Professional perspectives on applying the NICE and British Psychological Society Guidelines for the management of Behaviours that Challenge in dementia care: an e-survey

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Objectives. Behaviours that challenge (BtC) reflect the most costly and burdensome aspects of dementia where non-pharmacological interventions rather than antipsychotic medication have been recommended as first-line approaches for over a decade (NICE 2006). This paper outlines professionals' views about their application of the Dementia NICE Guideline 97 (2018) and a British Psychological Society, Division of Clinical Psychology (BPS-DCP) Briefing paper (2013) on alternatives to antipsychotics.

Methods. A mixed-methods 34-item e-survey, with five items about the use of the NICE Guideline 97 (2018) and the BPS-DCP Briefing paper (2013) for the management of BtC, was conducted. Participants were recruited through multidisciplinary professional dementia networks across the United Kingdom. Quantitative data were descriptively summarized and thematic analysis of open-ended questions undertaken.

Results. Two hundred and forty-seven participants completed the questions relating to guidelines. Mean ratings of 'moderately useful' for both the NICE and BPS-DCP guidance were obtained across professions and geographical locations, with the exception of psychiatrists who rated the NICE guidance as 'slightly useful'. The qualitative themes identified were a mix of positive and cautionary perspectives, relating to 'evidence base', the 'accessibility of the guides', 'problems with implementation', and 'lack of detail and clarity'.

Conclusion. Professionals were cautiously positive regarding the guidance for BtC management, but highlighted a need for improved clarity about the use of non-pharmacological approaches, and more specificity about how these can be implemented in clinical settings. Tailored 'setting-specific' toolkits are required to update and refine the BPS-DCP (2013) if the aspirations of the NICE Dementia Guideline 97 (2018) are to inform professional practice.

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Practitioner Points

- Owing to major concerns about the problematic side effects of using psychotropics in the treatment of behaviours that challenge (BtC), there is a need for national guidance on the use on non-drug alternatives.
- The NICE (2018) guidance was seen by participants as accessible and clear but lacking in detail in the use of non-pharmacological interventions, which are the first-line treatments for BtC.
- The BPS Guidelines on 'Alternatives to antipsychotics' (2013) were seen as having good structured advice for allocating non-pharmacological resources but were lacking in flexibility for meeting individual needs or what might be an acceptable fit for clinical services.
- The findings suggest that we need to develop UK-wide bespoke specific advice for practitioners and services for both the use and the delivery of non-pharmacological evidence-based interventions for BtC.

Introduction

During the course of dementia, most people will display one or more neuropsychiatric symptoms such as apathy, anxiety, agitation, depression, aggression, delusions, disinhibition, hallucinations, sleep and eating disturbances, or other behaviours considered inappropriate (Tible, Riese, Savaskan, Riese, Savaskan, & Von Gunten, 2017). The consequences of these symptoms cause management challenges for carers and services, often resulting in isolation of the person with dementia, increased referral to nursing homes (Toot, Swinson, Devine, Swinson, Devine, Challis, & Orrell, 2017), and high resource and financial costs.

The NICE/SCIE Dementia Guideline CG42 (2006) introduced the notion of 'behaviour that challenges' (BtC) to highlight the challenges for caregivers in managing behavioural changes associated with dementia. Whilst the causes of these changes are multifactorial, having biological, psychological, and social origins, BtC can be conceptualized as expressions of unmet need(s). Utilizing this conceptualization would suggest that the failure to meet people's needs detracts from their well-being, due to associated distress and the challenges that occur within the settings where they live (Cohen-Mansfield, 2000). If unresolved, this can exacerbate risks and harmful management responses.

Following concerns about overuse of antipsychotics (Banerjee, 2009) and associated policy targets to reduce these in dementia management, the British Psychological Society – Division of Clinical Psychology (BPS-DCP), published a briefing on 'alternatives to antipsychotic medication' (Brechin, Murphy, James, & Codner, 2013), with specific pathway-led guidance to facilitate service delivery of non-pharmacological interventions. This adopted a 'stepped-care' approach to the management of BtC, with four ascending levels of support, specifying 'who' would conduct supportive activity: step 1 – recognition and screening of problem behaviours/ GPs and Carers; step 2 – low-intensity management and good interpersonal skills/ Carers; step 3 – high-intensity management with protocol-led interventions/ mental health professionals; and step 4 – specialist management/ skilled BtC teams. Since its publication, two large-scale applied research programmes associated with BtC (Challenge-Demcare, Moniz-Cook et al., 2017; WHELD, Ballard et al., 2020) suggested that whilst antipsychotic prescribing had reduced in care homes, the quality of prescribing of these and other psychotropics was far from ideal. Particular gaps in the recognition of BtC in those living at home and support needs of family carers were highlighted in a second BPS briefing paper on the topic (James & Moniz-Cook, 2018). The second NICE Dementia Guideline NG97 (NICE, 2018; https://www.nice.org.uk/guidance/ng97/evidence/full-guideline-pdf-4852695709) focused on symptomatic groups of 'agitation, aggression, distress and psychosis' with evidence reviews considered for 'anxiety, depression, antidepressants / antipsychotics', sleep problems

and agitation / aggression' (see NICE, 2018 link above, pp 300). Its management recommendations remained cautious about the use of medication (see NICE, 2018 link above, pp 93–97; p 100; pp 102−103; pp 329–330). These evidence reviews failed to emphasize the role of behavioural approaches to management (for reviews, see NICE, 2018 link above, pp 298–330), known collectively as behavioural or functional analysis (NICE, 2006), where systematic reviews are available (see Abraha et al., 2017; Moniz-Cook et al., 2012). These types of interventions involve careful assessment and understanding of the behaviour in question including its function and maintaining factors, which are then formulated to develop and test individually tailored multicomponent interventions to meet the person's need(s).

The present study aimed to explore multiprofessional perspectives on the use of guidelines in routine clinical practice for this paradigm, given cautionary notes about medication management. Research questions focused on the updated NICE Guideline (2018) and service pathways outlined in the BPS stepped-care approach (Brechin et al., 2013) and participants' knowledge and views about other guidelines.

