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

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A thesis submitted in partial fulfilment of the requirements of the University of Kent and the University of Greenwich for the Degree of Doctor of Philosophy

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DECLARATION

I certify that this work has not been accepted in substance for any degree, and is not concurrently being submitted for any degree other than that of Doctor of Philosophy being studied at the Universities of Greenwich and Kent. I also declare that this work is the result of my own investigations, except where the thesis identifies work undertaken jointly with others. In these cases I have made clear exactly what was accomplished by others and what I have contributed myself, and have not plagiarised the work of others.

Charlotte Marie Mallon

Dr Shivaun Gammie

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ABSTRACT

Behaviour that challenges in people with dementia is complex and multifactorial; there is no single solution for its management. In 2009 the Department of Health in England called for a reduction in the use of antipsychotics for people with dementia. Instead, individualised non-pharmacological interventions were recommended first-line. 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.

The study used a mixed methods approach, incorporating five phases. Interviews were conducted with 41 care staff and managers from 11 care homes in South-East England, alongside observations of the care environment. Pilot interviews from this phase informed the design of a cross-sectional survey, distributed nationally (25.1% response rate). Three care homes participated in an ethnographic study of 12 residents and 17 care staff, involving 204 hours of participant observation. Exploring the use of medicines in each of the three homes sought to investigate the appropriateness of the medicines prescribed and the mechanisms of recording medicines administration. Finally, interviews with residents' relatives provided an alternative perspective of managing behaviour that challenges in dementia.

The findings from this study suggest that there is no one way to manage behaviour that challenges in dementia. Care staff did not believe that one size fits all, and the management of these behaviours changes from day to day and from person to person. Varying strategies were used; however these were not those advocated by practice guidelines, instead involving predominantly distraction and emotional reassurance. The level of antipsychotic use was lower than anticipated, however there was extensive use of other medications which were found to be questionable, indicating that perhaps the problems of managing behaviour that challenges are still present. Finally, relatives of people with dementia have valuable experience and opinion which must not be overlooked by researchers, or care home managers and staff.

This thesis provides an important examination of the ways in which behaviours that challenge in people with dementia are managed by care homes in England. It provides a picture of how care is delivered to people with dementia in care homes, particularly during incidents of behaviour that challenges. It has established the ways in which people with dementia are cared for during these incidents, and has exposed that, rather than following current guidelines, knowing the resident, understanding causes of the behaviour, use of the care team and the use of the care environment play a vital role in enabling staff to manage these behaviours.

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GLOSSARY

Abbreviation	Expansion	Definition
AAT	Animal Assisted Therapy	Used to encourage cognitive, emotional and social capabilities in people with dementia.
ABC	Antecedents, Behaviours and Consequences	A tool which identifies events occurring within a resident's environment, to document behaviour.
ACB	Anticholingergic Cognitive Burden Scale	A tool which identifies and classifies medicines by the severity of their anticholinergic effects on cognition.
ADI	Alzheimer's Disease International	Worldwide federation of Alzheimer associations, which support people with dementia and their families.
ADL	Activities of Daily Living	Routine activities that people tend do daily without needing assistance.
ADS	Anticholinergic Drug Scale	A tool which identifies and classifies medicines by the severity of their anticholinergic burden.
BPSD	Behavioural and Psychological Symptoms of Dementia	Non-cognitive symptoms of dementia.
BtC	Behaviour that Challenges	Behaviour which puts exhibiters and those around them at risk, or leads to a poor quality of life.
CBS	Challenging Behaviour Scale	A scale for staff caring for older people in care homes, to measure behaviours that they find difficult to manage.
CH	Care Home	Residential or nursing homes which provide care and accommodation to those living within them.
CMAI	Cohen-Mansfield Agitation Inventory	A tool to assess the frequency of manifestations of agitated behaviours in elderly people.
CQC	Care Quality Commission	The independent regulator of hospitals, CHs and care services across England.
DeNDRoN	Dementias and neurodegeneration Specialty	Brings together communities of clinical practice to provide national networks of research expertise.
EnRiCH	Enabling Research in Care Homes	A joint venture which aims to provide advice and guidance for researchers, research staff, and local research networks on how to prepare and carry out studies in a CH.
GP	General Practitioner	Doctor who provides primary and continuing medical care for patients in the community.
MAPDAQ	Management of Aggression in People with Dementia Attitude Questionnaire	Developed from MAVAS, adapted for use in CHs for people with dementia.
MAR	Medicines Administration Record	The primary record used in CHs to document the medicines prescribed and administered to each resident.
MAT	Medicines Analysis Tool	A tool which identifies and classifies Potentially Inappropriate Medicines and 'Other' errors in care home records.
MAVAS	Management of Aggression and Violence Attitude Scale	Tool used to measure the attitudes of respondents regarding causes of aggression, and ways in which to manage such aggression.
MeSH	Medical Subject Headings	The National Library of Medicine's controlled vocabulary thesaurus.
NHS	National Health Service	Publicly funded health care service in the UK.
NI	Neuropsychiatric Inventory	Comprehensive assessment of psychopathology in patients with dementia.

Abbreviation	**Expansion**	**Definition**
NICE	The National Institute for Health and Care Excellence	Responsible for developing a series of national clinical guidelines to secure consistent, high quality, evidence based care for patients using the NHS.
NIHR	National Institute for Health Research	Organisation funded to improve the health and wealth of the UK nation through research.
NOS-GER	Nurses' Observation Scale for Geriatric Patients	A rating scale for use in elderly patients that can be applied by nurses or other caregivers.
NPI	Non-Pharmacological Intervention	Any action intended to improve health or well-being that does not involve the use of medicines.
NRES	National Research Ethics Service	Reviews research proposals to protect the rights and safety of research participants and enables ethical research which is of potential benefit to science and society.
OECD	Organisation for Economic Co-operation and Development	An international organisation helping governments tackle the economic, social and governance challenges of a globalised economy.
ONS	Oral Nutritional Supplements	Typically used in addition to the normal diet, when diet alone is insufficient to meet daily nutritional requirements.
PCT	Primary Care Trust	Administrative bodies, responsible for managing NHS primary, community and secondary care. Abolished in 2013.
PIM	Potentially Inappropriate Medicine	Classification of medicines as a result of their ability to cause harm to, or adverse events in elderly patients.
PRN	Pro Re Nata	As required.
RCT	Randomised Controlled Trial	An experiment whereby people are randomised into an experimental group and a control group, and are followed up for the variables/outcomes of interest.
SOAS-R	Revised Staff Observation Aggression Scale	A tool to monitor the frequency, nature, and severity of aggressive incidents.
SCIE	Social Care Institute for Excellence	UK resource of good practice and knowledge aimed at improvement of social care services with focus on central role of people who use services.
SCREC	Social Care Research Ethics Committee	The national research ethics committee for research in social care.
STOPP	Screening Tool for Older People’s Prescriptions	A tool to identify medicines that are potentially inappropriate in people aged 65 years and over.
WHO	World Health Organisation	The public health arm of the United Nations.

Chapter 1 Introduction

The burden of dementia

Dementia is an insidious, devastating terminal illness that results in a serious impairment of memory, communication, reasoning, visual perception and mood[1]. The most common form of dementia, Alzheimer's disease, contributes to approximately two thirds of cases; other forms of dementia include vascular dementia, dementia with Lewy bodies and frontotemporal dementia[2]. Dementia is caused by brain cell impairment resulting in an increasingly damaged brain structure and chemistry over time, particularly within the anatomical sites responsible for memory and capacity to learn new information. As the illness progresses, other functions including cognitive ability, functional capacity, communication and reasoning become affected and these can present as behavioural and psychological disturbances, which can be challenging to both individuals and their carers[1].

Worldwide, there are currently 35.6 million people with dementia, and this is expected to double by 2030, and triple by 2050; 7.7million new cases occur each year[2, 3]. In 2013, there were reported to be 815,827 people living with a form of dementia in the United Kingdom, and this number was estimated to increase to one million by 2021[2], but has more recently been estimated as increasing to one million by 2025[4], if current trends continue. As such, it is one of the most difficult and demanding challenges society faces, and there is a pressing need for dementia to be placed on the public health agenda.

A joint report developed by the World Health Organisation (WHO) and Alzheimer's Disease International (ADI)[2] postulates that dementia accounts for 11.9% of the years lived with disability due to non-communicable disease, and is the primary cause of dependency and disability among older people. Only 17% of people with dementia suffer from this condition in isolation[5] and given that some subtypes of dementia arise due to the presence of other comorbidities (namely vascular dementia and Lewy body dementia), dementia often presents as multimorbidity[5]. Dementia causes multiple problems, and physical illness in dementia results in a number of co-morbidities, including malnutrition, urinary tract infection, urinary incontinence, falls and auditory or visual impairment[6-10]. People with dementia report fewer symptoms than their healthy counterparts, however in almost half of people with dementia presenting with an undiagnosed physical illness, these physical symptoms could be successfully treated[11, 12]. An Alzheimer's Society report suggests that the primary causes of hospital admission for people with dementia are a fall (14%), broken/fractured hip or hip replacement (12%), urine infection (9%) and chest infection or stroke/minor stroke (both 7%)[13]. Co-morbidity is common in people with dementia, however this co-morbidity is multifaceted, complex and poorly managed[1, 5].

The total cost of dementia to the UK society is £26.3 billion, £10.3 billion of which is spent on social care, both publicly and privately funded[4]. The economic burden of dementia is predicted to treble to over £50 billion over the next three decades due to informal care and social care costs, and therefore it is imperative that applied healthcare research is undertaken in order to reduce the distress placed upon both patients and carers [3, 14]. The number of people whose lives are irrevocably transformed by dementia combined with the financial encumbrance on carers, families and countries makes dementia a fundamental public health priority[3]. More pressingly, dementia is complex, and poorly managed: it is clear that a transformation in the way that individuals with dementia are perceived and cared for is urgently required.

As a catalyst for this transformation, in 2009 the National Dementia Strategy established an ambitious five-year plan, aiming to positively reform health and social care for dementia in England[15]. The strategy aimed to generate services that would enable every single person with dementia and their carers to live well, with access to care and support from which they would benefit. The strategy had three key steps to achieve this: firstly, ensuring better knowledge about dementia and removing the stigma; second, ensuring early diagnosis, support and treatment for people with dementia and their family and carers, and finally, developing services to better meet changing needs. The strategy lists seventeen key objectives, comprising of: improving public and professional awareness and understanding of dementia; good-quality early diagnosis and intervention for all; good-quality information for those with diagnosed dementia and their carers; enabling easy access to care, support and advice following diagnosis; development of structured peer support and learning networks; improved community personal support services; implementing the Carers' Strategy; improved quality of care for people with dementia in general hospitals; improved intermediate care for people with dementia; considering the potential for housing support, housing-related services and telecare to support people with dementia and their carers; living well with dementia in care homes (CH); improved end of life care for people with dementia; an informed and effective workforce for people with dementia; a joint commissioning strategy for dementia; improved assessment and regulation of health and care services and of how systems are working for people with dementia and their carers; a clear picture of research evidence and needs, and effective national and regional support for implementation of the Strategy.

Behaviour that challenges

Alongside the progressive decline in cognitive ability and functional capacity, the emergence of behavioural and psychological symptoms of dementia (BPSD) causes considerable problems for both those individuals affected and their carers[1]. Psychological symptoms include anxiety, depression, delusions and hallucinations, while behavioural symptoms include aggression, agitation, restlessness and shouting[16]. It is estimated that more than 90% of people with dementia develop at least one BPSD, with approximately 85% of these cases having severe clinical consequences including weight loss, incontinence and poor mobility[17]. Within the population of people with dementia living in long-term care- or nursing homes, the prevalence of one or more BPSD is estimated to be 78%[18] and there is some evidence to suggest that BPSD are predictors of nursing home admission in individuals with dementia[19]. BPSD is linked to the term 'behaviour that challenges' (BtC), due to the symptoms often resulting in challenging behaviours, and this is the term used by the National Institute for Health and Care Excellence (NICE)[21] to describe these behaviours in people with dementia. As such, within this thesis, BtC will be used to describe all challenging behaviours exhibited as a result of BPSD as identified by the Challenging Behaviour Scale (CBS) [20]. This was developed by Moniz Cook in 2010 and provides a 25-item list of BtC with a broad rating scale. In practice it can be used to provide a measure of residents' behaviours that care staff who manage difficult behaviours are required to manage. BtC is complex, and multifactorial; there is no single solution for its management, and as yet, there is no specific treatment.

Management of BtC

The current guidelines commissioned by a collaboration between NICE and the Social Care Institute for Excellence (SCIE)[21] state that for individuals with all types and severities of dementia presenting with BtC, pharmacological approaches should only be offered as a first-line treatment if the individual is severely distressed, or there is an imminent risk of harm, either to the person, or those around them. However, if distress is less severe in these individuals, the guidelines advise that individually tailored care plans that help both staff and carers should be developed, recorded and regularly reviewed, prior to any form of pharmacological intervention. These care plans, dependent on the individual's preferences, skills and abilities as well as the treatment availability, should be delivered by a variety of health and social care professionals and volunteers, and may include non-pharmacological interventions such as aromatherapy, multi-sensory stimulation, therapeutic use of music and/or dancing, animal assisted therapy and massage[21].

Non-pharmacological management of BtC

Non-pharmacological intervention (NPI) therapies are now increasingly available to people with dementia; these treatment methods contain areas of overlap and are rarely used in isolation[16, 22]. With regard to the effect of non-pharmacological management on BtC, it is generally acknowledged that such treatment must be tailored to the individual[21]. However, in practice this is not adhered to, as a consequence of an inadequate ratio of healthcare professionals to patients, who are able to carry out individualised assessment and intervention[23]. Despite the proposition of various NPIs developed for the purpose of enhancing cognitive function, reducing BtC and improving quality of life, a dearth of rigorous trials investigating these methods renders them weak in providing a robust evidence base.

England, Wales, Scotland and Northern Ireland each have an active dementia programme, which includes national strategies for dementia, national standards, and guidelines specific to dementia care. Underpinning these programmes are clinical guidelines produced by NICE in association with SCIE[21]. These guidelines state that people with dementia who exhibit BtC should ‘be offered an assessment at an early opportunity to establish the likely factors that may generate, aggravate or improve such behaviour’. The same guidelines implore health and social care managers to provide access to dementia care training and skill development. However, clear and concise guidelines regarding the implementation of non-pharmacological methods of managing BtC are non-existent. Instead, a range of NPIs are suggested, as listed above. A recent systematic review of specific practice recommendations for the management of BPSD established that despite a lack of agreement on recommendations for non-pharmacological management, guidelines did agree on the use of antipsychotic medication as second-line treatment after consultation with the person, their family, advocates and specialist colleagues, and provided that regular reviews of its continuation are conducted[24]. The majority of studies published to date have opted to investigate or observe pharmacological and non-pharmacological approaches as separate entities in the treatment plans for individuals with dementia.

Pharmacological management of BtC

Historically, BtC has been managed by the prescription of antipsychotic drugs, despite limited evidence of their efficacy[25]. Originally developed to treat individuals with schizophrenia, antipsychotic medication can abate the intensity of delusions and hallucinations, as well as induce calm or sedated behaviour, and has been shown to have greater effect than placebo in people with dementia, exhibiting aggression, agitation and psychosis[25-28]. A 2009 report by the Department of Health in England suggested that annually an estimated 180,000 patients with dementia were being treated with antipsychotic drugs for BPSD[1]. Of these, 140,000 patients per year were believed to be inappropriately prescribed such medication, raising significant issues regarding the prescription of antipsychotic drugs for people with BPSD, in particular quality of care and patient safety. The report's author estimated that although 36,000 patients per year may have drawn some benefit from this treatment, 1,620 cerebrovascular adverse events, and 1,800 deaths per year may have transpired as a direct consequence of the use of antipsychotic medication. A 2012 national audit of dementia and antipsychotic prescribing in England[29] reported that between 2008 and 2011, antipsychotic prescriptions for people with dementia reduced by 51.8%. However, strong regional variations were revealed and although the crude percentage of patients prescribed antipsychotics decreased, there was a simultaneous and significant drive for early diagnosis of dementia, and therefore it cannot be concluded that fewer patients were prescribed antipsychotics.

Antipsychotic drugs can play an important role in treating symptoms of dementia; however in long-term use they are associated with severe side effects, including blood clots, stroke and increased risk of mortality[25]. In the short term, antipsychotic drugs generate a state of apathy and inhibited initiative, with individuals demonstrating slow responses to external stimuli, reduced emotional output and increased drowsiness; aggressive behaviours are inhibited and intellectual function appears intact[30]. A major problem of antipsychotic treatment is antipsychotic-induced motor disturbances, which include involuntary movements, tremor and rigidity; additionally sedation, hypotension, weight gain, jaundice, dry mouth and blurred vision are also problematic[31]. For many years, the most commonly used treatments for BtC were older antipsychotics such as haloperidol and thioridazine, however, due to their associated short-term adverse effects, over the last decade these older antipsychotics have been increasingly replaced with newer agents such as olanzapine and risperidone, which exhibit a better short-term safety profile in comparison[32]. An American retrospective case-control study published in 2015, conducted in elderly patients with dementia, found that the absolute effects of antipsychotics on mortality may be higher than previously estimated, and increase with dose; the risk-benefit balance of antipsychotics continues to be questioned [33].

While BtC are a recognised and justifiable target for intervention in order to reduce agitation and harm to patients and carers - thereby increasing the quality of life for both - the overuse of antipsychotic medication as a first line treatment holds considerable risk[1]. A recommendation from the Department of Health's 2009 report into the prescription of antipsychotic drugs for people with dementia stated that 'the Care Quality Commission should consider using rates of prescription of antipsychotic medication for people with dementia, adherence to good practice guidelines, the availability of skills in non-pharmacological management of behavioural and psychological symptoms in dementia and the establishment of care home in-reach from specialist mental health services as markers of the quality of care provided by care homes'[1]. However, 'If we design services for people with one thing wrong at once but people with many things wrong turn up, the fault lies not with the users but with the service, yet all too often these patients are…presented as a problem'[34]. Additionally, the systems (residential homes, in this case), which are designed to deliver occasional care and treatment to usually healthy people are being used to provide care for people with complex and chronic conditions. Consequently these systems are unable to consistently provide appropriate, effective and safe care, since they are not designed around the needs of the people who need them the most[35].

Other pharmacological treatments used in people with dementia

One feature common to all subtypes of dementia, is degeneration of cholinergic neurotransmission. That is, the critical neuronal networks in the subcortical areas of the brain (associated with higher mental functions) deteriorate, leading to a reduced availability of acetylcholine, a neurotransmitter that is crucial to proper brain function. At the same time, abnormal protein aggregates and neurofibrillary tangles form in the brain[31, 36]. There is increasing evidence that the type of cholinergic deficits that have been established as being central to the cognitive symptoms of Alzheimer's disease, also contribute to the cognitive symptoms of vascular dementia[36, 37]. Cholinesterase inhibitors (anticholinesterases), which prevent the breakdown of acetylcholine, thus increasing brain levels, can reduce the decline in cognitive function in dementia, slowing its progression, and can benefit symptoms of depression, anxiety and apathy; however their benefit in managing BtC, particularly agitation or aggression is small[38]. Currently there are three cholinesterase inhibitor treatments licensed for mild to moderate Alzheimer's disease: donepezil, rivastigmine and galantamine. NICE and SCIE guidelines state that anticholinesterase drug treatments are clinically effective, but question their cost-effectiveness for people in the mild stages of dementia[39, 40].

There are a number of medicines that have anticholinergic effects, including antihistamines and sleep aids, antidepressants, drugs for urinary incontinence and antipsychotics, which are commonly used for a wide variety of conditions affecting older adults[31]. There is also potential for prescribing of anticholinergic drugs to treat the extra-pyramidal side effects of antipsychotic drugs[41]. While the evidence base for a causal relationship between long-term use of anticholinergic medication and cognitive decline was considered limited[42], a 2014 systematic review determining the effects of drugs with anticholinergic properties on relevant health outcomes found that these medicines have a significant adverse effect on cognitive and physical function (77% of the 46 included studies evaluating cognitive function (n= 33) reported a significant decline in cognitive ability with increasing anti-cholinergic load ($p < 0.05$))[43]. Nonetheless, polypharmacy involving the use of anticholinergic compounds is common, especially in CH residents[42]. Inappropriate polypharmacy is problematic in older people, and is associated with negative health outcomes: a 2012 systematic review reported that interventions to improve appropriate polypharmacy appear beneficial in reducing inappropriate prescribing and medication-related problems[44].

One of the most common psychiatric conditions in dementia is depression, as people with dementia are more likely to suffer with depression than their healthy counterparts[45-47]. This not only causes unhappiness and distress, but can also further impair cognitive function; therefore in a person with dementia, whose cognitive function is already compromised, independent capability and function will diminish as a result of doubly affected cognition[47]. While treating depression must be a clinical priority, the evidence base for doing so is sparse[46]. Antidepressants could be considered in addition to non-pharmacological interventions; however a 2002 Cochrane Review established weak evidence for the efficacy of antidepressants in dementia[48]. Banerjee et al[46] suggest that there is a need for alternative research into biological and psychological therapies for depression in people with dementia, given that depression in dementia is different to depression in non-demented populations. As such care must be taken not to generalise findings from non-demented populations to people with dementia, with regard to efficacy and harm of pharmacological agents.

In the UK a study investigating the use of medicines in CHs evaluated medication errors, and made recommendations for improving care[49]. The residents were taking an average of eight medicines each, indicating the complexity of their clinical conditions. The authors identified that 69% of residents had one or more medication error. A similar study also reported a high level of medicine administration errors in English CHs[50]. The authors identified that each resident received 9 different drugs and 90% of residents were exposed to at least one error.

Care homes and their management strategies

The Care Standards Act 2000 defines a CH as ‘any home which provides accommodation together with nursing or personal care for any person who is or has been ill (including mental disorder), is disabled or infirm, or who has a past or present dependence on drugs or alcohol’[51]. CHs provide either residential or nursing care: A CH with nursing, as defined by the Registered Nursing Home Association, differs from a residential CH, in that a nursing home ‘has to provide the kind of care which requires the specific skills…or the supervision of a qualified nurse’[52]. CHs for adults in England are regulated by the Care Quality Commission (CQC), which is the independent regulator of hospitals, CHs and care services across England.

Over one third of people with dementia live in CHs and at least two thirds of CH residents have dementia[53]. Because dementia is associated with numerous complex requirements including symptom management and long-term support, dementia care is challenging, involving time, energy and frequently, physical exertion[3]. As such, health and social care systems must tackle the significant need for help, from individuals with dementia and also their caregivers. The identification of the need to enhance both the standard and quality of residential care for individuals with dementia has been a catalyst in the introduction of alternative models of care, such as dementia care mapping and person-centred care, influencing clinical practice[2, 14, 54]. The only way we can improve quality of life of those individuals residing in CHs is by exploring, and improving quality of care: while it is tremendously important that CHs are available for the people that require them, services are variable[23].

In 2007 the National Audit Office identified that only a small proportion of care staff receive dementia care training, and in the United Kingdom approximately one third of CHs with specialist dementia services have no explicit dementia training for their staff[23]. Since most long-term residential care is for individuals with dementia, the training and education of staff should be widely available and specifically address managing BtC. The joint report between WHO and ADI supports this notion and stresses that there is a pressing need for dementia care training for the residential care workforce, responsible for the daily physical care of individuals with dementia[2].

The care environment can also play a part. People with dementia can become disorientated and may have difficulty recognising their physical, social and emotional environment, and environmental stressors such as background noise can increase frustration and disorientation in individuals with dementia. The use of vibrant colours, suitable sound levels and adequate floor space should be applied when designing the CH environment[55]. There is limited research into the appropriate design of care environments for older people, and strategies for assessing the CH environment tend to adopt an approach which observes the care environment as a single aspect of dementia care[56].

We need to recognise the importance of quality of life, for residents, staff and family; however to maintain a person-centred approach, research must be conducted in a manner wherein the resident remains the primary focus, around which staff and family rotate. In this thesis, a review was conducted to identify and examine the existing literature surrounding the evidence base for the attributes of resident-centred care that may aid the management of BtC and therefore improve quality of life for people with dementia living in CHs. This is discussed in Chapter Two.

Thesis outline

This is a thesis focusing on how CHs in England manage BtC exhibited by their residents with dementia. The study addresses the current dearth of knowledge surrounding care in practice, and explores the use of pharmacological and non-pharmacological interventions in this research area, which has been largely neglected. It begins to establish the components of a holistic and resident-centred approach to the care of people with dementia living in CHs that contribute to the successful management of BtC. While residents' experiences of this care are not directly examined, the thesis attempts to be inclusive of participating residents through both examining their personal histories, and their relatives' perspectives of care. The personal histories of residents in particular allow you, the reader, a richer insight into the real people involved in this research, while their relatives' perspectives illuminate the reality of living with and caring for a loved one with dementia.

This thesis examines the management of BtC in CHs, particularly exploring: pharmacological, non-pharmacological and environmental strategies; observed care in practice; relatives' perspectives of managing BtC in CHs and recruitment difficulties of conducting research in this subject area.

Chapter Two provides the context of this study through a review of the literature and evidence in this area. Gaps in the knowledge are illuminated, and the chapter closes with research questions and aims for the study, in order to begin to narrow these gaps.

Chapter Three provides a rationale for the methodological choice of a mixed method study, and defines and justifies the use of a pragmatic approach. Each phase of the study, starting with staff interviews and structured environmental observations, moving on to a CH survey, ethnographic participant observation, medication review and relatives' interviews is set out and justified.

Chapter Four describes the first phase of the study: semi-structured care staff interviews and CH environmental observations.

Chapter Five details the second phase of the study: a cross-sectional survey distributed to English CHs.

Chapter Six reports on the third phase of the study, which amalgamated an ethnographic observation of day-to-day CH management strategies, a review of residents' records and consideration of other factors that contribute to managing BtC.

Chapter Seven details the fourth phase of the study - a review of residents' medication records and an investigation into the use of medicines in CHs.

Chapter Eight describes the final phase of the study: qualitative interviews with residents' relatives.

Chapter Nine discusses the obstacles encountered in recruiting CHs, CH staff, residents and relatives to research studies, and provides recommendations for future research.

Chapter Ten discusses the findings from all five phases of the study, how the research questions have been addressed, and whether they have been answered. It also provides methodological triangulation, strengths and limitations of the study, contributions to knowledge and the implications for future practice and research.

Original contributions to knowledge

Banerjee's report in addition to NICE and SCIE guidance implored healthcare providers to reduce antipsychotic prescribing to manage BtC and use NPIs as a first-line treatment instead[1]. A review of the literature revealed a lack of evidence regarding the efficacy of NPIs, and very few studies have observed the day-to-day routine of CHs managing BtC. Therefore, this study has added to current knowledge about the management of BtC by exploring and observing the day-to-day challenges faced by front-line CH staff, and the practices they use to manage BtC. The original contributions to knowledge are:

- The interviews and survey have provided a picture of the current practices perceived by CH staff to be effective in managing BtC, and CH staff's experiences and views regarding managing BtC in practice.

- The survey has provided an estimate of medicines use by CHs in England, building on the existing literature by examining the use of these medicines on a national level.
- The environmental observations have added to a scant body of literature which has attempted to describe the care environment, by endeavouring to provide a true depiction of real care environments, and highlight the differences between CHs.
- The exploration of medicines use has added to the literature by examining more than just antipsychotic medicines use or medicines errors in CHs, and has provided a synthesis of CH Medicine Administration Records (MAR) chart data in the current climate.
- The exploration of medicines use has allowed the development of a Medicines Analysis Tool which could be used by future researchers or practitioners to identify prescribing problems in CHs.
- The ethnographic study has illustrated, through observations and collection of other data, the work of care staff: specifically how they manage BtC in practice, and who they care for.
- The ethnographic study is the first to apply the technique of participant observation in a CH setting.
- Interviews with residents' relatives have highlighted that relatives are an important component of research into CHs – in this study they had a wealth of knowledge regarding their family member and the CH transition, and must not be overlooked, since they can provide a valuable alternative viewpoint of care.
- The recruitment for this study trialled different recruitment methods for all phases, highlighting the alternative methods of recruitment which could be attempted in future studies.

Chapter 2 Literature Review

Introduction

For this thesis, a review was required to identify and examine the existing literature surrounding the evidence base for the attributes of resident-centred care that may aid the management of BtC and therefore improve quality of life for people with dementia living in CHs. The management of BtC is widely linked with a variety of professions including pharmacy, psychiatry, sociology, psychology and medicine, and therefore this review was conducted inclusive of those disciplines, to gain an understanding of how BtC is managed in practice. It critiqued the results from a series of structured literature searches, conducted in order to identify existing gaps in knowledge and key issues surrounding managing BtC in dementia, and to gain an awareness of where the boundaries of these gaps are. This informed the research questions and consequently the study design.

Aim

The literature review aimed to answer the following questions:

1. What non-pharmacological strategies are used to manage BtC and what is the evidence for their effectiveness?
2. What is the prevalence of antipsychotic use in CHs, what mechanisms have been used to ensure use is appropriate and is there capacity for reducing their use?
3. What are the experiences of formal carers in managing BtC, and what training exists to enable them to manage BtC?
4. What is known about the design of the CH environment and its impact on BtC?

Search terms

Medical Subject Headings (MeSH) and key-words were identified by consideration of relevant past articles on BtC in dementia. Details of the searches performed, search terms used for each electronic database and process of paper selection are included in Appendix 1. The following words have been used as search terms: *Dementia (MAJR), Alzheimer Disease (MAJR), nursing homes (MeSH), care homes, behavior (MeSH), intervention, attitude of health personnel (MeSH),* *non-pharmacological (MeSH), antipsychotic agents (MeSH) and environment (MeSH).* The MeSH terms were exploded to include all categories within them.

The literature search was conducted in two phases:

1. Searching for systematic reviews of all non-pharmacological interventions relating to the management of BtC, and adding to the results, any papers limited to non-pharmacological strategies to manage BtC.
2. Searching for any publications with relevance to the other search questions.

