outlining four stages of management for BPSD
 - c. Designed to treat carer distress
 - d. Used exclusively in care homes
 - e. A recently developed physiotherapy measure for the assessment of mobility

4. The term BPSD stands for:
 - a. Behavioural and Psychological Symptoms of Dementia
 - b. British Psychiatric Society of the Dementias
 - c. Behavioural Problems Seen in Dementia
 - d. Best Practice Services for Dementia
 - e. Brit-list of Psychotropic Side-effects of Drugs

5. ACME is
 - a. A holistic model for the management of BPSD, involving assessments, conceptualising, managing and evaluating processes
 - b. The name of a famous randomised controlled study concerning the treatment of BPSD
 - c. A company providing restraint equipment in dementia care
 - d. An occupational therapy program for assessing sensory abilities in dementia care
 - e. A form of music therapy used to treat depression in people with dementia

Abstract

NICE dementia guidelines inform us that nonpharmacological treatments are first-line treatments for Behavioural and Psychological Symptoms of Dementia (BPSD). While psychotropics used to be the main treatment strategy in the management of behaviours that challenge, there has been an increase in the use of biopsychosocial formulations since 2010, and there are now over a dozen formulations to choose from. However, many are overly focused on obtaining information about the agitation, and less specific about providing details of the 'actions' required to manage the behaviours. The NICE (2018) guidelines too fail to provide specific guidance on which nonpharmacological approaches to use. This article argues for giving equal weight to both the collection of meaningful information and to the development of 'informed-actions', because it is the actions that lead to change. This paper outlines a management programme, providing a framework for the assessment, formulation and treatment of agitation in dementia. The work draws on theory, evidence-based practice, and practice-based evidence in order to provide a model with both sufficient structure and flexibility to be useful for clinicians across a range of settings and professional groups.

Learning Objectives

After reading this article you will be able to:

- ☑ appreciate the complexities associated with treatment of BPSD.
- ☐ understand the importance of nonpharmacological approaches in the management of BPSD.
- ☐ have familiarised yourself with structured approaches, including stepped-care model, to manage BPSD.

Introduction

National guidelines, including in the UK, support the use of nonpharmacological approaches as first-line treatments in relation to Behavioural and Psychological Symptoms of Dementia (BPSD) unless there are immediate risks requiring tranquilisation or sedation (University of Exeter, 2017). Comprehensive reviews of the psychotropic treatment of BPSD, using antipsychotics, benzodiazepines, antidementia drugs, hypnotics and mood stabilizers, acknowledge the complex trade-offs between the costs and benefits of prescribing in this area (IPA, 2015). Of particular concern is the problematic side-effect profiles of many of the drugs, in light of only moderate

treatment efficacy (Tible *et al.*, 2017). The situation is made even more difficult because of the multi-morbidity, reduced drug metabolism and polypharmacy issues related to prescribing for this vulnerable group of patients. Owing to the complexities and problems associated with pharmacological management, NICE guidelines suggest to “offer psychosocial and environmental interventions to reduce distress” (NICE 2018, p25). However, this rather vague description of the nature of the nonpharmacological strategies offers no clear alternative to pharmacological solutions, thus resulting in a continued over-reliance on medication. It is estimated that 90% of people with dementia experience BPSD as part of their illness and over 70% of those living in care with dementia are displaying stress and distress at any one time. BPSD are associated with worsening cognition and higher levels of caregiver burden; they increase the risk of acute hospitalisation and institutionalisation within 24-hour care settings (IPA, 2015; Moniz-Cook *et al.*, 2017; Feast *et al.*, 2016). BPSD can be complex phenomena and to manage them appropriately a lot of information is potentially required, including details about a person’s physical and mental health, premorbid personality, dementia type, medication regimen, environment, etc. Two key features, or deficits, that often make treatment regimens for agitation different in dementia compared to many other presentations are: (i) short term memory (STM) loss, and (ii) loss of insight into having deficits. In terms of the first feature, a reduction in STM reduces the person’s ability to engage in standard therapies because new learning is prevented; as STM gets worse the person can potentially be unaware of time, place and orientation. They will become decoupled from the present reality, and become time-shifted, occupying their own reality (e.g. believing husband is still alive; they have young children). If such deficits are accompanied by a loss of insight, the person will not be aware that their thinking is faulty, and thus be less inclined to be persuaded that their perspective may be wrong. When both of these deficits are present, the focus for nonpharmacological treatments often shifts to the carers and away from the person with dementia. It is the carers who are required to adjust their communication style and interactions in order to reduce the likelihood of triggering the BPSD. In other words, the caregivers become the ‘agents of change’.

