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This is the author accepted version of the paper entitled:

Views and experiences of care home staff on managing behaviours that challenge in dementia: a national survey in England

Charlotte Mallon^{1,2*}, Janet Krska² and Shivaun Gammie²

¹Musculoskeletal Research Unit, University of Bristol, UK; ²Medway School of Pharmacy, Universities of Kent and Greenwich at Medway, Kent, UK

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Views and experiences of care home staff on managing behaviours that challenge in dementia: a national survey in England

Aim: To determine the views of care home (CH) staff in relation to experiencing and managing behaviour that challenges (BtC) in dementia and their experiences of training.

Method: Cross-sectional survey using a self-report questionnaire, distributed to staff employed in a 20% sample of all registered dementia-specialist CHs in England, either by postal or direct distribution.

Results: Questionnaires were returned from 352 care staff (25%), representing 5% of all dementia-specialist CHs, half were CH without nursing. Respondents estimated caring for 14,585 residents, 9,361 with dementia and 5,258 with BtC. 30.2% of residents with dementia were estimated as being prescribed a medicine to control BtC. BtC reported as experienced by most respondents were: shouting (96.6%), verbal aggression (96.3%) and physical aggression (95.7%), with physical aggression viewed as most difficult to manage. Top behaviours experienced every shift were: wandering (77.8%), perseveration (68.2%) and restlessness (68.2%).

Approaches rather than interventions, such as massage, aromatherapy and animal-assisted therapy, were viewed as key to managing BtC. These were: assessing residents, knowing them and treating them as individuals, identifying triggers, having time for them and using an appropriate style of communication.

Only 38% agreed/ strongly agreed medicines were useful to control BtC, which was related to the extent to which they were prescribed. Training was available, but variable in quality with on-line training being least useful and on-the job training most desirable.

Conclusion: BtC are commonly and frequently experienced by care staff, who consider individual approaches, having time and good communication are key to successful management.

Keywords: Dementia; behaviour that challenges; residential facilities; antipsychotic agents; non-pharmacological interventions

Introduction

There are over 850,000 people living with dementia in the United Kingdom, with this number estimated to increase to over a million by 2021 (Alzheimer's Society, 2012). Over one third of people with dementia live in care homes (CH) and at least two thirds of CH residents have dementia (Alzheimer's Society, 2012). Reduced cognitive ability, functional capacity, communication and reasoning in patients with dementia frequently result in behavioural and psychological symptoms of dementia (BPSD) (Ballard, O'Brien, James & Swann, 2001). The term 'behaviour that challenges' (BtC) is used to describe the resulting behaviours, which can be challenging to both individuals and their carers. Among those living in CHs with dementia, the prevalence of BtC is estimated to be 78% (Seitz, Purandare & Conn, 2010).

Historically, BtC has been managed by the prescription of antipsychotic drugs, despite limited evidence of their efficacy (Ballard, Waite & Birks, 2006). A 2009 report by the Department of Health in England suggested that annually an estimated 140,000 of 180,000 patients with dementia were being inappropriately treated with antipsychotics for BtC (Banerjee, 2009). Action to reduce this resulted in an overall reduction of 51.8% between 2008 and 2011 (Health and Social Care Information Centre, 2012). More recently, a large, cross-sectional national study across the UK has shown that antipsychotic use in dementia fell to 11.4% in 2015 (Donegan, Fox, Black, Livingston, Banerjee & Burns, 2017). However, there is some evidence that residents in CHs may be more likely to receive an antipsychotic than someone with dementia living in their own home (Child, Clarke, Fox & Maidment, 2012).

The most recent English guidelines for managing BtC in dementia state that all patients presenting with BtC should be offered a comprehensive assessment at an early opportunity to establish the likely factors that may generate, aggravate or improve such

behaviour. In addition, individually tailored care plans, should be developed, recorded and regularly reviewed, with non-pharmacological interventions, in particular aromatherapy, multisensory stimulation, music/dancing, animals, and massage, being tried prior to any pharmacological intervention (National Collaborating Centre for Mental Health, 2016). Relatively little research has explored the extent to which CH staff experience BtC or how they manage it in practice.