Search method

To capture as many relevant citations as possible, electronic international and national bibliographical databases were searched for all articles that were relevant to managing BtC in CHs, up to November 2015. The databases searched were: EBSCO Host Electronic Database (MEDLINE, PsycINFO, and CINAHL Plus with Full Text) and PubMed in order to cover the range of medical and sociological articles. Bibliographies of articles which were identified as being relevant to the research topic were searched manually, as were reference lists of key papers and the Banerjee [1] report. The searching of multiple databases led to duplication of some articles; therefore the total number of studies omits any duplicates.

Inclusion and exclusion criteria

Searches were restricted to the title and abstract of articles. Published articles were only included in this review if they met the inclusion criteria outlined in Table 2.1. Research that was unpublished at the time of the final review was excluded due to challenges in gaining full access to the articles.

Inclusion Criteria
Primary quantitative, qualitative or mixed method research studies, exploring:
Measurement AND/OR description of managing BtC in dementia. Papers investigating dementia care in CHs.
AND/OR
Non-pharmacological strategies of managing BtC in CHs
Prevalence of antipsychotic use in CH residents with dementia and capacity for reducing their use
CH staff opinion AND/OR experience of BtC
The design of the CH environment
Reviews of research relating to managing BtC in dementia
Exclusion Criteria
Research relating to non-human subjects
Research relating to other mental illnesses and learning difficulties
Research relating to end of life care
Research relating to hospital-based care
Research relating to non-professional caregiver AND/OR or family perspective AND/OR orientation AND/OR burden
Research relating to subjects exclusively under 65 years

Table2.1: Criteria for including or excluding articles resulting from the literature search into the management of BtC

Selection method and data extraction

A selection for inclusion was performed: on reviewing titles and abstracts, all studies that did not clearly meet the inclusion criteria were excluded from the review. If the studies appeared to meet the inclusion criteria or if there was any doubt, the full article was reviewed.

The following characteristics of each included study were documented:

1. Country and setting of study
2. Study design
3. Participants: inclusion and exclusion criteria; number of patients; sex; age; type of dementia and diagnostic instruments used; severity of the dementia and diagnostic instruments used
4. Type of method in the experimental condition(s); type of support in the control condition(s), features of methods
5. Outcome measures/instruments (BtC); number of participants who completed the study in the experimental and control conditions
6. A short description of the results

Literature review

The literature search identified both descriptive and analytical papers employing both qualitative and quantitative methods. For ease of purpose, this literature review has been divided into four sections, each section pertaining to the body of literature it sought to appraise: these relate to the questions which the review sought to answer.

What non-pharmacological strategies are used to manage BtC and what is the evidence for their effectiveness?

An important synthesis of current evidence, Dickson et al's March 2012 report commissioned by the Department of Health [57] included 30 systematic reviews of evidence from 220 studies investigating the use of NPIs for BPSD, in order to report on the scientific evidence of the effectiveness of NPIs in managing BtC. Of the 30 studies included, ten reviews presented results from studies conducted in long term care settings. Eighteen reviews reported results from acute care settings (including day or psychiatric hospitals), participants' homes, community-based settings or primary care provision, while two reviews did not clearly report the intervention setting. The review prioritised Cochrane reviews and randomised controlled trials (RCTs), examining eight broad categories of NPI: sensory enhancement and relaxation, social contact, cognitive and emotional approaches, physical activity and exercise, environmental modifications, behaviour management techniques, caregiver training and support and special care units. It found that NPIs showing a possible effect, but deficient in robust evidence were massage or touch, music therapy, multi-sensory stimulation and physical exercise. There was no substantial evidence to make recommendations regarding the use of relaxation therapy, white noise, transcutaneous electrical nerve stimulation, pet or animal therapy, one-to-one stimulation and environmental modifications. Contradictory evidence was found for light therapy, simulated interaction or family video, cognitive stimulation, reality orientation and reminiscence. The only NPI found to have no effect in managing BtC was validation therapy (used as a way of communicating with disorientated elderly people, validation therapy is based on the principle that confused behaviours have a meaning to the person with dementia; the response to these behaviours may not be correcting the person, but empathetically talking to them about their issue). Caregiver training and support, and behaviour management techniques were found to have the most reliable evidence for managing BtC; however the authors acknowledge the difficulty in identifying the exact component of training that resulted in effectively managing BtC.

Seitz's systematic review published in February 2012 [58] was not included in the Dickson review, but some of the reviewed studies were included in the Dickson [57] review. Seitz's review warrants discussion here, due to its focus on long term care settings. It explored the effectiveness and feasibility of using NPIs for BtC in 40 studies conducted in long term care settings. Any changes in the severity of BtC symptoms were measured using outcome measures reported in the included studies. Sixteen of the 40 studies reported statistically significant results in favour of non-pharmacological interventions, including staff training, mental health consultations, exercise, recreational activities and music therapy or forms of sensory stimulation; however 75% of the interventions needed resources outside of the care setting, or additional time requirements from staff. The authors posit that, at the time, there were limited large-scale studies of high quality in this area, and further research was required.

A more recent systematic review conducted in 2014 measured the clinical effectiveness and cost-effectiveness of sensory, psychological and behavioural interventions for managing agitation in older adults with dementia[59]. It included 160 quantitative studies of NPI. Similarly to the Dickson review[57], with only 33 moderately sized RCTs recruiting more than 45 participants, a lack of substantial evidence resulted in the authors being unable to make recommendations for many of the interventions, despite some high-quality studies. Person-centred care, communication skills and dementia care mapping, sensory therapy activities, and structured music therapies were all reported to reduce agitation in CH residents with dementia. There was no substantial evidence to make recommendations for the use of aromatherapy, light therapy or training family carers to use psychological intervention to reduce agitation. The authors note the need for permanently implemented evidence-based treatments to manage agitation in CH residents with dementia, however a lack of robust evidence makes this problematic.

An overview of 21 systematic reviews published in 2011 [60], which contained different papers to the Dickson review could also not make any recommendations for specific NPIs for BtC, despite finding some positive effects. Similarly to the Dickson review [57], the evidence was contradictory, insufficient or lacking.

A 2012 Cochrane review and meta-analysis [61] reviewing 18 trials examining functional analysis (used as a behavioural intervention, functional analysis explores the meaning or purpose of a person's behaviour with the aim of reducing distress) in BtC found that as a result of variable study designs, it was not possible to detach functional analysis from aspects of other interventions, despite showing a possible benefit. Therefore, no conclusions were made as to the efficacy of functional analysis in managing BtC in dementia.

Evidence exists that supports the use of multidisciplinary interventions [62], individualised activities [63] and multi-modal non-drug therapies [64], which were not included in Dickson's review [57]. In 2002, Opie et al [62] conducted a randomized controlled trial of multidisciplinary interventions for BtC in nursing home residents with dementia. An individualised treatment plan was implemented by a multi-disciplinary team consisting of a psychiatrist, a psychologist and two nurses, for 99 residents who had been identified by CH staff as having BtC. Residents were randomly assigned to an early group or late group, and repeated observations were conducted to identify behavioural patterns, triggers, usual treatments and staff approaches. The early group received intervention after four days of observation, while the late group received intervention seven days after. Three interventions - psychosocial, nursing and medical - were used and often combined: 46/99 received all three interventions, 47/99 received two, and six residents received only one intervention. A powerful Hawthorne effect was detected, through improvements in both groups, in the frequency and severity of BtC. However, a modest but significant reduction in BtC including restlessness, verbal disruption and inappropriate behaviours ($p \leq 0.005$) suggested that individualised psychosocial, nursing and medical interventions can lead to reductions in BtC. The authors discussed the feasibility and acceptability of strategies prior to commencing the study: those interventions that were unacceptable or impractical to CH staff were discarded early on. At follow up, care staff rated 73.5% of interventions as either very acceptable or acceptable; 14.3% of interventions as neutral, and 12.2% as unacceptable.

The results of a RCT exploring the effects of individualised activities, in order to increase positive affect and reduce negative affect and behaviour in 180 residents with dementia living in one large American nursing home [63], were published in 2015. Ninety-three residents received normal care, while the remaining 87 residents were assigned to one of two intervention groups: an attention control group (n=43), or individualised psychosocial intervention (IPI) (n=44). Individuals in the attention control group participated in standardised one-to-one activities with nursing assistants, while the IPI group participated in a nursing assistant-led activity matched to their abilities and interests. Outcome measures were assessed through direct observation by a research assistant, in the form of ten-minute 'behaviour streams', whereby residents' behaviour, location, and affect state were noted, along with the onset and cessation of each set of behaviours. Behaviours were then coded into three outcome categories: affect; behavioural states (non-verbal behaviours) and behavioural events (verbal behaviours). The two intervention groups experienced more pleasure, alertness, positive verbal behaviour, positive touch and engagement in comparison to the control group. However the attention group experienced increased anger, uncooperativeness and negative verbal behaviour compared to both the IPI and control groups. Individualised intervention may elicit more positive outcomes in behaviour and affect than standardised interventions or activities. The results of this study are limited however: the study was conducted in a homogeneous sample of Caucasian, Jewish elderly residents, from one nursing home. Also, research assistants observing the interventions may have been sensitive to being observed by staff and residents, and their direct observations and note taking may have been affected.

A 2012 longitudinal RCT investigating the effectiveness of multi-modal, non-drug therapy on dementia symptoms in 139 residents from five German nursing homes, found an association between improved levels of mood and memory, and the multi-modal therapy [64]. Over a period of six months, residents (n=71) participated in spiritual, physical cognitive and daily living interventions for two hours on six days of the week. The control group (n=70) received usual care. Two residents were excluded due to an incorrect diagnosis of dementia. Dementia symptoms were measured using the Nurses Observation Scale for Geriatric Patients (NOS-GER) sum score. Throughout the six-month observation period, mood, memory and social behaviour all improved. As such, the authors suggested that all nursing home residents and staff would profit indirectly as a consequence of improved behaviour. The study lacked a control group which received a placebo, rather than usual care. Data were recorded by observer rating scales without blinding, and as such the findings may be biased - the authors reject this as ‘unlikely’.

A 2011 Japanese observational study [65] of 12 experienced care staff investigated the ‘repeated appeal to return home’: the repetitious requests of CH residents to go back to their home, or to a place where ‘one has a history’ including calls of ‘I want to go home’, ‘I must go home’, and ‘I don’t want to be here any longer’. A five-step framework to managing these behaviours was suggested by the care staff group: Listen to the voice (appeal) and go with the flow of the behaviour; learn about the inner experience (fear, anxiety, discontent, loneliness); learn about the contextual environment (work history, life history, lifestyle); reflect on the care environment (restraint, care staff); find the keyword. The authors believe that the process of identifying needs, and implementing a five-step process as a problem-identifying and problem-solving method, could be used as a focus to managing the underlying needs of people with dementia, which could not only enhance the quality of life of residents with dementia but also increase staff satisfaction and reduce burnout and turnover. The study was limited to care staff working for one company, and therefore the findings are not generalisable. Additionally, the staff included in the study were identified as ‘experienced’ by their quantity of work experience, however no formal definition of an ‘experienced’ worker existed and the authors did not volunteer one. Finally, the context of the study is unique, and there may be many cultural variations. The third step (learning about the contextual environment) may differ between cultures, for example.

Dickson’s review [57] found no substantial evidence to make recommendations for pet or animal therapy as a non-pharmacological intervention. However two studies published since Dickson’s review sought to investigate the efficacy of animal therapy on BPSD in CH residents. The first, a RCT [66], randomly assigned 65 nursing home residents to a control group, who received normal routine, or an intervention group, who received normal routine with Animal Assisted Therapy (AAT), over a 10 week period. AAT is used primarily to encourage cognitive, emotional and social capabilities in people with dementia [67], and can include a variety of animals in service in health care including cats, dogs, birds and fish [68]. In the intervention group, residents maintained the frequency and severity of their symptoms of agitation, aggression and depression. In the control group, symptoms of agitation or aggression, and depression significantly increased over the ten weeks. The authors posit that AAT may delay the progression of behavioural symptoms associated with dementia. The second RCT investigated a dog-assisted intervention on BtC, in eight Swedish nursing homes over six months [69]. Thirty-three residents were recruited, and assigned to a control group (n=13) or intervention group (n=20). The intervention consisted of interaction with a therapy dog, which was captured in videos by the researcher over 10 sessions of 30-45 minutes once or twice per week. Results displayed no significant changes in the intervention group for BtC between baseline and follow up. Mean scores for non-aggressive behaviours and behavioural symptoms decreased between baseline and follow up, indicating fewer but not statistically significant BtC were present at follow up, while verbal agitation scores increased significantly. The authors acknowledge that the value of dog-assisted therapy requires further investigation, but suggest that it may complement pharmacological practice in managing or reducing BtC.

In summary, the evidence pertaining to the effectiveness of NPIs to manage BtC is disparate and inconclusive. The most reliable evidence for managing BtC encourages caregiver training and support, and behaviour management techniques; however the exact training programmes that result in effectively managing BtC are unclear. Indeed, Dickson et al acknowledged the difficulty in identifying the exact component of training that resulted in effectively managing BtC[57]. Rigorous conclusions regarding the most effective strategies to manage BtC have not been formed. As the most scientifically rigorous testing method, the RCT is regarded as the ‘gold standard’. Testing the efficacy and feasibility of NPIs has been attempted through RCTs, however it is impossible to blind participants and researchers, and there is a requirement for individualised intervention[70]. While the Dickson review[57] is an important synthesis of the evidence base for NPIs, it has limitations: the original studies included in each systematic review were not reviewed by Dickson et al, and the quality of those studies was assessed by other authors. The systematic reviews included in this review used variable terminology, and were not consistent in categorising NPIs; as such, there are problems in trying to compare their findings. Study designs are varied, often small in size, use varying assessment tools and have methodological limitations, and as such, they cannot entirely fill the gaps in the evidence base. It also appears that the majority of studies investigating NPIs do not consider any potential harmful effects on participants. A number of the interventions reviewed did not focus on the person with dementia or their care staff, and therefore it remains unclear how these interventions could be used in CHs. In addition, CH staff will require more knowledge in order to conduct these interventions, and studies have found CH staff lacking in this knowledge of NPIs. It is interesting to note however that validation therapy, functional analysis and stepped frameworks all appear to have limited or no evidence to recommend them as interventions to manage BtC, yet these NPIs are all similar in their approach, where understanding and effective communication are key. Replications of the studies are difficult to conduct due to limited information pertaining to the NPIs investigated, or conducted. There is a developing evidence base for the use of NPIs in BtC, however there is a dearth of high quality literature investigating their efficacy to manage BtC. Banerjee[1] suggests that a change in the approach to caring for people with dementia is crucial in order to successfully integrate NPIs into practice: it appears questionable as to whether this is possible, particularly given the weak evidence base for their success in managing BtC.

What is the prevalence of antipsychotic use in CHs, what mechanisms have been used to ensure use is appropriate and is there capacity for reducing their use?

It has been suggested that antipsychotics have been excessively used to manage BtC in people with dementia[1], particularly in CHs where manifestations of BtC can be challenging for formal carers[71], and where residents consequently may be subdued under a ‘chemical cosh’. Therefore, studies investigating the efficacy and safety of antipsychotics in people with dementia required exploration.

A systematic review published in 2015 aimed to quantify the effectiveness and safety of antipsychotic drugs on BtC in people with dementia[72] and 23 RCTs were identified with duration ranging from six to 26 weeks. After statistically combining the trials, results showed some benefits for the use of aripiprazole and risperidone on psychiatric symptoms and cognitive functions. However in 2009 the Department of Health committed to reducing the prescription of antipsychotics in people with dementia, having estimated that at that time in the UK, approximately 180,000 people with dementia were being prescribed an antipsychotic [1], approximately two thirds of whom, had there been appropriate support available, were being prescribed it unnecessarily. A lack of evidence at that time prevented the estimation of the prevalence of antipsychotic prescription specifically in CHs, and therefore the prevalence in CHs is assumed to be higher than the national estimation, due to the increased co-morbidities and profiles of CH residents[1, 5].

In 2013, Declercq et al[73] conducted an evaluation of the success of antipsychotic withdrawal in people with dementia living in CHs or the community. Nine RCTs were reviewed: seven conducted in nursing homes; one pilot study in an outpatient setting, and one in both settings. All studies used different measures to diagnose dementia. Three studies investigated included participants with mild to moderate dementia however the four other studies had no indication of the severity of dementia. Varying antipsychotics at different doses were withdrawn, at abrupt and gradual levels, and outcome measures were different and therefore difficult to compare. None of the studies assessed the presence or absence of withdrawal symptoms, and adverse events (including falls and extrapyramidal symptoms) were not systematically reported. The review concluded that many older people with dementia and BtC can be withdrawn successfully from their antipsychotic medication, with no harmful effects on their behaviour. The authors suggested that 'discontinuation programmes' could be routinely used, however people with more severe BtC, or those who had previously responded well to antipsychotic medication, may not benefit from this withdrawal.

One of the studies included in Declercq et al's review, was a randomised placebo-controlled, parallel, two-group treatment discontinuation trial aimed to assess whether continued treatment with antipsychotics in people with Alzheimer's disease is associated with an increased risk of mortality [74]. A follow up to this study found that people with Alzheimer's disease continuing to take antipsychotic medication had a long-term increased risk of mortality, compared with residents who were switched to placebo [75].

There are few studies reporting on the use of antipsychotics in CHs, and their estimated prevalence ranges between 33% and 43% [76-78]. One study investigating prescription trends in CHs found that older antipsychotics were used in more than 25% of residents prescribed an antipsychotic drug [77]. A study analysing the level of antipsychotic use in people with dementia, recruited through the UK Clinical Practice Research Datalink suggested that between 1995 and 2011, the use of antipsychotics had fallen from 19.9% to 7.5% [79]. However the study also found that within this time, there was a clear increase in the prevalence of antidepressant medication. In 2010, the Dementia Action Alliance launched a 'Call to Action' on the use of antipsychotics for people with dementia, whereby those people with dementia and prescribed an antipsychotic would receive a clinical review to ensure that their care and prescription was compliant with best practice and national guidelines [80]. The subsequent National Dementia and Antipsychotic audit, found the number of patients diagnosed with dementia who were prescribed an antipsychotic medication had fallen from 17% in 2006, to 7% in 2012 [29]. However, during that time, the number of people diagnosed with dementia increased as a result of a drive to increase early diagnosis. 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 is not necessarily indicative of a decrease in antipsychotic prescribing, and therefore it is not clear whether or not the target to reduce prescriptions by two thirds has been met. Hence there is value in exploring this subject area further.

In 2013, Backhouse et al [81] conducted the first study to estimate the prevalence of antipsychotic use for people with dementia in CHs. A postal survey was distributed to all (n=747) managers of CHs registered as specialising in the care of older people and/or older people with dementia within four counties in the East of England. Two hundred and ninety-nine CH managers responded (40% response rate). Despite only 66% of participating CHs being registered to provide dementia specialist services, 85% of CHs reported caring for people with dementia. Of the total 8579 residents in the 299 CHs, 1027 (12%) residents from 246 (82%) CHs were prescribed at least one antipsychotic drug. Approximately half of respondents reported experiencing behaviours they found difficult, with 52% reporting that the CH would admit people with BtC. Nearly half (49%) of CH staff reported experiencing an episode of BtC within the previous week. Aggression, both physical and verbal, was reported as the behaviour staff found most difficult to manage in 37% of homes; impact of behaviours on other residents or staff was found difficult to manage in 12% of CHs, and resisting care was found to be challenging to manage by 9% of CH respondents. With regard to managing these behaviours, antipsychotics were prescribed to at least one resident in 73% of CHs, with prescriptions to more than 5, and more than 10 residents in 23% and 8% of CHs respectively. The authors reported a significant difference ($t = -2.264$, $p<0.05$) between the level of antipsychotic prescribing in CHs providing qualified nursing care when compared to residential homes. This may suggest that homes providing nursing care have on average, more residents that are prescribed antipsychotic medication. Managers reported concurrent use of non-pharmacological interventions and antipsychotic medication, with 87% of CHs reporting to use at least one intervention to help manage behaviour. The most common NPIs reported as being used were reminiscence therapy (75% of CHs), music therapy (73%) and animal/pet therapy (64%). While 13% of CHs reported not using any non-pharmacological therapies, of these, 66% were not homes caring for residents with dementia. Aggression was reported to be the most challenging behaviour to manage, while a variety of non-pharmacological and pharmacological interventions were concurrently employed to manage it. The study has limitations however: the low recruitment rate may have been reflective of the disparate nature of CHs, with CH managers potentially reluctant participants as a result of negative media representations and stigma associated with the prescription of antipsychotics. In addition, the lack of standardisation of NPIs may have led to subjectivity and ambiguity in managers' responses regarding these interventions.

In 2012, a pharmacy-led intervention study conducted within General Practitioner (GP) surgeries within the Medway Primary Care Trust (PCT), collected data on antipsychotic usage to identify people on the dementia register within Medway PCT who were prescribed antipsychotics [82]. A specialist pharmacist then intervened in a cohort of people with dementia commenced on antipsychotics by primary care identified by the data search. The study found that 118 of 462 (26%) people on the dementia register living in CHs were prescribed antipsychotic drugs. Of the 161 people on the dementia register prescribed low-dose antipsychotics, 87 were receiving on-going treatment from local secondary care mental health services and four from the local Learning Disability Teams. The remaining 70 patients were included in the pharmacy-led intervention. Different surgeries accessed different levels of pharmaceutical support and, following the intervention, in 43 cases (61.4%), antipsychotics were withdrawn, or the dosage of the antipsychotic was reduced. Prescribing was focused in a small number of practices and the study found that a person with dementia living in a CH was almost 3.5 times more likely to receive a low-dose antipsychotic than their home-dwelling counterpart. The prevalence of antipsychotic prescriptions was higher than in other studies; however this may be as a result of including residents with increasing severity of dementia living in CHs. Additionally, the objective nature of this study (measuring prescribing of antipsychotics as opposed to asking care staff) could explain why a higher percentage was found. While the scope for the intervention was relatively limited, and no formal follow-up was conducted, this pharmacy-led intervention was successful in reducing the prescribing of antipsychotics.

In 2012, Richter el al [83] conducted a systematic review evaluating psychosocial interventions for reducing antipsychotic medication in CH residents. The four cluster-RCTs included in the review investigated diverse CH staff educational approaches. Three studies investigated education and training for care staff, while one study explored multidisciplinary team meetings as the primary intervention. The review found that the evidence on educational interventions is consistent with a reduction of antipsychotic medication prescription in CH residents, since every study found either a reduction in the proportion of residents administered antipsychotics, or a decreased number of days taking antipsychotics per 100 days per resident. However despite one high quality study, methodological weaknesses were limiting. One of the studies included in the review [84] is discussed later in this chapter in the section on staff training.

A controlled trial of a predominantly psychosocial approach to BtC assessed and treated thirty-three residents who had been referred to a community psychogeriatric service due to the manifestation of BtC [85]. The assessments and treatment focused on the causes of these behaviours, as well as the reasons for nursing staff perceiving there to be a problem. The service provided psychosocial methods of treatment predominantly, with adjunctive psychotropic medication if required. A control group of 22 residents who had been referred to a similar service, received predominantly psychotropic medication, with additional psychosocial methods of treatment if required. Antipsychotic use in the intervention group decreased over time, while it increased in the control group. Staff behaviour and response measures significantly improved in both groups at follow up of two and five months. While both groups required similar numbers of visits to the referral units, the intervention group received fewer alterations in their medication and experienced fewer side effects than the control group.

The evidence for the efficacy and safety of antipsychotic medication for BtC is multifaceted. RCTs are numerous, yet focus on various differing BtC, investigate different medicines and doses, use different measuring tools and have different outcome measures, including antipsychotic use, staff behaviour, side effects and antipsychotic prescription. This makes it difficult to clearly summarise, or provide recommendations. While there are few studies reporting on the prevalence of antipsychotics in CHs, only one study has provided an estimate of the prevalence of antipsychotic prescription specifically for people with dementia living in CHs. It is clear that the reduction of antipsychotic medication in people with dementia is a complex issue, debated around the best course of action while maintaining the best quality of life. Therefore, it important to weigh the risks and benefits of antipsychotic prescription and the literature examined suggests that there is a large variation in antipsychotic use within CHs. It appears that people with dementia can tolerate the withdrawal of antipsychotic use, however those with more severe symptoms may require and benefit from long-term use of antipsychotics and so withdrawal or cessation may be detrimental to them. Studies investigated showed small effect sizes for efficacy, and the evidence suggests that withdrawal from antipsychotic medication may be managed well by people with dementia who have less severe BtC. Withdrawing antipsychotic medication from these individuals however may cause increasing manifestations of BtC, and therefore there is a pressing need for investigation into alternative therapies, including pharmacological alternatives. It is clearly important to examine CH medication use, particularly given the high reported prevalence of antipsychotics, and the impact of withdrawal on quality of life.

What are the experiences of formal carers in managing BtC, and what training exists to enable them to manage BtC?

CH staff are the front line in caring for people with dementia living in CHs. Little is known about the attitudes of CH staff and their impact on BtC, despite a report by the Department of Health that they are often the least trained, with little support and are subject to stressful and emotional working practices [1]. The report recommends a need for care staff to develop appropriate skills in order to implement NPIs for BtC in dementia. However, CH staff are an under-researched population, and Banerjee acknowledges that implementing these changes takes time [1].

A study aiming to assess nurses' knowledge of non-pharmacological and pharmacological interventions, as well as the frequency, perceived barriers and efficacy of both interventions distributed a 43-item questionnaire to six rural care facilities in Australia [86]. The authors also investigated the resources and information sources that nurses used to manage behavioural problems associated with dementia. Respondents were aware and had a good knowledge of the causes of BtC, however they lacked a solid understanding of how to manage BtC, and what resources were available to them in order to manage it successfully. Additionally, nurses reported time constraints as a limiting factor in being able to manage BtC. The authors posited that help in identifying specific behaviours, managing those behaviours, and identifying appropriate resources are required.

A recent Dutch study published in 2015 aimed to determine the efficacy of a care programme for the BtC of CH residents on staff burnout, job satisfaction and job demands [87]. Seventeen special care units were recruited, to participate in a care programme containing an education package and assessment tools for guiding staff through the 'detection, analysis, treatment and evaluation' of BtC. Significant improvements in job satisfaction (0.93, 95% CI 0.48-1.38) were identified, however no other significant changes were found.

Pulsford, Duxbury and Hadi [88] conducted a survey which aimed to explore the views of nurses, and care staff as to the causes of, and most effective ways of responding to aggressive behaviour by older people with dementia in residential care, and to explore the strategies used in practice to respond to such behaviour in residential settings. The authors recruited staff in four nursing homes in the North West of England which were made up of six dementia care units, ranging from 15-30 beds. All staff were invited to complete the Management of Aggression in People with Dementia Attitude Questionnaire (MAPDAQ, adapted from the Management of Aggression and Violence Attitude Scale (MAVAS) [89]), which surveys the attitudes of staff members towards incidents of aggression. In addition, the authors carried out an audit of aggressive incidents using the Staff Observation Aggression Scale (revised over a 3-month period, SOAS – R) [90]. Data for the MAPDAQ was collected over a 13-month period, while the audit consisted of a three-month prospective data collection process. Thirty-six of the 52 care staff completed the MAPDAQ, while the authors collected 79 SOAS-R forms. Staff displayed a broadly person-centred approach to aggressive behaviour, while understanding that a more controlled approach was sometimes required. Staff expressed that their responses to aggressive behaviour were largely underpinned by a person-centred ethic. Aggressive behaviour by people with dementia was viewed by staff as deriving from the environment, situation or interactions with others, with restrictive environments being seen to be influential. However staff were ambivalent in response to ‘other people make people with dementia aggressive’. Broadly, staff felt that the causes of aggressive behaviour can be found in the immediate situation, and strongly supported interpersonal and non-physical means of responding to aggression, moderate use of medication, and were largely strongly opposed to the use of isolation and physical restraint. Aggressive incidents were managed using less intrusive strategies such as distraction and de-escalation. The most common identifiable cause of aggressive incidents was staff attempting to give personal care, while the second most common identifiable cause was interaction with other residents. While 75.9% incidents were targeted at a member of staff, 31.6% incidents were targeted at other residents, and 65.4% of incidents were managed with interpersonal or non-physical intervention. Staff reports in SOAS-R were largely reflective of their MAPDAQ responses. The study has several limitations: a small number of CHs were recruited to the study, and these were all owned by the same company, where a common ethos may have been present. SOAS-R incidents may not have been reflective of all incidents, especially as a number of residents were excluded from the study.

The authors note that it would have been useful to audit medication in the CH units, as a more objective measure of antipsychotic use and behaviour management.

A cluster RCT evaluating the effectiveness of training and support interventions for nursing home staff in reducing the proportion of residents with dementia who are prescribed antipsychotics was conducted in 12 nursing homes in London, Newcastle and Oxford [84]. A training and support intervention was delivered by a psychologist, occupational therapist, or nurse based in each of the three centres, to nursing home staff over 10 months, focusing on alternatives to drugs for the management of agitated behaviour in dementia. Staff received training in the delivery of person-centred care and skills development in training and supervision, and were supervised weekly over the study period by two of the authors, experienced in dementia care. The package involved a systematic consultation approach, which focused on “whole home” issues, such as environmental, care practice and attitudinal factors. The clinicians started and supported the use of activities through didactic training, skills modelling, and supervision of groups and individual staff. Key elements in the programme involved initial skills training, behavioural management techniques and ongoing training and support. Initial skills training for care staff involved the philosophy and application of person centred care, positive care planning, awareness of environmental design issues, the use of antecedent behaviour consequence models, development of individualised interventions, active listening and communication skills, reminiscence techniques and involvement of family carers. Behavioural management techniques included training in the Cohen-Mansfield approach (how to manage verbally disruptive behaviours, which may be a result of stimulus and social deprivation). Ongoing training and support included group supervision and further development of skills involving individual case supervision and supervision of issues requiring organisational change within the home. The proportion of residents in each home who were prescribed antipsychotics and mean levels of agitated and disruptive behaviour were measured by the Cohen-Mansfield Agitation Inventory (CMAI) [91] in each home at baseline and again at 12 months. At 12 months the proportion of residents taking antipsychotics in the intervention homes (23.0%) was significantly lower than that in the control homes (42.1%): average reduction in antipsychotic use 19.1% (95% confidence interval 0.5% to 37.7%). No significant differences were found in the levels of agitated or disruptive behaviour between intervention and control homes. The authors postulated that training and support interventions provide a feasible alternative to treating people with dementia exhibiting BtC with antipsychotic medication.