Method

A multidisciplinary online survey was developed from the views of professionals working in the field of dementia care in the United Kingdom. The perspectives were obtained using an adapted workshop-based Delphi-based method consisting of: (1) an initial steer from a small group of experienced practitioners (n = 13) and (2) a one-day consultation workshop organized by the BPS-DCP to review NICE guidelines and examine practice associated with BtC. The latter was attended by 74 stakeholders from a range of professions and organizations including psychology (50%), nursing (14%), psychiatry (8%), and occupational therapy (OT) (8%), and between 1 and 3 participants from family carer groups or other professions and organizations, for example, general practitioner, pharmacy, physiotherapy, care practitioners, social work, dementia charities, and NHS England. Participants were recruited via email from a network of clinical psychologists from dementia care services and from key professional organizations (e.g., Royal Colleges of Psychiatry, GP, Nursing, and OT), third sector providers, and family carer collaborators on known dementia research committees.

From the consultation event (see James, Moniz-Cook and Duffy, 2019), a 34-item questionnaire was developed on the topic of BtC. The resulting survey was composed of six sections (Paradigm name; Management strategies; Formulation; Training and supervision; Specialist teams; and Knowledge and value of Guidelines). All stakeholders (n = 74) attending the consultation event consented to be contacted and were sent the anonymized online survey. Additional professionals were contacted if known to have published in the area or to have a specific interest in the topic. This included experts from medicine (geriatricians/ GPs/ neurology), nursing, speech and language therapy, and social work, and those who had published in peer review journals. A cascading snowballing method for recruitment was used.

From the 34 items (for the survey, see https://drive.google.com/file/d/1NjORMqdYs-OfF-Cw0mPIMcdpBlB65HlG/view), five questions related specifically to Guidelines: Q1. How useful are the NICE (2018) dementia guidelines for your work with people displaying BtC (5-point Likert scale, 1 (not at all useful) to 5 (extremely useful)); Q2. Please give a reason for your response (free text); Q3. How useful is the BPS Stepped-care framework (BPS, Brechin et al., 2013) for your work with people displaying BtC (5-point Likert scale, 1

(not at all useful) to 5 (extremely useful)); Q4. Please give a reason for your response (free text); and Q5. Please name any other guidelines or publications you have found helpful in your work with BtC (free text).

Data analysis

Quantitative data were summarized using descriptive statistics, and qualitative data from free-text questions were analysed using framework analysis described by Gale, Heath, Cameron, Rashid, and Redwood (2013). Author KG generated initial codes for 30 of the statements and derived a coding template, HW (independent of the study) then applied the template to the statements. Next, the framework was amended and applied to a second set of statements in which rating agreement between KG and HW reached 85%. After this iteration, a final template was developed and KG coded the remaining statements based on this.

Ethics

The project was approved by University of Hull Faculty of Health Sciences Ethics Committee

Results

Three hundred and seventy-eight (378) people participated in the survey. Over a third (38.6%) were nurses, with psychologists being the next most frequent contributors (22.2%), followed by psychiatrists and OTs (see James, Mahesh, Duffy, Mahesh, Duffy, Reichelt, & Moniz-Cook, 2020, for a full account of participants). Two hundred and forty-seven (65.3%) participants provided quantitative data on the NICE guidance, with 158 (41.8%) giving a qualitative response (Table 1). Of those providing quantitative responses, over one third were nurses (34.8%), followed by psychologists (30%), 'Others' (16.2%), psychiatrists (11.7%), and OTs (7.3%). For the BPS guidance, 141 (37.3%) of 378 participants provided a quantitative response, with 78 (20.6%) giving a qualitative response. Psychologists comprised the greatest percentage of those providing a quantitative response (40.4%), followed by nurses (27%), 'Others' (14.9%), psychiatrists (11.3%), and OTs (6.4%). Table 1 summarizes professionals' ratings of NICE and BPS guidance across geographical location.

NICE scores

Two participants failed to identify a geographical location. The highest number of respondents were from Yorkshire ($n = 40$), followed by those from Scotland ($n = 35$), Midlands ($n = 32$), North East of England ($n = 31$), South England and the Channel Islands ($n = 29$), North West of England ($n = 21$), London and the surrounding area ($n = 18$), Northern Ireland ($n = 18$), and Wales ($n = 14$). The lowest number of respondents were from Cumbria and Lancashire ($n = 7$). All of the total average scores for the NICE guidance by profession were within the 'moderately useful' rating, with the exception of psychiatrists (mean = 2.87) who rated it as only 'slightly useful'. Nurses gave the highest total average rating (mean = 3.34). Most participants from the London area rated the NICE guidance low (in the 'slightly useful' rating category). Examining the

Table 1. Participants' ratings of the usefulness of guidance, separated by profession and geographical location