A survey involving 299 CH managers across the East of England area conducted in 2011 found 75% reported the use of reminiscence and 73% music therapy to manage BtC, but also estimated that 12% of residents were prescribed an antipsychotic. Over a third of these CH managers reported aggression as the behaviour they found difficult to manage (Backhouse, Killett, Penhale, Burns, & Gray, 2014). Attitudes towards aggression in people with dementia among staff in six CHs studied in 2009 found they viewed it as ‘deriving from the environment, situation or interactions with others’(Pulsford, Duxbury & Hadi, 2011), and managed it using strategies such as distraction and de-escalation. The staff in this study were in favour of the ‘moderate’ use of medication, but strongly supported a person-centred approach towards managing aggression.

In Australia, a study involving 247 staff in 21 CHs found that shouting, wandering and restlessness were encountered most frequently and also had the highest ratings for difficulty in managing (Koder, Hunt & Davidson, 2014). Discussing concerns with other staff was an important behavioural strategy and the study also recommended interventions targeted at lowering the frequency of BtC. A qualitative study in South Africa found all staff preferred interpersonal approaches to managing BtC over medication, but also highlighted an unmet need for training (van Wyk, Manthorpe & Clark, 2016).

To date, no national survey has been carried out in England to determine the views of CH staff in relation to experiencing and managing BtC in dementia and their experiences of training. This study describes a survey which aimed to obtain the views of a large sample of staff working in CHs with and without nursing across England on these issues.

Methods

Favourable ethical opinion was granted by a University Research Ethics Committee. The survey was conducted in October to December 2013.

Instrument development

The survey instrument was designed using findings from interviews conducted with care home staff (Mallon, 2015) and incorporating material from published sources, divided into four sections.

Section 1 was adapted from the Challenging Behaviour Scale (Moniz-Cook, Woods, Gardiner, Silver & Agar, 2001), (used with permission from the author), and included 25 behaviours. We asked respondents to indicate whether they had experienced each of the 25 behaviours (yes or no), how often they were experienced (every shift, at least once a week, at least once a month, less than every month), and to rate how challenging each of the behaviours were, using the scale 1 - I do not find this behaviour challenging to 5 - I find this behaviour very challenging. The opportunity was provided for respondents to add other behaviours they found challenging.

Section 2 consisted of a list of 14 interventions/ways of working, developed from NICE Clinical Guideline recommendations (National Collaborating Centre for Mental Health, 2007), asking respondents to indicate for each their agreement or disagreement with the statement 'the intervention helps people with dementia who have

BtC'. A further free-text question requested views on the best way to help residents with BtC.

Section 3 covered training experiences relating to managing BtC in terms of format, hours and sessions received, views on this and desire for further training.

Section 4 requested information about the respondents and the home in which they were working, including an estimate of the number of residents they cared for, number with dementia, number with BtC and number prescribed medicines to control BtC.

Survey piloting and distribution

Staff from nine CHs were selected to pilot the instrument, through convenience sampling of personal or local contacts, recruited by post, email or face to face. Those completing it were then contacted to ascertain their views on ease of understanding, instructions, relevant information omitted, time to complete and accompanying documentation. The instrument was shortened following the pilot, by merging the questions in Section 1 onto one page, reducing overall length without any loss of content.

The target population for the main study was CH staff employed in dementia specialist CHs in England, with or without nursing. A list of CHs which specialised in dementia was compiled from the Care Quality Commission's database of 17,482 registered CHs in England (at 9th August 2013), of which there were 6,992. CHs involved in the interviews which informed the instrument and in piloting were excluded from the main study. A separate research study was being undertaken in Kent, therefore all 190 CHs in the county were also excluded. Difficulties recruiting CH staff to participate in research and a potential for low survey response rates are well known

(Luff , Ferreira & Meyer, 2011), therefore we employed two distribution methods and personal contact for follow-up.

A convenience sample of 54 CHs was identified, which were visited in person. A random number generator was used to select a sample of 1,350 CHs from the remaining CHs for the postal survey, then the total sample checked to ensure that it was representative of the population for both type of CH (with and without nursing) and English region (Table 1).

Non-responding care homes were telephoned 2-3 weeks after the first contact and a further questionnaire supplied if requested. All questionnaires were accompanied by a covering letter/participant information sheet and were coded to ensure responses were anonymous. Informed consent was assumed by the receipt of a completed questionnaire.