A study investigating the non-pharmacological management of behavioural symptoms in nursing homes [92] was designed to overcome some of the weaknesses of previous studies and evaluated the effectiveness of a staff education intervention for the management of BtC in 306 older individuals with dementia. Sixteen nursing homes were randomly assigned to either the control group (usual practice and care processes, n=10) or the intervention group (staff training programme, n=6), and a baseline assessment was carried out by psychologists blind to the intervention arm, using the Neuropsychiatric Inventory (NI) [93], CMAI and an Observation Scale (OS). The 10 control homes with 132 residents provided usual care. An eight week staff training programme commenced in six nursing homes and a total of 174 residents, beginning with a teaching session on dementia which introduced staff to four 'Staff Instruction Cards'. The cards included guidelines on how to manage opposition, agitation, aggression, delusions, hallucinations or screaming; how to behave throughout the day to avoid or reduce occurrences of BtC; and direction on non-pharmacological approaches to managing BtC. The staff training intervention reduced BtC, with the effects still existent up to three months after the end of the programme, with a significant reduction in the global CMAI score in the intervention group between week 0 and week 8, and week 0 and week 20, which was not found in the control group. However, the authors note that choosing to randomise nursing homes as opposed to participants led to the two groups having different baseline characteristics: in particular, the intervention group had more severe BtC and so it is possible to infer that the global CMAI score in the intervention arm was invariably more likely to decrease. A further limitation considered by the authors is that of a bona fide NPI: the participants in this study maintained their existing pharmacological treatment. The study was also limited to CHs with nursing, and no CHs without nursing were included.

A 2007 study investigating the impact of an eight-session training programme for aged care staff in managing dementia-related BtC evaluated outcomes for 90 participating staff members and 113 residents with BtC from six aged care facilities [94]. Measures of staff attitudes and the behaviours of staff and residents were collected pre- and post-intervention, and at six month follow-up. Participation in the training programme with an additional five-session peer support group (n=29) was compared with both participation in training only (n=35) and a wait-list control condition, where no training was given (n=26). Staff members in both dementia training groups reported improved attitudes regarding their knowledge and skills in managing residents with BtC, immediately after the training and six months later. Managers rated the nursing performance of trained staff more positively, especially those who took part in a peer support group. The dementia training programmes, either with and without the inclusion of peer support, did not influence the levels of staff burnout or significantly reduce BtC among the residents. Therefore although training programmes may positively affect staff performance, the organisational physiognomies of CHs, such as a lack of management support for training programmes, limit the potential outcomes.

A study investigating the impact of training dementia staff caregivers in their sensitivity to non-verbal emotion was conducted in 91 residents with dementia from three nursing homes [95]. The residents and staff from all three homes were randomly assigned to one of two training groups (a non-verbal sensitivity group or a behavioural placebo group receiving instruction in the cognitive and behavioural aspects of dementia), or a control 'wait-list' group. Staff were trained by a clinical psychologist over 10 one-hour sessions. Resident symptomology (depression, agitation, behavioural symptoms), as reported by the staff, and positive and negative facial expressions of emotion were measured (facial expressions were elicited from a face-to-face interview, and then coded by trained researchers). Measures were taken at baseline and at four three-weekly intervals. Over the first six weeks, positive affect increased sharply after intervention in the non-verbal group, and no change was noted in the other two groups. There was a decline in negative affect over time for all groups. There was no significant effect noted for depression, agitation or behavioural symptoms.

A pilot study investigating staff training in UK CHs implemented the eight-week Staff Training in Assisted Living Residences (STAR) programme in two CHs with 25 care staff [96]. STAR is based on an integrated model of person-environment fit and social learning theory. It has three priorities: to reinforce values of dignity and respect for residents; to improve staff responsiveness to resident needs; to build specific staff skills to enhance resident care and improve job skill and satisfaction. Care staff were trained using two four-hour workshops, supplemented by four individualised on-site consultations and three leadership sessions. Assessments were made at baseline and at eight-week follow up after the intervention had ceased. While resident-rated quality of life and anxiety symptoms did not show any significant improvement, there were significant reductions in symptoms of depression and behavioural problems at eight weeks. Additionally, staff rated themselves as feeling more hopeful towards their residents, and rated themselves significantly more competent in founding relationships with their residents.

A case study of care staff training programmes for managing BtC was conducted in two female CH residents with dementia [97]. The main BtC for each resident was documented (difficulty in sitting, frequent visits to the toilet, avoiding contact with others), and the 10 care staff trainees caring for both residents were trained using an antecedent-consequence-behaviour analysis with differential reinforcement procedures. Staff then implemented individual care plans for both residents. Measurements of BtC frequency were taken at baseline, and after the intervention phase (staff training). In both residents, the absolute frequency of the documented BtC had decreased however there was a gradual increase during intervention and follow up. The alternative behaviour of engaging in leisure activities had increased during the intervention phase compared with baseline. Additionally, staff support for resident activities was higher in the intervention phase than at baseline. Results indicated that the training programme effectively decreased BtC however the authors maintained that support for care staff in aiding residents' activities is crucial.

Cohen-Mansfield et al [98] conducted a descriptive study of the barriers to conducting NPIs for BtC, in six nursing homes in Maryland, USA. Eighty-nine nursing home residents presenting with agitation had personalised interventions developed for them, by trained researchers using the Treatment Routes for Exploring Agitation decision tree protocol. The practicality of implementing these interventions was investigated, measuring Activities of Daily Living (ADL), cognitive functioning, depressed affect, pain, observed agitation and observed affect. The researchers categorised results into: resident barriers (unwillingness to participate, resident attributes), resident unavailability (asleep or eating), and external barriers (staff, family, environment and system process). They noted that interventions relating to food, drink and one-to-one interaction had the fewest barriers, while interventions relating to puzzle or board game, and art and craft activities had the highest number of barriers. After the intervention period the researchers identified fewer barriers on successful intervention delivery. They suggested that this was due to barrier identification being conducted by staff to tailor individual interventions.

A single-blind randomized controlled trial investigated the effect of staff training on the use of restraint in dementia [99]. Four nursing homes were assigned to either a control or intervention group. The intervention group received a full day seminar focusing on the use of restraint, followed by a one-hour session of guidance per month over six months. The control group continued usual practice. Neither clinical nor demographic variables differed between the intervention and control groups at baseline, however after the intervention there was a 54% reduction in the use of restraints in the treatment group, while the control group had increased by 18%.

A qualitative study examining working practices in long-term care settings utilised semi-structured interviews with 30 managers, care workers and nurses in hospitals and 10 CHs to attempt to make recommendations on care in practice[100]. While the authors also interviewed residents and relatives (not relevant to this literature review), they established a requirement for the training and education of staff, including managers, to be targeted appropriately, easily accessible, widely available, as a possible solution to managing BtC. The authors also noted that this level of training availability would have the potential to improve staff fulfilment.

Further research into the areas of educational interventions is pending: a study protocol for an optimised person-centred intervention to improve mental health and reduce antipsychotics amongst people with dementia in CHs was published in 2013 [101]. Additionally a study protocol for a cluster RCT on antipsychotic drug use in nursing homes using staff training interventions was published in 2015. [102]

In summary, there is a pressing need for care staff to develop appropriate skills in order to implement NPIs for BtC in dementia[1], however it is challenging to identifying the exact component of training that results in effectively managing BtC[57]. Nevertheless, training and support interventions have been found to provide a feasible alternative to treating people with dementia exhibiting BtC with antipsychotic medication[84]. Studies reviewed were limited by small sample sizes, and in one study [88], CHs were all owned by the same company, where a common ethos may have been present. In these studies, residents may have been excluded, and therefore it is likely that not all incidents of BtC were captured. Studies investigating medicines use used subjective measures, rather than objective measures such as audits. Descriptions of exact staff training programmes were weak, and varied between studies. Original training methods were frequently adapted and therefore it becomes difficult to quantifiably compare outcomes. Training is an important aspect of managing BtC, but there is no clear guide from the published evidence as to what training should involve. As such this warrants further investigation. In one study, the baseline characteristics of the participants differed and therefore the study opened itself up to bias. Again, the notion of a true NPI is idealistic, particularly since participants maintained their pharmacological treatment in addition to any CH staff interventions. The low level of management support for staff training prior to conducting interventions for BtC is a huge limitation, and was noted by one study. In these studies reviewed, staff were asked to rate residents' behaviours, rate their own competencies in delivering interventions, and rate their support for interventions. This introduced an element of bias, particularly if staff may have wished their CH (or indeed themselves) to be shown in a good light.

What is known about the design of the CH environment and its impact on BtC?

Papers reporting on environmental interventions and the design of the environment for people with dementia living at home suggest that remaining at home can be facilitated though methods such as home modification, and stress the ‘multitude’ of design principles, goals and interventions available to aid people with worsening dementia who wish to remain at home [103, 104]. There is however little research into the design of the CH environment, and as such studies investigating or reporting on environmental design or intervention are limited. Indeed, the purported ideal care environment is complex and often contradictory: residents need therapeutic stimuli, however they may also need a quiet and calm environment; the environment should encourage movement, yet it should prevent residents from walking constantly in circular pathways; it should be brightly coloured, yet evidence suggests some elderly residents prefer pastel colours [105-109].

A cluster randomised controlled trial of person-centred residential care (PCC) and environment (PCE) for dementia residents of 38 Australian CHs sought to improve PCC and PCE with the aim of reducing agitation and increasing the quality of life of its participants [110]. The CHs were randomised to one of a PCC group, PCE group, PCC + PCE group or a control group. Six hundred and one residents with dementia were assessed for agitation, emotional responses in care, quality of life, depression and care interaction quality, at pre and four months post intervention, and at eight months follow up. At follow up, there was a significant improvement in PCE and PCC for quality of life ($p=0.02$, $p=0.0003$ respectively) and for agitation ($p=0.05$, $p=0.002$), compared with the control group ($p=0.48$ quality of life, $p=0.93$ agitation). Depression scores did not change within any group. Significant improvements in care interaction quality ($p=0.006$) and emotional responses to care ($p=0.01$) were noted in the PCC+PCE group but not in the other groups. Despite this improvement in the PCC+PCE group, the authors noted that their hypothesis that PCC+PCE would improve quality of life and reduce agitation was not supported.

Cohen-Mansfield and Werner [111] conducted a national survey of long term care facilities to explore the features of outdoor wandering parks for people with dementia. Two hundred and eleven respondents were made up of directors of nursing (66%), administrators (13%), other positions, such as social worker (16%). Six percent of respondents did not specify their role. All respondents rated outdoor spaces as very useful and beneficial for their users, with 69% rating them extremely useful, however the authors did not provide a definition of ‘useful’ and this may have been open to interpretation. All facilities reported concrete-made walkways as part of their outdoor environment, which included trees (83.5% facilities), flowers (79.4%) and bird feeders

(59.4%). Handrails were present in 13.3% of facilities and 35.0% had pets in the outdoor area. Results from this survey showed that although some of the advice and guidance from architects and designers had been acted upon, there were still problems. For example, only 20% of outdoor spaces included decorative objects. The authors also made suggestions, including that lawn furniture needs to be tailored for the needs of the residents, and that outdoor spaces are enclosed for residents to be free to wander at their leisure, but that they are monitored by visual contact monitors. The authors suggested that their findings served as guidelines for those wishing to design, or create an outdoor space for people with dementia.

In summary, very little is known about the CH environment, or its impact on BtC. Most studies investigating BtC in dementia opt to examine NPIs, pharmacological agents or the approaches or opinions of care staff. There is little support for CHs in how to design an optimal environment, and the studies reviewed here display how contradictory the minimal available advice is. Sample sizes in these studies are low, and one study suggests that the environment alone will not reduce BtC in people with dementia. Adapting the care environments were not standardised across participating CHs due to restrictions by managers and staff, therefore this raises questions as to whether the designs could be successfully transferred to other CHs. CH staff rarely had authority to implement changes to residents' care (paying greater attention to residents' activity schedules, for example) and managers disregarded their proposed changes. Finally, in some CHs recruited, despite changes being made to the environment (newly constructed gardens, for example), CH staff did not enable residents to utilise these new facilities.

Discussion

Over the past six years there has been increasing interest in both dementia and the best ways to care for people with BtC, from the Government and the academic world. While the Government created recommendations and strategies for care, the research on which recommendations are based is limited and often of poor quality. In addition, the day-to-day routines of CHs 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. CHs, their staff and residents are an under-researched population, and while increasing attention is being given to their day-to-day care practices, robust research studies are still limited. Historically research suggests that antipsychotics were used routinely to manage BtC, however the literature would suggest that antipsychotic use for people with dementia is decreasing and the Dementia Action Alliance and subsequent National Dementia and

Antipsychotic audit clearly stated the (at the time) current status of antipsychotic prescriptions in the UK. Both publications highlighted the urgent need for rigorous research into non-pharmacological interventions for BtC, particularly within the CH setting. Training and support interventions have been found to provide a feasible alternative to treating people with dementia exhibiting BtC with antipsychotic medication[84]. This however may have implications on the economic burden CHs already face.

It is clear from the literature that there is not a clear, multi-dimensional solution to managing BtC in dementia. Systematic reviews in this area have not established a firm evidence base on which to build recommendations, particularly in selecting or implementing non-pharmacological approach to treatment for BtC. Indeed, for the vast majority of NPIs, the evidence is inconclusive, as a result of inconsistent or poor quality studies. As such, it is difficult to make policy and practice recommendations[1] and therefore ‘more and better’ research studies investigating alternative approaches to managing BtC are required. While it is widely accepted that non-pharmacological therapies should be used as a first-line treatment, the majority of studies reviewed have opted to investigate or observe environmental, staff, pharmacological and non-pharmacological approaches as separate entities in the treatment plans for individuals with dementia. It is also evident that while CHs may adopt a variety of strategies to manage behaviours in dementia, there is neither rigorous recommendation, nor a unified and agreed solution. It is interesting to note that validation therapy, functional analysis and stepped frameworks all appear to have limited or no evidence to recommend them as interventions to manage BtC, yet these NPIs are all similar in their approach, where understanding and effective communication are key. It is also apparent from the literature that training is an important aspect of managing BtC, but there is no clear guide from the published evidence as to what training should involve. While it is challenging to identify the exact component of training that results in effectively managing BtC[57], there remains an urgent need for CH staff to develop the skills required to implement NPIs for BtC in dementia[1]. As such this warrants further investigation.

This review has identified key areas of care that warrant further exploration in the management of BtC in dementia, in CHs: how CH residents with BtC are cared for and the strategies used by CHs to do this; how staff are supported in managing BtC; the design of the CH environment and how it affects BtC and the medicines that CHs administer to people with dementia, who have BtC. Finally, the perspectives of relatives on how family members with BtC resident in CHs are managed warrants further exploration.

Aim

This study series aimed to explore how BtC in people with dementia are managed by CHs, and observe how they are managed in practice.

Research question

What strategies exist to manage BtC in people with dementia in English CHs and how are these strategies used in practice?

The central research question was broken down into four sub-questions:

1. How are residents cared for during incidences of BtC?
2. What different strategies are adopted by CHs to manage BtC?
    a. What training and support do care staff have to manage BtC?
    b. What do different CH environments look like and what impact may these differences have on BtC?
3. What medicines are prescribed and administered to residents with dementia living in CHs?
4. What are residents' relatives' experiences of the dementia journey?
    a. What are their preferences for care?
    b. Are these preferences met by the CH in which their relative/friend resides?

Chapter 3 Study and Methods Rationale

Introduction

This thesis begins with the view that CHs and their staff and residents are an under-researched study population, while looking to further understand and develop the care for people with dementia who exhibit BtC. Every methodological design presents a range of challenges for researchers that require consideration and thought. Within the realm of the health sciences, a variety of research methods have been established which aim to effectively answer research questions. This study sought to explore the current practices for managing BtC in English CHs. I acknowledge that any methodological approach adopted for this study would have moulded the outcome of the research, and therefore I chose to employ a pragmatic approach, whereby methods were chosen which were best suited to the research problems, thus allowing myself the freedom to utilise any methods and procedures typically associated with qualitative and quantitative work, in a mixed methods study model. Given the importance of objectivity in research, I have attempted to critically examine the methods and conclusions for any possible bias throughout this thesis, therefore this chapter will define and present a rationale for my use of the pragmatic approach in guiding this research, discussing its strengths and limitations within this study.

The literature review identified large gaps in the evidence base surrounding attributes of holistic care working in practice, including care staff, the care environment and management strategies for BtC. There is no clear, multi-dimensional solution to managing BtC in dementia, and no consistent guidelines for implementing the use of non-pharmacological approaches to treatment for BtC, however it is widely accepted that NPIs should be used as a first-line treatment. Studies tend to either focus on dementia as a single disease rather than as a multi-morbidity, or focus on single management strategies. Therefore a cohesive and established panacea does not exist, yet it is unclear as to why. The gaps identified warranted further exploration of care staff opinion, relatives' opinion and investigation within CHs to identify current practices and application of guidelines. In order to explore these elements rigorously, a large, all-inclusive and comprehensive study seeking to gain an in-depth understanding of the resident-centred care approaches used in CHs to manage BtC, was required.

Determining the most appropriate approach

Given the differing characteristics of the research questions, which asked both ‘how’ and ‘what’, I needed to ensure that the study was designed to successfully capture all of the data required to answer each research question. This would therefore enable me to explore fully the management of BtC in CHs, any alternative approaches used, the care of residents and the preferences and opinions of residents’ relatives.

Debating traditional approaches to research

The purists of quantitative and qualitative research paradigms have long debated and defended their chosen research ideals; however an advantageous philosophical associate for mixed methods research is the pragmatism paradigm. While quantitative researchers[112, 113] assume a positivist philosophy, whereby the observer is separate from the entities that are subject to observation, and inquiry should be objective, qualitative purists[114-117] assume a constructivist or interpretivist philosophy, rejecting the emotional detachment and rhetorical neutrality and argue for multiple-constricted realities wherein research is value-centred and cause and effect cannot be fully differentiated. Both groups of purist researchers think their paradigms ideal in which to conduct research, and are advocates for rendering the two paradigms incompatible [118].

The objective of conducting a mixed methods research study is to neither replace qualitative nor quantitative paradigms, but rather to elicit the strengths from and reduce any weaknesses of both. Indeed, I believe that a mixed methods study design allows the researcher to develop skills and techniques that can be more accurately used in practice, and can help bridge the gap between qualitative and quantitative research. This study endeavoured to provide justified assertions about human beings and the environments in which they live, work and evolve[119], and in this study, this has led to the exploration of a plethora of data including opinions, experiences, attitudes, policy systems and culture. Johnson and Onwuegbuzie[120] argued the importance of researchers asking when each research approach is most helpful, as well as when and how they should be mixed or combined in their research studies. Indeed, the authors suggested that by adopting a non-purist philosophy, researchers are able to pick and choose the components of study methodology design that best suit their research questions, and that the link between research paradigm and method is unnecessary[118, 121]. Therefore, a mixed methods philosophy which attempts to piece together the expertise of both qualitative and quantitative research into garnering solutions to the research questions was justifiable in this study.

Choosing the pragmatic approach

In choosing a mixed methods design, consideration of the pragmatic method was warranted. Pragmatism suggests that the research should be approached and conducted in ways that offer the best chance for answering research questions, and the classical pragmatist Charles Sanders Peirce[122] stated that this method implies that we ought to *'…consider what effects, that might conceivably have practical bearings, we conceive the object of our conception to have. Then our conception of these effects is the whole of our conception of the object'.*

Another classical pragmatist, James Dewey[123] stated that *'…in order to discover the meaning of the idea [we must] ask for its consequences',* that is, we should take into account the empirical findings and practical consequences of any idea, since these are fundamental not only to understanding the importance of philosophical paradigmatic positions, but also to determining in which direction to move next, to further understand the real world. Johnson and Onwuegbuzie[120] explain this wonderfully:

> *'…it [pragmatism] offers an immediate and useful middle position philosophically and methodologically; it offers a practical and outcome-oriented method of inquiry that is based on action and leads, iteratively, to further action and the elimination of doubt; and it offers a method for selecting methodological mixes that can help researchers better answer many of their research questions.'*

Clearly as with any approach, pragmatism has its downfalls, therefore it was important that I endeavoured to be reflexive at every stage, and strategic in avoiding potential pitfalls in my work. The mixed methods logic of inquiry includes the use of induction, deduction, and abduction[124], and aims to validate the utilisation of several methods in order to answer research questions, as opposed to limiting researchers' choices. It is inclusive, suggesting that the researcher take a wide-ranging approach to both method selection and conducting research. According to Johnson and Turner[125] and Brewer and Hunter[126], multiple data should be gathered using a variety of strategies and methods in a way in which the ensuing amalgamation of data is likely to result in strengths and non-overlapping weaknesses, thereby ensuring the superiority of mixed methods research over monomethod approaches.

Study design

There is a dearth of knowledge surrounding management of BtC in CHs, and therefore this study was exploratory in nature. By establishing a clear purpose for the research, it became apparent that a mixed method approach was essential, as both quantitative and qualitative data were needed, and this mixed method approach also enabled triangulation of findings. The overall study explored how BtC in people with dementia are managed by CHs, and how they are managed in practice. The intended methodologies developed for this study were chosen in order to provide differing perspectives through data generated from different sources, with each phase contributing data which addressed the research questions in different ways. A Concept Indicator Framework is displayed and explained in Appendix 2. The study was originally designed to have two phases, starting with care staff interviews to elicit a broad snapshot of the current situation in Kent and the London Borough of Lewisham, and moving on to retrospectively collect data pertaining to CH residents' medical records, providing a more in-depth picture of current care practices and strategies within a small number of CHs, also located in Kent and the London Borough of Lewisham. Both phases were originally planned to be submitted within one ethical application form, however on writing the application, it became clear that incorporating both phases into one application was flawed, and so the study was split into a sequence of studies, comprising five phases:

Phase One: CH staff interviews and environmental observations – pilot and main study

Phase Two: Cross-sectional CH survey

Phase Three: Ethnographic participant observation

Phase Four: Use of medicines exploration

Phase Five: Relatives' perspectives

Phase One began with an amalgamation of two perspectives: the first, a phenomenological approach, was chosen to explore the views and experiences of care staff from CHs across Kent and the London Borough of Lewisham, through interviews; the second, observations of the care environment. Findings generated from the pilot CHs in Phase One were used to develop the questionnaire, and findings generated from the whole of Phase One were used in the development of the subsequent three phases. The second phase, a quantitative approach, was chosen to gather objective observations of the CH environment using reproducible quantitative methods. A cross-sectional survey was used to broadly explore 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: an ethnographic participant observation study, conducted in a sample of the CHs participating in Phase One. In Phase Four, the use of medicines in CHs was explored, within the participating CHs from Phase Three. Finally, in Phase Five, the views and experiences of CH residents' relatives were sought using interviews, conducted at each of the Phase Three CHs. A flow diagram of the whole study is illustrated in Figure 3.1, which also includes the numbers of CHs and participants in each phase. Each phase sought to answer the research questions by contributing a variety of results, and the five phases were conducted consecutively.

Methodology Map

		Aim	Study Design	Participants (n)	
Phase One	Jan 2013 – June 2014	To explore how different CHs manage BtC, establishing the current situation within CHs locally	Semi-structured interviews. Environmental observations	CHs (11) CH managers (11) CH staff (30)	Chapter 4

		Aim	Study Design	Participants (n)	
Phase Two	Sep 2013 – Jul 2014	To explore the views and experiences of CH staff of BtC through a self-completed survey, therefore establishing the current situation within CHs nationally	Cross-sectional survey	CH managers and staff (391)	Chapter 5

		Aim	Study Design	Participants (n)	
Phase Three	June 2014 – Feb 2015	To explore and observe how three CHs in Kent manage BtC in practice.	Participant observation	CHs (3) CH staff (17) CH residents (12)	Chapter 6

		Aim	Study Design	Participants (N)	
Phase Four	June 2014 – Feb 2015	To explore the medicines prescribed and administered to residents, in three CHs.	Data collection from CH medicine administration records	CHs (3) CH residents (12)	Chapter 7

		Aim	Study Design	Participants (N)	
Phase Five	June 2014 – Feb 2015	To seek an alternative perspective of dementia care, by exploring the views and experiences of relatives of residents living in three CHs.	Focus group discussion or interviews with residents relatives	CHs (3) CH residents' relatives (3)	Chapter 8

Figure 3.1: Summary of methodology

Rationale

Interviews

Phenomenological qualitative interviews were chosen for the first phase, to obtain the views and experiences of CH staff on managing BtC in people with dementia residing in their CH, and to obtain information pertaining to their experiences of training. In addition, environmental observations were conducted to quantifiably assess the interior and exterior design of the environment, and use of available facilities in the CH.

Speziale & Carpenter [127] defined the purpose of phenomenology as describing particular phenomena as lived experience: when practised within a health or social science perspective, phenomenology can therefore result in valuable knowledge about subjects' lived experiences. While quantitative results can be instructive, they cannot provide the empirical understanding of the nature or essence of the experience; a phenomenological approach to enquiry achieves this. Moreover the phenomenological approach involves searching for the meaning of the given experience for individuals, and consequently lays the foundation for building an understanding of fundamental importance.

Descriptive phenomenology involves the researcher assuming a readiness to listen to the descriptions of the lived experiences as described by the participants, in contrast to interpretive phenomenology, where the researcher uses their prior knowledge and perceptions to construe and expose hidden meanings with the aim of creating an intense, written illustration of the phenomenon described[128]. Taking into consideration the aims underpinning each of these phenomenological approaches, the use of descriptive phenomenology was better suited to exploring the experiences of CH staff, in providing care for residents with dementia who exhibit BtC. This approach was particularly apt in view of the dearth of research exploring this population and the urgent need for a fundamental understanding of their lived experience. The methodological guidelines chosen for this study were reflective of the descriptive phenomenological approach, by setting aside any preconceptions and manifesting them as clearly as possible. As such, a continuous process of bracketing was used to achieve this [129], by disregarding personal knowledge and bias when listening to and reflecting on the lived experiences of participants. While there are no clear guidelines for conducting bracketing, maintaining a reflective diary, practising neutral behaviours, refining active listening skills and engaging in honest conversations with mentors are suggested as effective research tools for developing bracketing skills [130].

Using purposive sampling, researchers select individuals for study participation based on their particular knowledge of a phenomenon for the purpose of sharing that knowledge [127]. This was an appropriate method to select the participants for a study using a descriptive phenomenological approach because the aim was to understand and describe a particular phenomenon from the perspective of those who have experienced it.

CH Survey

During the first phase, it was decided that a method designed to obtain data from a large, national sample of CHs was required in order to investigate whether the findings from CH staff interviews were replicated nationally. Therefore a cross-sectional survey was deemed to be the most appropriate method. The survey method is typically used to collect large amounts of data from a large pre-determined sample, using predominantly simple questioning; thus giving a high degree of inclusiveness while allowing respondents the time to reply. Using a survey allows a large amount of data to be gathered from a large sample, and could be done effectively in a relatively short space of time, allowing comparisons of variables across the responding sites. Therefore this method appeared most appropriate to glean information from CH staff regarding their understanding and experience of BtC, the different strategies that are adopted by CHs to manage BtC, and whether care staff are trained to carry these out, in addition to information regarding medicines prescribed to their residents. This provided a national picture of the views and experiences of care staff in managing BtC, and informed the next phase of the study. Postal surveys to CHs have previously been successful in gaining an overview of the CH status quo [81, 131] and this study endeavoured to achieve this for management of BtC, while also allowing comparison between CHs. An National Institute for Health Research (NIHR) methods review highlighted potential low survey response rates and difficulties recruiting CH staff to participate in research therefore the authors suggested multiple contacts by different means [132]. Another study [133] reported face-to-face contact as the most helpful strategy for gaining research access to American nursing homes. As such, two distribution methods were utilised. In order to maximise responses, few open questions were included in the questionnaire, however this was compensated for in the subsequent two phases.

Ethnographic Observations

> *'…the person who cannot abide feeling awkward or out of place, who feels crushed whenever he makes a mistake—embarrassing or otherwise—who is psychologically unable to endure being, and being treated like, a fool not only for a day or a week but for months on end, ought to think twice before he decides to become a participant observer'* [134]

Ethnography, in which observation and participation are interwoven, involves the researcher participating, in this case, overtly, “in people’s daily lives for an extended period of time, watching what happens, listening to what is said, asking questions” [135]. Ethnographic research places a strong emphasis on exploring the nature of a particular social phenomenon, through the investigation of a small number of cases [136], and starts from the theoretical position of describing social realities and their making. In this case, social realities constituted episodes of BtC occurring in CHs, as described by care staff interviewed for the previous phase of this research. Conducted systematically and carefully, observational studies can reveal and explain important features of life in health care settings, generating insightful and enduring concepts that can be applied to other settings, and which add to our knowledge of the social world [137]. The presence of an observer, particularly in the private setting of a CH, as opposed to the more public setting of a hospital ward or community pharmacy, may stimulate modifications in behaviour from those being observed: this is known as the Hawthorne effect. In addition, those being observed may also begin to reflect on their own activities and question the researcher as to their particular observations. The impact of the observer on the setting can be minimised by participating in the activities taking place while observing them [137]. Therefore for this study, participant observation appeared to be the most appropriate and suitable method for observing practice in CHs. This study utilised a ‘participant as observer’ methodology, in which a researcher’s observer activities are subordinate to their role as a participant, rather than ‘observer as participant’. This was in order for me to be “involved in the setting’s central activities, assuming responsibilities that advance the group, but without fully committing to members’ values and goals” [138].