One of the ways clinicians have attempted to help caregivers determine what they are required to do and say is by providing them with simple conceptual models or formulations. A popular model is the ‘unmet-needs’ conceptualisation. Authors such as Algase *et al.*, (1996) and Cohen-Mansfield (2000) have proposed that BPSD are an expression of distress that arises from physical or psychological unmet needs. For example, Cohen-Mansfield (2000) argues that BPSD often reflect an attempt by a person to signal a need that is currently not being met (e.g. to indicate hunger, to gain relief from pain or boredom, etc.), an effort by an individual to get their needs met directly (e.g. leave a building when they believe they must either go to work or collect children from school) or a

sign of frustration (e.g. feeling angry at being told they are not allowed to exit a building). In all of these situations, the actions are attempts by the individual to enhance and maintain their sense of well-being or to ease distress. It is suggested that finding and resolving the unmet needs should be the focus of treatment. Formulations are crucial for identifying and exploring unmet needs and are utilised regularly by clinicians. However there is a lack of a universally agreed definition of formulation, with different professionals bringing their own perspectives. Holle *et al.* (2016) undertook a systematic review, identifying 14 frameworks currently in use for BPSD. They suggested that formulations play an important role in the treatment of BPSD, however they failed to identify a particular framework as being significantly superior to others. The importance of formulations is a view further supported by Moniz-Cooke's Cochrane review (Moniz-Cook *et al.*, 2012) which examined the use of functional analytic approaches in the area.

Despite support for their use, because formulations can be time consuming and require training in order to be delivered effectively, they are not universally employed for all incidences of BPSD. Indeed, it is important to recognise that there are circumstances where formulations are not required. Consider the following:

- i. Not all behaviours are 'challenging'. We want people to be active and maintain interesting lives, in which they enjoy and explore their surroundings. Such activity is likely to lead 'people living with dementia' to transgress some rules or norms within the setting in which they are residing but this does not necessarily make those actions 'challenging' and therefore should not be pathologised.
- ii. Some BPSD have a specific physical cause which may be quickly treated via medication or physiotherapy input. For example, dementias are associated with old age, as are other illnesses such as delirium and pain which can be common triggers for BPSD. Therefore, a simple physical screening can readily identify treatable causes of BPSD without the need for a formulation.
- iii. A range of BPSD are predictable and we can target 'hot spots' of distress without the need for an extensive functional analysis. For example, we know that many confrontations are triggered when 'people living with dementia' are provided with intimate care tasks, and therefore BPSD can be reduced if we improve caregiver skills around the provision of intimate care activities.

Brechin and colleagues used the above notions when they produced the four stepped-care intervention programme for BPSD (Brechin *et al.*, 2013). The stepped care model suggests that formulations are important, but because they are either not always required, and/or are demanding

in terms of time, resources and skills, three less intensive steps should be used first. The stepped-care model is outlined in Figure 1.

Figure 1 placed here.

Step 1 - Recognition and screening: Many behavioural difficulties wax and wane and can be dealt with by caregivers through the sensitive use of good communication skills. In those situations where the behaviour is not risky for either the 'people living with dementia' or the caregivers, it may be appropriate for the circumstances to be tolerated for a period of time and many of the behaviours may resolve of their own accord (University of Exeter, 2017). In addition, checks for conditions that might be causing agitation should be undertaken. Commonly one would assess for: infections, delirium, depression, side effects of medication, pain or discomfort (arthritis, pain, including dental pain, etc.). The screening of such conditions is usually undertaken by medical staff, including general practitioners.

