

Evaluating interventions for Behaviours that Challenge (BtC) in dementia care - what instruments do specialist practitioners working in the UK use?

Rosie Dunn and Esme Moniz-Cook

Abstract

Written feedback was examined from participants who attended the February 2019 consultation. This informed the 35-item online survey that followed (May-June 2019). One item questioned practice on instruments used by specialist BtC practitioners to evaluate the effects of their interventions. Analysis of quantitative and qualitative data from this question is summarised in this article. We discuss what might be useful instruments for practitioners to use in routine practice in recognition of what might be considered clinically significant BtC in family and care home settings. We conclude that more work needs to be done with respect to evaluation of BtC work in family care settings. This should focus on use of instruments for recognition of BtC and evaluation of how families cope with BtC following the specialist interventions they have received.

Introduction

A Cochrane review on the management of challenging behavior in dementia care outlined studies in family and care home settings (Moniz-Cook et al. 2012). Each study used relevant valid instruments for measuring outcome of individually formulated BtC interventions. Thirteen of the 18 studies reviewed, were from family care settings; one, involving 120 participants from six Community Mental Health Teams for Older People (CMHTs-OP) in Yorkshire, reported reduction of reported behavioral problems and improved family coping (Moniz-Cook et al. 2008a). We attempted to upscale this work into routine services across England, using a manual-based individually tailored protocol for making decisions for biopsychosocial intervention combined with family support and treatment. Selected CMHTs-OP practitioners were trained to deliver this (see ¹ Resource note - free interactive online learning materials for the decision-support treatment protocol). Seven large NHS Trusts and 33 CMHTs-OP were included, but the trial was abandoned as the CMHTs-OP failed to recruit enough people to receive the intervention (Moniz-Cook et al., 2017 Chapter 5). From 5,360 referrals to the CMHTs-OP over approximately seven months, only just over 8% of people living at home with support by their family were accepted for care by these CMHTs-OP; the majority of CMHTs-OP work was directed at people with functional mental health problems (i.e. 37%); or those in care homes (i.e. 22%); and many were simply 'referred on' or returned to the GP (Manthorpe et al., 2018). One of several reasons for this was that practitioners did not use instruments to recognise BtC in people living at home, so the subtle needs associated with BtC in family carers, were unnoticed (see also the article by Beanland - this issue). The study noted that people supported at home by CMHTs-OP had higher levels of BtC than groups of people living in care homes with clinically significant BtC who were assessed during the same period; and those with clinically significant BtC living at home had mild dementia (Moniz-Cook et al., Chapter 6). For people living at home with clinically significant BtC, despite receipt of around 6 sessions of 'usual care' from their CMHTs-OP practitioners, levels of reported behavioural difficulty and family coping did not alter over six months (Moniz-Cook et al., 2017, Chapter 5). The NICE Quality Standard for this topic (See NICE 2019; Quality Statement 6 pp 26-27) limits measurement of successful outcome to reducing antipsychotic prescribing rates; and for family carers their 'quality of life' is seen as the outcome measure of choice (see NICE 2019; Quality Standard Statement 7 pp 30-31). Reduction in 'behavioural' symptoms or improvements in carer coping or experiences of BtC, are not suggested as measurable ways of evaluating interventions for BtC, despite work (shortly to be updated) on relevant instruments that can be used in both intervention research studies and in routine care (Moniz-Cook et al., 2008b; Mountain et al. 2015).

To provide guidance on evaluating the effects of our work with BtC, this study explored the instruments and assessment tools used by multidisciplinary practitioners, to evaluate their BtC dementia care work, across the variety of settings where BtC care is delivered.