An overt, classical ethnographic approach was adopted to explore care staff’s management of BtC, exhibited by the residents they cared for. Naturalistic observations were conducted, in order for me to be immersed in the ways in which residents socially interact with each other and with staff. I adopted the role of ‘participant as observer’ to minimise interference with these interactions and activities [139], by working as a care worker providing care in accordance with CH protocols for new members of staff, reflecting the working patterns and shifts of those already employed at each home. Despite the premise that audio or video recordings may provide “increased options for intersubjective assessment of interpretation…for taking into account interview and observer effects in the interpretation…and for theoretical flexibility” in comparison with “more selective memory protocols”[140], ethical dilemmas emerge regarding loss of anonymity for the participants. Specifically the more comprehensive the insight into the everyday life under study, the greater the potential scepticism and reservations on the part of the participants in the study [136]. Therefore in this case, where the researcher takes part in the events, maintaining the freedom of leaving the field to document notes would have been additionally difficult. As such, immediately after ending the daily individual field contact, a “cloistered rigor” [141] was used, whereby I carefully noted the observations, ensuring that distinctions were made between what had been observed and what had been condensed in interpretation. To this end, I kept a reflexive field diary in which to take in-depth notes, which were written as soon as I arrived at a location away from the CHs, after each shift had ended.

Resident Records

The concept of providing a holistic approach to caring for residents with dementia encompasses a 'person-centred' approach [142, 143] and this was fundamental to the whole study. I felt that while the residents may not have been able to participate actively in this research, creating a perspective which allowed them to be central to the research was hugely important to me. It also allowed me to remember the 'bigger picture' in conducting the research: that this study aims to shine a light on the potential for improvement of quality of care of the very people I was helping to look after during ethnographic observations. Therefore personal history records kept by the CHs were used to create profiles of participating residents, with the aim of making the person more alive, and present, serving as a substitute 'whole', for having a grasp of the resident appearing in field notes, if anything said about him or her was going to be meaningful. In doing so, it is not inferred that he or she is consistent, coherent or rational, but rather, simply visible. Collecting data pertaining to residents' records also allowed me to make comparisons within and between CHs as to the level of record keeping around residents' personal histories.

Medicine Administration Records

Collecting Medicine Administration Records (MAR) data was chosen to obtain an in-depth knowledge of the medicines prescribed to CH residents, and their uses. The exploration of medicines use has previously been conducted in research studies to provide a measure of antipsychotic prevalence in CHs[81] , however only one study measured the prevalence of antipsychotic use in people with dementia living in CHs. A review of the literature found only one study investigating the prevalence of medication errors in CHs[49]. As such no study exists which examines more than just antipsychotic medicines use or medicines errors in CHs, or synthesises CH MAR charts. Therefore for each resident participating in this study, their most recent one-month MAR chart was transcribed verbatim and then analysed. This allowed for an accurate investigation of medicines use in CHs, including what medicines and doses were prescribed, whether or when medicines were administered and the frequency and purpose of 'as required' (pro re nata [PRN]) medicines. While the interviews with CH staff as well as the CH survey attempted to discuss the use and perception of medicines for BtC, the data gathered from MAR charts provided more accurate, objective and detailed data not covered by the other methods. As such, the scope and nature of medicines use in CHs was illustrated, providing a clearer context for the rest of the data gathered.

Relatives' Perspectives

To gain a more truthful picture of the phenomenon in question, in this case the management of BtC in dementia, the use of more than one data collection strategy is often used in a phenomenological approach, therefore it appeared that including residents' relatives was an appropriate source of additional data, which would give an alternative perspective. To this end, focus groups (or face to face interviews, if focus groups could not be conducted) were deemed to be the most appropriate method to use, simply to cause as little disruption as possible to the lives and visit patterns of residents' relatives. The use of open-ended questions enables the participants to fully describe their experience and therefore results in collection of rich data [144]. With this in mind, the focus groups/interviews started with asking each participant to share their 'dementia journey'.

Methodological challenges

The inclusion of mixed methods design may add depth or breadth to a study, and potentially allows for a deeper understanding of the phenomena occurring [145]. However there are inherent challenges, in particular maintaining the rigour and trustworthiness of the methods used. Throughout the study, the different methods were conducted and analysed separately, allowing each component to be true to its paradigm [146]. As such, the findings served to complement each other at the point of interpretation, rather than integrating the methods and data prior to analysis.

Rigour and trustworthiness

It is important that this study demonstrated rigour and trustworthiness, and to that extent, I endeavoured to incorporate measures to ensure this. Lincoln and Guba [147] posited that ensuring credibility is the key to establishing trustworthiness within research, and as such, I have been able to promote the accuracy of my data collection and recorded data, by adhering to Shenton's [148] suggestions: I adopted well established research methods in qualitative inquiry, developed an early familiarisation with participating populations and organisations, conducted random sampling of participants in some phases of the study, and triangulated the data. Additionally, I endeavoured to tactfully ensure honesty and willingness from participants before and during data collection, allowing potential participants the opportunity to decline to participate if wished. I used iterative questioning in my interviews, which were all audio recorded and transcribed verbatim. I ensured I collected thick, rich and descriptive qualitative data. I had frequent debriefing sessions with the research team throughout the three-year period, during which I was also offered constructive criticism and feedback from my peers. I created and completed a reflexive diary, which was fundamental in enabling me to keep my emotions in check throughout my time as participant as observer. I have consistently reflected on my background and experience, also regularly examining previous research findings to comparatively review my own findings. My conduct throughout and during write-up, has been consistently rigorous and trustworthy and I have always endeavoured to produce explicit and transparent work, that has rationale and justification. That I am cognisant of those issues typically declared by critics of qualitative inquiry places me in a position able to address these issues, and defend my choices.

Indeed, it is to be expected that a different researcher conducting the same study would bring different skills, knowledge and experience, and therefore the study would have been different. To this end, it is important that you, the reader know a little about me, in order that you may be able to see how this study may have been influenced. I am the youngest of a large family, and have personal experience of dementia. I spent my teenage years helping and watching my grandmother care for my grandfather, before he moved to a CH some months before his death. I have no formal experience of care work, but was affected deeply by this disease and the transition from home to CH, and while this ultimately led to my choice to conduct research into resident-centred dementia care, it also strengthened my aim to be inclusive of those relatives, visitors and consultees who are often largely ignored in research, but who can add a valuable perspective. My education includes a BSc (Hons) in Mathematics and Sport Sciences, and an MSc in Sport and Health Sciences, where I ignited a passion for mental health. Both degrees included quantitative, qualitative and mixed method modules, as well as research design and analysis, which instilled in me an appreciation for both methods, and allowed me to formulate my own opinions and approaches to research paradigms. Throughout my PhD I took the opportunity to attend qualitative research training sessions, both within and outside of the Medway School of Pharmacy, and these skills sessions enhanced my ability to understand and conduct varying qualitative research methods.

Researcher influence

"It can be maintained that virtually no information about a person, group or social system exists without a relationship with that person or social system" [149]. As such, scrutiny and understanding of the self is a prerequisite of qualitative inquiry. Therefore, the choice and development of, and approach to the study, the construction and development of the research questions, the judgements made in progressing the study phases, the conduct of each of phase of work, and the analysis and interpretation of results were all influenced by me: my experiences; my background; my opinions; my assumptions and my knowledge. There are three key assumptions in the approach to this body of work: first, that BtC are challenging for carer staff; second, that BtC require managing on some level; third, that adopting a pragmatic approach to highlight these issues through a mixed methods design allows valid truths to be derived. The first two assumptions were generated from scientific and grey literature, particularly taking into account the Time for Action report [1]. The study design conforms to the literature surrounding mixed methods designs [150, 151], whereby it focuses on the use of component designs, throughout which the different methods are kept separate, “allowing each…to be true to its paradigmatic and design requirements” [146].

Ethical Considerations

Researchers are primarily responsible for ensuring the safety, confidentiality and informed consent of any participants. Throughout the research study there were a number of ethical issues to consider, particularly given that the study involved people with dementia. Each phase was granted ethical approval. The Medway School of Pharmacy has its own university ethics committee, which approved Phases One and Two; the Social Care Research Ethics Committee (SCREC) approved Phases Three, Four and Five. Substantial protocols were provided at each stage, which outlined clear research processes and justifications, while declaring ethical issues within the research and the protocols in place to guarantee ethical compliance. Including vulnerable people in research raises practical and ethical concerns, including their decision-making capacity and emotional disposition. However, without including CH residents with dementia in this body of research, it would not have been feasible to conduct such a resident-centred study. In addition, giving a voice to those people involved and experienced in the dementia journey (residents, care staff and relatives) allowed a truer picture to be painted of the current situation within CHs in England.

Chapter 4 Views and Experiences of Care Home Staff and Environmental Observations

Introduction

Chapter Three outlined the rationale for the design of this phase of the work. This chapter provides: the sampling and development, interview process, data analysis strategy, findings and a discussion of the pilot and main study of Phase One. As outlined in Chapter Two, there is a paucity of evidence in defining best practice for managing BtC in dementia, particularly with respect to CH residents. CH staff are an under researched population, and yet they are responsible for providing care to often vulnerable residents. Little is known about how CH staff perceive and manage BtC, therefore this phase of the study aimed to gain more insight into this. A mixed methods approach was chosen for this initial phase. A phenomenological perspective was utilised to 'elucidate the importance of using methods that capture people's experience of the world, without conducting a phenomenological study that focuses on the essence of shared experience' [152]. This phase utilised semi-structured interviews with a purposive sample of CH staff, caring for residents with dementia who exhibit BtC, to obtain the views and experiences of CH staff on managing BtC in people with dementia residing in their CH, and to obtain information pertaining to their experiences of dementia specific training. To ensure the content validity of the recruitment process and interview schedule, both were piloted. In addition, environmental observations were conducted to quantifiably assess the interior design of the environment, and use of facilities in the CH. The method of obtaining the observational data was also piloted.

Aim and objectives

The aim of this phase of the study was to explore how different CHs manage BtC, establishing the current situation within CHs locally. Objectives for this phase of the study were:

1. To investigate the views of CH staff on managing BtC in individuals with dementia.
2. To explore the methods of managing BtC used in people with dementia living in CHs, including pharmacological, non-pharmacological and environmental approaches.

3. To assess in a quantifiable and comparable way, the design and use of the environment in CHs for people with dementia.
4. To explore both staff and home manager experiences of CH staff training, with regard to BtC.

Ethical approval

For this study phase, favourable ethical opinion was granted by Medway School of Pharmacy Ethics Committee (letter included in Appendix 3). The participant information sheets were designed to include all of the information that participants required in order to decide whether to participate or not. Two information sheets and consent processes were developed: one for the manager or owner of the CH and one for the individual interviewees. Managers were asked to consent to the CH participating in the study, to the CH environment being observed and photographed and to being interviewed themselves. Photographs were only captured where there were no residents or personal information (such as names on doors) in view. Permission was always sought prior to taking every photograph to ensure transparency. Changes were made to the recruitment method, requiring amendments to the ethical approval, both during the pilot study recruitment stage, and after the pilot study had been conducted: this is described in the next section. Ethical approval was obtained for these amendments. Informed consent was provided by completion of the informed consent form, and was checked prior to interview. Incentives were offered to every participant, both in the pilot and main studies, in the form of a shopping voucher to the value of ten pounds. While incentivising research studies may be seen as coercive [153], it was deemed that a small incentive in this study would compensate participating staff for their time; it did not take priority over the principles of freely given, fully-informed consent. All transcribed interviews were coded to maintain CH and participant anonymity.

Sampling strategy

The initial target population for the main study consisted of CH staff employed in dementia specialist CHs with nursing in Kent, with the pilot conducted outside of Kent. However recruitment methods had to be changed, and ultimately, the CHs involved in the pilot study were included in the main study. The final target population was expanded to include all dementia specialist CHs in Kent. CHs were identified using the CQC database of eligible CHs (http://www.cqc.org.uk/content/care-homes).

Pilot study recruitment

The target population for the pilot study consisted of CH staff employed in dementia specialist CHs with nursing. CHs with nursing were initially chosen because they were deemed to be more likely to provide care to residents with a greater severity of dementia, and may have therefore experienced more BtC. Managers of all CHs with nursing, which cared for residents with dementia, in the London Borough of Lewisham were sent a recruitment pack, consisting of an introductory letter; participant information sheet and informed consent form (see Appendix 4). This was followed up by a telephone call within seven days of posting. Of the 12 invitations posted first class directly to the named manager, on telephoning, not a single CH reported receiving the invitation. Only one of these CHs agreed to participate in the study, therefore the target population was expanded, following ethical approval. As the intention was to include only CHs with nursing in the main study, for the pilot, CHs without nursing were selected. Homes in the county of Kent were approached, since the number of homes was larger: the same methodology was used. Eligible CHs were clustered into groups of ten, to aid the practicality of making telephone calls. The first ten CHs contacted declined to participate. The eleventh CH contacted agreed to participate in the study, explaining that she had heard of the Medway School of Pharmacy. The pilot was conducted in both consenting CHs, and no further CHs were contacted to participate in the pilot study.

Main study recruitment

Following the difficulties in recruitment highlighted by the pilot study, an amendment was made to the recruitment procedure for the main study. In addition, based on the interview data collected from the pilot CHs and the frequency of BtC described in the CH without nursing, it was decided to include both CHs with and without nursing in the main study. Instead of sending invitation letters by post, all eligible CHs in Kent were contacted by telephone in order to arrange a face-to-face meeting with the CH manager to discuss the project. The decision to recruit by telephone was supported by Garcia, Kelley and Dyke [133] who recommend face-to-face contact as a successful nursing home recruitment strategy. In order to confirm the CH's eligibility in accordance with the inclusion criteria, during the telephone call an early discriminator question, '*do you provide care for residents with behaviour that challenges*?' was asked of the manager or member of the management team. If the answer to this question was 'no', the CH did not meet the inclusion criteria for the project, and the call was ended. If however, the CH did care for such residents and the manager was interested in participating in, or further discussing the project, a meeting was scheduled at a mutually convenient time, and an information pack (consisting of a recruitment letter explaining the purpose of the research, a Participant Information Sheet and an Informed Consent Form (Appendix 5)), was either sent by post or by email, depending on the CH manager preference, prior to the meeting. By sending this information before the meeting the manager was afforded the time to consider the CH's participation in the project, without pressure or obligation to participate. Meetings were arranged with nine interested managers, during which the consent form was signed, and retained by the researcher.

CH staff were recruited once CH managers had given consent for the home to participate in the study. CH staff members were considered for inclusion if they had a patient-facing role and had worked in the CH for at least three months: this information was provided by the CH manager. Eligible staff members were provided with an information pack consisting of a participant information sheet and informed consent form (see Appendix 6). Those wishing to participate in the study were required to place their completed consent form in a post box left in the CH.

Interview schedule development and design

Two interview schedules were developed: one for managers and one for care staff. This decision was taken as it allowed for a more in-depth interview with managers, which included the topic of antipsychotic drug use in CH residents with BtC, particularly with regard to the national drive to reduce antipsychotic prescribing. The interview schedules were designed around a loose structure consisting of open ended initial questions surrounding BtC, before targeting the conversation in order to pursue each topic in more detail. Topics identified from previous published work exploring managing BtC were used to develop the interview schedule. The following topics were included:

- Participants' perceptions of BtC
- Participants' management of, attitudes and approaches to BtC
- The CH environment
- Barriers to managing BtC
- Antipsychotic prescribing in CHs (manager schedule only)

The interview schedules were subjected to several stages of development involving the supervisory team, made up of my primary and secondary supervisor: questions were reworded and reordered. Both staff and manager schedules were piloted using face-to-face interviews with seven CH staff and two managers, recruited from the two pilot CHs, to validate the content prior to acceptance of the final versions. On completion of these pilot interviews, while the broader question topics did not change, a further question was included in both schedules asking interviewees what they deemed BtC to be. Copies of the final interview schedules are included in Appendix 7.

Observations of the CH environment

Observations of the care environment were conducted to capture evidence of the use, decoration and colour of the environment as well as the amenities available to residents. In order to do this, an observation form (Appendix 8) was created and photography was used. The observation form included eight criteria that were used in the subsequent analysis of the data, and these criteria were derived from evidence obtained from the literature review (purpose built, living spaces, accessible garden, sensory room, activities, pets, corridor style and signposting (including art or reminiscence pictures)), and were added to during the interview process, if CH staff identified aspects of the environment that they perceived to influence BtC (accessible kitchen, hairdressers and café). The observation form detailed the rooms in each CH (activity room, sensory room, café, for example), as well as the facilities in each room (television, photographs, art depicting World War II aircraft, for example). The dimensions of the CHs were initially sought in order to provide a clearer picture of the shape and layout of buildings, enabling a potential comparison between older and newer homes. During the pilot study however, measuring the dimensions of the CH proved to be challenging, as residents were often present in corridors, meaning that these could not be measured without disrupting residents. Experience from the pilot study informed an adaptation of this method, which required the researcher to request copies of fire evacuation maps of each CH building and grounds. The purpose of this was to provide a more accurate measure of the dimensions of corridors, residents' private space and residents' communal space, by being supplemented by an initial measurement for scale purposes. Unfortunately, due to fire evacuation maps being nailed into the walls of most of the CHs, managers were reluctant to remove them, and therefore obtaining dimensions of the CHs was not feasible. Two maps could be photographed, however six of the fire maps were placed too high on a wall to be photographed, and in one CH the manager was unaware where the fire maps were located. Finally, one observation chart per room or area (Appendix 8) was used to detail the interior decoration, the facilities available, entertainment and add field notes pertaining to the CH environment.

Conduct of interviews

Once CH staff had consented to take part in the study, I made arrangements for them to be interviewed at a convenient time. Interviews took place in a quiet area in the CH; usually a tea room, or a manager’s office, owned by the CH site on which the research project took place. The advantage of these locations was the familiarity that participants had with them, as well as being on the premises that they worked, and therefore no additional travel costs were incurred. A further advantage was the safety of the interviewer. While venues such as a manager’s office (particularly when an ‘open door policy’ was held) may have influenced the topics discussed during the interviews, it was decided that the advantages outweighed any bias of the settings.

Manager interviews lasted approximately one hour and I conducted them according to the interview schedule (Appendix 7). CH staff interviews, lasting approximately thirty minutes, were conducted according to the interview schedule (Appendix 7). Informed consent was obtained in writing prior to the interview and again verbally, immediately before the interview, along with consent to the use of an audio recorder.

At the start of the interview process, I checked whether the participant had read and understood the participant information sheet that had already been sent to them. An opportunity was given at this point for the participant to raise any questions, or decline to be interviewed. During the consent process, participants were reminded that all information given during the interview was confidential, and that this would not be shared with their colleagues. Participants were also reminded that this confidentiality agreement would be broken if anything was disclosed which led me to believe that the participants’ safety, or the safety of another, was at risk. Participants were reminded that they could terminate the interview at any time. Once participants had received satisfactory answers to any questions they raised, the interview began, with the interview being audio recorded.

Each interview began with the same question ‘Can you tell me about your experiences of behaviour that challenges?’, and depending on the responses given, subsequent questions then explored further that topic, or moved to other topics in the guide, once all the prompts had been utilised. During the interview, notes were added to the interview schedule to indicate when a topic had been covered by a participant. Additional notes were made in my field note book to aid recollection of participants’ characteristics and disposition at the time of interview. Once I was satisfied that all the areas of the interview schedule had been covered by the interview, participants were asked if there was anything they would like to add, before the interview was terminated. Participants varied in their willingness to talk freely: some were very confident and eager to talk; others were more reluctant to answer questions and appeared hesitant in their responses. My active participation in the interviews enabled me to encourage and reassure participants where it was required, or employ a more passive technique where participants were confident in discussion.

Data analysis

Analysis of the CH environment was conducted by converting the observation form into a table (Table 4.1), which documented the rooms and facilities within each CH, and the previously defined analysis criteria allowed for this. As such, a comparison could be made between CH environments. Photographs were captured with a digital camera, and each photograph was saved onto a password protected computer into anonymised CH-specific folders. All of the photographs were reviewed, and the included photographs were chosen to best represent similarities and differences between CHs.

Interviews were recorded with a digital audio recorder, and each audio file was then saved onto a password protected computer, and given a code number. Codes of the audio files were written on a cover sheet alongside the name of each participant, and saved on a password protected computer. Recorded interviews were transcribed verbatim by myself and then a 10% random sample of transcriptions was checked by a second researcher, the project supervisor, to complete an accuracy check of the written transcripts. The transcription of the interviews assisted my immersion in the data, by listening to the transcripts repeatedly. Grounded Theory was initially considered for the analysis [154], however given the importance of the relevant literature, in addition to the complex nature of managing BtC, it was decided that a thematic analysis [155] would be more appropriate. This allowed me to adopt a 'theoretically-flexible' [155] approach, providing a rich, detailed description of the data, while freely drawing upon all knowledge sources. As such, analysis was not directed towards theory development [156]. A thematic analysis was used to develop a coding framework, from which themes emerged. The analysis process comprised six phases, identified by Braun and Clarke [155]: familiarisation of the data; generating initial codes; searching for themes; reviewing themes; defining and naming themes, producing an account of the data.

In order to familiarise myself with the data, I repeatedly read the interview transcripts, before generating codes to describe the data. Ideas, concepts, behaviours, interactions, incidents, phrases and terminology were identified, and each was given a descriptive label. I continued to generate codes while searching for themes, until all themes had been identified; at every stage I continuously modified the codes in light of the experiences and ideas developing, therefore earlier codes were adjusted as the full picture of analysis was established. On the basis of this, themes emerged which integrated significant sets of the coding and again, this process involved modification and adjustment in order to be able to review and define each theme sufficiently. Themes and patterns within the data were identified in an inductive way, where the themes identified are strongly linked to the data [157], and have not been driven by the researcher's theoretical interest, and do not fit the researcher's analytic pre-conceptions.

In order to maintain an iterative approach, interview analysis was commenced before all interviews had been completed. This allowed for changes to be made to the interview process. Although the same topics were addressed in all interviews, new themes emerging during the first few interviews (relatives as a barrier to managing BtC, for example) were incorporated into the interview schedule. In the analysis, the strength of particular views has been indicated by providing some detail about how often they were raised. Verbatim quotations have been included to explain, illustrate and deepen understanding of participants' views: they also served to augment the readability of the findings. Excerpts from transcripts were selected which best depicted the evidence for my interpretations, and helped to justify the findings and strengthen credibility. While any tangible evidence potentially lies in the thematic analysis of the interview data, I believe the presentation of direct quotations allows my interpretations to best be exhibited.

Findings

Care homes

For the pilot study, 142 CHs were approached to participate, and two CHs, one with and one without nursing, agreed. For the main study, 198 CHs were approached and nine CHs, seven with and two without nursing agreed. Reasons for declining to participate were varied and numerous and these are discussed further in Chapter Eight. Forty-one interviews were conducted in total. Nine pilot interviews were conducted between March 2013 and September 2013, and 32 further interviews were conducted between September 2013 and June 2014. The duration of the interviews ranged from 16 to 45 minutes (staff members) and 37 to 75 minutes (managers). Thematic saturation was reached around the thirty-fifth interview, and confirmation of this occurred when no new themes emerged during any of the interviews conducted at the CH recruited last. Observations of the CH environment were conducted in all 11 CHs.

Interview Participant Demographics

Eleven CHs yielded 41 interviews from 30 CH staff and 11 managers. Thirty-eight females and three males were interviewed. CH and interviewee demographics along with the total number of staff in each CH are presented in Table 4.2.

Two pilot homes were included in the main study because the main study sample had been expanded to include CHs with and without nursing, and the two pilot homes aligned with this. In addition, while there were some changes to the piloted interview schedules, these were not significant enough to warrant excluding the homes, and the valuable views and experiences of the staff within them.

Interview Code	Ownership	Role of Interviewee	Gender	Proportion Staff Interviewed
CH1 – CH without Nursing, Kent PILOT 1	Private	Care worker (1CW1)	Female	2/15
		Nurse (1N)	Female	
		Manager (1M)	Female	
CH2 – CH with Nursing, London Borough of Lewisham PILOT 2	Private	Care worker (2CW1)	Female	5/53
		Care worker (2CW2)	Female	
		Care worker (2CW3)	Female	
		Care worker (2CW4)	Female	
		Care worker (2CW5)	Female	
		Manager (2M)	Female	
CH3 - CH without Nursing, Kent	Private	Care worker (3CW1)	Female	3/42
		Care worker (3CW2)	Female	
		Care worker (3CW3)	Female	
		Manager (3M)	Female	
CH4 - CH without Nursing, Kent	Private	Care worker (4CW1)	Female	2/33
		Care worker (4CW2)	Female	
		Manager (4M)	Female	
CH5 - CH with Nursing, Kent	Private	Activities co-ordinator (5AC)	Female	2/32
		Nurse (5N)	Female	
		Manager (5M)	Female	
CH6 - CH with Nursing, Kent	Private	Care worker (6CW1)	Female	5/89
		Care worker (6CW2)	Female	
		Care worker (6CW3)	Female	
		Care worker (6CW4)	Male	
		Nurse (6N)	Female	
		Manager (6M)	Female	
CH7 - CH with Nursing, Kent	Private	Care worker (7CW1)	Female	3/75
		Care worker (7CW2)	Female	
		Care worker (7CW3)	Female	
		Manager (7M)	Female	
CH8 - CH with Nursing, Kent	Private	Care worker (8CW1)	Female	2/60
		Nurse (8N)	Male	
		Manager (8M)	Male	
CH9 - CH with Nursing, Kent	Private	Manager (9M)	Female	0/60
CH10 - CH with Nursing, Kent	Private	Care worker (10CW1)	Female	3/60
		Care worker (10CW2)	Female	
		Care worker (10CW3)	Female	
		Manager (10M)	Female	
CH11 – CH with Nursing, Kent	Social Enterprise	Care worker (11CW1)	Female	3/50
		Activities co-ordinator (11AC)	Female	
		Nurse (11N)	Female	
		Manager (11M)	Female	

Table 4.1: Interview participant demographics from Phase One

Emergent Themes

Four overarching themes were identified. These were: causes of BtC, knowing the resident, the CH family and the home-like environment. The sub-themes which formed each of these four overarching themes are detailed in Table 4.3.

Themes	Sub-Themes
1. Causes of BtC	Behaviours experienced, behaviours deemed to challenge, behaviour as a consequence of 'something else', staff approaches, strategies/therapies
2. Knowing the resident	Ways of managing behaviour, residents' personal history, residents' medical history residents' previous BtC
3. The CH family	Team, management support, training, organisation (or CH company) support, multidisciplinary teams, relatives
4. The home-like environment	Familiarity with home, environmental design

Table 4.2: Themes and associated sub-themes identified following analysis of CH staff interview transcripts

The following section describes each theme in turn, incorporating verbatim quotations from the interviews to validate the interpretations.

Theme 1: Causes of BtC

In conducting the interviews, one of the striking messages that emerged was the perception that BtC are a consequence of something else, and indeed all of the interviewees suggested this. Interviewees spoke about behaviours having a cause, and manifesting as a result of something else. This 'something' could be a resident's inability to express their needs or problems; an illness or pain, like a urinary tract infection, or a headache; a social problem, like not being able to find their handbag, or that someone has taken their newspaper; or worry, or fear, possibly of having personal care, being confused, or just not knowing where they are. Staff spoke repeatedly of BtC being caused by specific triggers, which were individual to each resident.

> *'The majority of cases, I would say challenging behaviour is triggered by something, and it's our job to find out what that something is and manage it. Then the challenging behaviour to all intents and purposes goes away' (5M).*

CH staff reported that they experienced a wide range of BtC, although physical and verbal aggression were cited by the majority of care staff as both the most challenging and frequently encountered. Interviewees described residents who have BtC as those residents who are aggressive *'physical and verbally' (2CW4)*, and who are *'physically resistive…maybe with* *care…or…a threat to others' (1CW2),* residents who have *'a two second memory' (1CW1),* and who get *'mixed up with their words' (1CW1).* While physical aggression was difficult to manage, verbal aggression was taken more personally, although learning not to take comments or insults personally was reportedly routine – sometimes staff needed a brief period of time away from the residents to build themselves back up and then continue providing care. Participants described the actions of BtC and their potential causes, showing an awareness of the reasons for BtC manifesting.

'She's gone to strangle me because she can't express…what she wants to' (1CW2).

This typifies the staff member's attribution of the BtC to a causal explanation, being an inability to express what is desired, by the resident. This attribution was verified by every interviewee, and went some way to explaining how CH staff are able to develop their management strategies, when incidents of BtC occur. The causal explanation was corroborated by a majority of participants particularly when discussing conducting personal care, but again there appeared to be a clear reason for the BtC they encountered.

'Residents are challenging while giving personal care…maybe they are shy…or maybe she is having some problem[s], like chest or UTI or something. Some problem will be there' (2CW5).

'Because it's not usually down to the fact that the behaviour's because…they don't want to do something, it's because there's another underlying problem. They've got an infection, they're in pain, and that's the only way they can express themselves' (5N).

Causes of BtC were not always reported by interviewees to be a result of immediate distress. In one case, the underlying cause of BtC was identified from a past experience, discovered by care staff when looking through the resident's care plan.

'We get some, women…go absolutely mad, when you do the lower part of their personal care. But then, the one I spoke to…she's been here I don't know, five years…I used to say…its really strange that you get to the lower half, and it's very distraught, and she was abused. So there's things like that, that went on years ago, that she's never spoke about' (3CW1).

Often BtC were either normalised by care staff, or compared with our own behaviours.

'They're not wandering, they're looking for something, searching for something so as far as I'm concerned' (3M),

‘Even for us, if we are not feeling well…we won’t be able to engage socially, so why to disturb them? Let them, leave them alone and approach them later’ (2CW5),

And [on shouting for their mother],

‘If you and me were unwell, we’d want our mum, because we want comfort, we want someone to look after us. And that’s what they want, that’s what they’re looking for. They want a cuddle, they want some nurturing.’ (3M).

The approach care staff had to residents in their daily work was reported to be fundamental in minimising BtC. CH staff talked about a number of strategies used to manage BtC, but all agreed that there was no one way to manage BtC, even for the same resident, on the same day.

‘We don’t know what’s wrong, but you know, you’ll try and sit with her, hold her hand, give her a chocolate, show her pictures of her family, and every day something different might work’ (3CW3).