Data analysis

Data were entered into SPSS Version 23 (Statistical Package for the Social Sciences) for analysis and quality checked. Data on estimated medicines use were categorised into low (0-33%), medium (34-66%) and high (67-100%) usage tertiles. Chi-square tests were used to test for associations between type of CH, role within CH and behaviours reported and for views on medicines with estimated medicines use. Independent t-tests were used to compare ratings for behaviours between sub-groups. Statistical significance was accepted for $p < 0.05$.

Responses to open questions were categorised into themes, which were agreed by two team members. Categorisation was undertaken by two researchers separately, with any differences resolved through discussion.

Results

Response rates

Questionnaires were distributed to 1,404 (20.1%) of the 6,992 dementia specialist CHs in England and completed responses were obtained from 352 (25.1% response rate), representing 5.0% of all dementia specialist CHs in England. There were 17 responses from the 54 CHs using direct distribution (31.5%) and 335 using postal distribution (24.8%). In addition, 19 surveys were returned: undelivered due to incorrect address, 'addressee gone away' marked or no reason (7), non-dementia homes or private residences (5) or unwilling to complete (7).

Demographic characteristics of respondents and details of CHs

The distribution of responses across England are shown in Table 1 and demographic characteristics of respondents in Table 2. Almost two thirds of respondents were managers and the large majority worked full-time. The majority of respondents (244; 69.5%) had worked in the home for over a year, many of these for more than 5 years (145; 41.3%), with only 79 (22.5%) indicating less than a year's experience in their home.

Half the responses were received from staff working in CH without nursing (Table 2). Respondents estimated that they provided care to a total of 14,585 residents (n=347; range 3 to 750) of whom 9,361 (64.4%) were reported to have dementia (n=344). Of the total residents, 5,258 (36.2%) were reported to have behaviours that challenge (n=338), however 25 respondents indicated more residents than those with dementia showed BtC. Respondents estimated that a total of 2,827 residents were receiving medicines to control behaviour, which equates to 19.4% of the total residents being cared for and 30.2% of those with dementia. The proportion of residents within

CHs estimated by 329 respondents to be prescribed medicines ranged from 0 to 100%, with a mean of $18 \pm 21\%$ and a median of 10%. There were 51 respondents (15.2%) who indicated medicines were not used to control behaviour in any of the residents for whom they cared, in 22 CH without nursing and 29 with. In contrast, five respondents (1.5%) indicated medicines were used in all residents, three homes with nursing and two without. Categorising homes into three levels of medicines use, the large majority (296; 86.8%) indicated they were prescribed for a third of residents or fewer, 37 (7.9%) indicated use in between one and two-thirds and 18 (5.3%) in over two-thirds.

Behaviours experienced by care staff

Table 3 shows the frequency with which respondents indicated they had experienced the 25 BtC listed in the questionnaire, the proportion experiencing these behaviours every shift and the rating of how personally challenging they found each of them.

Seven of the 25 behaviours were reported to have been experienced by over 90% of respondents, the most common being shouting (96.6%), verbal aggression (96.3%) and physical aggression (95.7%). Behaviours most frequently reported as being experienced every shift were wandering (77.8%), perseveration (68.2%) and restlessness (68.2%). The behaviours rated as most difficult to manage were physical aggression, non-compliance, dangerous behaviour, inappropriate sexual behaviour, spitting, and faecal smearing. The latter four behaviours were however among those least frequently experienced, although still experienced by over 50% of respondents, with the exception of dangerous behaviour, experienced by only 27.8%.

Three behaviours were reported as being experienced by more staff working in care homes with nursing compared to those without: screaming, demanding attention and inappropriate sexual behaviour (Table 4). The proportion of staff reporting experiencing shouting, non-compliance, physical aggression, verbal aggression and self-

harm every shift was higher in those working in homes with nursing than in those without (Table 4).

Managers were less likely than non-managers to report ever experiencing interfering (76.3% vs 86.1; $p=0.02$), inappropriate sexual behaviour (54.5% vs 65.3%; $p=0.03$) and lack of occupation (84.0% vs 92.7%; $p=0.014$). Managers were also less likely to report experiencing a number of behaviours at every shift than non-managers (Table 4). Mean ratings for difficulty in managing all behaviours were slightly higher for non-managers than managers, but these differences were significant for dangerous behaviour, inappropriate sexual behaviour, demanding attention, lacking self-care and suspicious behaviour (Figure 1).