Region & Number of participants	NICE					BPS				
	Nurse n = 86	Psychol. n = 74	Psychia. n = 29	OT n = 18	Other n = 40	Nurse n = 38	Psychol. n = 57	Psychia. n = 16	OT n = 9	Other n = 21
Yorkshire NICE n = 40, BPS n = 19	3.34 (0.79)	3.71 (0.70)	3.20 (0.40)	3.67 (0.47)	2.80 (0.87)	3.80 (0.75)	3.80 (0.75)	3.00 (0.71)	3.00 (0.00)	2.00 (1.23)
Midlands NICE n = 32; BPS n = 18	3.20 (0.87)	3.13 (0.60)	3.20 (1.327)	3.00 (0.00)	3.43 (0.73)	3.80 (0.75)	3.13 (0.64)	2.00 (0.82)	n/a	3.67 (0.47)
Scotland NICE n = 35; BPS n = 23	3.75 (1.09)	3.00 (0.95)	n/a	2.00 (0.00)	2.50 (1.50)	3.43 (0.50)	3.69 (0.72)	n/a	3.00 (0.00)	3.00 (0.00)
NE England NICE n = 31, BPS n = 21	3.43 (1.24)	2.83 (0.90)	3.00 (0.816)	2.00 (1.23)	3.75 (1.09)	3.78 (0.92)	3.67 (0.75)	3.00 (0.00)	4.67 (0.47)	4.00 (0.00)
S England & Channel Is NICE n = 29, BPS n = 13	3.80 (0.75)	3.50 (1.00)	3.50 (0.50)	3.00 (0.00)	3.43 (0.50)	3.34 (0.47)	3.83 (0.69)	4.00 (0.00)	n/a	2.67 (0.47)
NW England NICE n = 21, BPS n = 13	3.50 (0.87)	3.34 (0.47)	1.50 (0.500)	3.34 (0.47)	3.00 (1.00)	3.00 (0.701)	3.34 (0.94)	3.50 (0.50)	4.00 (1.00)	3.00 (0.00)
London area NICE n = 18, BPS n = 9	2.50 (0.50)	2.80 (0.75)	2.71 (0.881)	4.50 (0.50)	2.50 (0.50)	3.00 (0.00)	2.67 (0.94)	3.00 (0.00)	4.00 (0.00)	3.50 (0.50)
Northern Ireland NICE n = 18, BPS n = 13	2.60 (0.49)	3.25 (1.48)	3.00 (0.894)	4.00 (0.00)	3.67 (0.47)	3.67 (1.25)	4.00 (1.41)	3.00 (0.00)	5.00 (0.00)	4.00 (0.71)
Wales NICE n = 14, BPS n = 9	3.60 (1.02)	2.43 (0.73)	n/a	n/a	2.50 (0.50)	5.00 (0.00)	2.50 (0.50)	n/a	n/a	n/a
Cumbria and Lancashire NICE n = 7, BPS n = 3	3.00 (1.23)	2.67 (1.25)	n/a	n/a	n/a	n/a	3.34 (0.94)	n/a	n/a	n/a
Location not specified NICE n = 2; BPS n = 0	4.00 (0.00)	n/a	n/a	n/a	3.00 (0.00)	n/a	n/a	n/a	n/a	n/a
Totals	3.34 (0.46)	3.07 (0.38)	2.87 (0.60)	3.19 (0.83)	3.06 (0.46)	3.65 (0.57)	3.40 (0.48)	3.07 (0.56)	3.95 (0.76)	3.23 (0.65)

Table includes means/standard deviations.

regions providing the top ratings (scores in ranges of 4–5), Scotland and 'South England and the Channel Islands' show the highest profiles, due to high scores from the nurses and psychologists. The region providing the highest frequency of low ratings (scores 1–2) was the North East of England.

BPS scores

Most responses for the BPS guidelines came from Scotland ($n = 23$), followed by North East of England ($n = 21$), Yorkshire ($n = 19$), Midlands ($n = 18$), South England and the Channel Islands ($n = 13$), North West of England ($n = 13$), Northern Ireland ($n = 13$), London and the surrounding area ($n = 9$), and Wales ($n = 9$), with the least responses from those in Cumbria and Lancashire ($n = 3$). All of the total average scores by profession were within the 'moderately useful' rating category. There was a non-significant trend with higher professional average scores for all BPS ratings compared with NICE ratings. Psychiatrists assigned the lowest ratings for the BPS guidance (mean =3.07), and OTs gave the highest rating (mean =3.95). The highest frequency of top scores (ratings 4–5) was from the North East of England, and highest frequency of low scores (ratings 1–2) was from Yorkshire, North West of England, and Wales.

Themes

Thematic analysis was conducted on the qualitative responses for both the NICE and BPS guidance (Table 2). Statements made for the 'moderately useful' ratings (score of 3; see Tables S1 and S2) were broadly similar to the information captured in the thematic analysis shown in Table 2, with no new concepts being expressed. Therefore, here we present analysis for participants who rated the guidance *either* in the high range (scores 4–5, i.e., 'very useful' or 'extremely useful') *or* in the low range (scores 1–2, i.e., 'not at all useful' or 'slightly useful'). For NICE high range (scores 4–5), five themes were identified with one subtheme within 'Generic positive statement'. Five themes were also identified in the low range (scores 1–2). A number of the same themes were found in those giving high and low ratings in the thematic analysis of the comments made about NICE (see section 2 of Table 2). For the BPS guidance, three themes each were identified in both high range (scores 4–5) and low range (scores 1–2) responses. Some statements, particularly for high scores, contained mixed views revealing both positive and negative perspectives – usually in the form of caveats.

The themes are described below and illustrated with additional quotations.

NICE themes from high scores

Generic positive statements

The majority of participants in the high rating category gave a positive statement about the NICE guidance, including that they were useful, were good to refer to, and supported best practice.

> Useful as guidance – Clinical Psychologist

However, many participants provided no specifics about what aspects of the guidance were useful. A subtheme emerged from this category named as 'positive statements with

Table 2. Results of thematic analysis, separated into high rating and low rating for NICE and BPS guidance

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1. NICE guidance: themes identified by participants who rated guidance highly (either 4 or 5 on a Likert scale)

1.a Theme: Generic positive statements (*N* = 22):

'Good to have a reference to refer to' – Nurse

Subtheme: Positive statements with caveats (*N* = 6)

'It outlines the relevant points well. The problem is, I'm not sure how many front line staff have read them (and I include CP colleagues in that)'. – Clinical Psychologist

1.b Accessibility (*N* = 6)

'Easily accessible and understandable, can refer others to them, supports challenges with some approaches' – Admiral nurse

1.c Miscellaneous (*N* = 9)

'Are becoming more detailed as they evolve to be more meaningful' – Nurse

2. NICE guidance: the <u>same</u> themes identified by participants who rated guidance either high or low

2.a Medical Model

<u>high</u> ratings/endorsement – not overly focused on a medical approach (*N* = 4)

'They emphasis non-pharmacological approaches to distress and so help to validate the Stress & Distress work' – Clinical Psychologist

<u>low</u> ratings/endorsement – overly focused on a medical approach (*N* = 13)

'Medical model focus little emphasis on psychological approaches to distressed behaviour' – Nurse

2.b Evidence base

<u>high</u> ratings/endorsement – provides good information re. evidence (*N* = 3)

'Gives a framework and guidance for what the evidence-base suggests is best practice' – Assistant Psychologist

<u>low</u> ratings/endorsement – provides poor information re. evidence (*N* = 2)

'Modest evidence for limited recommended approaches' – Clinical Psychologist

3. NICE guidance: themes identified by participants who rated guidance low (either 1 or 2 on a Likert scale)

3.a Lacks detail/clarity/specificity (*N* = 19)

