

Nature of behaviours that challenge in residents living in aged care homes: Implications for psychosocial interventions and service development

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Background/Aims: *Competing theories exist regarding the causes and nature of behaviours that challenge (BC). The present study attempted to provide better insight into these behaviours and determine whether there were any underlying relationships for people living in care homes with and without dementia.*

Methods: *Cross sectional data for 2185 residents living in 63 UK care homes using the Challenging Behaviour Scale were collected. The incidence (i.e. presence/absence) of 25 commonly reported behaviours that challenge staff were determined using dichotomous scoring. Cluster analysis and Mokken scaling were used to examine underlying relationships. Mokken is a method of analysing data to determine whether there is a 'latent' structure within a data set.*

Results: *The prevalence of reported BC was 87.5 per cent. Cluster analysis revealed three main clusters: apathy, agitation with internal focus, agitation with active external focus. For seven of the 25 items a hierarchical model emerged, where behaviours at the bottom of the hierarchy tended to occur in the presence of those higher up. Behaviours at the bottom of the hierarchy (dangerous behaviour) were less frequently observed than the items at the top (lack of self-care, verbal aggression).*

Conclusion: *Some common BC may occur in groups and themed clusters. This study has shown that a hierarchical structure of BC in residents may be present. The findings testify to the complexity in the aetiology and treatment of BC and hence the need for focused high intensity bio-psychosocial interventions to be targeted towards those with high levels of 'unmet need'. Implications for future research and practice are discussed.*

Introduction

BEHAVIOURS that challenge (BC, Dementia: NICE-SCIE Guideline 2007 p.219) are defined as an interaction between behaviour and the way it is experienced by others (Bird & Moniz-Cook, 2008). These behaviours are also conceptualised as signs of neuropathology and hence described as Neuropsychiatric Symptoms or Behavioural and Psychological Symptoms of Dementia (BPSD – Finkel et al., 1997). The prevalence of BC is estimated at between 20 per cent and 90 per cent, depending on thresholds of severity or setting and on how behaviours are ascertained (Brodaty et al., 2003). BC are known predictors of break-

down of care at home and over 80 per cent of those with dementia admitted to nursing homes can have at least two or more of these (Bakker et al., 2011). BC may cause distress to the people with dementia experiencing them, are associated with reduced quality of life and in care homes have a negative impact on the wellbeing of other residents. They are associated with an increased risk of hospitalisation, Accident and Emergency use and production of excess disability, meaning functional abilities of people decline more quickly than can be accounted for in cognitive decline over the same period. In care homes they remain common (David et

al., 2010) and are associated with high costs (Ryu & Livingston, 2005). For example, at 6 month follow-up at least one clinically significant behaviour persisted in 80.4 per cent of residents (Ryu & Livingston, 2005) and rates of 76–82 per cent (Ballard et al., 2001) and 62.9–72 per cent (Bergh et al., 2011) are reported.

There is a conceptual and empirical tension surrounding what types of acts are considered ‘challenging’, around their aetiology or causation (Bird & Moniz-Cook, 2008) and quantification (Robert et al., 2007). One view is that causation of a given BC is idiosyncratic and multi-factorial, implying that interventions should address the cause(s) of the person’s behaviour in terms of presumptive expressed need (Stokes, 2000) and within its context (Bird & Moniz-Cook, 2008). At the other end of the spectrum is the notion that sub-syndromes of behaviours may have a common neurobiological pathogenesis or respond to similar treatment (Robert et al., 2007). Proponents of the former view draw on studies of the fluctuating course of individual symptoms (Bergh et al., 2011), many of which are episodic (Ballard et al., 2001) and subject to environmental provocations (Lyketos, 2007), where the resident’s distress or attempts to express an important ‘need’ can be misunderstood by the carer. Proponents of neurobiological perspective suggest that BC is a marker of disease progression (Robert et al., 2005) and draw on factor analytic studies describing a consistent presence of subgroups, related to dementia severity (Aalten et al., 2008). However sub-syndromes remain variable across factor analytic studies, ranging from two to six (Frisoni et al., 1999; Schreiner et al., 2005; Matsui et al., 2006; Petrovic et al., 2007; Aalten et al., 2008). Additionally, longitudinal investigation suggests that factors may be unstable (Bettney et al., 2012).

