

The use of non-pharmacological interventions for dementia behaviours in care homes: findings from four in-depth, ethnographic case studies.

Abstract

Background

Antipsychotic medications have been used to manage behavioural and psychological symptoms of dementia (BPSD). Due to the potential risks associated with these medications for people with dementia, non-pharmacological interventions have been recommended as safer alternatives. However, it is unknown if, or how, these interventions are used in care homes to help people experiencing BPSD.

Aim

To explore the use of non-pharmacological interventions in care homes to manage behavioural and psychological symptoms of dementia.

Methods

In-depth, ethnographic case studies were conducted in 4 care homes; in total they included interviews with 40 care-home staff and 384 hours of participant observations.

Findings

Non-pharmacological interventions, some of which are the focus of efficacy research, were used in care homes, but predominantly as activities to improve the quality of life of all residents and not identified by staff as meeting individual needs in order to prevent or manage specific behaviours. Socially relevant activities such as offering a cup of tea were used to address behaviours in the moment. Residents with high levels of need experienced barriers to inclusion in the activities.

Conclusions

There is a gap between rhetoric and practice with most non-pharmacological interventions in care homes used as social activities rather than as targeted interventions. If non-pharmacological interventions are to become viable alternatives to antipsychotic medications in care homes further work is needed to embed them into usual care practices and routines. Training for care-home staff could also enable residents with high needs to gain better access to suitable activities.

Key words: BPSD, Dementia, Care Home, Non-pharmacological Intervention, Activities

Introduction

People with dementia living in care homes commonly experience episodes of distressing behavioural and psychological symptoms of dementia (BPSD) such as aggression, agitation, anxiety, sexual disinhibition, walking about and repeated questioning [1-3]. Antipsychotic medications have been prescribed for people experiencing BPSD; yet these drugs can have limited efficacy [3-6] and have been found to be associated with serious adverse events such as stroke and death [5,7-10]. Concerned about the risk/benefit ratio, the Department of Health in England acted on a Government-commissioned report [11] and, in 2010, pledged to reduce the use of antipsychotic medications for all people with dementia. There have been parallel efforts to reduce antipsychotic prescribing in nursing homes in the United States [12,13].

Non-pharmacological interventions (NPIs), such as aromatherapy, multisensory stimulation, massage, animal therapy and music therapy, have been recommended by the National Institute for Health Care and Excellence (NICE) as alternative first-line treatments for BPSD, with the use of antipsychotic medications as a last resort [14]. Non-pharmacological interventions can work to reduce BPSD in two ways; directly by targeting behaviours or indirectly by improving quality of life [15]. Care approaches, such as person-centred care [16,17] or seeking to identify and address unmet needs, can also be helpful in the prevention and management of BPSD [14,18,19]. Patel et al. [20] argue that there should be a shift in the focus of NPIs, from managing BPSD, to improving well-being to reflect the distinct difference of NPIs from pharmacological interventions.

However, the evidence base is weak with overviews of systematic reviews and systematic reviews assessing whether NPIs are effective for BPSD limited by poor quality studies, inconsistency across studies, small sample sizes, or very little evidence available [21-23]. There is some evidence for activities and music therapy [18]. However, NPIs may need to be individually tailored [24], can be costly to implement [25], and are often time-consuming and reliant on the availability of knowledgeable staff [26]. Additionally, little is known about potential harms of NPIs [27].

In view of the changing emphasis from antipsychotic medications to NPIs, this study investigates the use of NPIs to work with individuals experiencing BPSD on a day-to-day basis in care homes. The organisational factors in care settings have been found to influence care practices [28] therefore care home contexts are important. Examining how NPIs (some of which are the focus of efficacy research) are used to manage BPSD within care home environments is necessary to find out how current practices manifest within these organisational settings.