'Guidance is very brief, limited detail , little to work with when developing clinical standards for care' – OT

3.b Implementation problems (*N* = 7)

'They offer a reference point, but they are seldom implemented' – Other

'Implementation and lack of user design' – Psychiatrist

3.c Miscellaneous (*N* = 9)

'The content shows little grasp of behavioural a management and understanding' – Clinical Psychologist

4. BPS guidance: themes identified by participants who rated guidance highly (either 4 or 5 on a Likert scale)

4.a Structure (*N* = 10)

'It helps identify what level of input is needed and which professional can provide that input. . .' – Nurse

'It gives a structure to care and a starting point to intervene. If one thing doesn't work you have a guide as to what to try next that is at the most appropriate level needed for an individual' – Assistant Psychologist

4.b Timely (*N* = 7)

'We changed our referral pathway to stepped care model and it has enabled us to meet the person's needs in a more timely manner' – OT

4.c Detailed and clear guidance (*N* = 5)

'Much more detail and recognition of different types of input that may be needed' – OT

4.d Miscellaneous (*N* = 12)

'This is a very useful document to use with Managers etc who do not understand BtC because it emphasises the importance of specialist services. However, it's usefulness is limited because it does not

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help identify who is most appropriate for what service, just what services should do' – Clinical Psychologist

5. BPS guidance: themes identified by participants who rated guidance low (either 1 or 2 on a Likert scale)

5.a Implementation problems (*N* = 4)

'They are useful as a conceptualisation but not easy to apply in practice' – Clinical Psychologist

5.b Lack of awareness of guidance (*N* = 3)

'A good model, but not being commissioned locally so limited impact' – Clinical Psychologist

5.c Lack of person-centred approach (*N* = 2)

'They do not have a strong person centred/enduring-self element to them, and miss the complexity of the care relationships. Too reductionist' – Clinical Psychologist

5.d Miscellaneous (*N* = 6)

'Lot of barriers' – Clinical Psychologist

'Little guidance on how to manage behaviours that challenge' – Nurse

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caveats'. Here, positive statements about the NICE guidance were accompanied by statements relating to problems with implementation or lack of awareness of the guidance within the clinical field.

> These are excellent guidelines, although sometimes difficult to implement across teams – Admiral Nurse

Accessibility

Participants commented that the NICE guidance was accessible to professionals, carers, and students. Good accessibility related to being able to find it online, in written form, and the document itself was viewed as being clear and understandable.

> Easily accessible and informative for new starters and students and other staff – Physiotherapist

Miscellaneous

Within the high rating scores, two participants positively mentioned the term 'detail', but this was not deemed a theme as the comments were considered too vague.

> Covered in reasonable details – Primary care specialist in Dementia

Two participants positively discussed the guidance in terms of how it presents behaviour – when referring to 'people living with dementia'; however, again, this was not considered a theme.

> I love the fact that the guidelines talk about distress and not challenging behaviours. . .this is so positive – OT

NICE themes identified in both 'high' and 'low' scores

Medical model focus

There were some contradictory statements surrounding lack of detail specifically relating to non-pharmacological interventions. Four participants in the high rating category praised the mention of non-pharmacological interventions.

> The guidelines are useful because they give guidance that follows a non-pharmaceutical, behavioural approach. . . – Nurse

However, thirteen participants in the low rating category noted that the guidance is too heavily focused on the medical model with not enough attention paid to non-pharmacological approaches.

> They are focused on the medical model and pay lip service to non-pharmacological interventions – Other

Evidence base

Similarly, there were contradictory responses surrounding the evidence base discussed by the guidance. Three participants in the high rating category stated the guidance provided information using a good evidence base.

> Relevant evidence base – Psychiatrist

However, in low rating themes there were comments about the guidance's poor use of the available evidence base.

> The guidelines have insufficient detail on evidence-based non-pharmacological interventions. . . – Clinical Psychologist

NICE themes from low scores

Lack of detail, clarity, and specificity

Participants commented that the guidance lacked detail, clarity, and specificity. Problems described related to confusion about what clinicians should be doing and the guidance being too general, consequently leading to a lack of person-centred approach.

> Doesn't tell us what to do for each person. Too General – GP

Furthermore, several participants mentioned the lack of detail specifically in relation to clarity around non-pharmacological approaches for BtC management.

> Lack of direction re. specific interventions for BtCs – Clinical Psychologist

Implementation

As well as implementation being discussed as a caveat in the higher rating category, it again emerged as a theme here. Reasons for implementation difficulties included problems in fitting within participants' services and a lack of detail on how to best implement the guidance.

> They give a list of requirements for assessment but very little guidance around how this can be effectively implemented or lead to a helpful intervention – Clinical Psychologist

Miscellaneous

Within the low rating category, one participant mentioned that they used SIGN guidance (2006).

> We also use SIGN guidelines in Scotland so both are useful to some extent – Clinical Psychologist

Another questioned the methodology employed by NICE.

> NICE cheat by comparing effect sizes, and they are now stating that guidance is advisory only – Psychiatrist

BPS themes from high scores

Structure

The BPS 'stepped-care' guidance was seen as providing structure for care delivery to identify the appropriate non-drug treatment and level of input required for an individual. Participants also noted that this allowed for appropriate use of resources and often resulted in the least restrictive approaches.

> Having staged levels of care plans, individually designed to meet the spectrum of an individual's presentation, means the least restrictive, proportionate approach is adopted which promotes patient choice and empowerment. – Nurse.

Timely care

The BPS guidance was seen as valuable in providing timely care to service users and in preventing difficulties and associated escalation of care. Often, the themes 'structure' and 'timely care' were discussed together.

> It helps identify what level of input is needed and which professional can provide that input. . .. We changed our referral pathway to a stepped care approach and it has enabled us to meet the person's needs in a more timely manner – Nurse.

Detailed and clear guidance
In contrast to the NICE guidance, participants viewed the BPS document as providing clear, detailed guidance, often linking the stepped-care approach to the appropriate allocation of staff and resources.

> Clearly identifies the steps that can be undertaken by all stakeholders to alleviate distress, ensuring appropriate allocation of resources – Clinical Psychologist

However, many participants who commented positively on the detail of the guidance failed to elaborate on how this worked in practice.