The conceptual tensions described above are crucial in relation to the selection of treatment strategies. For many years a medical model of BC has been used in which the behaviours were treated as diag-

nostic phenomena and medicated via strong sedatives and tranquillisers. This approach is now regarded as unwarranted and unethical (Banerjee, 2009), although the medical model remains resistant to change in many clinical settings.

Alternative treatments tend to take a biopsychosocial perspective, suggesting that BC are often the end-point of (usually) multiple causality with a complex interplay of biological, neurological, psychological and social factors (Bird & Moniz-Cook, 2008). New individually tailored approaches to intervention are needed (Robert et al., 2007) since many residents are either over-medicated, or undertreated (Ryu & Livingston, 2005), left in potential distress until their behaviours and distress resolve (Ballard et al., 2001) or are just ‘tolerated’ by staff (Moniz-Cook et al., 2001). ‘Stepped care’ models for the efficient delivery of complex interventions are an emerging area of research (Brechin et al., 2013) and practice (see for example NICE Practice Guideline number 90, 2009, ‘Depression in Adults’, page 28) where targeting high intensity specialist health interventions to those with the most severe ‘need’ is an important priority.

From a carer perspective, a better understanding of the behaviours will assist in the development of effective care practices. BC are frequently caused by the context surrounding the person with dementia, including environment and carer interactions characterised by lack of stimulation and engagement (Cohen-Mansfield et al., 2007) and can be the expression of unmet idiosyncratic need in response to poor quality care (Stokes, 2000). Brodaty et al. (2001) found significant variability between care homes in terms of the proportions of residents within each setting who displayed BC, indicating a care home level effect. In a negative care culture, staff may cope poorly with BC and react with confrontation, blaming and avoidance that constitutes a spiral of psychosocial decline resulting in more extreme BC. Caregiver behaviour therefore has a role in understanding the evolution and manage-

ment of BC (see also Bird & Moniz-Cook, 2008).

In-reach services across the UK aspire to improve the lives of people with dementia by targeting BC. The first briefing paper in this area was published in 2013 by FPOP (see Brechin et al., 2013) but given the polarity of the conceptual debate outlined above, it is not always easy to detect those residents vulnerable to severe distress as demonstrated by the behaviours they exhibit. Indeed, specialist community services working with BC are frequently called upon to work with residents without dementia. The aim of the present study was therefore to examine the nature of the BC occurring in care homes, amongst *all* residents, independent of their dementia status. The profile of behaviours will be examined with Hierarchical Cluster and Mokken analyses, the latter to identify possible latent structures within the data set.

Methods

Residents

An NIHR funded cluster randomised controlled trial of individually tailored psychological interventions for the management of BC in dementia was undertaken between 2008 and 2012 in England (www.challengedemcare.com). To establish eligibility of homes for the clinical trial, the Challenging Behaviour Scale (CBS, Moniz-Cook et al., 2001) was conducted with care staff in 63 residential and nursing homes for BC in 2185 residents. Homes had 25 or more beds, and had been rated as 'good' or 'excellent' by the Care Quality Commission (CQC). No demographic data are therefore available for this sample of residents. Although the diagnosis of each resident is not explicit, it can be assumed that between 52 per cent and 80 per cent dependent on age and home type had some form of dementia (Alzheimer's Society, 2013). Residents with physical or learning disabilities and longstanding mental health problems could not be excluded from this sample.