There were 39 respondents who described a total of 52 other behaviours they found challenging, all of which could be categorised using the list in the survey instrument. Some specific behaviours described included: eating faeces, taking food from others or from bins, locking themselves in and making false accusations.

Views on specific interventions

From the list of 14 potential ways to manage BtC provided in the questionnaire, CH staff agreed most strongly with “treating each resident as an individual” and least strongly with “giving medicines that control behaviour” (Figure 2). Overall, staff were less positive towards specific interventions such as aromatherapy, massage and animals and in favour of approaches such as having time to talk and assessing residents to determine factors causing BtC. Staff in CH with nursing were more likely to agree with giving medicines (41.4%) than those in CH without nursing (35.0%; $p = 0.033$), but managers were less likely to agree with this intervention (30.3%) than non-managers (52.0%; $p = 0.003$). There was a clear association between showing positive views towards medicines as an intervention and reported use of medicines, with only 33.8%

(99/293) of respondents from homes in the lowest tertile of medicines use agreeing/strongly agreeing with this statement, compared to 66.6% (18/27) from homes in the middle medicines usage tertile and 72.2% (13/18) from homes in the highest tertile ($p < 0.001$).

General views on managing BtC

A total of 271 respondents provided additional comments on how best to manage BtC. There were 72 suggestions made relating to communicating in an appropriate way with residents, focusing on the need for a calm, non-threatening manner.

Never challenge a person who is challenging, remain calm, keep voice quiet, treat residents with respect, do not hold eye contact, smile and turn away. (full time manager, CH with nursing)

Be patient, allow them to speak and tell you what their purpose is, let them process any information you give them. (full-time qualified carer, CH without nursing)

Try to gain their trust. Never force them to do anything. Encourage them as much as possible. One individual person dealing with them, rather than several different people helps as they then can trust that person. Speak clearly and calmly when interacting with them. Back off immediately if they become agitated. Try again later. (full time nurse, CH with nursing)

A further 61 comments described the need to know the resident as an individual and 50 specifically described the need to treat them as such, while 66 described looking for triggers to explain the behaviour.

You need to know each resident, recognise their uniqueness, likes and dislikes, promote their independence, allow them to make choices. (full time manager, CH with nursing)

Identifying triggers by using life histories and examining the environment for lighting, noise, patterns of decoration and changing where appropriate, to understand why they may behave/react in a certain way. (part-time manager, CH without nursing)

I try to put myself in their position, and think about their earlier upbringing/lives. This helps me to refocus and help residents. I also know each individual, and what they enjoy. So for example one lady enjoys coffee so I helped her purchase a coffee maker and am teaching her how to use it. Hopefully she can then invite her friends for coffee, *which should have a "ripple effect"*. (full time nurse, CH with nursing)

There were 53 respondents who emphasised the importance of having enough time for residents, to listen to them, talk to them and simply engage with them as individuals. However, several mentioned that inadequate staffing levels may mean there is insufficient time to allow this.

TLC, attention, simple communication and cup of tea. Sometimes giving space, listening and reacting to what they want. (full-time manager, CH without nursing)

Having the time to sit or spend time or go out for walking. Finding out what they wish to do even if it is just to sit and watch other people. (full-time manager, CH without nursing)

Twelve suggested removing individuals from the situation, while 24 mentioned distraction techniques, which included cups of tea, conversation or other activities.

we find taking to a quiet area if possible, removing from situation can help, sometimes just leaving to calm down is best. (full time manager, CH with nursing)

Always talk calmly to them and take them to a room so it's one on one. Always find something to do for the resident to keep their mind relaxed. (full-time qualified care worker, CH with nursing)

try distraction i.e. photos, reminiscing - cup of tea! (full time manager in CH with nursing)

There were 22 respondents who described sharing information with or involving other staff to learn from each other and ten who suggested involving families.

de-briefing of staff following incidents; obtaining views of staff and their concerns. (full-time nurse, CH with nursing)

Understanding the reason behind the behaviour that challenges, liaising with friends, family, other staff to find techniques that help. (full-time qualified care worker, CH without nursing)

Specific techniques suggested by 31 respondents included music, singing, television, painting, sculpting, providing jobs to do and reminiscing, both as general activities and as interventions when BtC occurred. The use of physical contact was also emphasised. The environment was mentioned by only two individuals, as a general aid, “safe, pleasant and stimulating surroundings”, rather than offering mechanisms to use as a distraction. No respondent mentioned the use of sensory rooms or outside spaces.