> Clear guidelines to follow – OT

Miscellaneous
One participant mentioned about the BPS guidance having a good evidence base, and two participants mentioned using the stepped-care model to direct training or to improve the education and delivery of knowledge to others.

> Good evidence base for best practice – Clinical Psychologist

Furthermore, one participant mentioned the benefits of using the stepped-care model as a means of evaluating a person with dementia's behaviour and changes over time.

BPS themes from the lowest scores

Implementation
Participants in the low rating category liked the 'conceptualization' of this guidance but identified problems with its implementation.

> In principle they make sense, but in practice they are almost impossible to apply – Clinical Psychologist

Participants also found that the structure of the stepped-care approach was often not flexible enough to fit with their service.

Lack of awareness of guidance
Participants noted that a potential pitfall of the BPS guidance was that although they personally might use them, other staff/professionals would not; this created a barrier to their use. It was noted that unless the commissioners were aware of their existence, they could not be commissioned locally – effecting their potential scope.

> Useful for qualified staff and professionals drawing up the care plan framework, but again, not acknowledged or seen as relevant by providers – Social worker

Lack of person-centred approach

Several participants noted that the stepped-care approach was too reductionist and was not sufficiently person-centred, but they failed to elaborate further.

> Not person centred enough. . . – GP

Miscellaneous

In the miscellaneous low rating category, one response was collected from a husband of someone with dementia praising the GP and psychologist working with their family for being 'experts'.

Summary of the 'Other' guidelines

One hundred and thirty-one participants provided responses to the question – 'Please name any other guidelines or publications you have found helpful in your work with BtC'. Four different types of responses were provided: published guidelines; names of associations/societies of published guidelines; key texts that informed practices; and names of key authors in the field who published on clinical practice.

Published guidelines

Seven guidelines were identified for the specific treatment of BtC. The remainder were more generic although each included dedicated sections relevant to BtC. Three documents were from the BPS (e.g., Inpatient document, FPOP, 2017; 'BtC briefing', James & Moniz-Cook, 2018), four documents from the Department of Health (e.g., NHS Protect, 2015), four from the University of Exeter (e.g., Optimising Care and Treatment for People with BPSD, 2017), three from Social Care Institute of Excellence, and two each from the NHS and King's Fund. Three participants cited Scottish guidelines; they mentioned a total of six guidelines – three Scottish government publications, two from NHS Education Scotland, and one from SIGN (2006). The Scottish, Welsh, and English dementia strategies were also mentioned, as was an international document (i.e., International Psychogeriatric Association, IPA, 2015) and one from Northern Ireland (Dementia Learning and Development Framework, HSCB, 2016). Three participants provided local guidelines, two citing an NHS Trust's clinical pathway and the other a guide from their local prescribing committee. The latter was one of two guidelines specifically about medication, the other being Banerjee's DoH report (2009) on the use of antipsychotics. Three responses cited a guide on Positive Behavioural Support, one on delirium, one on housing needs, and one on diversity issues.

Names of relevant associations

Five participants did not identify specific guidelines, but stated they would consult the literature to provide guidance; four stated they would use the BPS (e.g., power threat meaning frameworks), four mentioned NICE (e.g., dementia: independence and well-being quality standard; and dementia: support in health and social care quality standard), three stated they would use literature from the Alzheimer's Society, two mentioned Dementia Care Matters, and there was one mention each for the Royal College of

Psychiatrists, the Association of Dementia Studies at the University of Worcester, and DSDC resources.

Articles/texts
Fourteen articles, five books, and five training programmes were mentioned. Each of the articles was cited once (e.g., 'Non-pharmacological Treatment of Behavioural Disorders in Dementia', Cohen-Mansfield, 2020; WHELD trial papers, Ballard et al., 2020). The book mentioned most frequently (*n* = 19) was 'Understanding Behaviour in Dementia that Challenges' (James & Jackman, 2017), other books included: 'Dementia Reconsidered' (Kitwood, 1997), 'Being with Older People' (Fredman, Anderson, & Joshua, 2010), 'Dancing with Dementia' (Bryden, 2005), and the Oxford Textbook of Psychiatry. In terms of training models, 'CLEAR' (Duffy, 2019) was mentioned seven times, six participants mentioned the 'Validation' work (Feil & de Klerk-Rubin, 2015), five people mentioned the 'Newcastle approach' (James, 1999; James, 2011), and one person identified the training programme 'CAIT – Communication and Interaction Training' (James & Gibbon, 2019), which incorporates the Newcastle model. The training provided by NHS Education Scotland, and its associated literature were mentioned on three occasions (The Psychological Therapies Matrix, NES, 2015); this is based on the Newcastle model. Cognitive stimulation therapy was also identified by a participant, who suggested it should be 'prescribed without charging people.'

Clinicians (text reference detail not always indicated within participant responses)
In terms of the names of key authors, the most frequently cited names were James (29), Jackman (19 – as in James and Jackman text book), Kitwood (14), Stokes (7), Brooker (7), Moniz-Cook (5), Teepa Snow (4), Feil (3), Fossey (2), Bryden (2), Sabat (2) Livingston (1), Fazio (1), Champagne (1), Hodges (1), Weiner (1), and Sheard (1). 'Sam Sly', the dementia campaigner, was also mentioned.

Miscellaneous
There were three mentions of theories/models that professionals found useful: 'The Enriched model', 'Maslow's hierarchy of needs', and 'Trauma informed care'. There were two mentions of therapeutic lies (James & Caiazza, 2018) and one of doll therapy (Lee & James, 2016). There was one mention of having read about sensory integration and attachment styles, and two participants gave generic answers on utilizing a 'recent evidence base'. Three participants stated they would use articles from the 'Journal for Dementia Care' as a source of guidance.