Methods

Four in-depth, ethnographic case studies were conducted in separate care homes. Ethnographic case study methodology was chosen for this study because it is particularly suitable for examining complex practices in real life settings in which the researcher has little control, such as care homes [29,30]. In total, the 4 case studies included: 384 hours of observations; 37 interviews with 40 care-home staff, and the mapping of the administration of the psychotropic medications that some residents were prescribed. Data collection continued until saturation was achieved in each home. This paper focuses on the care practices and use of NPIs and draws on the observations and interviews: the qualitative data. Observations were conducted over a five- to six-week period in each home and covered weekdays, weekends, evenings and nights. The observations were overt and only took place in the shared spaces of the homes. The role of the researcher was 'observer as participant' [31]. This meant the researcher (*initials*, a female PhD researcher with 20 years' care work experience) was predominantly observing, but was able to help with small tasks within the homes such as assisting with activities, serving drinks and clearing tables in order to help develop rapport with residents and care staff. Notes were written up as soon as possible after each observational period. One-off interviews with staff members took place at the care homes at times convenient to each interviewee. These were recorded and transcribed verbatim. The wider study, of which the case studies were part, was reviewed and given a favourable opinion by the Social Care Research Ethics Committee prior to the commencement of the fieldwork. Pseudonyms are used throughout this paper.

Sampling

The results of a previous postal survey to care-home managers [32] were used to select suitable homes to target for the purposive sampling of the case studies. All eligible survey responses were analysed and sorted (n=291) and those homes most likely to be caring for people experiencing BPSD were selected as potential sites (n=80). Out of these 80, care home responses citing the most instances of difficult behaviours and/or NPI use were prioritised to guide which homes to contact for participation. This was to increase the likelihood of gaining relevant findings.

Recruitment

A letter about the study was sent out to care-home managers, with a follow up phone call made a week later with the aim of arranging a meeting to discuss the study. In total, 10 care-home managers (from the 80 eligible homes) were contacted; out of these, four agreed to a meeting and subsequently to have the researcher observing in their homes at different times over a 5-6-week period and conducting a number of interviews (Tables 1 and 2). Of the six non-participating care homes, two declined to take part without reason, two stated they were not interested, one had no manager in place at the time and one stated they might be interested in the future.

Care-home staff working closely with residents experiencing BPSD were prioritised as potential participants, since they would encounter symptoms frequently. A mixture of managers, senior staff, care workers and activity staff were recruited as participants and interviewees at each site. Purposive sampling was also employed to select residents. Those experiencing numerous or persistent BPSD were identified by staff as potential participants, since it was hoped their symptoms would illuminate more staff strategies. Although all residents encountered in the shared spaces of the homes were informed about the study, residents with BPSD were specifically sought to become participants. No data were written down or included about resident or staff non-participants, although since the researcher was in the homes over a long period of time friendly relationships developed with some people not formally participating in the study.

Staff members and care-home residents were informed about the study verbally and with participant information sheets. All participants consented individually to take part in the

study. In line with the Mental Capacity Act [33], personal consultees were identified and contacted to provide advice about the participation of residents without sufficient mental capacity to consent. In total 4 care-home staff, 1 resident and 2 consultees refused to participate in the research.

Analysis

Data were typed up, anonymised and stored securely. The Framework approach [34] was used to analyse the extensive qualitative dataset. This transparent approach has five phases: 'familiarisation' which involves immersion in the data to recognise key themes; 'identifying a thematic framework' which involves assembling ideas from the research questions and familiarisation stage into a framework; 'indexing' which involves the thematic framework (index) being applied methodically to the whole dataset; 'charting' which involves summarising the data under each thematic item in the framework with references to the source data, and finally 'mapping and interpretation' where associations, structures and patterns are identified and the dynamics and ranges of key themes or concepts examined. The analysis was primarily conducted by '*initials*' with '*initials*' also reading a subsection of the transcripts and notes and agreeing with the framework. Disagreements were overcome through discussions, using a third author if necessary, until consensus was reached. Themes, processes and interpretations were discussed, refined, and validated with all authors.

Results

Table 1 shows a breakdown of the data collection from each case study. The analysis of the data generated 97 aspects, which made up the framework. These were interpreted under 3 main themes: care home dynamics; strategies and behaviours; and issues and tensions. This paper reports findings from the strategies and behaviours theme. We draw specific examples from the interview data, however the observational data corroborated all of the arguments presented. Table 2 shows the characteristics of the 4 case study care homes.

