'Behaviour that challenges' in dementia care: An update of psychological approaches for home and care home settings[1]

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Introduction

OVER AND ABOVE the personal and financial costs associated with dementia, those for 'behaviour that challenges' (BtC) are significant (Lowry & Warner, 2009; Hermann et al., 2006). This briefing paper outlines the importance of having a psychological understanding of both the causes and appropriate interventions required for BtC. It highlights the role of clinical psychologists, ideally working within multi-disciplinary teams, in producing biopsychosocial formulations to meet the health and psychosocial needs of a person living with dementia (PwD). The paper also draws on relevant evidence including findings from a recently completed NIHR programme of work on the *Management of Challenging Behaviour at home and in care homes* (Moniz-Cook et al., 2017) to provide recommendations for action.

1. Defining BtC

A 'Behaviour that Challenges' in dementia is defined as:

> An expression of distress in the PwD, (or others in the environment), that arises from physical or psychological unmet need. Actions can also represent an attempt by the PwD to maintain a 'sense of self' and wellbeing, or to ease discomfort or distress.

During an episode of BtC the PwD's behaviour may be:

1. **an attempt** to meet a need (for example, to satisfy hunger, to find a spouse, or to protect oneself from a perceived harm); or
— **a signal** of a current unmet need such as discomfort, pain or relief from boredom; or
— **frustration** due to restrictions to liberty, receiving unwanted assistance with intimate care activities, or explanations that do not fit with the person's current reality (for example: 'Your child is no longer at school, she's now an adult'); or
— **general actions** caused by misperceptions and sensory problems that are perceived as challenging by others (for example habitual urination in a wardrobe because it is mistaken for the bathroom).

The way the carer or others in the environment respond to the behaviour can exacerbate distress for the person, the carer, or others. For example, the carer's unsuccessful attempts to de-escalate an episode of BtC through reasoning, distraction or restraint may lead to frustration and aggression.

For an action by the PwD to be perceived as challenging, a 'critical point' must be passed, requiring a judgement by others –

usually the family or staff carer. Carers often have different thresholds when they consider a given behaviour to be challenging. Therefore the judgement of behaviour is determined by the perceptions and attributions of others.

Hence, the phenomenon of BtC includes social constructs rather than a clinical disorder *per se,* and can rely more on how others construe the meaning of the behaviour (Moniz-Cook et al., 2012).

2. Psychological understandings of BtC

BtC are often referred to in the biomedical literature as Neuropsychiatric Symptoms (NPS) or Behavioural and Psychological Symptoms of Dementia (BPSD). These conceptualisations differ from psychological perspectives in at least two important ways. First, psychological approaches do not assume that BtC are direct symptoms of dementia, but may arise for other unrelated reasons (for example, history, personal preferences, boredom, etc.); second, psychological approaches take account of both the PwD and the caregiving environment within which the behaviour occurs including the context and carer responses. Hence, common problems such as 'resisting help' or 'non-compliance', which are often a consequence of breakdown in communication between the PwD and a caregiver, can be improved through intervening at the level of the carer and care system, rather than solely at the level of the PwD. The importance of the context, including the role of caregiver perception in the management of BtC was recognised within the NICE-SCIE Dementia Practice Guideline Number 42, where the term BtC was introduced (National Collaborating Centre for Mental Health (2007, p.220).

Experienced clinical psychologists are skilled at:

■ assessing the wide-ranging ways in which a PwD, and others in their environment, experience the phenomena of BtC;
■ formulating ways of moderating distress within the particular setting that people live in;

■ considering strengths and obstacles to engagement for a given care home or family system, in determining resources and sustainability of interventions; and
■ working within a multi-disciplinary team where the skills of psychiatrists, occupational therapists, nurses and other professionals can enhance perspectives to deliver tailored interventions.

In addition, clinical psychologists have systematic protocols for formulating with dementia care teams (see Bird & Moniz-Cook, 2008).

3. Identification of clinically significant BtC in the UK[2]

Identification of BtC requires more than just recognising that the behaviour is in some way problematic. The manner in which the carer interprets and reacts to the person's action frequently effects the way the episode of BtC is expressed. Reliable measurement of the caregiver perspective of a given behaviour is therefore not straightforward. Indeed services often find it hard to identify those with clinically significant BtC and significant need can be missed by specialist older people CMHTs and memory services (Moniz-Cook et al., 2017).

The Neuropsychiatric Inventories – the NPI (for home care) and NPI-NH (for care homes) – are well validated, widely used clinician rated measures of BtC in family and nursing home settings, respectively (Zuidema et al., 2011). However these measures do not describe behaviour in language that is used or understood by most caregivers.