Challenging Behaviour Scale (CBS)

The 25-item CBS (Moniz-Cook et al., 2001) measures problematic behaviours including those related to negative affect (Table 1) across incidence (yes/no), frequency and 'management difficulty' of resident behaviour. Only the incidence scores were used in the present study. The measure has good internal consistency, good test-retest reliability and adequate validity. Inter-rater reliability is good when staff receive training or when based on joint interviews with more than one informant. It was used for the following reasons: the CBS was developed on the basis of care staff descriptions of resident behaviours that were seen as challenging, distressing or difficult to manage; second, it is easy to apply and widely used in routine practice in the UK for monitoring service developments and individualised interventions and; third it has cut-off points for the severity of behaviours in a given resident.

Procedure

Residents' behaviours over the past eight weeks were assessed using the CBS-incidence. Care workers (usually key workers) completed the CBS for all residents in the home, regardless of diagnosis. Completed paper questionnaires for each resident were scanned and uploaded into an SPSS file. The data consisted of 2185 rows of 25 '1s and 0s' showing whether or not the resident had displayed each BC. There were two missing values, both for the same resident. These were recoded to 0 signifying the behaviour was absent.

Statistical Analysis

Hierarchical cluster analysis of the 25 CBS items was undertaken, using simple matching, complete linkage to identify thematic clusters within the data set. Clusters were labelled by a focus group composed of clinicians.

Mokken scaling was used to determine whether there was a 'latent trait' in the structure of the data. More specifically, we wanted to explore whether there is a hierarchical pattern associated with the incidence of BC.

Mokken scaling is a non-parametric item response theory method which assumes that items in a scale can be ordered by degree of 'severity', where severity refers to the ordering of items on a latent trait. More severe items have lower mean items scores in a group of respondents or observations and represent a greater presence of the latent trait. For example, in a scale measuring psychological morbidity, 'feeling unhappy' is likely to be a less severe item than 'feeling suicidal'. Its theoretical significance for clinical practice has been outlined and examples of its application are emerging in the literature on outcome measurement in health services (Fieo et al., 2010; Bedford et al., 2010). Mokken scaling should conform to the models of monotone homogeneity (MMH) and double monotony (MDM). Respectively, these mean that item response functions increase monotonically as the latent trait that is being measured increases (MMH) and that the item response functions do not overlap (MDM). For binary scored items, the MDM is equivalent to invariant item ordering (IIO) whereby the ordering of items on a scale (according to the mean score of the respondents) is also the order in which all respondents respond to items across the full range of the latent trait.

Reproducibility is measured by Loewinger's coefficient H_i for each item and H for the entire scale. The calculations of H_i and H depend on comparing the probability of errors in ranking, to the probability of such a ranking occurring in independent items. H_i and H will take values between 0 and 1. The probability (p) of obtaining the scale can be estimated, as can the reliability (Rho) of the scale; $Rho > 0.7$ indicates a reliable scale. In a strong scale all H values exceed 0.5 in value, > 0.3 and > 0.4 are considered acceptable but indicative of weak and moderate scales respectively. In this analysis we have chosen > 0.4 as our cut-off score for selection of individual items. Data saved in SPSS were converted to a form suitable for entry into the Mokken Scaling Analysis for Polytomous items for Windows Version 5.0 (iecProGAMMA, Groningen). The

programme was run using default settings of $H > 0.3$ and $p < 0.05$, thus omitting CBS items with a low H value.

Results

Of the 63 care homes surveyed, 11 were large homes consisting of 50+ beds, 20 consisted of 40–49 beds and 32 were smaller 25–39 bed homes. The prevalence of BC was high with 87.5 per cent of residents exhibiting one or more BC (Table 1). Nine homes showed high levels of BC with 40 per cent of residents scoring > 10 or more on the CBS.