Table 1: Breakdown of data collection by care home

Data categories	Case study data by Care Home (CH)				
	CH1	CH2	CH3	CH4	Total
Weeks at the care home	5	5.5	6	6	22.5
Sessions at the care home	20	23	25	26	94
Interviews	7	8	10	12	37
Interviewees	7	9	11	13	40
Observation hours	78.30	90.45	99.30	115.15	384
Resident participants	5	5	6	6	22
Staff participants	9	13	14	14	50
Total Participants	14	18	20	20	72

Table 2: Care home characteristics

Care Home Number	1	2	3	4
Care Home Type	Residential	Residential	Care Home with Nursing	Care Home with Nursing
Owner Type (Sector)	Voluntary	Independent	Voluntary	Independent
Registration	4 Dementia places/Old Age	Dementia	Elderly Mentally Infirm	Dementia/Old Age
Location	City	Village	Town	Very Rural
Number of residents	38	25	24	38
Residents reported to be prescribed antipsychotics*	3	17	4	3
Residents reported to be prescribed 'as required' antipsychotics*	1	4	0	0
Activity Staff	1	2	2	3
Total hours activity worker/s employed per week	27.5	10	16	39
Care staff on AM shift**	6	4/5	7	8/9
Care staff on PM shift**	6	4	7	7
Care staff on night shift**	2	2	4	4

*Information from a postal survey prior to the case studies [32]

**Includes carers and nurses/seniors on shift, but excludes management, activity, maintenance, office and domestic staff

The blurring between non-pharmacological interventions and activities

Table 3 shows the wide variety of NPIs or activities which were found to be used in the four care homes. The observation data showed that activities were used in several ways.

Activities such as the television, newspapers and jigsaws usually occurred without staff contact. Those such as massage, aromatherapy, reflexology, nail varnishing, helping staff with jobs and doll therapy occurred with individuals, although not necessarily those residents with high needs or those experiencing behaviours. Activities such as exercise (games, skittles, quoits, dancing, and catch), reminiscence, cognitive stimulation (quizzes, bingo, dominoes and cards), music therapy, arts and crafts, entertainment and church services were provided as group activities. Some activities such as walks outside, gardening or cooking were provided as either group or individual activities.

External practitioners facilitated some pre-arranged specialist activities at the homes including: music therapy, exercises, aromatherapy massage, entertainment and pet therapy (the Pat Dog at CH3). However, activities at all four case study sites were predominantly orchestrated by activity staff who generally worked short, fixed hours. To a lesser extent care workers also coordinated activities; however, the interrupted nature of their work could hinder this. This division of labour meant that activities needing facilitation predominantly occurred during the time activity staff were at the homes.

Non-pharmacological interventions or activities such as those in Table 3 were generally not perceived, or used, by staff as interventions (ways to intervene, offset or mediate behaviours) to directly manage BPSD. Rather than being tailored for specific individuals' needs they were viewed by staff as activities for all residents at the case study care homes (even if they were individualised activities) in order to improve overall quality of life or well-being. As Simon states:

“it’s ... about improving their stay here” (Simon, Activity Worker, CH4)

Table 3: Activities/NPIs observed at the case study care homes

Case Study Care Homes (CH)			
CH 1	CH 2	CH 3	CH 4
Television	Television	Television	Television
Arts and Crafts	Arts and Crafts	Arts and Crafts	Arts and Crafts
Walks outside	Walks outside	Walks outside	Walks outside
Newspapers	Gardening	Newspapers	Newspapers
Trips out	Bingo	Trips out	Trips out
Jigsaws	Jigsaws	Outside Entertainment	Music Therapy
Flower arranging	Music: CD	Music: CD	Music: CD
Reflexology	Dominoes	Dominoes	Dominoes/Cards
Quiz	Floor dominoes	Pat Dog	Games-quoits/skittles
Church service	Church service	Gardening	Aromatherapy massage
Staff leaving party	Jubilee celebration	Football/catch	Helping staff with jobs
Hand massage	Reading with residents	Helping staff with jobs	Read to residents
Exercises	Dancing	Aromatherapy massage	Church service
Nail varnishing	Nail varnishing	Olympic celebration	Halloween party
Cooking	Doll Therapy	Nail varnishing	Bingo
Outside Entertainment	Exercises	Cooking	Quiz/giant crossword
Reminiscence	Games-skittles/catch	Holiday	Reminiscence
		Behavioural therapy*	Multisensory bath
			Catch