Method

Written feedback was examined from participants who attended the February 2019 consultation. This informed the 35-item online survey that was developed and collected anonymously using Qualtrics online survey software. One item (Question 22) was on instruments used by specialist BtC practitioners to evaluate the effects of their interventions, as follows: *“What measures or assessment tools are used in the evaluation of your work with BtC? Please state where the measure is used: care homes/acute general hospital wards /mental health inpatient wards/those living at home”*. The survey was disseminated for 6 weeks (7th May - 14th June 2019) using a cascading approach to involve wide-ranging professionals, stakeholders and research networks across the UK. Descriptive data on the most commonly reported measurement tools used, and the setting in which this was used, was collated and tallied. Qualitative data was analysed thematically and compared to data collated from the consultation. Findings are summarised next.

Summary of Key Findings

Participants

241 professionals of various disciplines responded to Question 22 (see Table 1). They worked in all regions across the UK with the highest percentage from Yorkshire and Humberside (18.4%) and Mid and Southern Scotland (13.4%). Participants had worked in dementia care for 14.3 years (mean; range 1-45) and in BtC dementia care services for 10.76 years (mean; range 0-45 years). 55.4% worked in the community, 40% in care homes, 38.3% in mental health or dementia wards and 13.8% in acute general hospital settings.

Table 1: Professional breakdown by discipline

Profession:	Responses (Q.22) 'n'
Psychologist	82
Nurse	83
Psychiatrist	22
Occupational Therapist	20
Social Worker	5
Carer	3
GP	5
Other professions: (speech and language therapist; neurologist; geriatrician; pharmacist; physiotherapist; nursing home staff; dementia advisor, support worker, researcher)	21
Total number ('n'):	N = 241

Instruments used

As shown in Table 2, 102 (42.3%) respondents reported using an instrument to measure behavior changes in dementia. The CBS (Challenging Behaviour Scale; Moniz-Cook et al., 2001) was the most popular tool used (22.4%). 98 respondents (i.e. 40.7%) used ABC - type charts; 40 (i.e. 16.6%) preferred feedback and general observation as a method for evaluating their BtC work. Instruments measuring specific domains of BtC such as agitation or aggression and mood scales were reported by 25 (i.e. 10.4%) of respondents. 15 (i.e. 6.2%) reported assessing carers with instruments to evaluate burden, distress, satisfaction and quality of life. 36 (i.e. 14.9%) reported that they did not use any tools to evaluate their clinical work.

Other types of assessments such as: physical health (n=34 -14.1%) to measure food and fluid intake, changes in sleep, medications and antipsychotic use, delirium, and assessment of pain, and instruments for measuring Quality of Life (QoL) in people with dementia (n=26 -10.8%) were reported. Less commonly reported assessments included measures of: activities of daily living; staff rating scales, such as level of satisfaction, distress and staff sickness levels; specific profession-led assessments, such as OT / Psychology / Nursing assessments; Multi-Disciplinary Team (MDT) meetings; environmental assessments; frameworks/models of BtC in dementia; reviewing care plans; using custom-made tools (not tested for reliability and validity); use of supervision; use of restraint; length of stay on ward; reduction in 'constant observation hours'. Ten (i.e. 4.1%) respondents said this question was not applicable to them in their role.

Table 2: BtC assessment tools: responses, type of instruments and settings

Type of measurement/Instrument ¹	No. of responses (%)	Care home ²	Dementia ward ²	Home ²	Hospital ²
1. Measures of behavioural symptoms in PwD:					
NPI (Neuropsychiatric Inventory)	38 (15.8%)	9	6	7	1
NPI-NH (Nursing home)	5 (2.1%)	2			
NPI-Q (Questionnaire)	1 (0.4%)			1	
CBS (Challenging Behaviour Scale)	54 (22.4%)	21	16	3	1
HONOS (Health Of the Nation Outcome Scales)	3 (1.2%)				
BEHAVE-AD (Behavioural Pathology in Alzheimer's Disease Rating Scale)	1 (0.4%)		1		
Total responses % symptoms:	102 (42.3%)	32 (31.4%)	23 (22.5%)	11 (10.8%)	2 (1.96%)
2. Functional Analysis Measures / behaviour charts:					
Frequency charts / number of incidents	26 (10.8%)	9	11	4	1
ABC charts (Antecedent, Behaviour, Consequence)	44 (18.3%)	13	12	6	1
Behavioural charts	13 (5.4%)	3	2		
CLEAR behaviour record sheets / documentation	3 (1.2%)	1	1	1	
Other: e.g. behaviour charts suggested in FPOP document / traffic light system	12 (5%)	2	3		1
Total responses % behaviour charts	98 (40.7%)	28 (28.6%)	29 (29.6%)	11 (11.2%)	3 (3.1%)