While some strategies were used to manage BtC (distraction or emotional reassurance predominantly),

‘Normally it is taking the individuals away from the situation, so it would be distraction…and then comfort and reassurance’ (10CW1);

‘Sometimes a little joke can just snap them, or you know if I’ve said something funny and then I laugh, they will laugh and it just diffuses’ (11AC),

others were used to ensure residents were relaxed, and content, prior or subsequent to any emergence of BtC. These strategies included having pets in the CH, the use of music, or television if residents wished to have them on, painting, singing, knitting and gardening, which were classed by all of the CHs as ‘activities’, as opposed to management strategies. Ten homes provided ‘activities’ that were conducted with a specialist activity co-ordinator, who engaged groups of residents in a variety of activities often in a designated room or area of the CH. One home provided ‘activities’ that were conducted by CH staff, and were not part of a scheduled programme.

‘Try and pre-empt a problem. So, strategies are only something you do in retrospect in some cases. But we need to look at the strategies that prevent it [BtC]…preventing the challenging behaviour where possible, and then having strategies in place to manage it, if that can’t be’ (4M).

One CH adopted a 'Namaste Programme' of care, which sought to improve the quality of life for people with advanced dementia. Staff told me that a wide range of practices and activities which formed the programme were conducted every day, at certain times of the day. These involved, for example, hand massage, foot spas, aromatherapy, music and using finger foods to stimulate the senses while increasing relaxation. One member of staff went on to suggest that Namaste care had reduced the number of residents taking antipsychotic medication.

> *'Namaste it's a care, a particular activity for those people whose life has been compromised. For those people who [don't] know who they [are], where they live, or what they [were] before…So for those who have got capacity, they can engage in many activities, like that. But those people [with dementia]…they need some activities rather than sitting beyond the TV and sleeping all the day. So this Namaste is mainly the power of gentle touch…So Namaste involves the whole sense joined together' (2CW5).*

> *'It's very useful, and it calms them down because, how…agitated they were…after the massage and Namaste they kind of they are calm and they just sleep and relax' (2CW4).*

> *'So we have seen that the antipsychotic, those who are taking the antipsychotic has been reduced, or the dosage has been reduced. Both thing(s) happened. So Namaste care has had a greater influence in this I think' (2CW5).*

Interviewees discussed their approach to residents and how it can have an impact on BtC, particularly whether staff were smiling, felt happy, employed a certain type of body language, touched the residents, and spoke their name. One manager suggested that BtC was generally a result of the way staff approach residents, and explained that this was targeted specifically in training.

> *'From my experience it's [BtC] generally because of the way they're [residents] approached, not because they have challenging behaviour. So it's what we do that elicits that behaviour. Umm, and that's one of the biggest challenges is around training staff, in that, they will have the tendency to label people as a behaviour, and not understand that it's because we're perhaps not using a person-centred approach' (6M).*

Communication skills of the staff were recognised as key, and along with their approach, what they communicated had an impact on manifestations of BtC by some residents. Often talking residents through what was happening to them minimised BtC, or taking the time to communicate with them clearly, so they had some level of involvement in decisions such as personal care, being toileted or having to take their medication. In particular, poor communication by staff resulted in residents feeling a reduced level of control over their life.

'Most of the behaviour is due to poor communication. Or communication that somebody doesn't like. They can be disempowered' (3M).

Theme 2: Knowing the resident

A large part of the interviews were taken up by discussing how participants personally managed the behaviours they experienced, and the overarching message gleaned from the CH staff was the significance of knowing who you were caring for. The majority of interviewees alluded to the importance of knowing who they were caring for, and many of them suggested that they ensured they worked to this recommendation. Knowing the resident reportedly allowed staff to keep the resident safe, while controlling the situation during incidents of BtC. Acknowledging that all residents are different was fundamental, and every staff member discussed how individualised and person-centred their care provision was. As such, they talked about the importance of knowing residents' likes and dislikes, often in order to implement behaviour management strategies.

'…knowing their behaviours and their patterns, absolutely' (1CW2)

'It's amazing that for instance, one of our residents doesn't really talk a lot…But if you sit her in a room where there's music, she'll sing every word. And she knows every word. All these songs. So it's in there, it just took the rhythm you know, to bring it out, and for her to remember it' (4CW2).

Residents' background, medical history and personal history was reported to be established through the use of life books, photographs, family stories and ensuring that care plans were written with a life history of the resident. Knowledge was obtained from families, friends and residents themselves, and often was a successful way of predicting behaviours, explaining them and managing them. In particular, CH staff found it helpful to learn from families how residents' behaviours had changed, by looking back at who the person was and comparing that person to the resident living in the CH at that moment. This enabled staff to explain BtC either simply as a trait of residents' personality, not requiring intervention, or as an unusual, new behaviour, which may be a problem requiring attention, manifesting as BtC. Additionally, knowing whether residents were simply having a bad day allowed CH staff to manage and modify their behaviour management strategies.

> *'People go through good and bad times and I think it's just…the key is understanding the resident' (7CW2).*

This personal knowledge helped staff to not only deal with difficult situations, but also to stop predictable incidents of BtC occurring, particularly if it had happened before.

It was clear that staff did have this personal knowledge, and many talked about individual residents, and gave specific examples of how their knowledge helped them in managing BtC. Knowing residents allowed staff to involve them to a greater extent in their day to day care, particularly where activities were concerned. A staff member from one particular CH alluded to one of their residents who wanted to fix everything in the CH (which at three o'clock in the morning constituted a BtC for them); they told me *'he was an engineer' (2CW2)*. They described how the CH bought him some plastic toy tools, *'he has got some tools…not real, but toys…he plays with that sometimes' (2CW2)* and so when at 3am he gets up and gets ready to go to work with his toy toolkit, it was no longer challenging, because they understood why he was doing it. Another staff member talked about the gentlemen within their CH who liked to go for walks around the CH after eating dinner: it transpired after staff spoke to their relatives, that going for a walk after dinner was something they had always done while living at home.

Staff appeared to have behaviour-centred knowledge as well as person-centred knowledge, distinguishing between times when knowing a residents' previous or usual behavioural patterns was more helpful in managing behaviours than knowing their personal history, and vice versa. In this way, care staff discussed their abilities to differentiate between when to adopt strategies to manage behaviours, and when to focus on the needs of the resident exhibiting BtC. In one example, an activities co-ordinator talked about using a dog to diffuse incidents of BtC and managing that behaviour outright. In another case, knowing that a particular resident likes to put objects into her mouth made the interviewee modify her activities, in order for the resident to be involved.

> *'But it's good with the dog, because I can go over, put my arm round that person and say, 'come on, shall we go and walk the dog?', and usually, they kind of use the dog as 'oh what a lovely dog you've got, let's take the dog for a walk', and it does help calm the situation down' (5AC).*

> *'There's one lady, in particular, that everything's got to go in her mouth, so therefore with her, I work with like, biscuits, she can eat that. If we do cake icing…she can eat it' (5AC).*

Theme 3: The CH family

The CH team, or 'family' as it was sometimes referred to, was recognised as an important factor in dealing with and managing BtC in CH residents, by all of the interviewees. This family was made up of a number of people, including managers, colleagues, receptionists, pets, relatives and often extended to outside support (usually when it was perceived to be good), including social services and other local mental health teams. It was clear from the interviews that the CH 'family' was of emotional significance to many, and the term provided a picture of the reality of who the CH staff perceived themselves to be in the eyes of the residents.

> *'Everyone's welcome to visit, its open visiting, we've got no restrictions on visiting…And the families are treated as part of our family.' (4M)*

> *'At the end of the day, when we admit anybody into the home, we don't just admit that person, we admit the family, whether that be the husband, the wife, daughters, sons, and we end up becoming [a] community effectively'. (5N)*

One manager I interviewed spoke about how when she was younger, she was not interested in geriatric or dementia care, because she thought she would prefer general nursing as it was cleaner and less stressful; however she went on to justify her choice of career, referring to her team of staff: I believe it beautifully sums up the significance of a team of workers caring for elderly, vulnerable people.

> *'And if you get a whole bunch of people together who are passionate about what they do, you actually start to unravel the residents and you meet them. Collectively, the first time you meet a home you think, oh okay, but then you get to know them and they're people. And you get to know their characteristics and their families, what they like to wear, what they like to eat. Why they're upset, when they're upset. When they're happy. You share their lives with them. As muddled and confused as they may be. And then you look at yourself and you think, why didn't you want to do this?' (5M).*

In talking about their work in managing BtC, most interviewees alluded to their colleagues,

> *'It's like a big family here' (P1CW1)*

and how working as a team was fundamental in successfully managing challenging residents. One staff member described how if one particular management strategy had worked for her that day, she would note down the details of that strategy and pass the information on to her colleagues.

'Let other people know and when she's like that again they might try it and if it works it works' (3CW3).

Communication diaries were described, whereby staff could detail successful (or unsuccessful) strategies for incidents of BtC in particular residents. Managers appeared to support this cohesion, particularly by employing a mix of care staff on each shift.

'The staff will also mix, so everybody's involved. Because otherwise if…one's scared of that client, you're not going to get a result. So it's getting everyone on board, and saying 'oh actually can I have that one today? I get on well with her' (3M).

The successful cohesion of the staffing unit was cited by some CH managers and staff as a result of effective training. Training programmes were varied, and staff discussed face-to-face on the job training, information technology (IT) and training by managers. CH staff reported completing a lot of their training as teams, although there were some discussions about using computer packages to complete training tasks. It was clear however that no single specific training programme was implemented, and training types and sessions were wide-ranging. One manager praised his home's training programmes.

'In this company its excellent, we have a monthly IT programme and face-to-face training…as long as the staff get something valuable from them, we'll continue to do them…from a management point of view there's no cap on funding' (9M).

Managers conducted a lot of the training sessions, adopting various strategies in leading sessions. Many asked the staff to consider their own families when they go about their work, and to also keep how the residents may be feeling at the forefront of their minds when they were delivering care.

'I get them to feel, be that person. With dementia…I will say, you're stuck in an airport…lost your passport, nobody speaks English…tell me how you're feeling…It's them experiencing what it feels like…. And asking them, well would you put your mum in here? And if they would, then we're caring well' (3M).

'I can't bear it if I see a carer standing up doing it [assisting a resident with their food]. Have to be sitting down, have to be facing them, or next to them, not this, at the side. And I'll deliberately go and stand next to the carer, quite close, so they've got to turn their head to me, and they don't like it. They feel uncomfortable immediately. And it makes them realise how uncomfortable other

> *people will feel. And before you know it, you've got challenging behaviour. Over nothing. You know, 'oh why did that person get angry with me?' well because you wasn't looking at them, because you were threatening them, because you were standing close, you were invading their space' (4M).*

Staff spoke positively about their training experiences, talking of how they changed their approaches, attitudes and behaviours towards the residents they cared for, as a result of the training programmes they had experienced. Training varied however: in one CH, I interviewed a Head of Dementia Care who had experienced no dementia specific training; in another, a member of CH staff who had received some external training initially, but due to budget cuts, subsequently received only in-house training.

> *'After…the dementia training, I understood how important their life is, and how they might [be] feeling each day…It helped to give more person-centred care…I really understood how they might feel each day, when they have difficulties. So…from that period, I really changed my approach to the residents. I started to give the care more…from my heart, more sincerely. I feel so satisfied, you know?' (2CW1).*

> *''No, I haven't had dementia specific training, but they have been offering it now and again. Because we can only send a few staff members off at a time to do the training, we're all just catching up' (8CW1).*

> *'When I first started here, I had quite a good training experience, umm, I had…a full two-days course on everything, every aspect of the care, dementia as well, and it was really intriguing, and the people, you know that done the training they really knew what they were talking about, and they'd had a lot of experience. Umm, but now, I think, with budget cuts, the recession and so forth, umm, we've really just had in-house training' (4CW2).*

CHs discussed their 'unit', 'family' or 'team' in many ways, and in each CH the relatives of residents were always included within this description. However interviewees differed in their opinions of whether relatives could sometimes be a barrier to managing BtC. In the majority of homes, managers had generally positive views towards the involvement of relatives in care; however CH staff appeared to be less positive, possibly because they are often the first port of call for complaints or queries regarding residents' care. Managers also perceived a need to support family members in addition to the resident.

> *'Family's really important, we've got a few good, good family members who will come and be part of us, as a family…they'll join in as if everybody's fine and there's no dementia...just talking to people, regardless of the fact that what they might say to you is coming out backwards and upside down' (5M)*

> *'I do feel the underlying thing is they're [relatives] not coping, they're anxious themselves, they're fearful of what the future holds because they know there's only one way it's going to go' (9M)*

CH staff however often spoke of their frustration at relatives, particularly at mealtimes: either with relatives attempting to modify behaviour, despite this often not being in the best interests of the resident, because of interruptions during mealtimes which affected staff's ability to ensure residents ate enough, or simply by questioning the whereabouts of residents' belongings within the home.

> *'They're trying to help, but…he might be picking his dinner up with his hands, it really doesn't matter how he eats it, he's eating, and they'll be like 'no dad, use your fork', he's going to get agitated' (3CW3).*

> *'Relatives don't really help. Sometimes they come and interrupt meals, or they'll come in just before a meal and leave half way through, which means the resident will be upset for the rest of the meal and not eat properly' (7CW5).*

> *'Where's my mum's scarf, she's missing a scarf', 'well I'm really sorry but they all swap clothes, we try and replace them…but if we did that all day we'd never be able to care for them' (10CW1).*

These conflicting opinions on the best interests of the residents were discussed by many CH staff, often citing managers as the people whom families or relatives could broach with their frustrations. Managers however were open about the importance of inviting family members as well as the resident into the CH community, and realising that the transfer from home to CH was often a painful, complex and emotional process. Relatives were considered by managers as part of the team, comprising CH staff, managers and local mental health team support, including social services. In contrast, less CH staff considered families as part of the team, but this may be because they often described themselves as relatives' first point of complaint when they were unhappy about residents' care. Opinions regarding support outside of the CH were mixed, and managers described how they felt under supported by their local mental health teams. In particular, they disagreed with advice from local mental health teams in managing residents with BtC, particularly with regard to medication. CH staff reported to have less knowledge about using medicines to manage BtC. In CHs with nursing, care workers told me that nurses managed residents' medication, and this was confirmed by nurses, who stated that they spent much of their time administering medication and determining the medicines management strategies to adopt with individual residents.

> *'At the end of the day, elderly are on a lot of multiple medications, for multiple other conditions, from breathing problems, heart-related problems, lung, kidney, and they're prone to infections. If you give them too many other drugs, they can obviously [contra]-indicate, they can hide other issues, so it can sometimes mask other things that we're trying to look for. And…dementia it's masking a lot of things already; I don't need a drug to mask any more of what I need to find out. And I need to look at that person as an individual.' (5N)*

In CHs without nursing, medicines were reported to be less understood, however the majority of interviewees talked about using medicines as a last resort to control or manage BtC, particularly when residents were unaware of what medicines they were taking. It appeared that the lack of support from external services did not help their understanding.

> *'Umm, to be quite honest there's not a lot a lot of support around the mental health team. Their answer is antipsychotics... give them another antidepressant or antipsychotic. Well you can never get it down them when they're so agitated. There's no way' (3M).*

> *'I don't like the idea of medication being used unless it's absolutely necessary. However, when it's necessary, we need to be able to access it, and I need the proper advice… Because I don't believe that's something particularly, in this home in this area, is very easily accessed…Because I mean if you have got someone that's really challenging, you need to deal with it now, not next week or in a month's time. So yeah I think medication definitely has a place, but obviously we need that advice to know which medications would suit, umm and how best to, when, to administer them and to, to facilitate better quality of life for people.' (5M)*

> *'Some of them [residents]…they know what it [medicine] is, they understand what it is. But some of the high dependency, they don't know what they're taking…So that's when I think it's a bit…not cruel…but I think you need to…that's a last resort. There's so many other things we should try before giving them that' (3CW3).*

Theme 4: The home-like environment

Staff had varied opinions on what the CH environment should be like, but all agreed on one key factor: it had to be like home. Each care environment was referred to as the residents' home, which centred on them. Staff acknowledged limitations of their CH environment, whether it was too small, too straight, too old or too bland, but each interviewee described creating an environment in which residents felt comfortable. Some CH staff members discussed being unable to change or control changes in the environment, including its design: they felt unable to always do what they thought was best due to this lack of control, and often spoke of how they thought a CH should be designed. One staff member considered residents having an input into the design of the CH.

'Some homes are clinical. And I think that can be quite frightening, or other people might prefer that. But this home is more of a home; it's their home, it's not our home, we're the guests here so to speak' (4CW1).

'What you should have, which I know we haven't got…you need to have a through colour in every room, all the way through...this is red and then that's blue and they think it's a step and then they have to try and step over and that can be…really detrimental to their safety' (5N).

'I haven't got any say in that [design of environment] but, yeah I mean, if we came to decorate again in the conservatory, they [residents] should have a say in it really' (4CW2).

Often staff reported how helpful it was if bedrooms were designed in collaboration with the residents' families, so residents had a choice and some level of involvement in the design of their rooms. Residents and their families were reportedly encouraged to bring in as much as they wanted to from home, or provide soft furnishings in addition to those supplied by the CH itself. The perceived importance of creating bedrooms in which residents were relaxed and at ease was profound, and the enormity of the transition from home to CH was not underestimated.

'If their room's completely bare and empty, it's not their room…It's not their home, they don't, they can't see themselves being there' (3CW3).

'It's traumatic for a client to come from their home, and lose everything. So we try and get them to come in and bring things in that they relate to. And make it as comfortable so as they can see it as a home, in their room' (3M).

Staff alluded to residents' rooms being similar to the bedrooms and environment they experienced in their own home, having photographs and familiar objects. The support from families in accomplishing this was discussed by every interviewee, and conversations with relatives about the design of their own homes and bedrooms were alluded to, in order to create a similar environment within the CH, in which residents would feel calm, safe and as orientated as possible, with minimal feelings of isolation.

> *'He used to have a lot of photographs, in his own home…so…his wife…took all the photographs, and put [them on] the walls. So he feels that he is at home, in his own room. And he is happy with that. He touches the photos' (2CW2).*

> *'Their room should be as near as it was at home, with all the familiar objects, you know, those things will make them feel secure and comfortable' (1CW2).*

With regard to the design of residents' doors, CH staff had differences in opinion; some found that signs or photographs on the doors were helpful in enabling residents to orientate themselves, however others disagreed.

> *'On their bedroom doors they have a photograph to identify themselves and their door number' (4CW1)*

> *'If we…put a picture or a window boxes or something on that, they would break them, or try to pull them off the wall. They will not see it or relate to it. So a lot of homes will put those up, the memory boxes, but they don't relate to them. So we found by putting doors, street doors, that look like front doors, we found by doing that, and asking relatives what colour their street door was, that they relate better to that' (3M).*

> *'I mean I've seen a number of dementia signage places popping up recently, and they charge horrific amounts of money for these dementia signs, and actually I don't think there's enough benefit' (6M)*

Visual impairment in residents with dementia can bring about a profound sense of disorientation, and as such may induce episodes of BtC. Staff were concerned about the safety of their residents, particularly where residents struggled to maintain ambulation or independence as a result of the design of the environment. These visual impairments were discussed by the staff, and they told me how it was necessary for the design of the environment to be shaped accordingly. However, it was apparent that CH design was a trial and error process, which changed depending on the severity of dementia or types of BtC. One manager admitted,

> *'We did however do a wrong'un by putting lino in the bathroom that was blue, and our clients are scared of going in there. They see it as water. So what they was doing was 'oh no I'm going to get*

> *wet feet' and they wanted towels and were trying to use it as stepping stones. So we have changed and put different colour flooring down' (3M).*

> *'These carpets are…the worst. Because of the flecks in them, anybody who's got…visual disturbances…they think it's moving. And you'll see them trying to pick things up. It's like a hallucination, but it's not. They physically feel that that's moving underneath them' (5N).*

The design of the CH environment was deemed to be influential in exacerbating BtC, particularly where corridors were straight and closed, as these forced residents to stop walking and physically turn around in order to keep walking: continuous circular corridors were preferred. In CHs with straight and closed corridors, staff reported the exacerbation of BtC.

> *'What I would have changed, is the dead ends, at the end of the suites, and had it so that it was a continuous circle…Because, people with dementia don't like to feel like they can't continue, or that they're being kept in somewhere again. So they can walk, it's [CH6] like a c-shape, and they get to this bit and they come to a door, and they go back to this bit, and they come to another door. If they could go all the way around, the feeling of freedom seems to improve… So that would be the one thing I would change about this environment if I could' (6M).*

In one CH, a glass door leading to the front porch was frosted, to conceal the outside view from the residents: the CH manager described how residents' episodes of frustration and agitation had significantly decreased since frosting the glass, because of the consequent lack of awareness of the world outside.

> *'The inner doors have got glass, so they could see through, and see the front door. And ultimately the road. And when people were upset sometimes they would shake those doors and try to get out that way, and it was always for drawing them. So initially I had a button where you had the button and push at the same time, put on the inside doors to stop the residents being able to go into the porch, so they didn't be drawn to the front. Umm, that wasn't very successful because they could still see. So they were just rattling a different door. So then I had the windows frosted, and they never do it now. Because they can't see it, so they never do it. They might try the door occasionally, just because it's a door, but when it doesn't open and there's nothing to see, they just keep walking. So the only place they're really drawn to is the garden, which they're allowed to go in, so it's [request to leave] never a no.' (4M)*

Within the same CH, staff reported the usefulness of having a back garden that residents could maintain, enabling them to continue participating in activities that they may have done prior to living in the CH.

> *'Having a vegetable patch put in, because a couple of gentlemen like going out there. A few of the gentlemen here have got their own overalls and when we need maintenance done on the fence, they come and help us; it's just like an activity basically. And they paint the fence' (4CW1).*

Nine CHs had an activity co-ordinator, responsible for a set programme of daily activities for all residents, but only one had a designated room for activities (see Table 4.1). Varying environmental strategies were discussed by many staff, including the use of gardens, activity rooms and sensory rooms to manage and minimise BtC.

> *'Our sensory room, it's really good…Especially with people with quite severe dementias, if they become anxious, we can sort of say would you like to come along to our room, and nine times out of ten they will come. And we'll sit with them for a while and chat with them, or just hold their hand, and you can guarantee somebody that has been very agitated or anxious, will, nine times out of ten drift off to sleep, and have a quiet little snooze.' (4CW1)*

> *'They've got a sensory room, on our floor as well, which has got sort of lights, a couple of sofas, relaxing music. Its dark as well, so if they're really agitated we can, just sort of sit down with them in there with a cup of tea, and normally that just chills them out a bit. It's quite quiet so you can close a couple of sets of doors, so you can get it so it's completely silent in there, and then it'll help them calm down a little bit as well' (4CW5)*

Observations of the CH Environments

Of the 11 participating CHs, three were owned by the same company, and their interior and exterior designs were similar. Four CHs were not purpose built (CHs 2, 3, 4, 5), while seven were. They ranged in size, caring for between 28 and 112 residents in total. CH design varied enormously: some had bright, decorative interiors; others had painted pastel, more subdued tones on the walls (Photographs 1 and 2). Some had photographs, signs and objects to encourage reminiscence (Photographs 3 and 4), while others had more modern designs (Photographs 5 and 6). One bedroom in each CH was observed; photographs were present in all of the 11 bedrooms observed (Photograph 7) and in most homes, signposting in some form was present on residents' doors (Photograph 8). One CH had a designated activity room, however activity equipment varied between homes, and included indoor and outdoor facilities and games, in addition to a hair salon (present in three CHs), and the inclusion of pets (present in four CHs). Table 4.1 displays the design of and facilities in each CH. Seven of the CHs had a kitchen accessible to residents and nine of the CHs had an accessible garden. Two of the gardens were used by staff to assist residents in gardening; herb gardens and pot plants were very popular. It is noteworthy that of all the purpose built homes, all but one had continuous, circular corridors, to enable residents to walk between units. All CHs had a living room and a dining room.

Photograph 1: Bright décor

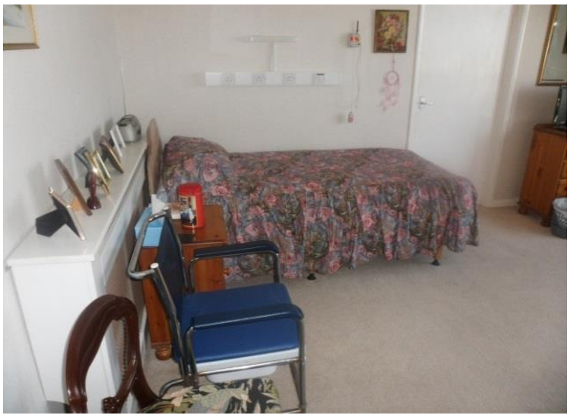
Photograph 2: Neutral decor

Photograph 3: Reminiscing

Photograph 4: Reminiscing

Photograph 5: Modern décor

Photograph 6: Modern decor

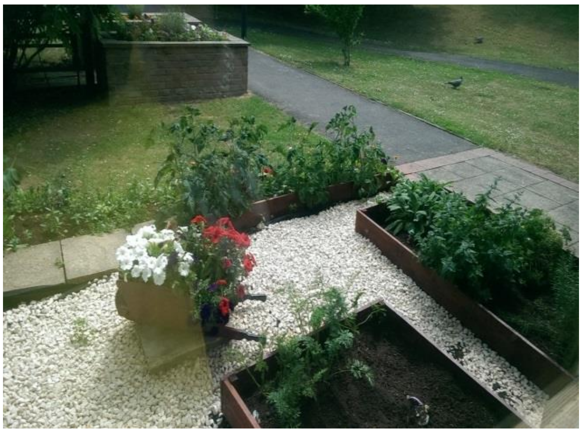


Photograph 7: Photographs present in all bedrooms

Photograph 8: Signposting on doors

Photograph 9: Activities: the hair salon

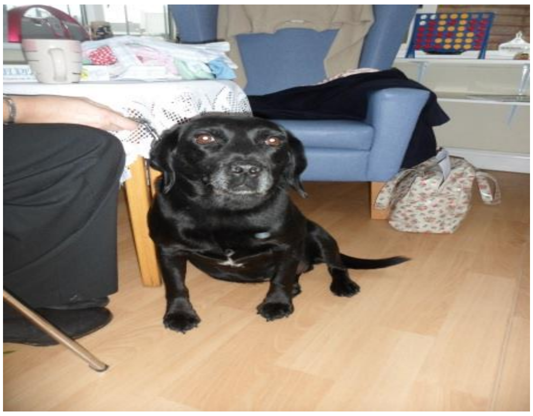
Photograph 10: Activities: sensory games



Photograph 11: Activities: the herb garden

Photograph 12: Activities: what's on

Photograph 13: Pet therapy



Photograph 14: Pet therapy

CH	Total number of residents	Purpose Built	Accessible Kitchen	Accessible Garden	Sensory Room	TV	Radio	Circular Corridors	Pets	Signposting and art	Other
1	51	✓	✓	✓	✓	✓	✓			✓	
2	30			✓		✓	✓			✓	Quiet lounge
3	46					✓	✓		✓	✓	
4	28			✓		✓	✓	✓		✓	
5	34					✓	✓		✓	✓	
6	112	✓	✓	✓		✓	✓	✓		✓	Café open to public
7	89	✓	✓	✓	✓	✓	✓	✓	✓	✓	
8	60	✓	✓	✓	✓	✓	✓	✓		✓	
9	76	✓	✓	✓	✓	✓	✓	✓		✓	
10	90	✓	✓	✓	✓	✓	✓	✓		✓	
11	40	✓	✓	✓	✓	✓	✓	✓	✓	✓	Activity room

Table 4.3: Design features and facilities of participating CHs

Discussion

This phase of the study has provided an insight into how CH staff perceive and manage BtC. The data confirm that CH staff experience BtC amongst their residents, and report adopting a variety of strategies to attempt to manage these behaviours. However, it is clear that there exists no explicit, consistent method of management and CH staff do not believe that one size fits all. That is, the management of BtC changes from day to day, and person to person. All of the 11 CHs explored in this study were unique, differing in many aspects; however every interviewee had experienced a variety of BtC. CH staff's attitudes and beliefs varied in some respects, and were consistent in others. It appears that there is a difference between how staff reported to manage BtC – distraction and emotional reassurance – and minimise BtC - ensuring residents are either stimulated, or relaxed. The CHs which took part in this study appeared to do a great deal to minimise potentially difficult behaviours, and CH staff talked about a variety of activities routinely provided by their home, in order to keep residents engaged. Most CHs had an activity co-ordinator, responsible for a set programme of daily activities for all residents. It is noteworthy that the current literature surrounding managing BtC in dementia focuses on these activities as NPIs and their effectiveness in managing BtC [57, 83]. 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. Indeed, the designated activity co-ordinators are responsible for providing activities for every resident, regardless of whether they present with BtC.

Where BtC are exhibited, CH staff are required to read the situation, often quickly, and apply various techniques to restore calm. In line with the findings of Pulsford [88], staff talked about their experiences of aggressive behaviour, suggesting that using distraction or reassurance, their knowledge of the resident and the help of their colleagues was often the best strategy to diffuse potentially difficult situations. As was found by Pulsford [88], CH staff viewed BtC as causal, deriving from the environment, situation or interactions with others.

The presentation of multiple problems associated with dementia [6-10] was clearly acknowledged by CH staff, who suggested that BtC has a cause. A number of strategies were reported to be implemented by CHs and their staff to minimise and manage BtC, including both non-pharmacological and pharmacological approaches. In line with current guidelines [21] however, non-pharmacological strategies were discussed more prominently, and staff reported using these most frequently and prior to any pharmacological intervention for BtC. While there appeared to be no consistent behaviour management strategy, all interviewees discussed the importance of knowing who they were caring for: their life history; their family; their personality and their behaviours. In this respect, the strategies used had similarities to some strategies used in research studies (validation therapy, functional analysis and the use of stepped frameworks). This knowledge helped staff to manage episodes of BtC, and enabled them to share strategies with other colleagues. The sharing of new ideas and successful interventions was reported widely, and managers often praised their 'family' of staff. CHs appeared to be encouraging of staff training, and offered a wide range of programmes: yet again, no single training programme was consistent across all homes, and managers often led sessions themselves. Contrasting opinions were evident regarding the quality and efficacy of training; therefore it is likely that this area warrants further research. CH staff in this study reported receiving training, however not all staff reported receiving dementia specific training, a finding which may add to the growing evidence that the delivery of dementia specific training to CH staff is low [158]. In the UK, approximately one third of dementia specialist CHs report having no specific dementia training for their staff [23]. While evidence suggests that the quality of dementia specific training is variable[23] this study did not set out to determine training quality.