*Not used with a resident experiencing BPSD

When the majority of activities or NPIs occurred they were typically pre-arranged rather than responsive to a perceived need in order to prevent or to de-escalate a resident experiencing BPSD. Karen talks about her daily routine here:

“basically I do a group activity in the morning, which is for anyone to come even dementia ... I do one-to-ones in the afternoon ... start at room one ... do about four or five ... and then just keep rotating” (Karen, Activity Worker/Senior Care Worker, CH1)

Although activity staff in three homes (all except CH1, the care home with the least residents with dementia) stated that pre-organised activities were often not easy to adhere to, this was contrary to the majority of the case study observations, where it appeared that many of the larger activities (such as games, trips out and music therapy) were pre-arranged. A flexible approach was sometimes used to decide which activities to do in the moment; this appeared to reflect resident or staff choice and was not specifically driven by behaviour/s.

Individualised 'activities' observed to be targeted towards residents experiencing BPSD were: playing music from a compact disc (CD) (especially at CH2 and CH4), playing football with a resident, or taking a resident out for a walk. In these instances the activities were used spontaneously to de-escalate a resident from a specific agitated state. For instance, at CH3 the approach that Hazel talks about here was observed:

"I think it depends on the individual too ... you've got to act very passive ... and try to distract them from what is actually aggravating them ... okay let's go for a walk or let's go in the garden and play football" (Hazel, General Nurse, CH3)

Hazel speaks of trying to 'distract' residents with individualised interventions. This approach was used most of the time, by the majority of staff, as the primary strategy at each of the four care homes if a resident was starting to experience BPSD. Teresa and Eileen provide examples:

"he starts the shaking and the heavy breathing and if I can distract him and get him watching a little DVD or just walking around the building with me ... he forgets and he stops shaking" (Teresa, Activity Worker, CH4)

"I know it sounds the old cliché, but you try and sit them down with a cup of tea"
(Eileen, Senior Care Worker, CH1)

Generally, staff members appeared to perceive what they termed as 'distraction' (through individualised interventions, which often also involved attention and conversation) as a successful strategy. Offering a 'cup of tea' was a key intervention for BPSD used across the four sites.

Although most activities were not specifically targeted at the residents experiencing BPSD, they were perceived by care-home staff as being worthwhile. Naomi talks of the general benefits of activities in care homes:

"it's stimulation isn't it? It's having something to do through the day ... it's like a bit of a circle isn't it ... if you've burnt some energy off then you're going to sleep better through the night and just, it just always helps" (Naomi, Care worker, CH2)

Naomi reinforces the idea that activities were targeted at improving quality of life and mentions the benefits they can have on all residents, including those who experience BPSD. Overall the data indicated that activities, although predominantly not targeted directly at managing BPSD, were perceived by staff to have a valuable role in care homes for all residents including those with dementia.

Barriers to including residents in activities

Barriers to including residents in activities could be either staff- or resident-led. The inclusion of residents with severe physical or mental difficulties or those experiencing BPSD in activities was avoided by some staff members. Therefore, the residents experiencing BPSD, for whom NPIs are recommended as first-line treatments [12] or those with greater physical or mental impairment, could perhaps have less access to these activities than residents with higher capacity and functioning. Activity worker, Jess, provides an example:

“I feel awful saying this ... it’s just very hard to actually get them to do, that they can physically do anything ... once they [care staff] did suggest maybe go and put a tambourine in their [the residents’] hand ... I just found that must be patronising to be honest ... I didn’t feel comfortable doing that ... I suppose I’ve kind of veered away from those residents um, because ... it’s very hard to know activity wise what to do.”
(Jess, Activity Worker, CH3)