The most frequent behaviours (Table 1) were the three items of 'acts of omission' phrased as 'lack of'. Within the Cluster analysis these items formed a meta-cluster which we have labelled 'Apathy' (Table 2). The two other meta-clusters identified were 'Agitation with internal focus' and 'Agitation with an active external focus'. Table 2 presents the CBS items in their clustered groups, alongside themes devised within the focus groups. Five themes were identified: apathy, dis-inhibition, control seeking, repetitive agitation, and self-preservation and signals of distress. The 'Agitation with internal focus' is composed of themes of 'dis-inhibition' and 'control seeking', and it was felt that the items in these clusters reflected distress and coping taking place within the person (i.e. most of the behaviours did not require another person to be around to be expressed). In contrast, many of the items in the 'Agitation with an active external focus' involve a greater degree of social engagement and interactions directed at others. For example, in the 'Repetitive agitation' group, the behaviours are likely to bring the person into social contact with others. In the 'Self-preservation and signals of distress' grouping we see a number of anti-social activities.

The scalability of the Mokken analysis satisfied the assumptions of the Mokken model for seven of the 25 Challenging Behaviour Scale items. This was statistically significant ($p=0.001$), moderately strong i.e. $H=0.38$ with a reliability of $Rho=0.85$, therefore demonstrating a latent trait

which was broadly consistent with the BC occurrence ratings (Table 1). In selecting our items for inspection we have taken the conservative cut-off score of ($H>0.4$) to ensure we are analysing a moderate to strong trait/structure. Thus, we can say that those residents who displayed ‘dangerous behaviour’ were more likely to have displayed those behaviours with a higher mean significant Mokken value. This hierarchical relationship exists across the shaded items in Table 1, although occurring mainly in the top section of

the table. Hence, those exhibiting ‘dangerous behaviour’ had a high probability of also displaying ‘non-compliance, perseveration, shouting, restlessness, verbal aggression, lack of self-care’. Of note, 18 CBS items were rejected from the Mokken profile (see Table 1 non-shaded areas). H values for these items were below the cut-off score ($H<0.4$), suggesting that they do not have the same hierarchical probabilities and relationships with the shaded items. In summary, the six items at the top of the CBS frequency table

Table 1: Occurrence of behaviours that challenge and Mokken analysis.

Behaviours ¹	Abbreviation	Percentage occurrence [n=2185]	Mokken	
			Mean Item Score ²	H ³
Lack of self care	Scar	66	1.66	0.44
Lack Motivation	Motv	50	1.50	n/s
Lack of Occupation	LOcc	44	1.44	n/s
Verbal Aggression	VbAg	36	1.36	0.48
Restlessness	Rest	34	1.34	0.40
Shouting	Shou	34	1.33	0.45
Perseveration	Pesv	31	1.31	0.40
Non Compliance	NCom	30	1.30	0.40
Sleep problems	Slee	30	1.30	n/s
Wandering	Wand	26	1.26	n/s
Physical Aggression	PAgg	25	1.25	n/s

¹ Shaded items are moderately scoring items (>0.4) from Mokken analysis; ² mean scale score = 22.09; standard deviation=3.72; skewness=0.75; kurtosis=0.43; ³H=0.38; p=0.001; Rho 0.85; n/s=non scaling items

Table 1 (continued): Occurrence of behaviours that challenge and Mokken analysis.

Behaviours ¹	Abbreviation	Percentage occurrence [n=2185]	Mokken	
			Mean Item Score ²	H ³
Suspicious	Susp	25	1.25	n/s
Demands Attention	DAtt	24	1.24	n/s
Interfering	Intf	21	1.21	n/s
Screaming	Scrm	21	1.21	n/s
Clinging	Clng	14	1.14	n/s
Self Harm	SHar	14	1.13	n/s
Smearing	Smer	13	1.13	n/s
Manipulative	Manp	13	1.14	n/s
Pilfering or Hoarding	PiHo	12	1.12	n/s
Stripping	Stri	11	1.11	n/s
Inappropriate Urination	Urin	10	1.10	n/s
Spitting	Spit	5	1.05	n/s
Inappropriate Sexual Beh'r	Sexb	4	1.04	n/s
Dangerous Behaviour	Dang	4	1.04	0.40