CH staff reported attempting to provide support for residents' families, as proposed by the National Dementia Strategy [15], and residents' relatives were invited to share their photographs, memories and stories with the CH staff, and were asked to help design the bedroom environment. Managers acknowledged that they not only cared for residents, but also for their residents' families, who can often struggle with the CH transition, consequences of a dementia diagnosis and unusual behaviours.

The care environment was reported to be a prominent aspect of managing, or minimising BtC, although opinions regarding the best practices for orientating residents within CHs were mixed. Of all the purpose built homes, all but one had continuous, circular corridors, to enable residents to walk between units, and therefore this may have limited residents' frustrations compared with non-purpose built homes. Signs and resident photographs on bedroom doors in the CHs were both advocated and criticised, and this was evident in the observations of the care environments, where most CHs had signposting in some form on residents' doors, but not always in communal or toileting areas. Furnishings such as photographs within rooms were discussed by care staff, and these were observed to be present in all of the 11 bedrooms observed. Posters depicting relevant scenes (World War II aircraft, for example), allowed staff to initiate conversations, adding to their knowledge about residents, although some CHs opted for more modern furnishings, as noted during the observations. The findings from this study suggest that a familiar, home-like environment is a key facilitator in minimising behaviours. However, differences in opinion on specific aspects of the care environments, such as signposting, suggested that CHs adopt approaches that work for them, often after a trial and error process. Evaluation of the King's Fund's 'Enhancing the Healing Environment' has proved that it is possible to enhance the quality of life of people with dementia staying in hospital, by changing the environment around them to a more dementia-friendly design [159]. This tool can be used in CHs to assess the quality of their care environments, and although the changes required for some CHs in this study would be significant and potentially costly (changing corridor structure in non-purpose built homes, for example), the King's Fund recommend completing the tool in order to secure financing from CHs boards to improve the care environment.

Further work is required to identify an evidence base for what CH staff are doing in practice: this study has highlighted that CH staff report having theories about what works to manage BtC, however it has not investigated whether they are actually using them in practice. It is also noteworthy that CH staff reported using music, aromatherapy, pet therapy and reminiscence therapies to minimise and manage incidents of BtC. While the Dickson et al [57] review found promising but limited evidence for alternative therapies such as aromatherapy and music, the evidence base for pet therapy is scant. However one CH staff member suggested that because her pet (dog) was living and breathing, this provided more stimulation than a teddy or doll. For the vast majority of 'activities' or treatments, the evidence considered by the Dickson review [57] is inconclusive due to inconsistencies in studies, poor quality studies, or almost total lack of evidence. As such, the review does not make recommendations, but rather encourages further research in this area. This phase of research has suggested that these activities and treatments are being used in CHs, but did not set out to quantify the extent of their use or study their effectiveness in managing BtC in dementia. The use of medication as a strategy for managing BtC was not discussed in depth in this phase of the study, but opinions were mixed. Some managers reported not wanting to use antipsychotic medicines; others suggested they had a place, however, again, this phase of the study did not set out to determine what truly happens in practice. Care workers, who made up the majority of interviewees, were less knowledgeable regarding medicines, and declined to provide firm opinions on the use of medicines to manage BtC. However, their opinions on medicines use to manage BtC was sought in less depth than CH managers. Therefore the use of medicines in practice warrants further investigation.

Strengths and limitations

This study brings together the views and experiences of CH staff and managers on how BtC in dementia are managed in practice. The phenomenological approach and limitation to one geographical area of England were used to explore this under-researched area, in order to inform and develop future work, and provide an initial evidence base on which to structure the rest of the study. While it is difficult to generalise the findings from this phase due to the small sample size, they provide a number of indications from individual care staff, which may apply to the wider CH community. Views were sought from care staff in CHs with and without nursing, in order to ensure all levels of CH were obtained, and the sample size of 41 care staff allowed for a wide range of views and experiences to be collated. The use of incentives for all participants, while supported by the literature, may have served as a recruitment bias, with atypical participants being recruited, however the value of the incentive was sufficiently small that it was not deemed to be a significant factor in the data obtained in this phase of the research. CHs were self-selected from a large sample who were invited to participate in the study, and therefore those who perceived their practice to be good, were more likely to participate. Additionally is it likely that those individuals participating were interested in dementia, and in the care of their residents. As such, it is possible that care may be superior in these homes, given that staff in CHs where they suspect care is substandard may be less willing to volunteer for studies that could show failings in care. No data were obtained from the 131 CHs and their staff who declined to participate in the research study, however some CHs did explain their reasons for refusal. Several homes cited having newly appointed management teams or CH staff, others suggested that they had a lack of time to engage in a research study and many homes were simply not interested in participating. Three of the CHs recruited to this study were owned by the same company, which aided recruitment, but also generated a potential bias in the data obtained. The numbers of residents being cared for in the 11 CHs ranged from 28 to 112, and therefore practices, routines, organisation, facilities and supervision and management were likely to vary. Staff were not recruited individually, although I took every opportunity to answer any questions they may have had: instead managers assisted in choosing the units from which staff were recruited, which may have affected which staff were willing to participate, also adding to selection bias. Managers reported asking all staff from each unit however. While there did not appear to be any coercion from CH managers on their staff to participate, I cannot be absolutely confident that none occurred prior to my visit, or while I was absent from the CHs. Additionally, managers appeared reluctant to talk about using medicines to manage BtC, possibly because they were aware that the scope of my study focused on alternatives to medicines, and were asked about their knowledge on the drive to reduce antipsychotic prescribing for BtC. Managers were not always interviewed prior to their CH staff being interviewed, however it is possible that managers could have primed their staff about what to say while informing them about the study.

Observing the CH environment was limited by being able to only capture images where residents were not present. As such, a complete picture of the care environment was impossible to portray, however the photographs and descriptions of each CH's interior and exterior serve to add to the data gathered from interviews with care staff and managers. The data from the environmental observations illustrate the differences in care environments between CHs, and are the first sources of photographic data which allow an insider view of CHs and their facilities. The appointments made to observe the CHs and interview staff were booked in advance, and therefore it is possible that on the occasions I visited, the care environments were modified or improved in some way, in order to show their best facilities. On every visit I was accompanied by a member of staff to take photographs, and they may not have been willing to show me every area of the home, in the event that I observed evidence of bad practice.

Implications for practice

CHs have been encouraged by NICE and SCIE to provide person-centred care, and the CHs in this study reported that they are currently providing this, as a priority. The study summarises the key challenges faced by staff when managing BtC, and describes the management strategies utilised in order to cope with these behaviours. There were important and contrasting views on the use of pharmacological agents in managing BtC, and additionally a variety of non-pharmacological therapies were alluded to; however there was no clear, unanimous opinion of what constitutes best practice in these situations. While there did appear to be fairly wide use of a range of methods reported, for which there is some evidence of preventing BtC, these were not universal. Therefore further research is needed to determine the most effective methods of managing behaviours in practice, as there is little published work in this area. Observing the CH environment has provided a clearer picture of the differences between CHs' interior and exterior design, facilities available and structure. There is little research on the best design of a care environment, and it was clear from the interviews that many CHs are using a trial and error approach. The differences in designs of CHs illustrate this, and future research is needed to determine the impact of varying care environments on managing BtC.

Rationale for commencing second phase

The decision to move forward with the second phase of the PhD was made after careful consideration of the pilot data. The pilot study informed the next phase of the research, and it was clear at that time, that a broader study was required to capture the views and experiences of care staff in England, on managing BtC. Ethics for the cross-sectional survey was approved in

September 2013, shortly after interviews for the main study commenced (see Table 3.1). The main interviews were believed to have reached saturation after the 41st interview had been completed in June 2014, due to no new themes emerging from completion of the 37th interview in the penultimate CH. At this stage, the emergent themes were deemed to be sufficiently strong to continue with the development of the ethnographic phase of the study. The findings of this phenomenological study were used to inform and develop the next phases of research.

A quantitative approach was chosen for the second phase, using a cross-sectional survey to broadly explore the views and experiences of care staff across England, on managing BtC in dementia and how they perceive those experiences. Phase Three used an observation tool to conduct an ethnographic study exploring how three CHs manage BtC in dementia, in practice. The fourth phase used a medicines analysis tool to investigate the medicines used in CHs. Finally Phase Five sought to obtain the views and experiences of CH residents' relatives through interviews, conducted at each of the three CHs recruited in the third phase. These phases are discussed in Chapters Five, Six, Seven and Eight.

Chapter 5 Cross Sectional Survey

Declaration: This phase of work was completed by my primary supervisor (SG), nine undergraduate pharmacy students (UG) and myself (CM). The questionnaire was designed by SG with input from CM. UG conducted the pilot study and presented suggestions for revision of the draft questionnaire; prepared the mailings for their allocated CHs (following a protocol which they had developed under supervision with SG and CM), contacted and visited allocated CHs in the direct distribution method CHs (following a protocol developed by SG and CM), and inputted data into SPSS, which was checked and amended by CM. Analysis and write up was completed by CM.

Introduction

Chapter Three outlined the rationale for this study design. This chapter provides: the survey sampling and development, the data collection process, the data analysis strategy, the results, and a discussion of, the second phase of the study: a cross-sectional survey utilised to obtain the views and experiences of CH staff on managing BtC in dementia. Backhouse et al [81] conducted the first study to estimate the prevalence of antipsychotic use in people with dementia living in CHs, using survey methodology in the East of England. Of the total 8579 residents in 299 CHs, 1027 (12%) residents from 246 (82%) CHs were reported to be prescribed at least one antipsychotic drug. Antipsychotics were reported to be prescribed to at least one resident in 73% of CHs, and this was higher in nursing homes than residential homes: a significant difference was found ($t = -2.264$, $p<0.05$) between the level of antipsychotic prescribing in CHs providing qualified nursing care when compared to residential homes. Aggression was reported to be the most challenging behaviour to manage, while a variety of non-pharmacological and pharmacological interventions were concurrently employed to manage these behaviours. The most common NPIs were reminiscence therapy (75% of CHs), music therapy (73%) and animal/pet therapy (64%). A more accurate data source utilising prescribing records, Child et al's data on antipsychotic usage found that 118 of 462 (26%) people on the dementia register living in CHs were prescribed antipsychotic drugs [81]. The study also found that a person with dementia in a residential home was nearly 3.5 times more likely to receive a low-dose anti-psychotic than someone with dementia living in their own home.

An NIHR methods review highlighted potential low survey response rates and difficulties recruiting CH staff to participate in research and suggested that multiple contacts by different means may be necessary [132]. Garcia, Kelley and Dyck [133] suggested face-to-face contact as the most helpful strategy for gaining research access to American nursing homes. Therefore this Phase Two study employed two methods to distribute surveys to a sample of staff working in CHs in England (both with and without nursing) to obtain their views and experiences of caring for people with dementia who exhibit BtC. Given the drive to reduce antipsychotic prescribing, along with NICE and SCIE recommendations to adopt first-line non-pharmacological approaches to managing BtC in dementia[21], obtaining this snapshot of how things are at a specific time [160], from the CH population provided a dataset spanning a range of CH practices, as well as a picture of the CH climate at the time of data collection.

Aim and objectives

The aim of this phase of the study was to explore the views and experiences of CH staff of BtC through a self-completed survey, therefore establishing the current situation within CHs nationally. Objectives for this phase of the study were:

1. To measure CH staff experiences of BtC
2. To measure CH staff views of BtC
3. To measure CH staff views on what helps manage BtC
4. To measure CH staff experience of training they have received for BtC
5. To measure CH staff's differing experiences of BtC according to their home registration, role, number of residents with BtC, training and frequency of medicines use

Ethical approval

For this study phase, favourable ethical opinion was granted by Medway School of Pharmacy Ethics Committee (Appendix 9). The survey and covering letter/participant information sheet were designed to include all of the information that participants required in order to decide whether to participate or not. Informed consent was assumed by the receipt of a completed questionnaire: a statement, 'By completing and returning this questionnaire, you are giving your consent to be part of this project and for your data to be used as described in this letter and the Participant Information Sheet which can be found overleaf' was included in the covering letter page. All surveys were coded to maintain anonymity; non-responders were identified and noted on a separate list.

Sampling strategy

The target population for the study consisted of CH staff employed in dementia specialist CHs, both with and without nursing, located in England. Within this population, two samples were established, which enabled evaluation of two different recruitment methods: (i) a convenience sample was selected from the Care Quality Commission’s database of eligible CHs, on the basis of geographical locations that were in appropriate travelling distance for student researchers to be able to visit, taking into account the location of the nearest train station, the local transport network, car parking availability and the walking distance from a station or car park to the CH; (ii) a random sample was generated from data collected from the CQC database of eligible CHs, which excluded those homes in method (i). Initially, the CQC website (http://www.cqc.org.uk/content/care-homes) was searched for dementia specialist CHs in England. The CH information included in the database consisted of: CH name, address, region, local authority, telephone number, website, whether the CHs were registered to provide care with or without nursing, how many residents could be housed, and any specialisms offered by the CH (dementia-specialist, for example). CHs not registered as providing dementia-specialist care were excluded from the sample. The results were downloaded into a spreadsheet, and sorted according to Local Authority, region and registration (CH with nursing, CH without nursing and dual registered), to ensure that the sample was representative of the population for CHs with and without nursing, and region of England. A download from this website on 9th August 2013 identified 17,482 CHs. Staff from nine CHs were selected for a pilot study either through convenience sampling or through personal or local contacts: these CHs were excluded from the two study samples.

A convenience sample of 54 CHs were selected for recruitment method (i), based on the pragmatic estimate of nine student researchers acting as direct data collectors visiting six homes each, working in pairs. These CHs were excluded from the postal survey sample, in addition to the two pilot CHs recruited to Phase One. All CHs in Kent were also excluded from the postal survey sample, since recruitment for the main Phase One study was not complete at that stage. Once the target postal survey sample had been established, a random number generator was used to randomly select a sample of 1,350 from the remaining CHs (n=17,417), based on a pragmatic estimate of nine student researchers acting as data collectors for 150 CHs each. The sample was then checked to ensure that it was representative of the population for both CHs with and without nursing, and English regions. Surveys were distributed to staff employed in registered dementia-specialist CHs in England, either by direct distribution - method (i) (n = 1,170 (staff employed in 54 CHs)), or post - method (ii) (n=1,350 CHs). The number of questionnaires required for the direct distribution method was based on a pragmatic estimate of approximately 20 questionnaires per CH (totalling 1080 to 54 CHs), however one CH was large, and requested to receive far more than 20 questionnaires, and other CHs expressed a wish for students to deliver more than 20 on the day of the visit. Therefore a total of 1170 were distributed. This suggests that using a pragmatic estimation was limiting, however given the eventual response rate, can be justified.

Survey development and design

To ensure that potentially relevant questions were asked, the survey was designed jointly by my supervisor and me, using findings from conducting pilot interviews with care staff (Phase One). It became clear in conducting the interviews that the CH population was under-researched, yet had a wealth of opinion and experience in managing BtC. The Phase One study prompted a need to investigate current CH practices and ask similar questions to the interviews, on a much broader geographical scale, and with a larger sample: something which had not been attempted before (Backhouse studied the views of CH staff in the East of England, and Pulsford studied the views of CH staff in four purposively selected CHs owned by the same company). Therefore conducting a national survey was essential.

The initial survey was developed using a 25-point observation rating scale (CBS) based on reports of care staff [20]. The CBS provides a comprehensive list of BtC which is quick to complete and is being used to evaluate psychosocial interventions in care settings. Permission to include the CBS was sought and granted by the author, who requested to be sent a copy of the survey, and to be included on any publications that may arise. This continues to be adhered to. In addition to the CBS, NICE and SCIE Clinical Guideline recommendations for interventions for non-cognitive symptoms and BtC in people with dementia[21] were also used.

The survey went through several stages of development involving my primary supervisor: questions were reworded, merged and reordered. The survey was piloted with 19 care staff to inform the design of the survey prior to acceptance of the final version. Each student researcher identified two or three current or recently current CH staff, who were either local or personal to them, as potential participants. Participants were recruited by post, email or face to face, and then asked to complete the pilot survey. After completing the questionnaire, the student researchers contacted willing participants, and asked questions pertaining to the completion of the questionnaire. Respondents provided comments on the content, structure, ease of answering and duration of completion of the survey. Feedback from the respondents was positive: recommendations included shortening the length of the survey, and consequently alterations were made to merge the first two questions with the aim of making the survey quicker and easier to complete. A cover letter and participant information sheet (Appendix 10) and revised questionnaire (Appendix 11) were designed, edited and finalised after the pilot. The final survey design consisted of open, closed and multiple-choice questions, within four sections:

1. Your views and experiences of BtC;
2. Your experiences of what helps in managing BtC;
3. Training for BtC;
4. About you and the care home you work in.

Section One asked respondents to state (yes or no) whether they had experienced 25 different BtC (derived from the CBS), to state how often they experienced them (every shift, at least once a week, at least once a month, less than every month), and to rate how challenging each behaviour was (a scale of 1-5 was used, where ‘1’ constituted “I do not find this behaviour challenging” and ‘5’ constituted “I find this behaviour very challenging”). Respondents were then asked to state whether they found any other behaviours challenging, before completing the frequency and rating of these additional behaviours.

Section Two asked respondents to indicate their level of agreement or disagreement with the statement ‘The intervention helps people with dementia who have BtC’, for 14 given interventions, derived from the NICE Guideline (CG42) recommendations for interventions for non-cognitive symptoms and behaviour that challenges in people with dementia[21]. A free text question was included at the end of this section asking respondents to describe the best way to help residents with BtC.

Section Three encompassed training for BtC, and asked respondents to indicate their level of agreement or disagreement with three statements pertaining to training received, whether training had helped, and whether they would like more training, using a scale of agreement (strongly agree, agree, neutral, disagree, strongly disagree). Respondents who reported having received training were then asked to complete questions pertaining to the types of training they had attended, number of sessions, hours of training and rating, before being invited to add any other comments regarding the training they had received. The final section comprised of eight questions pertaining to the respondent and the CH in which they worked. The home registration, and numbers of residents, residents with dementia, residents with BtC and residents prescribed medicines to control their BtC were sought, using open questions. In addition, respondents were asked to state their role within the CH, whether they work full or part time and shifts, and finally the longevity of their employment as a carer (experienced carers were denoted as those with five or more years of experience), using multiple choice options.

Postal distribution Method (Method ii)

A single questionnaire was sent by 2nd class post addressed ‘FAO Care staff working in the Care Home today’ to every CH in the sample. Non-responding homes were contacted by telephone two to three weeks after the first mailing. If during this telephone conversation, CHs were receptive to the study, and willing to complete the survey, a second personalised mailing was sent immediately.

Direct distribution Method (Method i)

A telephone call was made to each CH, to request an appointment to deliver questionnaires for care staff working at the home, and a script was devised and used for this telephone conversation. The name of the person spoken to on the telephone was recorded, and a visit was arranged. The CHs were visited at the agreed times to deliver 20 surveys (although many CHs required more) for the care staff working in the home, and a script was developed and used for the survey delivery visit. A poster was created for homes to display in an appropriate place so that it would be seen by care staff, which explained the project and sought to encourage participation. Despite each participating home’s agreement to display the poster, it is not clear whether this was completed, and this may have affected care staff recruitment to the study. CHs where less than 50% of the surveys supplied had been received after two to three weeks received a follow-up telephone call and further copies of the questionnaire and envelopes were supplied, on request.

Data analysis

Data were coded and entered into SPSS Version 22 (Statistical Package for the Social Sciences). Data entry was completed by the undergraduate students, and I checked these entries. Responses received from the two methods of survey distribution were analysed separately to compare and contrast the distribution methods, and also to investigate the possibility of the distribution method influencing the results. Data from both methods were combined for demographic findings, frequency and rating of BtC, usefulness of interventions, the specific intervention ‘giving medicines that control behaviour’, training experience and training type, sessions and hours.

Closed questions (experienced behaviour, for example) were coded as nominal variables, while numerical data (number of residents, for example) were coded as scale data. Multiple-choice questions were coded with respect to the tick boxes: each tick box was coded as a nominal variable to enable comparisons of each response category. Missing data were coded as 99, and omitted from the analysis. Free text responses were collated, sorted and then subject to a simple thematic analysis, whereby each response was coded, to identify the key themes emerging from the data, before being used to inform and illustrate points highlighted by the quantitative analysis of the closed questions. In total, 172 SPSS variables were generated. Once all data had been entered, the data were checked against the corresponding surveys in order to ensure the reliability of the data and check for errors or missing data. Data analysis was conducted using descriptive statistics and cross-tabulations, and statistical tests were conducted to test for independence and statistical differences.

A chi-square test for independence was applied to determine whether there was a significant association between two variables. In these cases, this approach was appropriate where the variables under study were categorical, and the expected frequency count was at least 5 in each cell of the contingency table. Statistical significance was accepted for $p<0.05$. The data on role in each CH were dichotomized into: manager and non-manager; care worker with formal qualifications and care worker without formal qualifications; full time and part time workers, experienced or less experienced staff (experienced carers were denoted as those with five or more years of experience, in their current CH and also in any previous homes) to ascertain any differences in views and experiences between different staff sub-groups. Means were calculated for the ratings of how difficult respondents found behaviours. The median number of residents in the direct distribution sample was calculated due to skewed data, where the mean value of the dataset was distorted.

Results

Response rate

In September 2013, a total of 2520 surveys were distributed (n=1170 direct distribution (i), n=1350 postal distribution (ii)), and 391 surveys were returned (15.5%). Of these, 56/1170 (4.8% response rate) surveys were from 17/54 (31.5% CH response rate) CHs (method (i)) and 335/1350

(24.8% response rate) were from 335/1350 CHs (method (ii)).)). In total 352/1404 (25.1%) CHs responded.

A further nineteen surveys were returned unanswered. Seven were returned by the Royal Mail, with either an inaccessible address, ‘addressee gone away’ marked or with no reason for return. Five were returned with notes identifying themselves as non-dementia homes, or as private residences. This highlights errors present in the current CQC database of registered CHs. Seven further surveys were returned blank with personal messages stating homes were unable to assist with the study. A full breakdown of demographic data is outlined by CH and by respondent, in Tables 5.1 and 5.2 respectively.

	Method (i)	**Method (ii)**
Total CH	17	335
CH with Nursing	7	157
CH without Nursing	10	171
Missing Registration Data	0	7
Number of Residents	48 (median/home)	13,186
Number with dementia	30 (median/home)	8,214
Number with BtC	20 (median/home)	4,243
Number prescribed medicines for BtC	24 (median/home)	2,289

Table 5.1 CH demographics from postal and direct distribution methods

	Method (i)		Method (ii)		Total (n=391)	
Total responses	56	100.0%	335	100.0%	391	100.0%
Respondents from CH with Nursing	33	58.9%	157	46.9%	190	48.6%
Respondents from CH without Nursing	20	35.7%	171	51.0%	191	48.8%
Missing Registration Data	3	5.4%	7	2.1%	10	2.6%
Manager	8	14.3%	216	64.5%	224	57.3%
Non-manager	48	85.7%	119	35.5%	167	42.7%
Nurse	9	16.1%	65	19.4%	74	18.9%
Non-Nurse	47	83.9%	270	80.6%	317	81.1%
Care worker with formal qualifications	32	57.1%	57	17.0%	89	22.8%
Care worker without formal qualifications	11	19.6%	14	4.2%	25	6.4%
'Other' worker	6	10.7%	36	10.7%	42	10.7%
Full time	39	69.6%	296	88.4%	335	85.7%
Part time more than 20 hours per week	15	26.8%	24	7.2%	39	10.0%
Part time less than 20 hours per week	2	3.6%	9	2.7%	11	2.8%
Works day shifts	27	48.2%	156	46.6%	183	46.8%
Works night shifts	17	30.4%	54	16.1%	71	18.2%
Works weekends	16	28.6%	79	23.6%	95	24.3%

Table 5.2 Respondent demographics from postal and direct distribution methods

A comparison of the responses from each method, to the national picture of CH status, region and local authority to prove the sample's representativeness of England, is displayed in Table 5.3. The sample is not representative of the population because Kent was excluded, however more responses were received from the South East than were expected, possibly due to a local influencing factor. A greater number of managers responded to the postal distribution than the direct distribution.

	Population		**Direct Distribution Sample**		**Postal Distribution Sample**		**Difference Postal vs Direct**	**% CH included in Postal**	**Difference Postal vs Direct**	**% CH included in Direct**	**Responses (Direct)**		**Responses (Postal)**	
	n	**%**	**n**	**%**	**n**	**%**					**n**	**%**	**n**	**%**
Total CH	6992		54		1350						17	31.5%	335	24.8%
CH with Nursing	2493	35.7%	20	37.0%	480	35.6%	0.1%	19.3%	-1.4%	0.8%	7	41.28%	154	46.0%
CH without Nursing	4290	61.4%	33	61.1%	823	61.0%	0.4%	19.2%	0.2%	0.8%	10	58.8%	171	51.0%
Dual Registered CH	209	3.0%	1	1.9%	47	3.5%	-0.5%	22.5%	1.1%	0.5%	0	0.0%	3	0.9%
Missing Data											0		7	2.1%
Yorkshire and The Humber	711	10.2%	0	0.0%	144	10.7%	-0.5%	20.3%	10.2%	0.0%	0	0.0%	29	8.7%
North East	425	6.1%	0	0.0%	77	5.7%	0.4%	18.1%	6.1%	0.0%	0	0.0%	18	5.4%
North West	880	12.6%	0	0.0%	181	13.4%	-0.8%	20.6%	12.6%	0.0%	0	0.0%	38	11.3%
East Midlands	712	10.2%	0	0.0%	136	10.1%	0.1%	19.1%	10.2%	0.0%	0	0.0%	39	11.6%
West Midlands	775	11.1%	0	0.0%	162	12.0%	-0.9%	20.9%	11.1%	0.0%	0	0.0%	35	10.4%
East of England	827	11.8%	18	33.3%	164	12.1%	-0.3%	19.8%	-21.5%	2.2%	10	58.8%	30	9.0%
London	555	7.9%	36	66.7%	94	7.0%	1.0%	16.9%	-58.7%	6.5%	7	41.2%	16	4.8%
South East	1222	17.5%	0	0.0%	208	15.4%	2.1%	17.0%	17.5%	0.0%	0	0.0%	62	18.5%
South West	885	12.7%	0	0.0%	184	13.6%	-1.0%	20.8%	12.7%	0.0%	0	0.0%	67	20.0%
Total	6992	100.0%	54	100.0%	1350	100.0%	0.0%	19.3%	0.0%	0.8%	17	100.0%	334	99.7%

Table 5.3 Total survey responses shown within the national picture of CHs

Postal distribution (Method ii)

Three hundred and thirty-five surveys were returned (24.8%), of which 157 (46.9%) were from CHs with nursing (including dual registered homes), and 171 were from CHs without nursing (51.0%) [missing data for 7 (2.1%) CHs]. Respondents estimated that they provided care to a total of 13,186 residents (mean 39.84; standard deviation 45.61) of whom 8,214 (62.3%) were reported to have dementia. Of the total residents, 4,243 (32.2%) were reported to have BtC.

The sample of the postal distribution to the south-east (15.4%) was lower because Kent was excluded, however the response rate (18.5%) was higher possibly as a result of local effect.

Behaviours experienced by care staff

Care staff were asked to indicate whether they have experienced a list of 25 given BtC, whilst at work. The results are shown in Table 5.4. It is important to note that not all respondents answered all questions, and therefore data was over-written for questions answering ‘yes’ or ‘no’ based on each participant’s response to whether they had provided data on the frequency with which they experienced BtC.

BtC	Experienced (%)		Not experienced (%)		Total
Shouting	327	98.2%	6	1.8%	333
Verbal Aggression	324	97.0%	10	3.0%	334
Perseveration	323	97.0%	10	3.0%	333
Wandering	324	96.7%	11	3.3%	335
Lack of Motivation	324	96.7%	11	3.3%	335
Physical Aggression	321	96.1%	13	3.9%	334
Restlessness	316	94.6%	18	5.4%	334
Lacking Self Care	308	92.5%	25	7.5%	333
Sleep Problems	304	91.8%	27	8.2%	331
Screaming	304	91.3%	29	8.7%	333
Non-Compliance	299	90.6%	31	9.4%	330
Lack of Occupation	296	89.7%	34	10.3%	330
Demanding Attention	294	89.4%	35	10.6%	329
Suspicious Behaviour	289	86.8%	44	13.2%	333
Stripping	282	84.9%	50	15.1%	332
Pilfering	281	84.1%	53	15.9%	334
Interfering	275	83.1%	56	16.9%	331
Inappropriate Urination	272	81.9%	60	18.1%	332
Clinging	267	80.7%	64	19.3%	331
Faecal Smearing	261	78.6%	71	21.4%	332
Spitting	244	74.2%	85	25.8%	329
Manipulation	223	67.8%	106	32.2%	329
Inappropriate Sexual Behaviour	214	64.5%	118	35.5%	332
Self-Harm	193	58.3%	138	41.7%	331
Dangerous Behaviour	124	38.0%	202	62.0%	326

Table 5.4 Care staff reported experience of 25 given BtC

Eleven of the 25 behaviours were reported by over 90% of respondents to have been experienced; the top five most experienced behaviours were reported as: shouting (98.2%); verbal aggression (97.0%); perseveration (97.0%); wandering (96.7%) and lack of motivation (96.7%). The least experienced behaviour as reported by care staff was dangerous behaviour (38.0%). For all behaviours, comparisons between experienced behaviour and staff role (manager or non-manager) and CH registration (with or without nursing) did not show any significant differences.

For each of the 25 behaviours, care staff were asked to indicate approximately how often they experience residents with the behaviour at work. Not every respondent who reported having experienced each behaviour provided an answer to this question. Additionally, those respondents who reported a frequency but did not tick ‘yes’ to experiencing the behaviour were included, and their response was changed to ‘Yes’, for the statement, ‘I have experienced this behaviour’. Valid responses are shown in Table 5.5.