Step 2 - Low Intensity: These are approaches used by non-NHS or non-specialist clinicians to identify behavioural patterns, emotions and the basic needs of people with dementia. Interventions would include: providing opportunities for fun and occupation to relieve boredom; altering the environment to ensure privacy, reducing overcrowding or noise levels, obtaining more information about people's personal histories in order to communicate and interacting better.

Step 3 - High intensity (Protocol led interventions): In this step, assistance is provided by professionals trained to work with older people, such as nurses and occupational therapists, with input from psychologists and psychiatrists in order to tailor interventions to individual presentations or needs. Generic protocols are used, and often involve the use of monitoring charts (diaries, or checklists) and behaviour checklists (McCabe *et al.*, 2015). Caregivers are supported by experienced, well trained therapists in the use of behavioural techniques and more sophisticated forms of de-escalation.

Step 4 - Specialist interventions: formulation-led approaches: In many situations the three previous approaches will be sufficient to treat the BPSD. However, when it is difficult to determine the need and/or employ appropriate protocols to treat BPSD a more bespoke approach is required. This involves clinicians collecting additional information about the person and his/her circumstances. It

is at this point Brechin *et al.* recommend the use of a biopsychosocial formulation, involving the use of a comprehensive assessment, integration of information, the development of a conceptualisation and a formulation-led care plan, and support for implementation.

While Brechin's work produced a comprehensive treatment approach, it is potentially flawed in its clinical application, in that it does not explain *how* to appropriately use the knowledge gained from the assessments and formulations in order to bring about changes in behaviour, thus limiting its efficacy. A more fine-grained 'how to' set of guidelines is required.

An equally extensive BPSD management programme has been provided by Kales *et al* (2015) in their DICE framework. Unlike the previous methodology DICE does not contains steps, but the approach is applied whenever a behaviour is perceived as being 'sufficiently' challenging. DICE was developed in 2014 by a group of experienced US psychiatrists and other clinicians. They ran a series of consensus meetings to devise a protocol to produce a treatment template for BPSD, the product of which was the DICE framework (Describe, Investigate, Create, Evaluate). The model suggests there are three areas to assess and treat under each of the DICE headings: the person, the carer, and the environment. This approach was specifically developed for people with dementia living in their own homes rather than in care settings. In the first stage (Describe), a thorough description of the BPSD and the context in which they occur is required. This is achieved through discussion with the 'people living with dementia' and the caregiver. The second stage (Investigate) involves the clinician identifying and excluding any underlying causes (e.g. undiagnosed medical conditions, infections, etc.) and investigating any caregiver or environmental factors (e.g. noisy environment, caregivers communication style, etc.). The information gathered in this stage is then utilised in the third stage (Create), whereby the 'person living with dementia', caregiver and clinician work collaboratively to create and implement a treatment plan. The final stage is to Evaluate the treatment strategies employed in stage 3, focusing on their efficacy for the BPSD and assessing how well the carers implemented them.

DICE is a helpful example of a treatment approach combining clear structural and process elements within a systemic conceptualisation. Some clinicians may suggest that the roles of 'carers' and 'environmental' features are addressed in other 'person-centred' models, but the explicit emphasis of these features within DICE is different as it is aimed at own-home settings. As such, carers in DICE receive a similar level of focus of attention as the patient does, i.e. the carer is also in receipt of treatment. Furthermore, DICE presents a flow diagram which identifies key components and their relationships, a mechanism of change, and builds assessment and management strategies around these structures.

Despite these positives, DICE has a number of shortcomings. First, it was developed for people with dementia (and their families) in their own homes, and not for those living in care, and as a result it is more limited in scope. The DICE approach does not formally support the use of a formulation, and so it is unclear about how the information it gathers is integrated and prioritised. Its lack of a clear end product or care plan runs the risk of producing a confused set of recommendations. A final difficulty is that the DICE approach is trademarked, meaning its use may be restricted and can neither be adapted nor supplemented with materials or tools.