The use of soft, calm music helps a great deal in my experience. Photo album of memorable faces and places. Touching the face, gentle strokes. Holding hands. (full time manager, CH with nursing)

Stimulation is the key, whether that is simply staff having enough time to talk/touch/be touched etc by the person in need or to provide an activity for them - stimulation and time are essential. (full time manager, CH without nursing)

Only 15 mentioned drugs within their responses, six from staff in CH with nursing, five of whom qualified the use in some way, such as short-term, last resort, severe cases, or when the resident is anxious every day, while the majority of those working in CH without nursing also considered medicines as secondary to other

strategies. However, four respondents gave comments suggesting wider use of medication.

Suitable medications to reduce severity of behaviours as care homes are communal environments (full time manager, CH without nursing)

Giving adequate medication to keep them calm (full time manager, CH with nursing)

Experiences and views of training

The large majority of staff agreed/strongly agreed that training had been received (336; 96.3%) and that training had helped them care for people with BtC (327; 94.2%), however a high proportion (268; 77.0%) also agreed they would like more training, which was similar among both managers and non-managers.

Staff reported accessing a variety of training methods (Table 5). On the job training was reported to be least frequently used (34.1%), but was rated excellent by the highest proportion of respondents (62.1%). Face-to-face training outside the care home was most frequently accessed, by two-thirds of respondents (238; 67.6%), with a total of 4,293 hours of training reported as being received. On-line training was reported by almost half the respondents, but was least highly rated of all training formats, only 26.4% rating it as excellent.

A total of 102 respondents provided additional comments regarding training. Many provided more detail of the training received or provided and had positive things to say about it, one even describing the impact it had on their CH.

Our care home and company invests a lot of time on training, reassuring excellent dementia care (full-time manager, CH with nursing)

The Alzheimer's society training, which was a 4-day course in the foundation certificate, was beneficial. I am encouraging the whole care team to complete the

training. We have made adaptations to the environment and care planning as a result of the training. (part-time manager, CH without nursing)

However, there were also many negative comments, concerning the variability in training quality, relevance and accessibility.

I do think personally, the care home DO NOT have the appropriate training from the company that employs me. I have an excellent PCT in the area that gives me support. I feel that OUR company is very good in e-learning which in my opinion is VERY BAD. We/I just CLICK and then finished the course. NO training ??? at all. (full-time manager, CH with nursing)

Complete waste of time, it was centred around me not being affected by the behaviour rather than management and defusing the behaviour, assessing for triggers etc. (full-time manager, CH without nursing)

Several were of the view that experience itself was very important and that learning from experienced others was beneficial.

On the job training is the best way as you learn whilst dealing with difficult situations. (full-time manager, CH without nursing)

We need more insight in how a person with dementia sees his or her world. Online training is not good. Need to hear from someone who works with people with dementia and pass on tips on how to manage difficult behaviour. (full-time nurse, CH with nursing)

Discussion

This is the first national survey of staff working in CHs in England, which gathered information on the frequency of experiencing BtC, views on how challenging staff find these and how best to manage them, as well as experiences of training. Respondents came from 5% of all CHs with dementia beds, covering over 14,500 residents, in homes

with and without nursing. The data provide an estimate of 36.2% of all residents in the 352 homes having BtC and show that BtC are commonly encountered by CH staff on a regular basis, with physical aggression being both commonly experienced and difficult to manage. There were some differences in the frequency of specific behaviours encountered between CH with and without nursing, while managers encountered BtC less frequently than other staff.

There was clear agreement that approaches were key to managing BtC, rather than specific interventions, as shown by responses to pre-set options, and fully supported by free-text comments. Not only treating residents as individuals, but knowing them as individuals was viewed as of paramount importance, enabling potential triggers for BtC to be identified and managed. Assessing residents was an important part of this, including ensuring lack of pain. Having time for residents, to be with them and to talk to them was also a key need, while the style of communication was also judged important. Massage, aromatherapy and animal-assisted therapy, interventions advocated by national guidance, were judged effective by fewer respondents than the approaches outlined above, although music was strongly supported. These views may have been affected by some respondents having no experience of specific interventions. Use of sensory rooms and the outside environment were not recognised at all as mechanisms for managing BtC.