3. Feedback and general observation:					
Feedback	5 (2.1%)				
Feedback from staff	8 (3.3%)	1	1		1
Feedback from carers / family	9 (3.7%)	1	1	2	1
Feedback from patient	3 (1.2%)				
face to face review of patient	3 (1.2%)	1		1	
Observation/informal monitoring of progress/reduction in observed distress/change in situation	12 (5%)		3		
Total responses % feedback	40 (16.6%)	3 (7.5%)	5 (12.5%)	3 (7.5%)	2 (5%)
4. Agitation / aggression scales:					
Agitation scale/overt agitation scale	3 (1.2%)		1		
MOAS (Modified Overt Aggression Scale)	2 (0.8%)				
CMAI (Cohen-Mansfield Agitation Inventory)	17 (7.1%)	5	3	1	2
Pittsburgh agitation scale	1 (0.4%)				
RAGE (the Rating Scale for Aggressive Behaviours in the Elderly)	2 (0.8%)				
Total responses % agitation/aggression	25 (10.4%)	5 (20%)	4 (16%)	1 (4%)	2 (8%)
5. Mood / mental health scales:					
RAID (Rating for Anxiety In Dementia)	4 (1.7%)	1	1		
SAST (Short Anxiety Screening Test)	1 (0.4%)				
Cornell Scale for Depression in Dementia	13 (5.4%)	3	4	2	
GDS (Geriatric Depression Scale)	2 (0.8%)				
HADS (Hospital Anxiety and Depression Scale)	3 (1.2%)				
BPRS (Brief Psychiatric Rating Scale)	2 (0.8%)				
Total responses % mood	25 (10.4%)	4 (16%)	5 (20%)	2 (8%)	0 (0%)
6. Carer rating scales:					
Zarit Burden Interview	6 (2.5%)			1	1
NPI-D (caregiver distress)	2 (0.8%)	1			
Carer / family satisfaction questionnaire	2 (0.8%)	1			
PEDIC (carer satisfaction questionnaire)	1 (0.4%)				
C-DEMQL (carer)	1 (0.4%)	1			
AC-QOL (Adult Carer-Quality Of Life)	3 (1.2%)			2	
Total responses % measure carer coping etc	15 (6.2%)	3 (20%)	0 (0%)	3 (20%)	0 (0%)

¹ Instruments for physical health, Quality of Life / Wellbeing measures in PwD; and 'None Used' available from first author

² Respondents may have not stated where they use a measure/or that a measure is used in more than one setting.

Summary of qualitative data

- (i) Eight respondents specifically reported using a combination of instruments pre and post intervention, to evaluate their work. For example:

“Repeat CBS is used to evaluate final outcome.”/ “in care homes we will go back and evaluate what difference they has been and use the CBS score.”

“We use the Neuropsychiatric inventory (NPI) and Bradford Wellbeing Profile pre and post all interventions with care homes. We send a family satisfaction questionnaire developed by the team to all families following intervention with their family member, in the care home.”

“Behaviour charts suggested in FPOP document. I have directly observed staff being able to use them and be able to reflect on a person with dementia’s possible emotions and possible reasons for their behaviour as a result of completing one of these. I think these can be helpful in promoting reflection and empathy. ”

“behaviour charts - compare pre- and post-intervention.”