Discussion

The data on guidelines discussed in this article were taken from a larger survey on aspects of BtC (James et al., 2020; Wolverson et al., 2019). Quantitative data on the use of the NICE (2018) and BPS (Brechin et al., 2013) guidelines with respect to clinical practice were examined, and thematic analyses from related free-text questions provided insight into the practice implications of guidance. We recruited a good representation across key professions and geographical locations (Table 1). A strength of this study was its

recruitment of multiprofessional dementia practitioners specifically concerned with BtC work. Overall, neither guidance was viewed as being overwhelmingly positive or negative. NICE (2018) was rated as 'moderately useful', with the exception of psychiatrists who as a group saw this as only 'slightly useful'. This difference between psychiatrists and other professions about the value of guidelines may be due to the pressures that medical practitioners (GPs and psychiatrists) have been under to reduce antipsychotic prescribing, with perhaps few resources or guidance to offer alternative approaches. This was expressed in strong views such as '*NICE cheat by comparing effect sizes, and they are now stating that guidance is advisory only' – Psychiatrist,* and an observation '*Not person centred enough. . .' – GP*. The average rationgs for all professions were slightly higher for the BPS guidance than for the NICE guidance, but both sets of guidance were overall rated as 'moderately useful'. The highest frequency of low ratings (scores 1–2) for the NICE guidelines and the high rations for the BPS Guidance (scores 4–5) were from the North East of England. This may be due to decades of clinical work using the 'Newcastle model for BtC' in that region and perhaps wide interest and dissemination of the BPS-DCP Guidance in the North East where key authors of that document worked.

Our participants saw merits in both documents being reviewed, though examination of qualitative data suggests that on balance, NICE was seen as being too medically focused and lacking detail for implementation of non-pharmacological interventions. The BPS guidance was less well known, and lack of awareness by multiprofessional groups was therefore seen by those who had accessed it to be an obstacle for achieving 'buy-in' in their services. NICE guidance was described as more accessible to all professionals and described as 'readable', compared with the BPS guidance. The BPS guidance was seen as helpful in its structure for providing a timely starting point for care. However, there were concerns that its reductionist structured approach, focusing on service delivery rather than on person-centred care, may not meet the needs of all people living with dementia. Considering that these two documents were designed specifically to directly inform clinical practice, these findings are disappointing. They reflect how little impact guidelines do have on the ground, especially in a sector where much of the provision occurs outside the NHS and is possibly more removed from established mechanisms for audit and quality improvement. The themes that emerged in a number of categories highlight particular problems with implementation of both the NICE and BPS guidelines. In terms of 'other guidelines' in addition to NICE and BPS, we see a wide range of resources being used but, with the exception of the work by James in Newcastle and the structured approach employed in Scotland (NES, 2015), a lot of good work remains unfamiliar and underutilized by clinicians. This suggests that better coordination of available resources is required.

Practice implications

Problems with implementation emerged as themes for both sets of guidance. This is concerning as implementation turns guidance into a 'reality' for services. Therefore, difficulties in this process leaves guidance effectively 'unactionable'. Issues relating to 'detail and clarity' were mentioned in three of four categories and appeared to underlie some of the implementation difficulties. These were associated with allocation of resources within services and with delivering flexible individually tailored support. The latter finding reflects a shift in perspective between the first (NICE, 2006) and second (NICE, 2018) NICE guidelines. The tension for practitioners is seen where NICE (2018), for example, recommends to 'offer personalised activities to promote engagement,

pleasure and interest' (NICE, 2018, p330, item 99) for people living with dementia who experience agitation or aggression, whilst the 2006 NICE Guidelines recommended a comprehensive, person-centred assessment, leading to an individual care plan that would include physical health issues and the care context and environment. Our survey found contradictory examples of both positive and negative themes for the NICE guidance regarding 'the evidence base' and non-pharmacological approaches. Many responses indicated that the NICE guidance was too focused on the 'medical model' and did not include enough detail on first-line non-pharmacological interventions. This may be because many of the 'recommendations' for this paradigm relate to the administration of psychotropic drugs (see NICE, 2018, section 14, pp 298). Of note, none of the participants commented on the return to a 'symptom' focus (aggression, apathy, sleep, etc.) with respect to BtC in the latest NICE guidelines.

Recommendations

The lack of provision of good guidance is problematic, leaving practitioners unclear in terms of 'what to do'. The qualitative analysis, and our previous work on intervening to prevent and manage BtC in dementia care, enables us to propose the following recommendations regarding the first-line non-pharmacological guidance:

- Redress the balance of current evidence for first-line non-pharmacological intervention associated with BtC as a particular aspect of dementia care. This should focus on the needs of individuals with the condition and their carers, rather than on simply targeting reductions in antipsychotics (Kales, Gitlin, & Lyketsos, 2019). Currently, NICE recommends the use of non-pharmacological interventions as the first-line approach, but then leaves clinicians unclear about what to do due to a 'poor evidence base'.
- Improve accessibility and clarity on who the guidelines are aimed at (i.e., professionals, lay people, families, hands-on care staff) via different media (i.e., online, in print), ensuring clear detailed presentation on the one hand and flexibility for individualized care on the other. The NICE guidance was seen as accessible and clear but lacking in detail for implementing individually formulated non-pharmacological interventions. The BPS Guidelines were seen as having good structured advice for allocating resources but lacking in flexibility for meeting individual needs or what might work for whom.
- Update the BPS guidance (Brechin et al., 2013) and strengthen dissemination activity to enhance 'buy-in' of all professionals and services. This survey engaged mostly dementia care professional groups and organizations and demonstrated that there is motivation to collaborate to resolve the problems experienced in implementing evidence-based individually tailored non-pharmacological interventions for unmet need(s) in people with dementia and behaviour that carers experience as 'challenging'.

Reflecting on our results, and drawing on wider ideas from work in the area, the following additional recommendations are also made:

- Consider an algorithmic approach for the management of BtC that systematically takes into account unmet needs in the person *and* the needs of the particular family or care home system. Individual formulation-led interventions for BtC (Holle, Halek, Holle, & Pinkert, 2016) are an important method of delivering first-line non-pharmacological support and published frameworks exist (see DICE, Kales, Gitlin, & Lyketsos, 2015). However, a related paper from the present programme of work noted that currently clinicians use in excess of thirty 'named' formulation frameworks for the treatment of

BtC (James et al., 2020); hence, it is important to develop an evidence base for the frameworks and conceptual models we employ.