In contrast, another well validated and widely used measure is the 24-item Revised Memory and Behaviour Problem Checklist – RMBPC (Teri et al., 1992). This describes common 'everyday' BtC in family settings

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[2] Details of cut-points for clinical significant BtC of the RMBT and CBS are available from the first author: E.D.Moniz-Cook@hull.ac.uk

and has a measure of 'carer coping'. For care homes, a widely used measure is the Cohen-Mansfield Agitation Inventory (CMAI, Cohen-Mansfield, 1986). It describes BtC in language relevant to care staff and has a more reliable change index than the NPI-NH, but does not measure staff coping. In the UK the 25-item Challenging Behaviour Scale – CBS (Moniz-Cook et al., 2001) is widely used by practicing clinical psychologists and non-medical professionals. It has become popular since it was developed from staff reports of difficult to manage behaviours in care homes. A study of the CBS with 2185 residents from 63 care homes found a structural framework within the measure which provides guidance for a stepped process in the treatment of BtC (James et al., 2017).

4. Interventions for BtC: relevant evidence

Following the Department of Health commissioned report *Time for Action* (Banerjee, 2009), BtC intervention literature and practice guides in the UK have been driven to review antipsychotic use for BPSD, and to promote 'non-pharmacological' psychosocial alternatives as a first line approach (Brechin et al., 2013). The policies mostly targeted the third of people with dementia who live in care homes, probably because they have a higher use of these drugs than home care settings. Use of antipsychotics has indeed reduced since then, but the quality of prescribing for all psychotropics is far from ideal (Moniz-Cook et al., 2017). There remains a real need to produce effective non-pharmacological alternatives.

Central to psychological approaches to BtC is alleviation of distress by overcoming difficulties encountered by the PwD and/ or others in the environment, frequently employing a biopsychosocial perspective. The practitioner conceptualises the person's behaviour through an analysis of biological features (such as pain, effects of multiple medications, ill-health and/or delirium), psychosocial and contextual features (such as needs, environment and carer communication) to formulate a plan that is

tailored to the person's particular requirements (Brechin et al., 2013).

Clinical psychologists can enhance these formulations using:
— **behavioural interviewing and observations of** 'trigger' antecedents or setting ('A') of a given behaviour ('B') and the responses ('C') of others (Moniz-Cook et al., 2012);
— **knowledge of cognitive functioning** that contributes to BtC;
— **understanding of personal profiles** that can render a PwD or a family carer vulnerable to distress due to the challenges associated with dementia;
— **understanding of emotions and beliefs** in BtC (James & Hope, 2013);
— **understanding of the caregiving system** (the care home or family that supports the person with dementia).

The purpose of these formulations is to collaboratively develop targeted interventions for BtC via a care-plan. Detailed case studies and systematic reviews (Holle et al. 2016; Bird & Moniz-Cook, 2008) show that these individually formulated 'case-specific' approaches for BtC are the way forward for intervening in BtC within both family and care home settings. Many also point to the importance of behavioural observations and associated improved communication between the PwD and carer, in the management of BtC (Bird et al., 2016). These multi-component approaches often also involve training of caregivers (Spector et al., 2012).

It is important to note, however, that caregiver training is not sufficient to reduce BtC. On-site regular support is crucial, where carers require clinical supervision to communicate well with the PwD, particularly in cases of clinically significant BtC (Bird et al., 2016).

Clinical Psychologists can support these interventions by offering
— **micro-skills training** for therapist-practitioners to provide highly specific support in areas where BtC occur fre-

quently, for example when assisting with intimate-care (help with washing, meal times, use of the bathroom, etc);
— **training to enhance caregivers'** communication to effectively deal with episodes of BtC (James, 2015).

5. Services to support BtC at home and in care homes

Psychological approaches to BtC have a pragmatic focus on the contextual and environmental needs of the systems within which the PwD is being cared for. Thus the family, paid carers or staff in care homes, become key foci for support programmes. The term 'eco-psychosocial intervention' has been used to emphasise the requirement to take account of the environments and contexts within which care is delivered.

Interventions for people living at home have to be designed separately from those living in care homes. The former involve working with family members who have differing motivations, understandings and capacities. The latter involve multiple staff, working in complex dynamic systems with each care home having its own organisational strengths and constraints (Moniz-Cook et al., 2017).

