medway school of pharmacy

Managing behaviours that challenge within English care homes: an exploration of current practices

PhD Thesis: Executive Summary

Dr Charlotte Mallon

Supervised by: Dr Shivaun Gammie and Professor Janet Krska

UNIVERSITY of GREENWICH

University of Kent

Background

Behaviour that challenges (BtC) in people with dementia is complex; there is no single solution for its management. Instead, individualised non-pharmacological interventions are recommended first-line. Over the past six years there has been increasing interest in both dementia and the best ways to care for people with BtC, from clinical bodies such as NICE, and the academic world. While the Government created recommendations and strategies for care, the research on which these recommendations are based is limited and often of poor quality. In addition, the day-to-day routines of care homes involved in research studies are largely ignored. As a result, professional carers find themselves trying to implement individualised care plans, with little training or understanding of the interventions, and in times of economic difficulty.

Care homes, their staff and residents are an under-researched population, and robust research studies are limited. Randomised controlled trials (RCTs) are the 'gold standard' way of assessing an intervention, and while testing the effectiveness and feasibility of non-pharmacological interventions has been attempted using RCTs, it is impossible to blind participants and researchers, and individualised interventions are difficult to study in RCTs.

Historically antipsychotics were used routinely to manage BtC, however in 2009, Sube Banerjee's Time for Action report set out the need to reduce the prescription of antipsychotics for BtC. This was because these medicines have only a limited effect in managing BtC, but more importantly they can cause significant harm in this population, including stroke and death. In 2010, the Dementia Action Alliance launched a 'Call to Action' on the use of antipsychotics for people with dementia. This required that people with dementia prescribed an antipsychotic would receive a clinical review to ensure that their care and prescription complied with best practice and national guidelines. The subsequent National Dementia and Antipsychotic audit found the number of patients diagnosed with dementia who were prescribed an antipsychotic medicine had fallen from 17% in 2006, to 7% in 2012. However, during that time, the number of people diagnosed with dementia increased as a result of a drive to increase early diagnosis. Also, those people in the early stages of dementia are less likely to exhibit BtC, and are therefore less likely to require antipsychotic medicines. As such, the reduction by 10% in prescribed antipsychotics was not necessarily indicative of a decrease in antipsychotic prescribing, so it is worth exploring this further.

A feasible alternative to antipsychotics to manage people with dementia exhibiting BtC are training and support interventions (person-centred care and skills development in training and supervision for example). This however may have implications on the economic burden care homes already face.

Since there appears to be no clear, multi-dimensional solution to managing BtC in dementia, it is difficult to make policy and practice recommendations and therefore 'more and better' research studies investigating alternative approaches to managing BtC are needed.

Aim

The aim of this study was to explore how behaviour that challenges in people with dementia is managed by care homes in England, and how they are managed in practice.

Methods

The study used a range of methods, in five phases:

- Phase One began with an amalgamation of two perspectives. Interviews were conducted with 42 care staff and managers from 11 care homes in South-East England, to explore their views and experiences of managing BtC in dementia. Additionally in this phase, the care environment and its design were captured using photography and an observation tool.
- Phase One interviews informed the design of a cross-sectional survey, Phase Two, distributed nationally (25.1% response rate), which explored the views and experiences of care staff across England, on managing BtC in dementia.
- An observation strategy was developed from the findings of Phase One, which informed Phase Three. In this phase, three care homes who had participated in Phase One took part in an ethnographic study of 12 residents and 17 care staff, involving 204 hours of participant observation.
- In Phase Four, the use of medicines was explored, for the 12 residents living in the participating care homes from Phase Three. This sought to investigate the appropriateness of the medicines prescribed and the mechanisms of recording medicines administration.
- Finally in Phase Five, the views and experiences of care home residents' relatives were sought using interviews, conducted at each of the Phase Three care homes, in order to provide an alternative perspective of managing behaviour that challenges in dementia.

Findings from the different phases of the study

- The interviews and survey together provided a picture of the current practices perceived by care staff to be effective in managing BtC, and care staff's experiences and views regarding managing BtC in practice. Interviews found that rather than adhering to current guidelines, knowing the resident, understanding causes of BtC and the occasional use of the care home environment were central to enabling staff to manage BtC.
- The survey provided an estimate of medicines use by care homes in England, showing that 17.4% of residents were prescribed medicines (antipsychotics or other medicines) to manage BtC. It also showed how often these behaviours can occur; nine different behaviours were reported by over 50% of care staff to be experienced during every shift, with physical aggression being the behaviour most staff found very difficult to manage.
- Staff interviewed considered that a familiar, home-like environment was a key facilitator in minimising behaviours, but in practice, differences in specific aspects of the care environments, such as signposting, colour schemes and modernisation were apparent. This suggests that homes adopt approaches that work for them, often after a trial and error process. Signs and resident photographs on bedroom doors were both advocated and criticised, but photographs and posters were observed to allow staff to initiate conversations about residents' personal interests. An outdoor environment and supervised access to kitchens can provide distractions when BtC presents.