Although the above management techniques (DICE & Stepped Care) are useful, we have found them to be impractical to use clinically and therefore consider it necessary to present a new framework for the management of BPSD. Nevertheless, in the new approach we have clearly borrowed from these two models (Stepped-care and DICE) and also from the rest of the work discussed earlier in this paper. We have named the new model ACME. The acronym represents the four stages of our approach (Assess, Conceptualise and Care plan, Manage, Evaluate), and is the Greek term for 'the peak of perfection'. The term was also used in the Looney Tunes cartoon series the 'Roadrunner', where it represented the company that supplied Coyote with ideas and tools to capture the elusive Roadrunner.

ACME

In terms of the stepped-care model, ACME is best positioned at step 4. Prior to utilising ACME there are three categories of response one should employ, which are not strictly hierarchical. The first category is the use of good basic communication skills; a style which we refer to as 'customer care' skills (James & Gibbons, 2019). This involves being polite, trying to see the other person's perspective, negotiating, etc. These simple verbal and non-verbal processes are often highly effective in reducing agitation, and maintaining and restoring the person with dementia to a state of wellbeing. If these types of approach are not effective, many caregivers can employ a slightly more sophisticated set of responses. There are a range of techniques and protocols that can be utilised, such as: distraction, delaying techniques, de-escalations, therapeutic lying (James, Medea & Reichelt, 2021). The caregiver may also refer to the GP to check for physical difficulties.

The third category of responses are anticipatory in nature. They attempt to use forward planning to deal with scenarios (such as intimate care interventions) that commonly trigger BPSD. Caregivers are aware their actions during 'intimate care tasks' may trigger aggression, embarrassment, or shame in the person with dementia: hence, specific coaching may be required to help promote

dignity (and reduce distress) during such tasks. In most situations, the BPSDs that arise on a daily basis are dealt with through skilful application of these three categories of response.

The ACME approach is only required when good communication and de-escalation skills and protocols have proven unsuccessful in reducing the severity of the behaviours, meaning that a more thorough assessment and functional analytical approach is required. It is worth noting, however, that all of the processes described are integral to the use of ACME. The only feature that is unique to ACME is its framework, which allows clinicians to use the communication skills and protocols in a more systematic and targeted manner (i.e. the approaches are packaged in a more bespoke way for each individual). The ACME framework incorporates unmet needs at its centre; consider the following flow diagram (Figure 2).

Figure 2 placed here.

This model has 'needs' at its centre, and suggests that the needs are influenced (moderated) by the individual requirements of a person and their caregivers. The needs in this model are mediated by (i) the degree of emotion and drive associated with satisfying the need, and (ii) the abilities of the person to meet the need themselves. On the left, we have a scenario where a person has both the cognitive and physical abilities to satisfy their needs; 'satisfying' in this sense means being able to physically or intellectually achieve desired goals or outcomes. In cognitive terms this would suggest the person can form an intention, carry out goal directed behaviour, problem solve, or have sufficient insight to know they cannot meet the goal at this moment in time. In contrast, on the right hand side of the diagram we have a person with cognitive impairment. They may no longer have the problem-solving or attentional abilities to satisfy their needs. Further, a lack of insight might compound the issue, with the person no longer being able to recognise that their needs cannot be met. The lack of insight combined with the unmet needs is likely to bring the person into a confrontational situation with their caregivers. It is relevant to note that the person on both the left and right-hand side of the diagram will be engaged in multiple behaviours. However, because of the greater level of impairment of the person on the right, fewer appropriate problem-solving attempts will be utilised and a higher percentage of their behaviours may be deemed 'unacceptable' and 'challenging'.

The moderating features of this model (person and caregivers) are influential in how the BPSD are interpreted and managed. Therefore, they require some form of assessment.

Person factors: the person engaging in the BPSD is clearly a focus of any treatment regime (Hughes & Beatty, 2018). Important person-centred factors include a person's: physical health, psychological wellbeing medication regimen, needs, personality, strengths/resilience, coping style, cognitive deficits, current outlook/reality, access to meaningful activity and relationships, etc.