- (ii) Some participants reported reviewing their work without using instruments. For Example:

“staff feedback re whether the support plans have made a difference.”/ “Care reviews at home.”

“Change in situation - no formal tools used. Have things improved?”

“Objective changes on ward / not formally measured.”

“Draw up a plan based around the VERA Framework and review if this is successful.”

“At home, regular review and evaluation of care plans with pwd and carers/family”

- (iii) Several respondents reported difficulty in persuading staff to consistently complete instruments for the purposes of evaluation; and some questioned the value of these. Others reported difficulty with the language of common instruments. There was also some uncertainty about how to demonstrate the effects of interventions, and suggestions for improvements in the future. Examples are outlined next.

- **Examples of concerns:**¹

¹ [G= general; C= care homes/hospital; F= family care]

G: *“How do you make sure the needs checklist doesn’t become a tick box exercise?”*

G: *“Need to be careful not to be too reductionist”*

C: *“General hospital - ABC charts, NPI - although difficulties with consistent completion”*

C: *“NPI – in-patient ward - but not used as frequently as it could be”*

C: *“CBS “though this is rarely completed.”*

C: *“My experience is that care homes rarely use standardised assessment scales as part of people’s support plans.”*

F/G: *“Managing expectations- change in behaviour might not be what families want”*

F/G: *“Do we really understand the scale of this? How could we systematically measure **no** people with BtC?”*

- **Examples of Language:**

“I have experienced difficulty in finding a measure that has wording that encourages a helpful narrative. A lot of the measures use unhelpful terminology that promotes less empathic understanding.”

“In Acute ward setting: 24 hour Challenging Behaviour Chart (negative title unfortunately).”

“Assessment scales are helpful, but the wording used is very important. I prefer more descriptive terms that are about what a person does e.g. ‘walking for long periods’ rather than ‘wandering’.”

Good to take focus off ‘behaviour’ and onto ‘needs’ in assessment.”

“look at this as a wellbeing assessment rather than a challenging behaviour assessment.”

- **Examples of requests for guidance**¹

¹ **[G= general; C= care homes/hospital; F= family care]**

G: *“How do we provide evidence for non-pharmacological interventions that we use?” / “Importance of scales / checklists but which ones to use in practice?”*

G: *“We need a checklist for care (mal) practices that challenge”*

G: *“Need to gather more than one person’s opinion on what is working.”*

C / G: *“How can we link intervention to outcome measures? Probably will need to give explicit examples to help care staff as needs arise.”*

C: *“Would use of scale prevent over medication on ward?”*

C: *“Care home nurses find it difficult to explain needs to staff and families – list could be turned into a checklist / crib sheet.”*

C *“What is the clinically significant cut-off of the CBS?”*

C: *“We need to do more work to identify setting-specific cut points and what constitutes clinically significant change on the CBS in response to biopsychosocial interventions. Do we also need a ‘well-being behaviours scale’: incidence, frequency, intensity / in settings.”*

C: *“Should collect feedback from carers and care workers about their level of satisfaction with formulation – perhaps wellbeing measure? However, even if level of distress / BtC reduce, might not mean a person’s wellbeing will improve or be captured on wellbeing measure”*

C *“Staff wellbeing might also be a measure here if people find work less challenging.”*

F: *“How to collect information (observations, ABC Charts) especially in people who still live at home with family?”*

F: *“BtC at home with family caregivers may not be seen as ‘behaviour’ – more about emotions (and needs/relationships)?”*

Commentary

Aside from ten (i.e. 4.1%) respondents (consisting of hands-on-staff caregivers, service managers / commissioners or family carers), this survey of 241 professionals found that only 42.3% of practitioners specifically interested in working with BtC appear to use psychometrically valid instruments to evaluate their work. The combined quantitative and qualitative data suggests that much of the work using such instruments is within care home settings. Less is known about use of psychometrically valid instruments for evaluation of BtC support within family settings.