Jess’s acknowledgment that she ‘veered away’ from residents who had considerable physical or mental impairments due to being unsure about what she could do with them was not an isolated case. Other activity staff also mentioned the difficulty in involving some residents. Not knowing what to do to engage particular residents, avoiding those with BPSD due to feeling ‘uneasy’ around them and through fear of upsetting them, and staff perceptions that an activity appeared ‘babyish’ or condescending were reasons given as to why residents were left out by activity staff. Care staff were not dissimilar in this avoidance:

“It’s like outings ... I don’t think they’re [care staff] willing to help out as much because they don’t want to help people with dementia. Where they’re more willing to help people that ... have got their full faculties ... so I think some dementia people do get, um, misunderstood and mistreated, um, not saying physically mistreated, or, I’m

just like neglected with ... activities” (Karen, Activity Worker/Senior Care Worker, CH1)

The excerpts from Jess and Karen highlight inequality in the delivery of activities. Residents least able to engage in activities independently, and perhaps most in need of support, were as a result less likely to get that support.

Sometimes staff assumed that residents with cognitive or physical impairment or BPSD wanted or did not want to attend activities. This appeared to be a habitual screening, with those usually taking part assumed to want to attend and those not usually participating often no longer asked. At all four case study sites there appeared to be the same core of residents taking part in activities or attending events. Staff appeared to be aware of this.

“it’s normally the same people, the same little group” (Holly, Activity Worker, CH2)

Teresa, an activity worker at CH4, talked about the ‘favoured few’ residents who were always identified by staff to be included in activities. She made a conscious effort to spend time with those residents who she perceived as being more isolated, either through severe mental or physical disability or BPSD. Similarly, Barbara pointed out differences between those residents:

“that are able to voice or ... can show their frustrations about not having something to do, whereas other people that are sitting in their chair might feel equally as bad, but can’t voice it or express it in any way” (Barbara, General Nurse, CH3)

Residents more obvious in their demands appeared to gain more input from activity staff (and in some situations care staff). The activities or interventions residents may be exposed to appeared to depend on how each person was perceived by staff. Overall, the interview (and observation) data indicated some inequality in the allocation of activity provision, with specific residents (particularly those willing, able, undemanding and easily manageable) benefitting more than others (often those difficult to engage due to their physical or mental impairments or behaviours).

Some activity workers at the homes (except CH4) had dual roles as care workers, kitchen staff or laundry workers. At times of staff shortages the activity staff would often be reallocated to their other roles, meaning no activities occurred on those days.

“a lot of people just see the activities side as a bolt-on” (Susan, Manager, CH2)

This reflects another barrier to the use of NPIs, the prioritisation of fundamental tasks over activities and a view that activities are extras.

Many residents at the case study sites, except CH3 where limited group activities occurred, were reluctant to take part in or attend activities and would either decline to join in or leave the area as soon as one was being organised. This created a difficult issue for activity staff who appeared to believe that certain residents might gain some emotional benefit from the activity if they were to take part. The balance between encouragement and coercion to get residents to partake in activities was a difficult judgement for staff to make. Holly, an activity worker, touches on the issue:

“I have to try and get them ... say ‘oh come on, do you want to do it?’ ‘no, no, no’ ‘come on’ but once they’re doing it they’re absolutely fine, it’s like when we done all the sunflowers ... Mable was going ‘oh I can’t do that, I can’t draw’ but ... she absolutely loved it in the end” (Holly, Activity Worker, CH2)

Holly suggests encouragement was worthwhile since it would sometimes get residents to take part and subsequently they would enjoy the activity. However, even after encouragement, there were a number who refused to take part in anything going on at the care homes.

Discussion

Our findings show that care-home staff are working hard to engage residents and improve their well-being. Individualised interventions (such as, offering a cup of tea, taking the resident for a walk and chatting), viewed by staff as ‘distraction’ techniques, were used as first-line treatments for BPSD in the four case study care homes. Non-pharmacological interventions, such as aromatherapy, music therapy or massage, were not being used as first-line treatments for BPSD in these four care homes. Instead, in-line with the recommendation from Patel et al. [20], NPIs were predominantly viewed, and used, as activities and aimed at the whole group of residents of the home as a means to improve quality of life/well-being. In this way it is likely the activities could have contributed to a person-centred care approach [16,17], addressed unmet needs [14,18,19], and improved

the general psychosocial environment for all residents, all of which could have benefitted people with dementia and pre-empted instances of BPSD.