Behaviour	n	Every Shift I Work (%)		At least Once a Week (%)		At least Once a Month (%)		Less than Every Month (%)	
Wandering	319	261	81.8%	31	9.7%	13	4.1%	14	4.4%
Restlessness	306	227	74.2%	56	18.3%	12	3.9%	11	3.6%
Perseveration	318	228	71.7%	59	18.6%	15	4.7%	16	5.0%
Demands Attention	284	176	62.0%	68	23.9%	24	8.5%	16	5.6%
Lack of Self Care	299	176	58.9%	57	19.1%	31	10.4%	35	11.7%
Lack of motivation	321	184	57.3%	99	30.8%	23	7.2%	15	4.7%
Lack of Occupation	285	160	56.1%	72	25.3%	30	10.5%	23	8.1%
Shouting	321	166	51.7%	90	28.0%	33	10.3%	32	10.0%
Interfering with other people	269	136	50.6%	73	27.1%	32	11.9%	28	10.4%
Pilfering or hoarding	274	132	48.2%	77	28.1%	32	11.7%	33	12.0%
Clinging	261	119	45.6%	81	31.0%	25	9.6%	36	13.8%
Sleep Problems	298	129	43.3%	108	36.2%	36	12.1%	25	8.4%
Screaming / Crying out	297	126	42.4%	81	27.3%	45	15.2%	45	15.2%
Non-compliance	292	123	42.1%	108	37.0%	33	11.3%	28	9.6%
Suspiciousness	282	99	35.1%	85	30.1%	47	16.7%	51	18.1%
Inappropriate urinating	264	91	34.5%	72	27.3%	40	15.2%	61	23.1%
Verbal Aggression	317	102	32.2%	111	35.0%	58	18.3%	46	14.5%
Manipulative	216	65	30.1%	66	30.6%	47	21.8%	38	17.6%
Spitting	237	70	29.5%	58	24.5%	34	14.4%	75	31.7%
Faecal Smearing	254	57	22.4%	73	28.7%	54	21.3%	70	27.6%
Stripping	274	61	22.3%	68	24.8%	66	24.1%	79	28.8%
Self- Harm	189	40	21.2%	41	21.7%	31	16.4%	77	40.7%
Physical Aggression	314	59	18.8%	117	37.3%	48	15.3%	90	28.7%
Dangerous Behaviour	119	12	10.1%	13	10.9%	18	15.1%	76	63.9%
Inappropriate sexual behaviour	203	20	9.9%	41	20.2%	42	20.7%	100	49.3%

Table 5.5 Reported frequency of 25 given BtC, experienced by care staff

Nine behaviours were reported by over 50% of care staff to be experienced during every shift. These were: wandering (81.8%), restlessness (74.2%), perseveration (71.7%), demanding attention (62.0%), lack of self-care (58.9%), lack of motivation (57.3%), lack of occupation (56.1%), shouting (51.7%) and interfering with other people (50.6%). Moreover three of the top five most experienced behaviours (shouting (98.2% experienced), perseveration (97.0% experienced) and lack of motivation (96.7% experienced)) were also reported to be the most frequently experienced. The least frequently experienced behaviours (as determined by 'less than every month'), were reported to be: dangerous behaviour (63.9%), inappropriate sexual behaviour (49.3%) and self-harm (40.7%). A comparison between CH registration, and frequency of BtC experience was made for all 25 behaviours. For those behaviours reported to be experienced every shift, significant differences were found for six behaviours. These are displayed in Table 5.6. The frequencies of all behaviours were higher in CHs with nursing.

Behaviour	CH with Nursing (n=157)	CH without Nursing (n=171)	P value
Physical Aggression	43 (27.4%)	15 (8.8%)	p < 0.0001
Shouting	96 (61.1%)	69 (40.4%)	p = 0.003
Screaming/Crying out	76 (48.4%)	49 (28.7%)	p= 0.017
Restlessness	113 (72.0%)	111 (64.9%)	p = 0.011
Spitting	41 (26.1%)	28 (16.4%)	p= 0.013
Non-compliance	73 (46.5%)	48 (28.1%)	p = 0.018

Table 5.6 Comparison between nursing and non-nursing home respondents' behaviours reported to be experienced every shift

A comparison between staff role (manager versus non-manager), and frequency of BtC experience was made for all 25 behaviours. For those behaviours reported to be experienced every shift, significant differences were found for five behaviours. These are displayed in Table 5.7. The frequencies were all higher in non-manager respondents.

Behaviour	Manager (n=205)	Non-manager (n=106)	P value
Physical Aggression	33 (16.1%)	26 (24.5%)	p = 0.033
Verbal Aggression	54 (26.3%)	48 (45.2%)	p = 0.013
Self-Harm	19 (9.3%)	21 (19.8%)	p = 0.043
Shouting	97 (47.3%)	68 (64.1%)	p = 0.032
Spitting	39 (19.0%)	30 (28.3%)	p = 0.003

Table 5.7 Comparison between managers' and non-managers' experience of BtC every shift

Care staff were asked to rate how challenging they personally find each behaviour using a given scale. For all those respondents reporting experiencing each behaviour, a rating of how difficult they personally find each behaviour was asked for. Those respondents who reported not having experienced the behaviour, either did not rate the behaviour, or ticked ‘I don’t know’. For the purposes of analysing the behaviour ratings, those respondents’ answers were omitted. Valid responses for rating frequencies are shown in Figure 5.1. Physical aggression was most frequently cited as the behaviour staff found most challenging, and wandering was reported by most staff to be found least challenging. Two analyses were conducted for all 25 behaviours, to determine whether differences existed in how challenging respondents found the behaviours, dependent on CH registration, and staff role (manager versus non-manager) , however no significant differences were found.

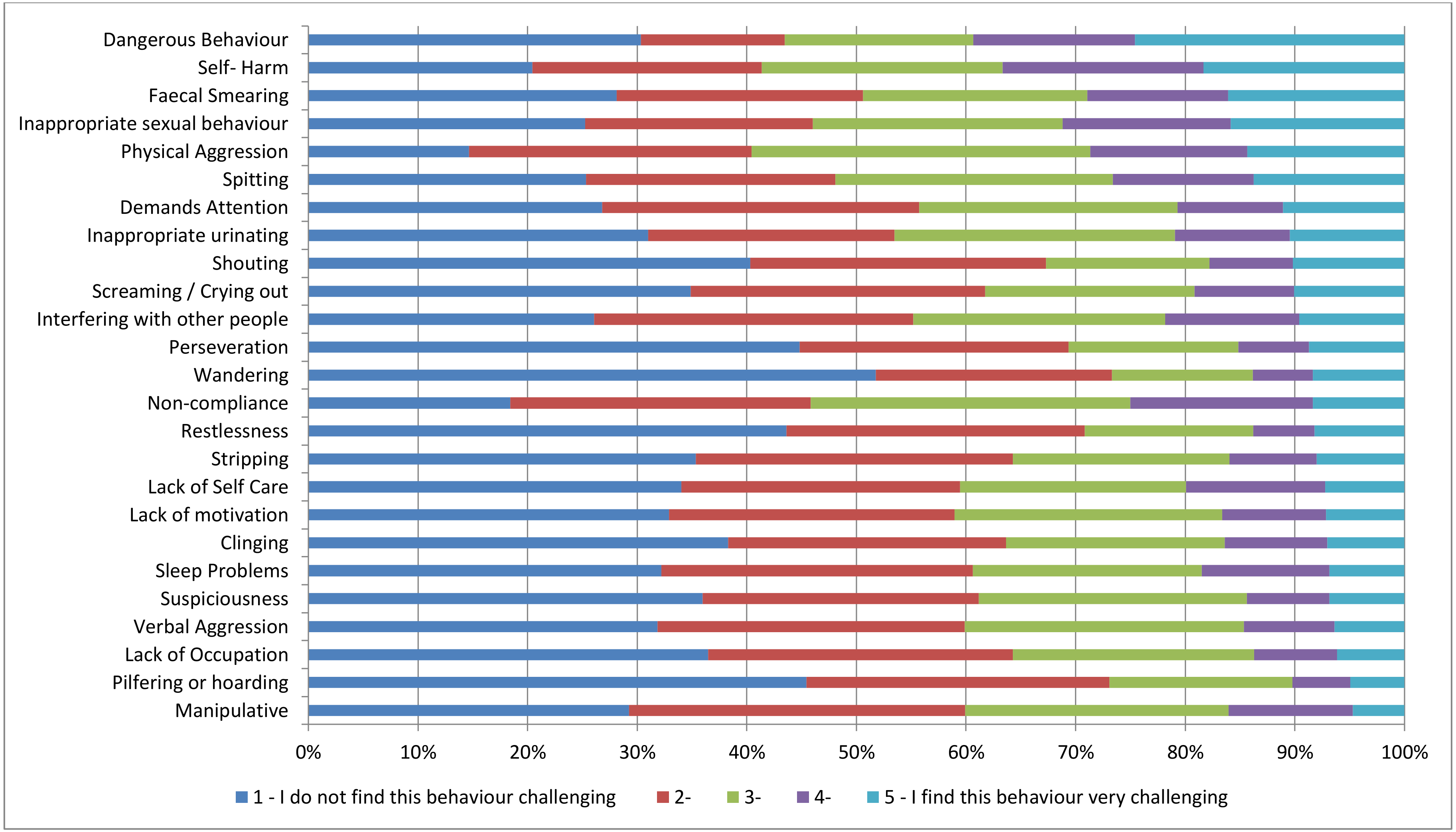


Figure 5.1 Reported rating of how challenging care staff personally found 25 given BtC (1 – I do not find this behaviour challenging; 5 –I find this behaviour very challenging)

The mean scores for each behaviour are presented in Figure 5.2. Results indicate that self-harm had the highest mean score (2.9), and pilfering or hoarding had the lowest mean score (1.8). However it is interesting to note that all but two (pilfering or hoarding, and wandering) of the behaviours received a mean score of 2 or above, indicating that care staff appear to experience at least some level of personal difficulty in managing these behaviours. It is noteworthy that while self-harm had the highest mean difficulty rating, it was reported to be the second least experienced behaviour (58.3%), and second least frequent behaviour (40.7% experienced less than every month).

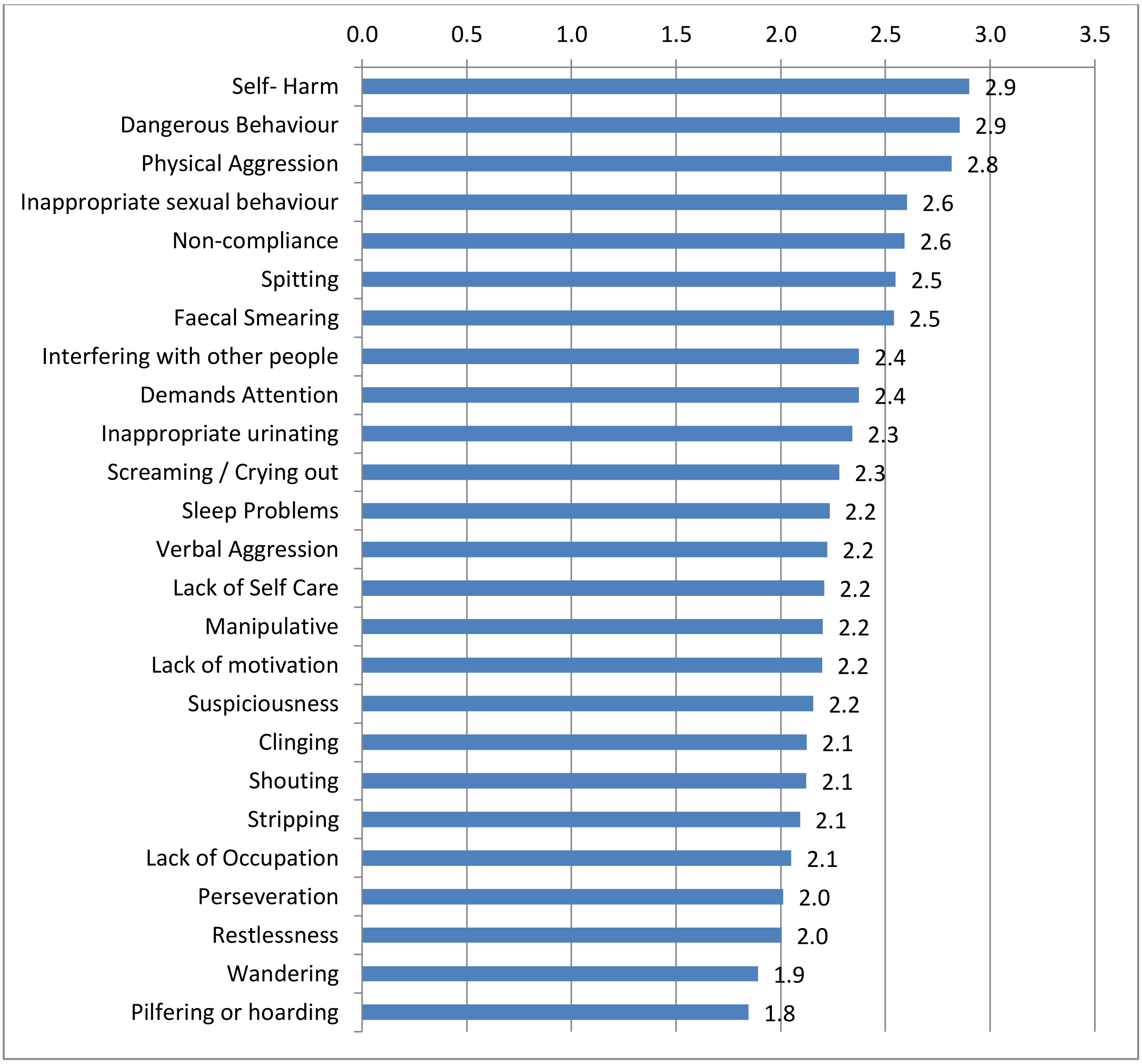


Figure 5.2 Mean reported rating of how challenging care staff personally found 25 given BtC

The use of interventions by care staff to manage BtC

Respondents were asked to indicate their views on the usefulness of 14 given interventions in managing BtC. Responses are shown in Figure 5.3.

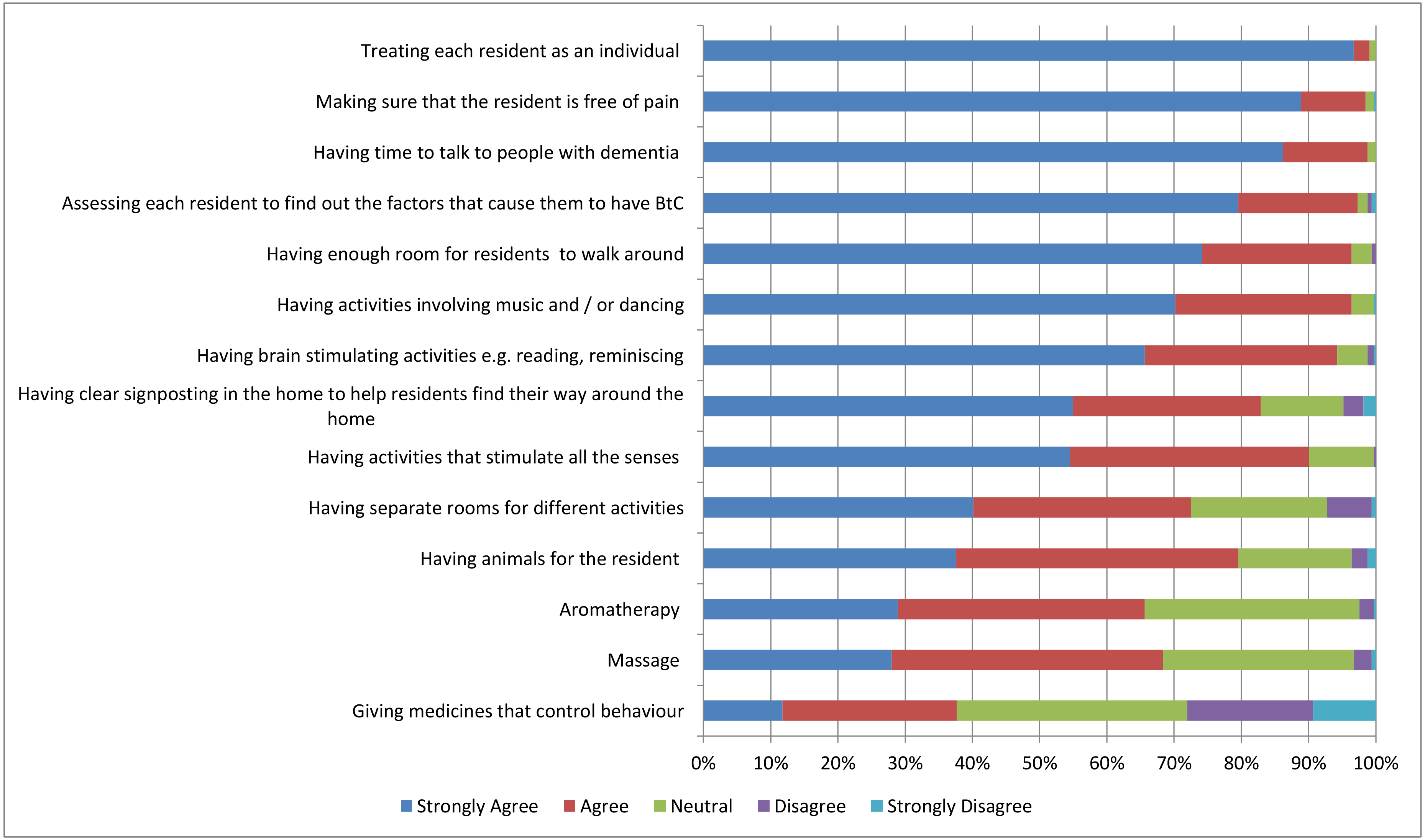


Figure 5.3 Care staff’s reported level of agreement with the statement ‘The intervention helps people with dementia who have BtC’ for 14 given interventions

Over 90% of respondents reported strongly agreeing or agreeing that eight interventions help people with dementia who have BtC: ‘Assessing each resident to find out the factors that cause them to have BtC’, ‘Having enough room for residents to walk around’, ‘Having activities involving music and / or dancing’, ‘Having brain stimulating activities e.g. reading, reminiscing’, ‘Having activities that stimulate all the senses’, ‘Having time to talk to people with dementia’, ‘Making sure that the resident is free of pain’ and ‘Treating each resident as an individual’. This was much higher than the proportion (37.7%) who strongly agreed or agreed that ‘Giving medicines that control behaviour” helps.

A comparison analysis of the responses between managers and non-managers was conducted on the intervention data (Table 5.8). Results indicate that there was a greater level of agreement by managers compared to non-managers, that the following interventions help people with dementia who have BtC:

- ‘Assessing each resident to find out the factors that cause them to have BtC’
- ‘Having enough room for residents to walk around’
- ‘Having activities involving music and / or dancing’
- ‘Having brain stimulating activities e.g. reading, reminiscing’
- ‘Having activities that stimulate all the senses’
- ‘Having time to talk to people with dementia’
- ‘Making sure that the resident is free of pain’
- ‘Treating each resident as an individual’

Over 90% of managers reported strongly agreeing or agreeing with all of these interventions, compared with ‘Giving medicines that control behaviour’, where only 29.9% strongly agreed or agreed. However, 51.3% of non-managers reported strongly agreeing or agreeing with the intervention ‘Giving medicines that control behaviour’. Indeed, a significant difference was detected between managers’ and non-managers’ reported level of agreement with the intervention ‘Giving medicines that control behaviour’ ($p<0.005$, two-sided Pearson’s Chi-squared test).

Intervention	n	Managers	n	Non-Managers
Assessing each resident to find out the factors that cause them to have BtC	214	210	116	111
		98.1%		95.7%
Having clear signposting in the home to help residents find their way around the home	214	172	116	101
		80.4%		87.1%
Having enough room for residents to walk around	214	203	116	115
		94.9%		99.1%
Having separate rooms for different activities	214	151	114	88
		70.6%		77.2%
Having activities involving music and / or dancing	214	207	115	110
		96.7%		95.7%
Having brain stimulating activities e.g. reading, reminiscing	214	202	115	109
		94.4%		94.8%
Aromatherapy	214	145	115	72
		67.8%		62.6%
Massage	214	149	115	78
		69.6%		67.8%
Having activities that stimulate all the sense	214	193	115	105
		90.2%		91.3%
Having time to talk to people with dementia	214	211	116	115
		98.6%		99.1%
Giving medicines that control behaviour*	214	64	115	59
		29.9%		51.3%
Making sure that the resident is free of pain	213	210	116	115
		98.6%		99.1%
Having animals for the resident	214	172	116	90
		80.4%		77.6%
Treating each resident as an individual	214	212	116	116
		99.1%		100.0%

Table 5.8 Comparison of managers and non-managers who reported strongly agreeing or agreeing with the statement ‘The intervention helps people with dementia who have BtC’ for 14 given interventions (*=$p<0.005$)

Medicines use

Respondents were required to estimate the number of residents prescribed medicine for BtC. Of the total residents, 2,289 (17.4%) were reported as being prescribed medicines to control their BtC. These data were categorised into low (0-33%), medium (34-66%) and high (67-100%) usage tertiles for each CH. The highest proportion of homes self-estimated their use of medicines was low (123; 43.6%), but 78 (27.7%) and 81 (28.7%) of homes estimated medium and high usage respectively.

Comparisons were made between the use of medicines as an intervention to help manage BtC, and: CH type, reported levels of medicines use, staff role (manager or non-manager, nurse or non-nurse, care workers with and without formal qualifications), hours worked (full time, part time 20 or more hours per week, part time less than 20 hours per week) and shifts (days, nights, weekends).

There was a clear association between agreement that medicines were useful and: reported use of medicines to control behaviour (p=0.0001); staff role (manager or non-manager) (p=0.004); and hours worked (full time versus part time), (p=0.022). These results are displayed in Table 5.9. Unlike the data presented in Table 5.20, there was no clear association between agreement that medicines were useful and: CH registration; nursing role; or care worker role.

		Agreement that medicines are useful	**Disagreement that medicines are useful**	**P value**
Reported use of medicines to control behaviour	High	54.3%	21.0%	p = 0.0001
	Low	21.1%	40.7%	
Staff role	Manager	29.9%	31.8%	p = 0.004
	Non-manager	51.3%	21.7%	
Hours worked	Full Time	35.0%	28.6%	p = 0.022
	Part Time	56.8%	24.3%	

Table 5.9 Association between care staff level of agreement that medicines are useful and reported use of medicines to control behaviour, staff role and hours worked

Training needs and experience

Three hundred and thirty respondents each answered all three questions concerning training. Results are displayed in Table 5.10.

Statement	**Strongly Agree n (%)**	**Agree n (%)**	**Neutral n (%)**	**Disagree n (%)**	**Strongly Disagree n (%)**
I have received training to help me care for people with BtC	230 (69.7)	91 (27.6)	9 (2.7)	0 (0)	0 (0)
The training I received has helped me to care for people with BtC	212 (64.2)	101 (30.6)	16 (4.8)	1 (0.3)	0 (0)
I would like more training to help me care for people with BtC	153 (46.4)	100 (30.3)	62 (18.8)	4 (1.2)	1 (0.3)

Table 5.10 Care staff reported level of agreement with three given training-related statements

A strong level of agreement was reported by care staff both that training had been received (321, (97.3%) agreed) and that training had helped staff care for people with BtC (313 (94.8%)), however there was also a high proportion who agreed that they would like more training (253 (95.5%)). No differences were found between respondents' level of agreement with each statement, and their job role (manager or non-manager); 97.8% of managers either agreed or strongly agreed that training had been received, compared with 97.4% of non-managers. In addition 93.5% of managers either agreed or strongly agreed that training had been helpful, compared with 97.3% of non-managers. Finally, 76.8% of both managers and non-managers agreed or strongly agreed that they would like more training. There were also no statistical differences between responses to these statements, and: CH registration; nurses versus non-nurses; experienced or less experienced carers; full or part time carers; carers who work days, nights or weekend shifts, or carers with and without a formal qualification.

Respondents were asked to give an estimate of the number of sessions and hours of training received. Staff reported using a variety of training methods (Table 5.11). On the job training was reported to be the least attended training (34.0%), while face–to-face training outside the CH was reported to be the most frequently used (67.7%).

Training Type	**n**	**% total sample**	**Mean**	**Std. Deviation**
Face to Face Training Outside CH	227	67.7	3.1	4.0
Face to Face Training Within CH	203	60.6	4.1	6.3
Online Training	160	47.8	1.7	4.3
Written Training	178	53.1	2.4	4.3
On the Job Training	114	34.0	2.5	5.4

Table 5.11 Care staff reported attendance at five given types of training to help look after people with dementia, over the previous five years

Respondents also reported receiving a varied amount of training. This is displayed in Table 5.12. On the job training and online training were reported to be the least number of training hours received (median 2 hours), while face to face training outside the CH was reported to be the most number of training hours received (median 9 hours).

Training Type	**n**	**Minimum**	**Maximum**	**Median**	**Interquartile Range**
Face to Face Training Outside the CH	209	1	360	9.0	3.5-24.0
Face to Face Training Inside the CH	202	1	16000	6.0	3.0-15.0
Online Training	143	1	160	2.0	0.0-6.0
Written Training	141	1	2016	6.0	0.0-21.5
On the Job Training	84	1	150	2.00	0.0-12.0

Table 5.12 Care staff reported number of training hours attended over the previous five years

A summary of this data (training sessions, hours and ratings) is provided in Table 5.13.

Training Type	**n**	**% total sample (n=330)**	**Total sessions attended**	**Total hours attended**	**% Excellent/ good Rating (n)**
Face to Face Training Outside the CH	209	67.7	730	4820	99.1 (230)
Face to Face Training Inside the CH	207	60.6	867	18757	97.4 (229)
Online Training	119	47.8	299	809	76.8 (138)
Written Training	171	53.1	464	4190	96.0 (201)
On the Job Training	149	34.0	558	5087	99.4 (172)

Table 5.13 Summary of training sessions, hours, and rating for five given training types, attended by care staff over the previous five years

Direct distribution (Method i)

Fifty-six surveys were returned (56 [4.8%]), from staff working in 17 CHs (31.5% CH response rate). Of the surveys returned, 33 (59%) were from CHs with nursing (including dual registered homes), and 20 (36%) were from CHs without nursing [missing data for 3 (5%) respondents]. In total, responses came from 7 CHs with nursing, and 10 CHs without nursing. Results are displayed in Table 5.14. It is noteworthy that more managers responded to the postal distribution method than the direct distribution method. Therefore it is possible that method (i) obtained views from more day-to-day carers who are likely to have different perspectives to managers.

CH (number of respondents)	**Median Residents (Range)**		**Median Residents with Dementia (Range)**		**Median Residents with BtC (Range)**		**Median Residents Prescribed Medicines for BtC (Range)**	
1 (4)	124	20-750	119	20-740	119	20-750	119	20-750
2 (6)	40	17-60	27	10-41	23	6-50	10	0-41
3 (3)	40	23-45	5	0-36	5	0-36	5	0-36
4 (1)	60	60	20	20	40	40	2	2
5 (9)	96	26-146	35	0-100	24	0-73	20	0-146
6 (1)	10	10	8	8	8	8	0	0
7 (5)	3	3	2	2	1	1	0	0
8 (3)	6	6	3	3	3	3	2	2
9 (3)	47	47	40	40	20	20	10	10
10 (1)	19	19	15	15	2	2	2	2
11 (5)	60	60	58	50-60	5	0-40	0	0-60
12 (1)	60	60	60	60	4	4	1	1
13 (2)	10	10	3	0-6	3	0-5	2	0-3
14 (4)	60	56-62	35	10-60	23	7-40	8	0-35
15 (3)	40	40	30	30	40	20-40	30	0-30
16 (2)	53	50-55	27	25-28	9	3-15	2	0-3
17 (3)	49	44-49	49	44-49	20	6-22	0	0-6

Table 5.14 Mean resident demographic data collected from the total seventeen responding CHs

Results analysed by CH indicated that all 17 CHs had residents with BtC, and 15 (88%) had at least one resident prescribed medicines for BtC. Fifty-one (91%) respondents indicated that their CH had one or more residents with BtC and 37 (66%) respondents indicated that one or more of their residents were treated with medicines. There was a wide variation in responses from different staff working in the same CHs. As such, calculating the mean from the data is problematic, and therefore could not be justified. This is a limitation of the data, since it is self-reported data and so may not be accurate. In the postal distribution method only one response was received per CH but there may still have been a similar level of inaccuracy.

Behaviours experienced by care staff

Responses are shown in Table 5.15.

Behaviour	Experienced (%)	Every Shift I work		At least Once a week		At least Once a month		Less than Every month		Missing	
Physical Aggression	56 (100%)	26	46%	15	27%	7	13%	8	14%	0	0%
Verbal Aggression	51 (91%)	24	47%	20	39%	4	8%	3	6%	5	9%
Self- Harm	45 (80%)	18	40%	10	22%	7	16%	10	22%	11	20%
Shouting	50 (89%)	38	76%	7	14%	4	8%	1	2%	6	11%
Screaming / Crying out	54 (96%)	39	72%	7	13%	4	7%	4	7%	2	4%
Perseveration	50 (89%)	36	72%	8	16%	4	8%	2	4%	6	11%
Wandering	50 (89%)	38	76%	8	16%	2	4%	2	4%	6	11%
Restlessness	50 (89%)	37	74%	10	20%	2	4%	1	2%	6	11%
Lack of motivation	49 (88%)	27	55%	16	33%	4	8%	2	4%	7	13%
Clinging	48 (86%)	22	46%	15	31%	5	10%	6	13%	8	14%
Interfering with other people	48 (86%)	24	50%	11	23%	5	10%	8	17%	8	14%
Pilfering or hoarding	50 (89%)	25	50%	13	26%	6	12%	6	12%	6	11%
Suspiciousness	47 (84%)	22	47%	15	32%	5	11%	5	11%	9	16%
Manipulative	42 (75%)	19	45%	12	29%	9	21%	2	5%	14	25%
Lack of Self Care	49 (88%)	35	71%	9	18%	4	8%	1	2%	7	13%
Spitting	46 (82%)	17	37%	16	35%	7	15%	6	13%	10	18%
Faecal Smearing	42 (75%)	14	33%	13	31%	5	12%	10	24%	14	25%
Inappropriate urinating	46 (82%)	16	35%	17	37%	4	9%	9	20%	10	18%
Stripping	49 (88%)	12	25%	18	37%	9	18%	10	20%	7	13%
Inappropriate sexual behaviour	38 (68%)	6	16%	9	24%	3	8%	20	53%	18	32%
Sleep Problems	40 (71%)	18	45%	14	35%	5	13%	3	8%	16	29%
Non-compliance	46 (82%)	23	50%	18	39%	4	9%	1	2%	10	18%
Dangerous Behaviour	28 (50%)	6	21%	5	18%	4	14%	13	46%	28	50%
Demands Attention	46 (82%)	32	70%	10	22%	3	7%	1	2%	10	18%
Lack of Occupation	43 (77%)	29	67%	10	23%	2	5%	2	5%	13	23%

Table 5.15 Reported frequency of 25 given BtC, experienced by care staff

Twelve behaviours: interfering with other people (50%), pilfering or hoarding (50%), non-compliance (50%), lack of motivation (55%), demands attention (70%), lack of self-care (71%), perseveration (72%), screaming/crying out (72%), restlessness (74%), shouting (76%), wandering (76%), and lack of occupation (67%) were reported by over 50% of care staff to be experienced during every shift.