Carer and interpersonal factors: the role of the caregiver is important to assess from two related perspectives. The first is an examination of the interpersonal and communication style of the carer. This is particularly relevant in the management of BPSD because as noted earlier, the caregivers are the 'agents of change' in many of the treatment strategies. However, a feature that is not always given the appropriate attention is the further requirement to undertake a formal assessment of the personality, mental and psychological health of the caregiver. The latter feature is most apparent when working with people in their own homes, but is also relevant to 24 hour settings due to these sometimes being stressful places to work. Various papers (e.g. Moniz-Cook, Woods & Gardiner, 2000) highlight that cultural factors such as job satisfaction and perceived management support dictate how capable staff feel in coping with distressed behaviours. In all of these situations the wellbeing, or ill-being, of the caregiver should be considered.

The ACME framework is summarised in the table below.

Table 1 placed here.

It is important to highlight that the agents of change in this framework are the caregivers and thus they are vital in each phase of ACME.

Phase 1 – Assess

The initial phase of ACME is to assess the needs of both the caregiver and the 'person living with dementia', assessing their emotions, abilities and surroundings to identify causes for the BPSD. An initial biopsychosocial screening should be carried out to rule out any physical or environmental causes for the behaviour (for example, infection or noise levels). During this initial phase, the caregiver can aid in providing rich descriptions (using ABC and time series charts where appropriate) in order for the clinician to gain a clear understanding of the BPSD.

Phase 2 – Conceptualise & Care plan

The second phase of ACME is split into two interlinked components; first to conceptualise the BPSD and second to care plan. One should conceptualise the BPSD using frameworks that help to understand behaviours and the unmet needs underpinning them, drawing upon the unmet needs framework and the conceptual models of understanding BPSD (Figure 2). Irrespective of the framework chosen, it is important that bio/psycho/social data gathered within the assessment phase are distilled into a clear and digestible written or visual summary.

A care plan should then be devised, identifying features that currently aid the wellbeing of both the ‘person living with dementia’ and the caregiver and help to de-escalate challenges and reduce risks at the time of a crisis. The care plan should take into account the feasibility of delivering the intervention i.e. how realistic is this for the caregiver to be able to do it consistently and effectively. To aid with the structure of the care planning the concepts from Positive Behavioural Support (e.g. traffic light analogy, Sells & Shirley, 2010) are important. Indeed, knowing how to keep people in the ‘green’ phase is just as important as planning what to do in both the ‘amber’ and ‘red’ phases of the BPSD.

Phase 3 – Manage

The third phase of ACME is to employ techniques to ‘Manage’ the BPSD, meeting the needs of the ‘person living with dementia’ and the caregivers. The carer, clinician and ‘person living with dementia’ should work collaboratively to identify appropriate interventions to help manage the BPSD, appreciating the need to tailor interventions depending on what stage of the cycle the ‘person living with dementia’ is in. It is in this phase that support and training for caregivers is crucial in order to implement the content of the care plan. Appropriate training should be delivered, supporting the use of both well-being strategies and de-escalation techniques. The training is best delivered in the form of coaching because many of the skills involved in ‘formulating, constructing and delivering of care plans’ are difficult to attain and require support and scaffolding. A coaching programme designed to support the delivery of ACME is called Communication and Interaction Training (CAIT, James & Gibbons, 2019); an online version of this program is being launched in Spring 2021. CAIT contains qualitative and quantitative measures for evaluating its impact in relation to both people with dementia and carers.

Phase 4 – Evaluate

The final phase of ACME is to evaluate the impact of the interventions employed in the management phase for both the 'person living with dementia' and the caregiver, i.e. how feasible were the interventions and how did they affect the BPSD. This can be achieved using formal questionnaires and discussions with various stakeholders (families, friends, staff, etc.). This information should then be fed back into the framework and alterations made to the management interventions if necessary.

Figure 3 shows that the key aspect which informs all the ACME framework is the 'conceptualisation'. The conceptualisation involves the integration of three models (i) the unmet needs perspective, (ii) the mechanisms through which the BPSD occur, and (iii) the formulations which takes account of the person and caregiver needs. This central aspect informs all the other aspects of ACME (i.e. what should be assessed, contents of the care plan, the treatment strategies and their evaluation).