We have argued in the introduction that all the BC items have multi causes, but the shaded items are related through a 'latent' factor. Also, in the case of the latter items, those lower in the hierarchy (ie. lower in the table) tend to occur in the presence of those items above them. Such that the 'verbal aggression' tends to occur with 'lack of self care', while 'restlessness' tends to occur in presence of both 'verbal aggression' and 'lack of self-care'. Thus in the case of 'dangerous behaviour', it tends to occur in the presence of all the other shaded items.

are broadly consistent with the Mokken analysis, and overall 7 CBS-items demonstrate a moderate-strong latent hierarchical structure.

Discussion

Prevalence of challenging behaviour in care homes

These findings demonstrate that BC are prevalent even within a general population

of residents in care. One-eighth of residents did not display any BC ($N=274$), while 40 per cent displayed 10 or more. The high prevalence is in keeping with the majority of studies in care homes with previous rates of 82 per cent (Ballard et al., 2001), 80.5 per cent (Selbaeck et al., 2007) and 91.7 per cent (Bergh et al., 2011); although lower rates of 20 per cent have also been recorded when using more conservative methodologies (Bowman et al., 2004).

The most frequent behaviours were 'acts of omission' relating to our theme of 'Apathy'. This was consistent with the pan-European study of Aalten et al. (2008) where apathy was the most common challenge for staff, occurring in 56 per cent of their sample ($N=2808$).

Clinical implications

BC occurred concurrently, consistent with previous studies (Lyketos, 2007; Volicer et al., 2007). Such a finding argues against the common clinical practice of treating a particular BC independently of the rest of the person's presentation (e.g. using risperidone to treat agitation, Holmes & Muthalagu, 2009). Rather it is more consistent with the notion of behaviours being manifestations of general distress, that require more comprehensive assessments of behaviour to identify underlying unifying causes of the full range of the resident's problematic presentations.

The cluster analysis identified five themes, nested within three meta-clusters (Table 2). It is hypothesised that the theme 'apathy' may be related to paucity of meaningful activities occurring in the settings (Kitwood, 1997) or the high levels of resident depression. The theme 'dis-inhibition' is potentially linked to executive deficits, although our research design prevents us from establishing an association between the themes and cognitive status. 'Control seeking' could be related to the residents trying to exercise autonomy. The themes of 'repetitive agitation' and 'self preservation and signals of distress' have a more social

character, with the former bringing residents into greater degrees of contact with others (residents and staff); while the latter theme highlights the signalling of distress and aggression aimed towards others. Overall, the cluster analysis suggests underlying patterns within the behaviours, although more work is required to determine the robustness of the themes. If found to be sufficiently robust, this thematic framework could be used to develop interventions and undertake preventative work. For example, providing higher levels of meaningful activities to reduce levels of apathy; ensuring the activities provide sufficient levels of autonomy to increase levels of perceived control; improving staff communication and interaction skills to facilitate positive social engagement (James, 2015), thereby reducing social agitation.

The Mokken analysis shows that the significant items (shaded items in Table 1) come from across the meta-cluster groups of Table 2, but the significant Mokken items occur predominantly in the 'Agitation with active external focus' cluster. The column labelled 'Mokken-mean items score' of Table 1 shows that the hierarchical Mokken relationship is linked to the frequency of occurrence in the top half of the table. In other words, those who display 'non-compliance', also tend to display the other frequently performed CBS activities of 'perseveration, shouting, restlessness, verbal agitation and lack of self-care'. Once again our findings appear to suggest that there is an underlying relationship within many of the items we have previously labelled as 'agitated with an active external focus'. Of note, the Mokken statistic has uniquely given us a clue to how the behaviours may be related to each other. For example, the findings suggest that 'lack of self care' might happen entirely by itself, without the presence of other CBS items. However, if 'verbal aggression' occurs, it will tend to happen in the presence of 'lack of self care'. Furthermore, every time we go down the hierarchical table, we are likely to witness higher levels of distress/agitation

Table 2: Results of Cluster analysis of CBS items.