The CBS (Moniz-Cook et al., 2001) appears to be widely used by respondents of this survey, probably because it is quick to complete (5-10 minutes with an interview by a specialist BtC practitioner and key staff carers); and because it was included in guidance by Brechin et al. (2013). Views about the CBS from both the consensus event (February 2019) and this survey raises the question on whether, two decades since the measure was conceived, new research is needed to refine some of its items. It was developed using the (then) language of staff in care home settings. It can be used reliably within inpatient settings but lacks face validity for family care. The same observation can be made about validity in family care, of the Cohen-Mansfield Agitation Index - CMAI (Cohen-Mansfield, 1989), which was first used in care homes. Of note is that three respondents report using the CBS with families (Table 2). This survey does not reveal enough about use of the Neuropsychiatric Inventory - NPI (Cummings et al. 1994, versus the NPI-NH (Wood et al., 2000). Although the items of these two instruments are similar, the important aspect of caregiver experience of BtC is reflected in the 'burden' sub-scales (see Cummings et al., 1994 and Wood et al., 2000). Yet we see examples of the NPI rather than the NPI - NH used in care homes and wards (Table 2).

The issue of 'scale' relates to whether services focus on prevention of BtC or whether specialist teams should concentrate on clinically significant BtC. Recent large studies in England demonstrate that it is indeed possible to prevent /reduce BtC in care homes using person-centered care protocols (see WHELD; Ballard et al., 2018), but that perhaps more intensive work is required when the target group are those with clinically significant BtC (see Challenge Demcare; Moniz-Cook et al. Chapter 3). This latter study also noted (Chapter 6) that CBS incidence scores ≥ 4 are equivalent to clinically significant challenging behaviour on the NPI-NH, with a cut-off point of ≥ 10 as indicative of severe challenging behaviour.

For family care settings the debate about 'scale' is perhaps premature, since specialist BtC practitioners may need to start by recognising ('detecting') clinically significant BtC. They also need to have a clear understanding of the level of psychological need in family, since for those whose 'sense of loss of their relative' is severe (i.e. the identity of the person they once knew is perceived as lost), their experience of BtC may also be severe (see Feast et al., 2016). The Revised Memory and Behaviour Problem Checklist (RMBPC –Teri et al., 1992) is suggested as a useful measure to use since it is easy to complete in routine practice, within a structured interview, or as self - report by families; and a study in England (Moniz-Cook et al., 2017 Chapter 6) noted that RMBPC incidence scores of ≥ 5 were equivalent to clinically significant challenging behaviour on the NPI. Another (now old) instrument that was developed by Chris Gilleard in the early 1980's (see the 34-item Problem Checklist – PC, Agar et al. 1997) has been lost to practice. This instrument used descriptions of the concerns of relatives of people with dementia living at home. It was seen as useful by practitioners in helping them and families to agree on the problem(s) they wished to address with a given intervention during our training of practitioners to deliver individualised interventions to families with clinically significant BtC. It was incorporated into the decision-support system for intervening with families (Moniz-Cook et al. 2017 Ch.2). It may be useful as a process measure for practitioners who wish to structure their work with families. To our knowledge there are no family sensitive instruments to measure perceived loss of the person associated with, but we welcome information.

Meanwhile, skilled practitioners working with families in memory / dementia services can, we suggest, make clinical judgments about families in need of psychological support in coping with BtC - see Moniz-Cook 2008c; Table 8.1 'carer characteristics' pp. 428; and eight profiles for decision-making about levels of support in family care (Moniz-Cook & Rewston - forthcoming in March 2020).