- Develop UK bespoke specific advice for practitioners and services, including case examples and clinical pathways, for delivery of non-pharmacological interventions for BtC. Guides on communication (James & Gibbons, 2019), practical manuals (Fossey & James, 2007), and algorithmic evidence-based approaches for flexibility of family and care home needs (Moniz-Cook & Rewston, 2020) are emerging. However, these remain largely hidden from the range of service providers.
- Consider resource allocation within services detailing the level of setting specific support. For example, preventive strategies such as person-centred care delivered within care homes achieve positive distal outcomes relating to BtC over time (see WHELD, Ballard et al., 2020). In contrast, recognition and management of clinically significant challenges for carers may require specialist trained multidisciplinary BtC services, integrated supervision of therapists, and ongoing monitoring for the more vulnerable carers and care systems (Challenge Demcare, Moniz-Cook et al., 2017).

Study limitations

All 74 participants who attended the consultation and thus contributed in some way to the survey development were sent the anonymous 34-item survey. This may have biased the survey findings. However, the first question (not included in the survey found on: https://drive.google.com/file/d/1NjORMqdYs-OfF-Cw0mPIMcdpBlB65HlG/view?usp=sharing), related to participation in the consultation event showed that only 27 'consultees' completed the 34-item survey, reflecting just 7% of the total ($n = 378$) survey respondents.

Secondly, we did not receive an equal amount of responses regarding both guidelines: sixty-five per cent (65.3%) of participants registering on the survey provided a rating for the NICE guidance, with 41.8% offering a qualitative response. Fewer participants responded to the BPS guidance questions (37.3%), with only 20.6% offering a qualitative response. This may be due to the BPS guidance being unfamiliar to many professionals (see Table 2 'lack of awareness') and the NICE guidelines being more aligned to national policy drivers.

Thirdly, we did not ask participants about their degree of knowledge of the NICE and BPS documents. Close examination of participant comments suggest that many were commenting on the 'Recommendations' (i.e., the 43 page summary of NG97) rather than the evidence base for non-pharmacological intervention described in the full report as 'generally inconclusive or poor'. Professionals also appeared unaware of Cochrane reviews on the topic and large-scale applied research studies (apart from WHELD, Ballard et al., 2020), perhaps suggesting a disconnect between academic-based knowledge and that of jobbing clinicians. Finally, given the differing focus of the first and second NICE Guideline, we did not explore respondents' views on the shift in emphasis between the two guidelines. In retrospect, it would have been interesting to explore whether the emphasis on individually tailored multicomponent interventions (NICE 2006) had altered practice in the past and whether NICE (2018) had in fact resulted in practice tensions due to this shift.

Conclusion

The results of our survey suggest that the participants were cautiously positive about the NICE and BPS guidelines, expressing concerns about both guides. This is particularly troublesome because of their importance in guiding, responses to BtC across England and more widely across the United Kingdom. The NICE (2018) dementia guidelines were known to most participants, but the opportunity to provide clearer guidance on the content, structure, and processes associated with the use of first-line non-pharmacological approaches appeared to be missed. Both sets of guidance were seen as lacking specificity about setting-specific formulated individualized care for BtC. Indeed to be viewed as being relevant by clinicians working directly in the community and 24-hour settings, it is important that this care gap in current guidance about non-pharmacological interventions for BtC is addressed. Such guidance will need to be clearly structured but flexible enough to be used within local service resources, and include measurement of outcomes associated with BtC and other outcomes such as reducing use of psychotropic drugs.

Acknowledgements

Author contributions

Frances Duffy (Conceptualization; Methodology; Writing – original draft; Writing – review & editing) Ian James (Conceptualization; Data curation; Formal analysis; Funding acquisition; Investigation; Methodology; Project administration; Supervision; Writing – original draft; Writing – review & editing) Katharina Reichelt (Formal analysis; Project administration; Writing – original draft; Writing – review & editing) Kristina Lily Gray, BSc (Hons) (Data curation; Formal analysis; Methodology; Project administration; Resources; Validation; Writing – original draft; Writing – review & editing) Esme Moniz-Cook (Conceptualization; Data curation; Funding acquisition; Investigation; Methodology; Resources; Writing – original draft; Writing – review & editing)

Conflict of interest

Funding

References

Abraha, I., Rimland, J. M., Trotta, F. M., Dell'Aquila, G., Cruz-Jentoft, A., Petrovic, M., . . . Cherubini, A. (2017). Systematic review of systematic reviews of non-pharmacological interventions to treat behavioural disturbances in older patients with dementia. The SENATOR-OnTop Series. *British Medical Journal Open*, *7*(3), e012759. https://doi.org/10.1136/bmjopen-2016-012759

Ballard, C., Orrell, M., Moniz-Cook, E., Woods, R., Whitaker, R., Corbett, A., Aarsland, D., Murray, J., Lawrence, V., Testad, I., Knapp, M., Romeo, R., Zala, D., Stafford, J., Hoare, Z., Garrod, L., Sun, Y., McLaughlin, E., Woodward-Carlton, B., Williams, G., . . . Fossey, J. (2020). Improving mental health and reducing antipsychotic use in people with dementia in care homes: the WHELD research programme including two RCTs. *Programme Grants for Applied Research*. 8(6), https://doi.org/10.3310/pgfar08060

Banerjee, S. (2009). *The use of antipsychotic medication for people with dementia: Time for action*. London, UK: Department of Health.

Brechin, D., Murphy, G., James, I. A., & Codner, J. (2013). *Briefing paper: Alternatives to antipsychotic medication: Psychological approaches in managing psychological and behavioural distress in people with dementia*. Leicester: The British Psychological Society.

Bryden, C. (2005). *Dancing with dementia: My story of living positively with dementia*. London: Jessica Kingsley Publishers.

Cohen-Mansfield, J. (2000). Use of patient characteristics to determine non-pharmacological interventions for behavioural and psychological symptoms of dementia. *International Psychogeriatrics*, *12*(1), 373–380.

Duffy, F. (2019). *CLEAR Dementia Care © A model to assess and address unmet need*. London: Jessica Kingsley Publishers.

Feil, N., & de Klerk-Rubin, V. (2015). *V/F validation: The Feil Method 3rd Edition: How to help disoriented old-old*. Cleveland, Ohio: Nook Books. Edward Feil Production LLC.