Figure 3 placed here.

The conceptualisation depicted for ACME in the present paper reflects the philosophy and approach towards BPSD (James & Jackman, 2017) being used by the majority of the current authors, and best practice guidelines (James & Moniz-Cook, 2018). It is worth noting, however, that clinical teams and Units holding different conceptual views of BPSD to the ones expressed in this paper will employ the treatment regime consistent with their own views.

Let us consider two scenarios relating to the treatment of BPSD by two Mental Health inpatient units:

Unit 1 – this inpatient unit follows the version of ACME described in this paper. The approach is coordinated and interlinked from assessment to evaluation. All patients receive a needs-led formulation, family members are consulted and assessed. Biopsychosocial care plans are written and implemented, and the impact of the management strategies assessed holistically in relation to the person with dementia and his/her family. The work is supported by worksheets and instructive animations which outline the philosophy of the approaches used (James & Birtles, 2020).

Unit 2 – this inpatient unit's conceptual view regarding the treatment of BPSD is a more restricted biological perspective, focusing on physical health and psychotropic drug treatments. The team do not employ formulations, but have comprehensive 'medication' care plans based on an assessment of the nature of the BPSD and underlying physical health presentations. The main management

strategies are medication, and evaluation is seen through the prism of the balancing of the beneficial impacts versus side-effects of the drugs.

These case scenarios highlight the advantage of the more holistic perspective, by providing a far greater range of treatment methods consistent with the aetiologies and presentations of BPSD. The comparison between scenarios illustrates the key role played by 'conceptualisations' in directing treatments. Indeed, it suggests that all clinical teams need to reflect on their conceptualisations and philosophical approaches to BPSD. In order to get good consistent clinical practice all members of a clinical team should be clear about these perspective, and the conceptual beliefs should be shared with families, stakeholders, and where possible people with dementia.

In summary, ACME is a system for coordinating the delivery of effective management strategies for the treatment of BPSD. When following best-practice principles it is a person-centred and holistic approach, incorporating many of the features previously discussed in the paper:

- It incorporates the unmet needs perspectives.
- The framework utilises the 'conceptual model for BPSD' and so ensures we are not over-pathologising behaviours and we are only treating appropriate 'problematic' behaviours.
- Through the use of a comprehensive assessment phase at the outset of the ACME process any physical and environmental problems can be addressed early. This may result in a BPSD being resolved or reduced. At the very least, the information gathered from the assessment phase can be utilised in the conceptualisations.
- It supports the use of biopsychosocial formulations that also consider the needs of the caregivers.
- The design of the management strategies highlight the caregivers are the 'agents of change'.
- ACME incorporates some of the notions of a stepped-approach, and emphasises the key role that good communication skills play in the management of BPSD.
- ACME can be used in both home and inpatient settings which is a critical difference compared to DICE, which deals exclusively with 'own home' scenarios.

Conclusion

This is a rather wide-ranging paper moving from medication, frameworks, formulations, care planning, and finally addressing some of the existing and newer conceptual models. The authors

have finished the article by proposing a new model called ACME, which clearly requires further development. Nevertheless, the article has presented a series of arguments that have led us to conclude that there is a place for such a holistic approach. We have unashamedly borrowed from other sources and credited this work. During our construction of the ACME model we have been ever mindful of the need to produce 'informed-actions' which are sufficiently specific that clinicians, at whatever level, can implement the suggestions directly. Indeed, we believe that too many previous reviews and guidelines have failed to be sufficiently practical and concrete in terms of what actions to undertake to manage BPSD. As a consequence the existing literature has not always enabled clinicians to apply their recommendations directly to their practices, resulting in a status quo regarding management strategies used in care homes and wards. It is envisaged that when the next national guidelines for BPSD are being produced, the panels of experts will have holistic programmes similar to both ACME and DICE to draw upon in order to provide clearer guidance about effective psychosocial interventions as alternatives to psychotropic medications.

Declaration of interest – none.

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