Meta-cluster	Themes (Common words used in focus group) ¹	Behaviours that Challenge from CBS
1 Apathy	Apathy (self neglect, withdrawal)	Lack of self care, Lack of occupation, Lack of motivation.
2 Agitation with Internal focus	Dis-inhibition (impulsive, over activity)	i. Sexual behaviour, Spitting, Dangerous Behaviour (jumping from a height) ii. Inappropriate urination, Stripping. iii. Smearing, Clinging, Hoarding.
	Control seeking (detrimental to self, attention seeking)	i. Self harm (injuring self, refusing food). ii. Manipulative (gain some advantage for self). iii. Sleep problems (refusing to go to bed, getting up at night).
3 Agitation with an Active External focus	Repetitive agitation (unsettled, lack of stimulation, stuckness)	i. Wandering, Restlessness, Perseveration.
	Self preservation & Signals of distress (distress, resistance behaviour)	i. Suspiciousness, Demands Attention, Interfering. ii. Verbal Aggression, Shouting, Physical Aggression, Screaming. iii. Non-compliance.

¹The labelling for these items was arrived at through focus group run with clinical staff. The words commonly used by members of the focus group are included to provide an idea of thought processes of the group.

and thereby greater levels of behavioural disruption consistent with the hierarchy. The only item in Table 1 not following this pattern is ‘dangerous behaviour’, and it is not clear how this behaviour is linked to the other significant Mokken items.

Currently, we are not fully able to make sense of the hierarchy found, but a more targeted methodology in subsequent studies may lead us to better clarify the underlying relationships we have observed. This will enable us to plan our clinical services, by achieving greater understanding of how to

investigate and assess referrals. For example, from the current data, we can suggest that referrals indicating ‘non-compliance’ (aka. ‘resistive to care’) warrant queries about the presence of a prescribed set of additional ‘externalising agitated behaviours’ (perseverating, shouting, etc.).

Limitations: measurement and methodology

The CBS as an outcome measure is not widely used worldwide, although translations and validations are ongoing across Europe and the Far East. However, it was developed from

staff reports of behaviours they perceived as challenging and thus was seen as an acceptable instrument for measurement.

In the absence of descriptive information on age, length of stay, level of cognitive impairment and diagnosis we could not determine whether the findings from the structural analyses were specific to, for example age, dementia-diagnosis and stage, or physical disability. Further study of this may refine the profiles we outline (Table 1), to assist with the targeting of specialist health interventions for residents living in care homes.

Our sample did not consist of residents referred to clinicians for help. Future service related research would elucidate the value of this framework in the growing number of BC services that are emerging in dementia care in some countries.

Conclusion

The strength of our new analysis of BC in a large cross-sectional sample of residents in 63 care homes is that it is now possible to quantify, within structural frameworks (e.g. a hierarchy), groups of residents with severe BC. This timely development is supported by national guidelines in England calling for increased understanding of BC and development of appropriate skills for care home staff in non-pharmacological treatments of BC. Given reports of inadequate specialist services for unmet needs in residents (Purandare et al., 2004) there is scope to focus different types of services and intensities towards both resident and staff that support them. These may include programmes of person centred care, staff training and support, withdrawal of anti-psychotic medications (Fossey et al., 2006), interdisciplinary services (Opie et al., 2002) and case-specific functional analysis-based interventions

for those with severe BC (Stokes, 2000; Moniz-Cook et al., 2012). Future research is now required to validate a stepped care decision making process to include different intensities of these interventions in the targeting of specialist mental health care services for residents living in care homes.

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