Activities such as those recommended as first-line treatments by NICE (for example, individually tailored aromatherapy, massage, animal assisted therapy, multisensory stimulation, and music or dancing) [14] did not appear to be identified by staff as key activities especially for use with those residents experiencing BPSD. This discrepancy could be due to a lack of knowledge about NPIs and their use for BPSD, limited available resources, a lack of evidence or guidance on which NPI to use, or difficulties incorporating NPIs into practice for behaviours.

Our data highlighted some inequalities in the involvement of residents in activities, with residents difficult to engage due to their mental or physical impairments or behaviours less likely to be included. NICE guidance [14] recommends equal access to services regardless of diagnosis, so the inequality in the delivery of activities is a concern. The avoidance of including residents with high levels of need or behaviours could reflect a fear of doing the wrong thing, a lack of training about how to cope with behaviours that present difficulties for staff, especially in group settings or anxiety about the unpredictability of behaviours and the responsibility of managing them. Whichever it may be, avoidance of these residents indicates that staff are aware that there is an issue.

Findings from this study portray the situations in four separate care homes and cannot be generalised. However, the in-depth nature of the case studies has led to the exploration of some current practices and has provided useful insights and transferable knowledge. Throughout this paper we have focused on the voice of the care-home staff member to provide direct experiences of the participants, however the arguments portrayed also directly reflect the findings from the observational data.

The researcher is an essential tool in ethnographic fieldwork, since they interpret everything they observe and hear. The researcher (*initials*) who conducted the data collection for this study has many years of paid care work experience with older people. This experience helped the researcher to cope with the emotional aspects of this work and enabled good rapport and trust to be built between the researcher and participants, which, we argue, enhanced the quality of the data. The perspective of the staff members has been prioritised

in this study in order to answer the central research question of how they use NPIs to manage BPSD.

Conclusions

Important engagement work is happening in care homes to improve the general well-being of residents, which has the potential to prevent BPSD. Additionally, situated, socially relevant activities (for example, offering cups of tea) are being employed to address BPSD in the moment. However, a gap seems to exist between rhetoric and practice, with NPIs predominantly being subsumed within group activities or open to all residents and not being viewed, or used, as individually tailored interventions for residents experiencing BPSD. Furthermore, residents who might benefit the most from NPIs (those with greater cognitive or physical impairment or those experiencing BPSD) were often excluded, given that activities were generally provided for those residents with the highest mental capacity or functioning.

There is a need for further empirical research to assess the outcomes of 'distraction' techniques, increased funding for activity staff in care homes, and some amelioration of the way NPIs are used in care homes. The role of care-home activity staff may need adapting to allow more flexible practice. Training and guidance need to be provided, so activity staff have ideas and understanding about which activities to use and when for people with moderate to severe cognitive or physical impairments and for all care-home staff to have knowledge about the role NPIs could have in behaviour management. Work also needs to take place to help alleviate the fear and uncertainty that exists so the avoidance of residents with greater cognitive or physical impairments or those experiencing BPSD is eliminated and more equality in the delivery of activities is created. Finally, action is needed to aid the incorporation of NPIs into usual care practices, so they can be used in the moment with specific individuals as behaviours occur.

Key Points

- Non-pharmacological interventions were predominantly being used as activities for all residents and not targeted at BPSD.
- Important engagement work by care staff was happening in care homes to improve the overall well-being of residents.

- Activities were generally provided to those with the highest functioning or capacity.
- Staff members' lack of knowledge, confidence or training can inhibit the inclusion of residents with impairments in activities.

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Conflicts of interest

None declared

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Ethical Statement

This study was reviewed and given a favourable opinion by the Social Care Research Ethics Committee (Reference number: 11-IEC08-0028). All participants consented individually to take part in the study. In line with the Mental Capacity Act (2005), personal consultees were identified and contacted to provide advice about the participation of residents without sufficient mental capacity to consent to participate.

References

The very long list of references supporting this paper has meant that only the most important are listed here and are represented by bold type throughout the text. The full list of references is available as Supplementary data, Appendix A, available in Age and Ageing online.

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