Understanding how to measure coping with BtC is not straightforward when people with dementia relocate from one setting to another. This is particularly the case for transfers from home to wards, or care homes and vice versa, when setting-specific instruments do not translate well. The NPI, NPI-NH is an exception but this requires trained skilled practitioners to interview caregivers. Instruments such as the CBS and the CMAI (where items are close to what is observed in care settings); and the RMBPC / PC, (where items reflect the day to day problems in family care), are relatively easy to use in psychosocial practice. Using combinations of the NPI with measures closer to the experiences of caregivers (i.e. CBS/CMAI; RMBPC/PC) may be a way forward for those practitioners who wish to combine research and practice for particular projects.

One source of difficulty for practitioners appears to be around understandings about assessments for formulating relevant interventions (see Reichelt et al., this issue) versus instruments for evaluating outcome of an intervention in an individual case. This may be why some practitioners reported that they did not use psychometrically valid instruments. This difficulty may be exacerbated by understandings of system-level evaluation of outcomes, such as quality indicators – QIs (see Vasse et al., 2012 - for 12 dementia QIs, with two QIs for behavioural problems and one for carer stress/mood). Closer to practice in the UK are broad system-level targets to 'reduce antipsychotic use' in people with dementia and generalised recommendations to improve 'quality of life' for carers (NICE, 2019). Perhaps it falls on highly trained clinical psychologists, to maintain the work we do by collaborating with other skilled professionals, and introducing easy to use outcome measures that are aligned to biopsychosocial practice, in our work with BtC.

The concern about language surrounding the BtC paradigm is also reflected in the qualitative data from this study. The issue cannot be resolved easily - even with re-conceptualisations associated with 'distress'. Careful large scale instrument development work done with family carers, to capture their day to day challenges in living with dementia, may be a future aspiration in instrument development for BtC.

Conclusions

The 25-item CBS is widely used in BtC services working into care homes in the UK. Its suggested cut-point(s) for clinical significance may be of use for some services but its items may require updating. Reliability depends on more than one care staff agreeing on the challenges they face (Moniz-Cook et al., 2001), but it can in itself be used to facilitate changed practice. For example in research study, some staff interviewed with the instrument, were stimulated to make connections about potential causes of behavior and thus, without direct specialist help, appeared to change how they supported the resident (Moniz-Cook et al., 2017 Ch.3/4).

The 24-item RMBPC is an instrument worth considering if family carers' needs associated with BtC are to be recognised. A potential cut-point is suggested for clinically significant BtC. However in the UK, working systematically with families and BtC at home appears to be at an early stage of practice, and good instruments to detect psychological and emotional need(s) in carers are hard to find. Therefore practitioners should be cautious in their care of people and their families when individualised biopsychosocial support for the person at home has, in their view, been delivered. Some families may need subtle ongoing family sensitive support from skilled practitioners, if they

are to balance a deep sense of loss on the one hand with living as well as they can on the other. The case described by Beanland (this issue) reminds us that we should strive to compete with resignation that 'nothing can be done'. The need for BtC family centred pathways of care, with skilled practitioners who have regular access to multi-professional advice for every family they serve, has been included in the BPS Call to Action on this topic (BPS, 2018). This article will, we hope, stimulate practitioners to use instruments to monitor how family carers cope with BtC.

¹ Resource note - Free online interactive resource for BtC protocol -

<http://www.dementiahull.co.uk/challengedemcareonline.html> click on 'click here to access the course' at the top of the page; Please note it is best used on Google Chrome / Internet Explorer 11. Module 3 is what most people have found useful - so you might want to look at that first. It teaches the user within 9 case studies of graded difficulty to easily gather information for a biopsychosocial assessment for decision-making about personalised intervention(s). It also reminds practitioners to consider the needs of care home staff and family carers. The plans for intervention are organised as: health (bio) needs; psychosocial needs; and system (caregiver) needs i.e. needs of the supporting staff/care home or family member. We would welcome feedback using the following link (also found at the end of Module 3): <https://hull.onlinesurveys.ac.uk/challenge-demcare-survey>

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Authors: Rosie Dunn (corresponding) R.J.Dunn@hull.ac.uk & Esme Moniz-Cook, University of Hull, HULL, UK

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