5.1 Specialist services for people living at home with BtC, require urgent improvement

A recent NIHR programme on the management of challenging behaviour in family settings (Moniz-Cook et al., 2017) noted that:
— higher levels of BtC were recorded in people living at home who were referred to specialist community dementia services, compared with those in care homes.
— those with clinically significant BtC living at home tended to have milder dementia (i.e. 60 per cent with clinically significant BtC had mild dementia).
— CMHTs-OP were commissioned to provide care to those with mental health problems including those with dementia and BtC, but the majority of care was directed towards those without dementia.

— despite some evidence for the use of individualised multi-component interventions for BtC in family care settings, care provided by specialist CMHTs-OP practitioners consisting of an average of nine contacts over six months did not alter levels of BtC reported by families.

Recommendations from this programme were that the currently somewhat overlooked group of home-dwelling PwD and families with clinically significant BtC could be helped if CMHTs-OP staff delivered formulation-led interventions and that such support should be combined with clinical supervision and a sustained case management approach.

5.2 Specialist in-reach care home BtC services are emerging (37)

In the UK, BtC services have evolved from experience by dedicated clinical teams. The following points are worth highlighting:
— Many formulation-led approaches draw on the well-known Newcastle care home protocols, which use a 12-weeks structure for treating BPSD, including 6 weeks of support for implementation of the care plan (James & Jackman, 2017).
— The Newcastle protocols now have additional contextual practice developments to improve communication skills in staff.
— The structure provided by Clinical protocols combined with 'clinical support' have been shown to be an optimum approach. A dilution of this combination is less effective and clinical supervision is a key to the sustainability of BtC interventions (McCabe et al., 2015).
— Delivering service improvements within care home settings is complex, often relying upon features of good governance and structural or process issues occurring within the care settings; good management and organisational support systems are often crucial (Brooker et al., 2016). Good knowledge of the shifting cultures of local homes is also important which is best achieved by specifically

(2001) suggests that BtC 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.), or an effort by an individual to get his needs met directly (e.g. leave a building when he believes he must either go to work or collect children from school), or a sign of frustration (e.g. feeling angry at being told he is not allowed to exit a building). In all of these situations, the actions are attempts by the individual to enhance and maintain his sense of well-being or to ease distress.

Evidently, however, the perspectives (function vs need) are rather similar; one might even argue that the functions are a sub-ordinate level of needs. Currently within our revised models of care in the North-East (James, 2016), we are working with nine key needs in dementia care (Physical comfort, Perception of safety, Intimate touch, Love and belonging, Esteem needs, Control over environment and possessions, Meaningful touch, Occupation and exploration, and Fun (James, 2016; James & Jackman, 2017).

Despite some similarities an important difference between LD and dementia conceptualisations is the focus of people's needs and the associated functions of the BtC. So while LD formulations conceptualise the function of a behaviour in relation to the self, in dementia care many of the needs driving the BtC are related to protecting and supporting someone else (e.g. concerns for the safety of children, or parents – 'I want to collect my children from school'; 'My sick mother is waiting for me at home, she's all alone' James & Jackman, 2017). This is an important distinction, and is also a reason why meeting the needs of people with dementia is often difficult to do (e.g. a support worker is unable to let the PWD leave the ward to see her mother, who died 25 years ago). This issue is related to memory and time-shifting (James, 2015), and is one of the reasons for the ongoing debate about the use of therapeutic lying in attempting to meet such outdated needs (James et al., 2006).

Having highlighted some differences, it is worth focusing on what could be gained from incorporating PBS frameworks in dementia care. Firstly, we would benefit from the cross-fertilisation of ideas and concepts in relation to assessment, measurement, treatment and training across specialties. A product of obtaining various perspectives has been the recent special edition of *Clinical Psychology Forum* (Positive Behaviour Support, 2017). In this Forum, Allan Skelly edited seven articles on PBS from different specialities (child and families, personality disorder, etc.) and psychology traditions (attachment).

Secondly, we may benefit from a new look at data collection, which is a key aspect of PBS (Noone & Chaplin, 2017). From our perspective, we think that the potential use of PBS challenges those of us working in the field of dementia about whether or not we are making sufficient use of our behavioural charts. Indeed, on reflection we believe our formulations are 'data-lite', failing to make use of available data and as a result at times we are producing poor care-plans.

Thirdly, we think the PBS frameworks may also allow us to reflect on our treatment processes, and get us to consider whether some of the people we are treating could be taught new skills and replacement behaviours. In truth, when working with PwD we often intuitively make adjustments for people's cognitive status. Yet the notion of 'replacement behaviours' is not commonly used in our literature, despite it being a characteristic of the work of our occupational therapy colleagues (Pool, 2008). Hence, it would seem sensible to assess such features more overtly and consistently within our assessments protocols and produce care plans which reflect the potential for new learning on the part of the person with dementia.

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