Fossey, J., & James, I. A. (2007). *Evidence-based Approaches for improving dementia care in care homes*. London: Alzheimer Society, Gordon House.

FPOP (2017). *Psychological best practice in inpatient services for older people. Division of clinical psychology*. Leicester: BPS.

Fredman, G., Anderson, E., & Stott, J. (2010). *Being with older people: A systemic approach*. London: Karnac.

Gale, N. K., Heath, G., Cameron, E., Rashid, S., & Redwood, S. (2013). Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Medical Research Methodology*, *13*(1), 1–8.

Holle, D., Halek, M., Holle, B., & Pinkert, C. (2016). Individualized formulation-led interventions for analyzing and managing challenging behavior of people with dementia – an integrative review. *Aging & Mental Health*, *21*, 1229–1247. https://doi.org/10.1080/13607863.2016.1247429

HSCB (2016). *Dementia learning and development framework. health and social care board*. HSCNI www.HSCB.Hscni.net

IPA (2015). *The IPA complete guides to BPSD – specialists guide*. International Psychogeriatric Association.

James, I. A. (2011). *Understanding behaviour in dementia that challenges: A guide to assessment and treatment*. London: Jessica Kingsley.

James, I. A., & Caiazza, R. (2018). Therapeutic lies in dementia care: Should psychologists teach others to be person-centred liars? *Behavioural and Cognitive Psychotherapy*, *46*, 454–462. https://doi.org/10.1017/s1352465818000152

James, I. A., & Gibbons, L. (2019). *Communication skills for effective dementia care: A practical guide to CAIT*. London: Jessica Kingsley Press.

James, I. A., & Jackman, L. (2017). *Understanding Behaviour in Dementia that Challenges: a guide to assessment and treatment* (2nd ed.). Jessica Kingsley Publishers.

James, I. A., Mahesh, M., Duffy, F., Reichelt, K., & Moniz-Cook, E. (2020). UK clinicians' view on the use of formulations for the management of BPSD: a multidisciplinary survey. *Aging and Mental Health*, 1–8. https://doi.org/10.1080/13607863.2020.1830944

James, I. A., & Moniz-Cook, E. (2018). *Evidence briefing: Behaviours that Challenge in Dementia*. BPS. Accessed 18 January 2020. Retrieved from: https://www.bps.org.uk/sites/www.bps.org.uk/files/Policy/Policy%20-%20Files/Evidence%20briefing%20-%20behaviour%20that%20challenges%20in%20dementia.pdf

Kales, H. C., Gitlin, L. N., & Lyketsos, C. G. (2015). Assessment and management of behavioral and psychological symptoms of dementia. *BMJ*, *350*(mar02 7), h369. https://doi.org/10.1136/bmj.h369

Kales, H. C., Gitlin, L. N., & Lyketsos, C. G. (2019). When less is more, but still not enough: Why focusing on limiting antipsychotics in people with dementia is the wrong policy imperative. *Journal of the American Medical Directors Association*, *20*, 1074–1079. https://doi.org/10.1016/j.jamda.2019.05.022

Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Berkshire: Open University Press.

Lee, R., & James, I. A. (2016). Newcastle doll therapy programme. In G. Mitchell (Ed.), *Doll therapy in dementia care*. London: Jessica Kingsley Publishers.

Moniz Cook, E. D., Swift, K., James, I., Malouf, R., De Vugt, M., & Verhey, F. (2012). Functional analysis-based interventions for challenging behaviour in dementia (2012). *Cochrane Database of Systematic Reviews*, Issue 2. Art. No, CD006929. https://doi.org/10.1002/14651858.CD006929.pub2

Moniz-Cook, E., Hart, C., Woods, B., Whitaker, C., James, I., Russell, I., . . . Manthorpe, J. (2017). Challenge Demcare: Management of challenging behaviour in dementia at home and in care homes – development, evaluation and implementation of an online individualised intervention for care homes; and a cohort study of specialist community mental health care for families. *Programme Grants for Applied Research*, *5*, 1–290. https://doi.org/10.3310/pgfar05150

Moniz-Cook, E. D., & Rewston, C. (2020). Choosing psychosocial interventions for people with dementia and their families: Protocols for decision-making. In: J. Manthorpe, & E. D. Moniz-Cook (Eds.) *Timely psychosocial interventions in dementia care. Evidence-based practice* (pp. 30-47). London: Jessica Kingsley Publishers. Chapter 2,.

NES (2015). Promoting Excellence in Dementia Care, NES/SSSC. 11.

NICE Guidelines (2018). Accessed 18 January 2020. Retrieved from https://www.nice.org.uk/about/what-we-do/our-programmes/nice-guidance/nice-guidelines

NICE-SCIE (2006). *Dementia: Supporting people with dementia and their carers in health and social care*. National Clinical Guideline No. 42. Leicester: British Psychological Society.

Protect, N. H. S. (2015). *Meeting Needs and Reducing Distress: Guidance on the prevention and management of clinically related challenging behaviour in NHS settings*. Department of Health (www.nhsprotect.nhs.uk/reducingdistress

Scottish Intercollegiate Guidelines Network (2006). Management of patients with dementia: A national clinical guideline. SIGN No. 86.

Tible, O. P., Riese, F., Savaskan, E., & Von Gunten, A. (2017). Best practice in the management of behavioural and psychological symptoms of dementia. *Therapeutic Advances in Neurological Disorders*, *10*, 297–309. https://doi.org/10.1177/1756285617712979

Toot, S., Swinson, T., Devine, M., Challis, D., & Orrell, M. (2017). Causes of nursing home placement for older people with dementia: a systematic review and meta-analysis. *International Psychogeriatrics*, *29*, 195–208. https://doi.org/10.1017/s1041610216001654

Wolverson, E., Birtles, H., Moniz-Cook, E., James, I., Brooker, D., & Duffy, F. (2019). Naming and framing the behavioural and psychological symptoms of dementia (BPSD) paradigm: Professional stakeholder perspectives. *OBM Geriatrics*, *3*, 1–19. https://doi.org/10.21926/obm.geriatr.1904080

Supporting Information

The following supporting information may be found in the online edition of the article:

Table S1. Qualitative statements for NICE Guidance.
Table S2. Qualitative statements for BPS Guidance.