Using medicines was by far the least supported intervention, particularly among staff working in CH without nursing and managers. However, the data provide an estimate that 30.2% of CH residents with dementia were receiving medicines to manage BtC. In the majority of homes, the proportion of residents reported receiving medicines was 33% or fewer, but the proportion range from none to 100%. Views on the

effectiveness of medicines as an intervention was related to the extent to which they were reportedly used.

Training was widely available and accessed, but variable in quality, with on-line training being judged least useful, although most frequently used. On-the-job training, learning from others with experience, was viewed as most beneficial, but least utilised, and findings suggest a need for more of this.

Our findings are similar to the only other survey carried out in England, in that aggression was the behaviour which staff found most difficult to manage (Backhouse, Killett, Penhale, Burns, & Gray, 2014). They also resonate with previous qualitative work, which found that distraction was a useful mechanism for managing BtC and which advocates the use of a person-centred approach (Pulsford, Duxbury & Hadi, 2011). A similar study in Australia found that behaviours occurring frequently were shouting, restlessness and wandering, which was also found in our study (Koder, Hunt & Davidson, 2014). This latter study suggested that involving other staff in discussing behaviours was beneficial and a number of respondents to our study also indicated this as a strategy. The need for more training of CH staff has also been found in a small South African study, which also suggested that training was not widely available (van Wyk, Manthorpe & Clark, 2016). In England, NICE guidance requires that all staff working with people with dementia have access to dementia-care training, and specifies, among other issues, applying the principles of person-centred care, as well as the need for training in anticipating behaviour and how to manage aggression. Our survey indicates that training is available and used, and that staff do have a good appreciation of how to deliver person-centred care, but that there is a desire for more training, of better quality. Although we did not request respondents to indicate the areas of training

they felt were needed, it is interesting that managers desired more training to the same extent as other staff.

The estimate of 30% of residents with dementia being prescribed medications to manage BtC is higher than the 12% on antipsychotics reported by Backhouse et al in 2011 (Backhouse, Killett, Penhale, Burns, & Gray, 2014), however our survey did not specify the type of drug group used. There is a possibility that alternative medicines may have been substituted for antipsychotics (Olivieri-Mui, Devlin, Ochoa, Schenk & Briesacher, 2017), recent work suggesting that antidepressants may be more widespread (Donegan, Fox, Black, Livingston, Banerjee & Burns, 2017), which could have contributed to the relatively high estimate we found.

Strengths and limitations

This survey covered 5% of all CHs with dementia residents distributed across the whole of England and, unlike a previous local survey (Backhouse, Killett, Penhale, Burns, & Gray, 2014), involved staff as well as managers. The care workforce is a busy one, and care staff may not have had the time, or willingness to complete the surveys. The response rate of 25% is characteristic of this kind of research (Backhouse, Killett, Penhale, Burns, & Gray, 2014; Purandare, Burns, Challis & Morris, 2004; Rodriguez, Sackley & Badger, 2007), and is likely to be biased towards those with positive experiences or views, moreover respondents may have wished to portray their workplace and job in a positive light. The methodology relied on self-reporting of BtC and respondent estimates of resident numbers, however the high proportion of managers responding means they should have reasonable knowledge on which to base such estimates. Stigma associated with the overprescribing of antipsychotic medication may have led to underestimates in reporting medicines use and we were unable to verify these data. The very high proportion of respondents providing free-text comments

indicates willingness to engage with this study. The findings support and add considerable depth to the quantitative results.

Conclusion

BtC are encountered commonly and frequently by staff working in CHs, who find physical aggression not only common, but also most difficult to manage. Individual approaches to managing BtC were viewed as key, with fewer respondents being supportive of or advocating specific interventions recommended in national guidance. Music therapy was seen as effective by more respondents than other interventions. Although training is available, quality is variable and more is needed, particularly on-the-job training, which should focus on the approaches outlined here.

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Disclosure of interest

The authors report no conflicts of interest.

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