- The exploration of medicines use examined more than just antipsychotic medicines use or medicines errors, providing an overview of care home Medicine Administration Record data. All 12 participating residents had at least one potential medicines-related issue. Residents took an average of 9 medicines, showing both the complexity of the clinical conditions of care home residents and the necessity for review.
- The ethnographic study was the first to apply the technique of participant observation in a care home setting. It illustrated the work of care staff, specifically how they manage BtC in practice. No explicit, consistent method of managing BtC in practice emerged. There also appears to be a difference between how staff perceive they manage BtC and how they do so in practice. There was also evidence of underreporting of BtC in care homes. In practice, distraction and emotional reassurance are frequently used to manage BtC. By simply finding out about the resident from reading their records, it is sometimes possible to identify the best way in which to diffuse a situation involving that individual.
- Interviews with residents' relatives highlighted that they are an important component of research into care homes – they had a wealth of knowledge regarding their family member which is often overlooked, but which can provide a valuable alternative viewpoint of care to support the management of BtC.
- The recruitment for this study trialled different recruitment methods for all phases, but was difficult, highlighting the need for more involvement of care homes in research studies.

Summary of Findings

The principal finding of this study is that there is no one way to manage BtC in dementia. Care staff interviewed in Phase One and surveyed in Phase Two do not believe that one size fits all, and Phase Three observations showed that the management of BtC changes from day to day and from person to person. Care staff acknowledged and were observed adopting different ways to manage BtC, however these were not strategies or activities defined by practice guidelines, or studied using RCTs. Instead, they were simply based on knowing the resident and understanding that BtC has a cause. The staff in the three care homes which took part in Phase Three were observed doing a great deal to manage BtC, and often demonstrated caring, sympathetic approaches to those residents who were agitated or confused. Where BtC were exhibited, care staff often responded quickly, and thoughtfully.

A further important finding is that BtC is common and was experienced by every care home staff member participating in Phases One, Two and Three. The high frequency of BtC both described through self-report in interviews and questionnaires and through direct observation suggests that care staff are faced with these behaviours on a regular basis. Moreover, care staff find them difficult to manage.

Numerous and varying approaches were used in care homes to manage BtC, however most non-pharmacological interventions were used to minimise or prevent BtC and were provided to all residents, regardless of whether they exhibited BtC or not. Therefore while care homes are using non-pharmacological interventions in practice,

they are not used directly to formally manage BtC, but rather to prevent it, providing activities for all residents to engage in if they wish to. The current literature surrounding managing BtC in dementia focuses on these activities and their effectiveness in managing BtC. However in reality, it would appear that using these strategies to manage BtC in practice does not happen: rather, they are used to keep incidents of BtC at bay, which may indeed reduce their overall incidence. The strategies observed being used to manage BtC when they did occur were predominantly distraction and emotional reassurance and were employed by care home staff routinely, often regardless of the type of behaviour exhibited.

The data collected from the survey and the data obtained during observations suggested that the level of antipsychotic use was low (17.4% survey; 17% observed) compared to the most recent studies (33%-43%) indicating that there has been some progress in better managing BtC in people with dementia since the 2009 Banerjee report. However during the observations, use of other medicines was seen, which could be regarded as questionable, indicating that perhaps the problem of managing BtC, and caring for this population in general, is still very much present. The dementia journey is challenging, not just for care home staff, but also for relatives of people with dementia, who have valuable experience and opinion, and who are not involved in their relatives' care, by care home staff as much as they perhaps should be. These experiences and opinions must not be overlooked, either by future researchers, or by care home managers and staff.

Strengths and limitations

The major strength of this PhD study is the use of multiple methods, some of which were highly novel. The biggest limitation is the recruitment bias: care homes and care staff participating in this study were likely to think that they were doing a good job, and that those participants were interested in dementia, and the care of their residents.

Conclusion

The need to enhance the standard and quality of care for individuals with dementia must not be ignored.

The only way the quality of life of those individuals residing in care homes can be improved is by exploring and improving the quality of care these homes provide. This research focused on how care homes in England are managing BtC exhibited by their residents with dementia, with the lack of existing knowledge surrounding care in practice underpinning the study. It has provided a picture of how care is delivered to people with dementia in care homes, particularly during incidents of BtC, and has demonstrated some of the ways in which people with dementia are cared for during incidents of BtC. It has found that, rather than adhering to current guidelines, knowing the resident, understanding causes of BtC and the occasional use of the care home environment play a vital role in enabling staff to manage these behaviours.

Further research is needed to investigate staff practices and training, medicines use in dementia, what constitutes 'knowing the resident' and the use of the environment in managing incidents of BtC.

Acknowledgements

Thank you to the Medway School of Pharmacy, and Kent Health, who have provided financial support throughout a three year studentship. This study would not have been possible without the participation of those it sought to include. I am grateful to the care home managers and staff who welcomed me into their care homes, and to the care staff who allowed me to interview them. To those managers and staff who completed the surveys, I express my sincere appreciation. Heartfelt thanks go to my supervisors, Dr Shivaun Gammie and Professor Janet Krska, for their continuous commitment to supporting and questioning my understanding, and their tremendous contributions of time and ideas. Special appreciation and thanks must go to my Pharmacy Practice colleagues and friends, to the contributing undergraduate students, and to Professor Moniz Cook for her permission to use the Challenging Behaviour Scale. My greatest thank you goes to my wonderful family for their unfaltering love, presence and support; and to Sam, for his love, belief, encouragement and faithful support throughout.