Ratings of how difficult respondents personally reported to find each behaviour are shown in Figure 5.4. Physical aggression was cited by the majority of CH staff as the behaviour staff found most challenging, and shouting was reported by most staff to be found least challenging. Clinging was identified by the least number of staff as the behaviour they found most challenging.

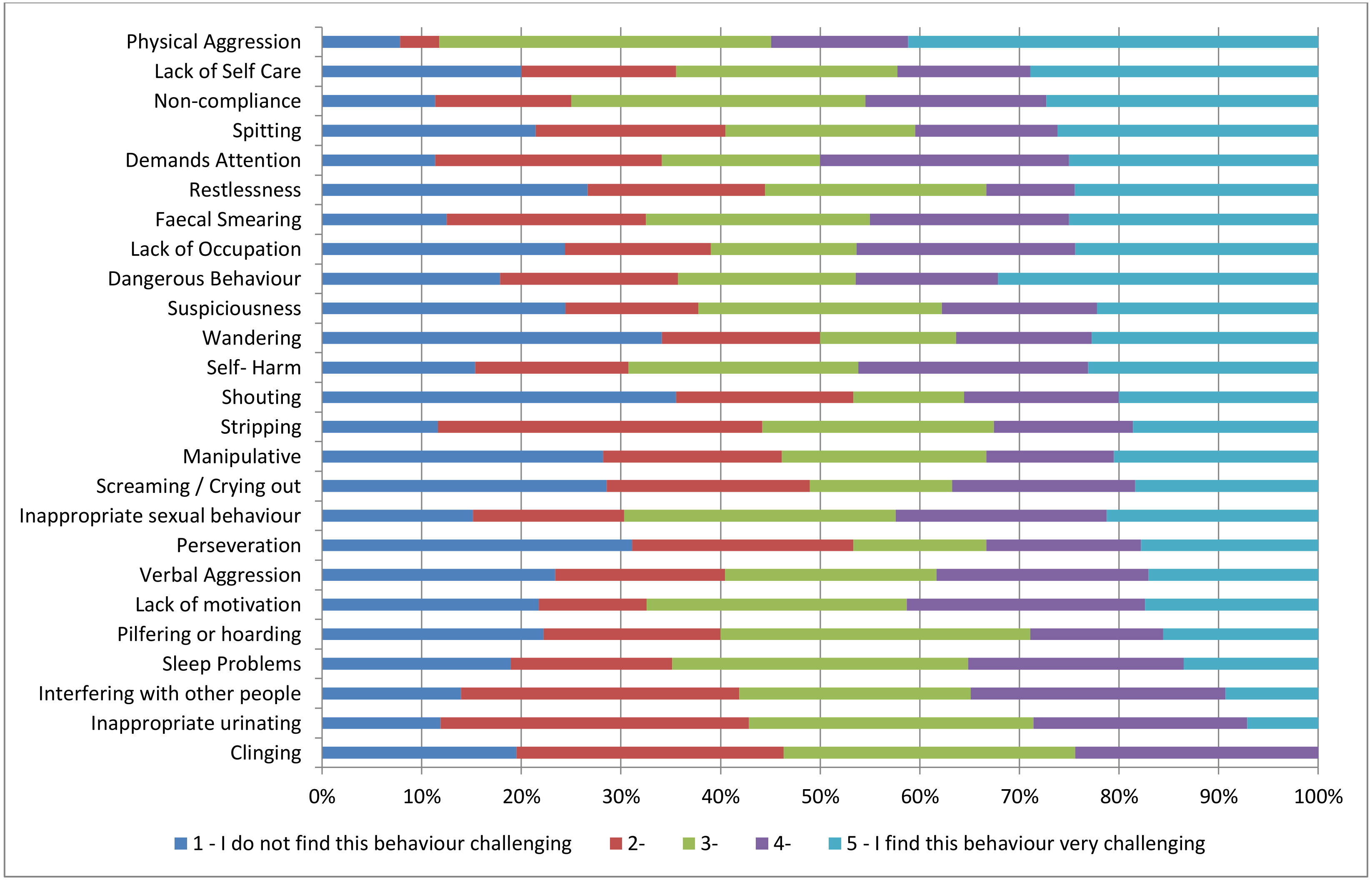


Figure 5.4 Reported rating of how challenging care staff personally found 25 given BtC (1 – I do not find this behaviour challenging; 5 –I find this behaviour very challenging)

Results indicate that physical aggression had the highest mean score (3.4), and dangerous behaviour had the lowest mean score (1.9). It is interesting to note that only one behaviour (dangerous behaviour) received a mean score lower than 2, indicating that care staff in this sample appear to report experiencing a level of personal difficulty in managing these behaviours to a lesser extent than those staff in the postal sample.

The use of interventions by care staff to manage behaviours that challenge

Agreement with the usefulness of 14 possible interventions is shown in Figure 5.5.

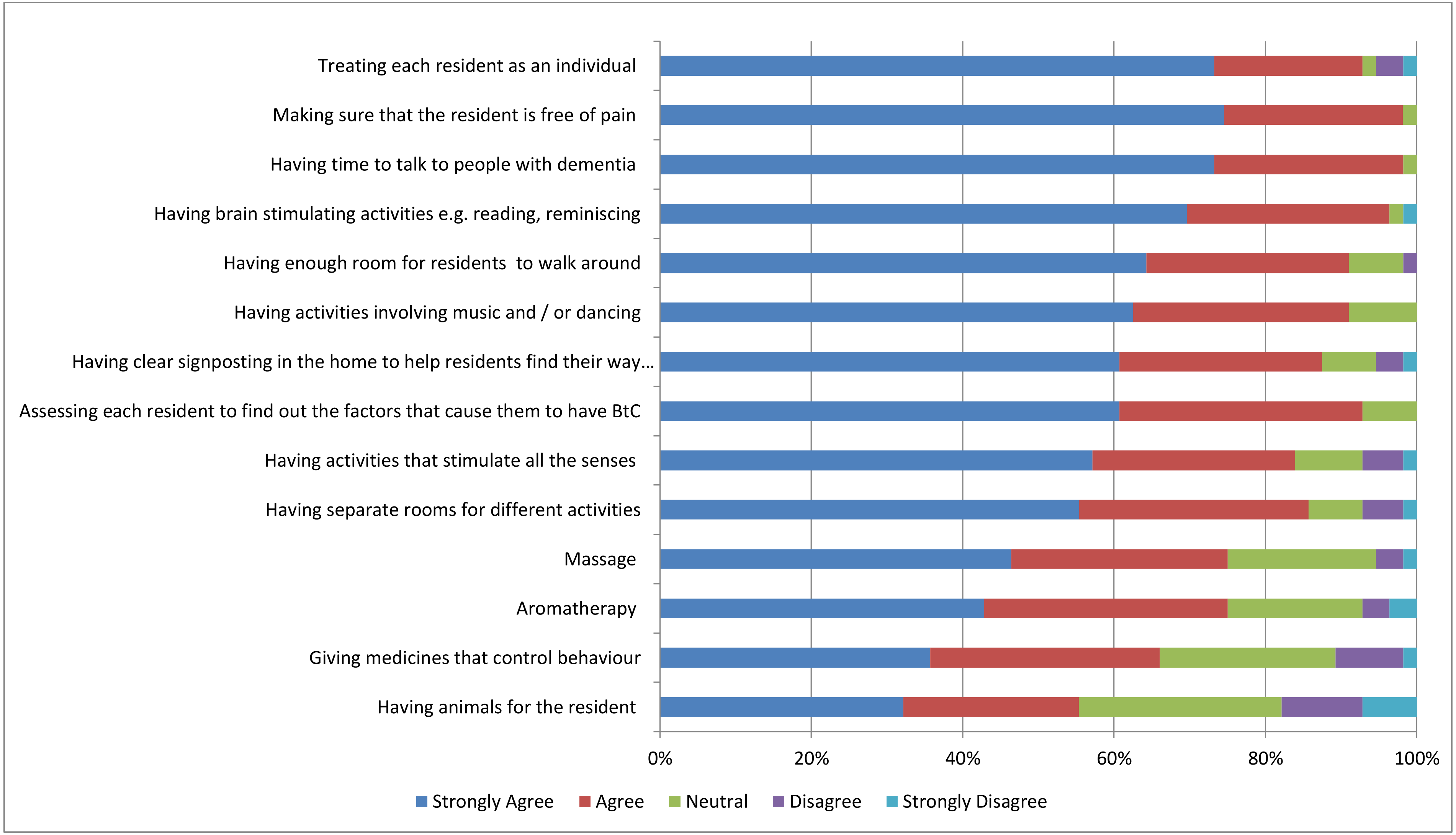


Figure 5.5 Care staff's reported level of agreement with the statement 'The intervention helps people with dementia who have BtC' for 14 given interventions

Similar to findings from the postal method, for six of the interventions over 90% of respondents reported strongly agreeing or agreeing they help people with dementia who have BtC, whereas fewer (66%) strongly agreed or agreed that ‘Giving medicines that control behaviour” helps. The data are compared directly in an analysis of data from the combined sample in ‘Interventions’.

A comparison between managers’ and non-managers’ views was not possible due to the small number of managers recruited.

Medicines use

As with the postal distribution survey data, respondents were required to estimate the number of residents prescribed medicine for BtC. These data were categorised into low (0-33%), medium (34-66%) and high (67-100%) usage tertiles. The proportion of responding staff who reported considering their CH used medicines in a high proportion of patients was 65% (26/40) compared to 18% (7/40) who thought they were used in low and intermediate proportions.

Comparisons between the reported use of medicines as an intervention to help manage BtC, and: CH type, reported levels of medicines use; staff role (manager or non-manager; nurse or non-nurse; care workers with and without formal qualifications), hours worked (full time; part time 20 or more hours per week; part time less than 20 hours per week) and shifts (days; nights; weekends) were not valid due to the small sample size obtained using this methodology.

Training needs and experience

Fifty-three respondents each answered all of the questions. Results are displayed in Table 5.16.

Statement	**Strongly Agree n (%)**	**Agree n (%)**	**Neutral n (%)**	**Disagree n (%)**	**Strongly Disagree n (%)**
Training received	30 (57)	18 (34)	1 (2)	3 (6)	1 (2)
Training helped	31 (59)	14 (26)	4 (8)	3 (6)	1 (2)
Would like more training	34 (64)	11 (21)	5 (9)	1 (2)	2 (4)

Table 5.16 Care staff reported level of agreement with three given training-related statements

Proportionally fewer care staff from this direct distribution sample compared to the postal survey sample agreed that training was received (91%), that training helped (85%) and that they would like more training (85%).

A comparison was made between respondents' level of agreement with each statement, and their job role (manager or non-manager); 5/7 (71%) managers either agreed or strongly agreed that training had been received, compared with 43/46 (94%) of non-managers. In addition 5/7 (71%) of managers either agreed or strongly agreed that training had been helpful, compared with 40/46 (87%) of non-managers. Finally, 5/7 (71%) of managers agreed or strongly agreed that they would like more training, compared with 40/46 (87%) of non-managers. Statistical comparison is not valid on this data given the small number of managers, however these views are included in an analysis of data from the combined sample in 'Training needs and experience'.

Tests conducted to ascertain any statistical differences between the statements and various populations were not valid given the small sample size.

Respondents were asked to give an estimate of the number of sessions, and hours in which they had received training. Again, staff reported attending a variety of training sessions. Their responses are recorded in Table 5.17. On the job training was reported to be the least attended training (23%), while face–to-face training outside the CH was reported to be the most frequently used (45%).

Training Type	n	% total sample	Mean	Std. Deviation
Face to Face Training Outside CH	25	45	5	6
Face to Face Training Within CH	20	36	7	9
Online Training	16	29	9	14
Written Training	21	38	6	10
On the Job Training	13	23	7	9

Table 5.17 Care staff reported attendance at five given training sessions to help look after people with dementia, over the previous five years

Respondents also reported receiving a varied amount of training. This is displayed in Table 5.18. Online training was reported to be the least number of training hours received (median 4 hours), while on the job training was reported to be the most number of training hours received (median 18 hours).

Training Type	n	Minimum	Maximum	Median	Interquartile Range
Face to Face Training Outside the CH	19	1	200	16	6-24
Face to Face Training Inside the CH	20	1	200	7	2-20
Online Training	16	1	300	4	1-10
Written Training	18	1	50	8	1-23
On the Job Training	10	0	40	18	0-26

Table 5.18 Care staff reported number of training hours attended over the previous five years

Comparison of distribution methods

To assemble a comprehensive and representative picture, the results from both distribution methods have been compared.

Recruitment

The direct distribution method (i) elicited a greater CH response rate than the postal method (ii) (31.5% CH response rate compared with 24.8%). However, a greater proportion of respondents to the postal survey were managers (64.5% of all respondents) compared with direct distribution (14.3%). Additionally more managers responded to the postal distribution method than the direct distribution method. Therefore it is useful to combine the data to enable a wider perspective to be obtained.

Experience of BtC

Eleven of the 25 behaviours were reported by over 90% of total postal distribution respondents to have been experienced; the top five most experienced behaviours were reported as: shouting (98.2%); verbal aggression (97.0%); perseveration (97.0%); lack of motivation (96.7%) and wandering (96.7%). The least experienced behaviour was reported by care staff as dangerous behaviour (38.0%). For all behaviours, comparisons between experienced behaviour and staff role (manager or non-manager) and CH type (with or without nursing) in both distribution methods did not show any significant differences.

Frequency of BtC

Nine behaviours were reported by over 50% of all care staff to be experienced during every shift. Figure 5.6 shows the proportion of respondents from each method who experienced each behaviour on every shift. The graph shows clear differences in BtC experienced every shift, particularly with screaming/crying out (69.6% direct distribution versus 42.4% postal distribution) and physical aggression (46.4% direct distribution versus 18.8% postal distribution).

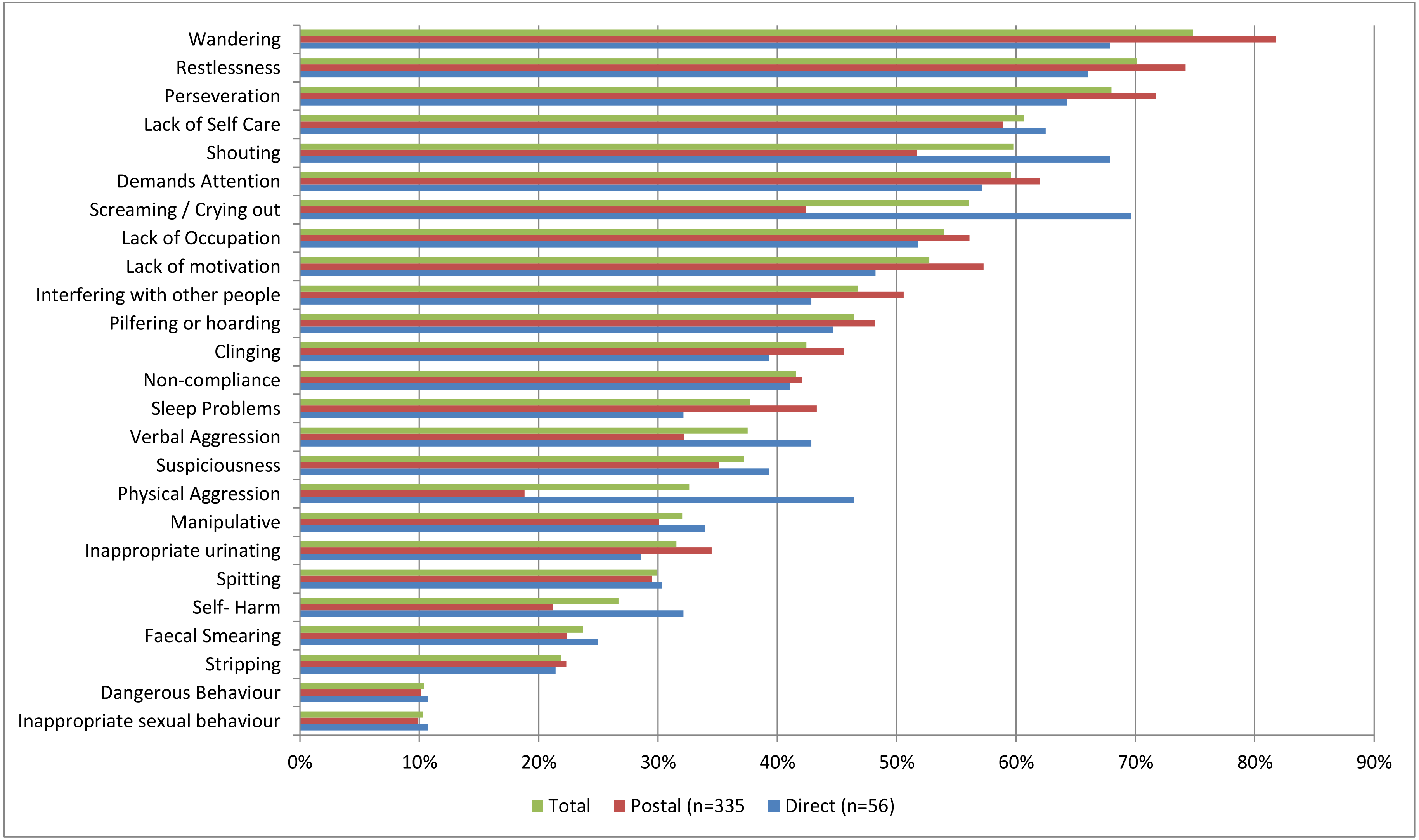


Figure 5.6 Proportion of respondents from each method who reported experiencing each behaviour on every shift

In rating BtC as difficult to manage, care staff from method (i) indicated that physical aggression had the highest mean score (3.4), and dangerous behaviour had the lowest mean score (1.9), however care staff from method (ii) indicated that self-harm and dangerous behaviour had the highest mean score (2.9), and pilfering or hoarding, and wandering had the lowest mean score (2.0). However it is interesting to note that only dangerous behaviour (i) and pilfering and hoarding and wandering (ii) received a mean score equal to or lower than 2, indicating that care staff appear to experience at least some level of personal difficulty in managing all of these behaviours. Figure 5.7 shows the mean score for each behaviour for both methods, with a combined total score. Using combined scores, physical aggression had the highest mean score (3.2), and sleep problems and dangerous behaviour had the lowest mean score (2.4). The scores for all of the other behaviours ranged between 2.5 and 2.8, suggesting that care staff do experience some level of difficulty in managing all BtC. The biggest differences in mean scores were evident in the reported ratings of screaming/crying out (mean score 3.3 (i) versus 2.3 (ii)), and dangerous behaviour (1.9 (i) versus 2.9 (ii)).

The data were combined for managers' (n=223) and non-managers' (n=164) ratings of each behaviour, and significant differences were found for five behaviours. These behaviours are displayed in Table 5.19, with managers' and non-managers' mean rating for each. It is noteworthy that in rating these five behaviours, managers' scores were all lower than non-managers', indicating that managers report finding these behaviours less difficult to deal with than non-managers.

Behaviour	**Manager Mean Rating**	**Non-Manager Mean Rating**	**p**
Physical aggression	**2.8** (n=210)	**3.2** (n=152)	p=0.034
Inappropriate sexual behaviour	**2.6** (n=127)	**3.1** (n=106)	p=0.013
Sleep problems	**2.3** (n=199)	**2.5** (n=128)	p=0.043
Non-compliance	**2.6** (n=191)	**3.1** (n=138)	p=0.032
Dangerous behaviour	**2.7** (n=89)	**3.3** (n=59)	p=0.003

Table 5.19 A comparison of managers' and non-managers' mean ratings of BtC

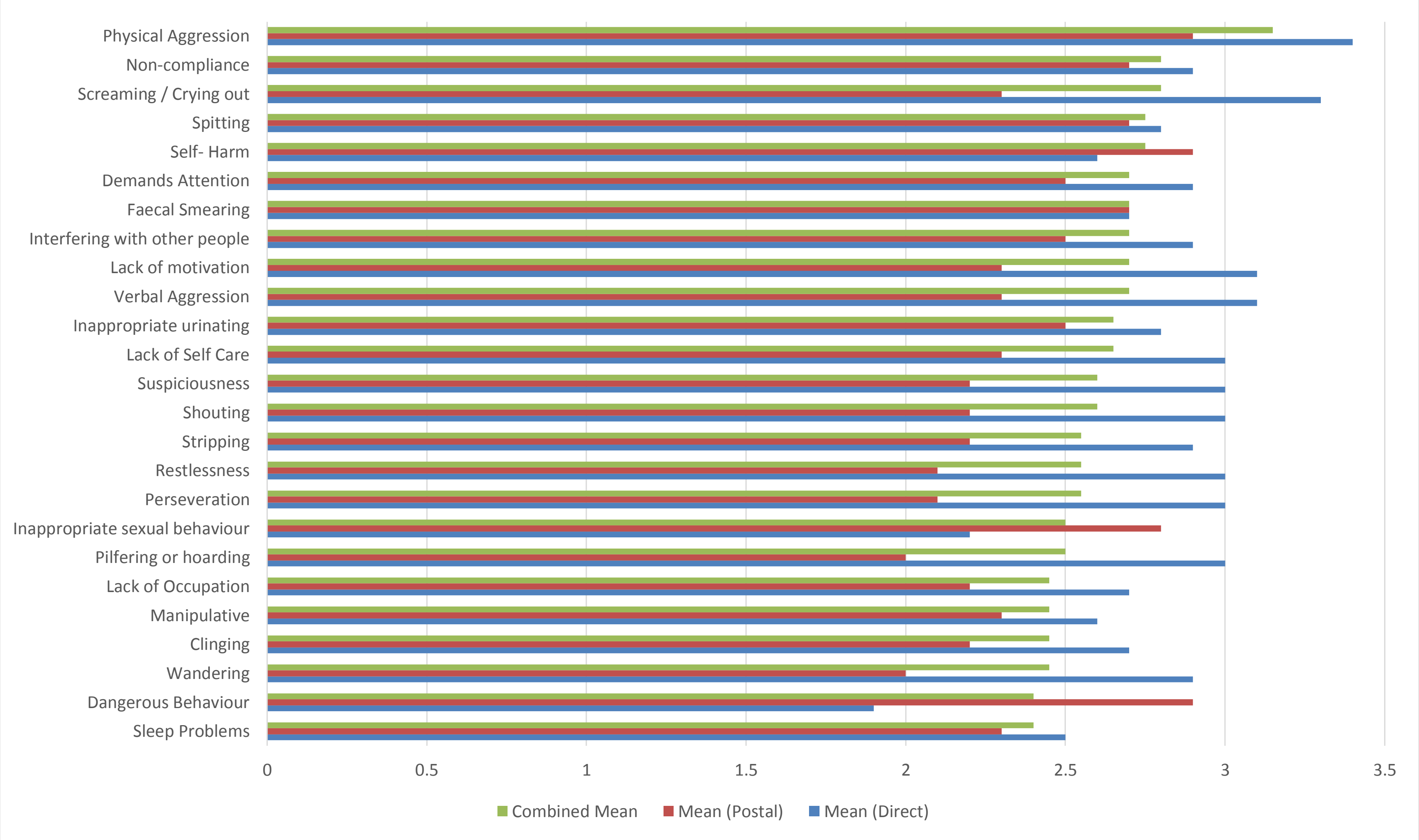


Figure 5.7 Mean and combined mean score for each given BtC for both distribution methods

Interventions

There was a strong level of agreement from respondents in both samples for seven interventions for which over 90% of respondents from both methods reported strongly agreeing or agreeing they were effective in controlling BtC. However there were different proportions who agreed with the intervention ‘Giving medicines that control behaviour’ (66.1% for method (i) compared with 37.7% for method (ii)). Data are displayed in Figure 5.8.

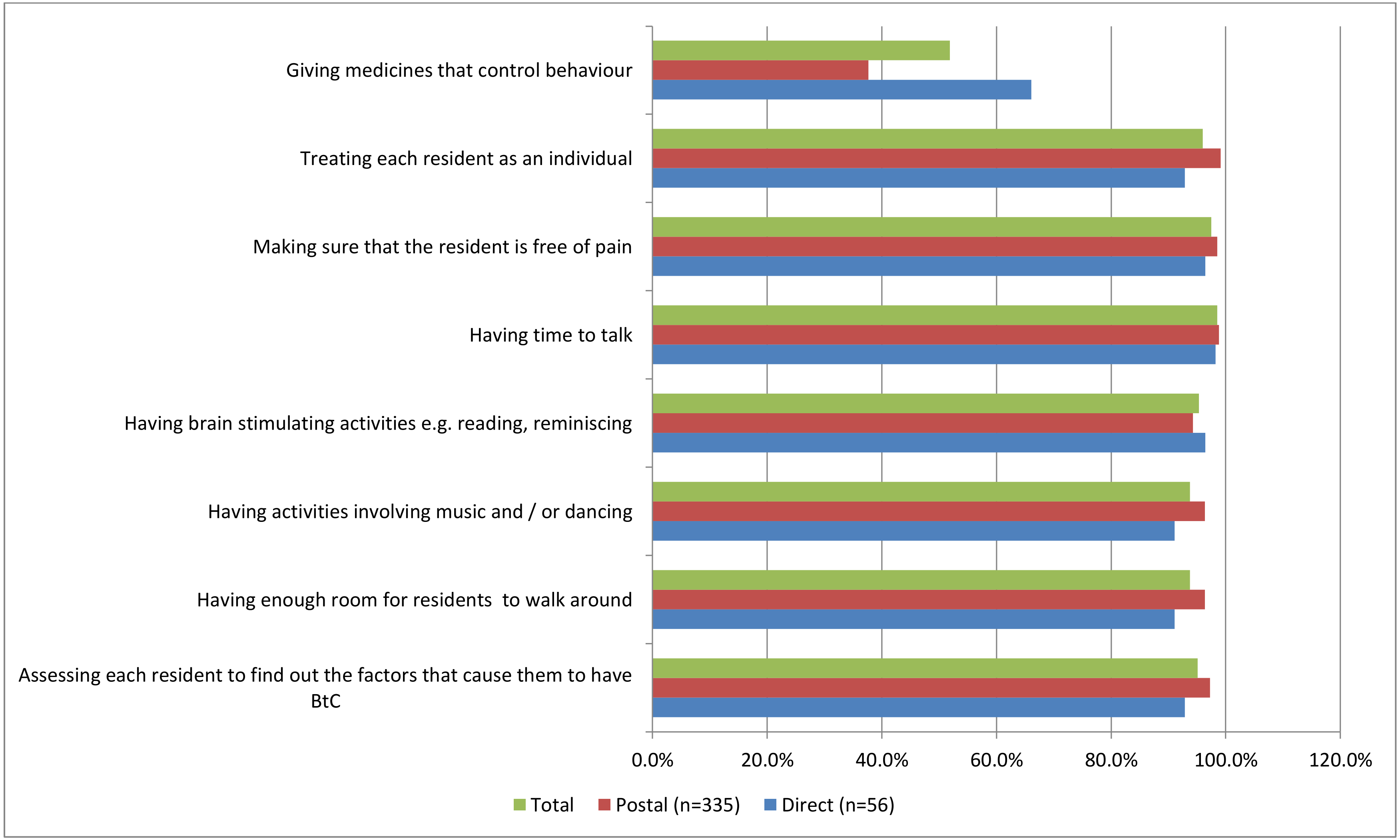


Figure 5.8 The seven interventions with which over 90% total respondents reported agreeing or strongly agreeing, compared with 'Giving medicines that control behaviour'

The combined data were used to examine the proportion of managers and non-managers agreeing or strongly agreeing with each intervention (Table 5.19). Statistical analysis of this data revealed only one significant difference between managers' and non-managers' agreement (Giving medicines that control behaviour, p < 0.0001).

Intervention	Manager	Non-manager
Assessing each resident to find out the factors that cause them to have BtC	217/222 (97.7%)	156/164 (95.1%)
Having clear signposting in the home to help residents find their way around the home	178/222 (80.2%)	144/164 (87.8%)
Having enough room for residents to walk around	210/222 (94.6%)	159/164 (97.0%)
Having separate rooms for different activities	157/222 (70.7%)	130/164 (79.3%)
Having activities involving music and / or dancing	213/222 (95.9%)	155/163 (95.1%)
Having brain stimulating activities e.g. reading, reminiscing	209/222 (94.1%)	156/163 (95.7%)
Aromatherapy	149/222 (67.1%)	110/163 (67.5%)
Massage	153/222 (68.9%)	116/163 (71.2%)
Having activities that stimulate all the senses	198/222 (89.2%)	147/163 (90.2%)
Having time to talk to people with dementia	218/222 (98.2%)	163/163 (100.0%)
Giving medicines that control behaviour*	67/222 (30.2%)	93/163 (57.1%)
Making sure that the resident is free of pain	218/221 (98.6%)	161/163 (98.8%)
Having animals for the resident	176/222 (79.3%)	117/164 (71.3%)
Treating each resident as an individual	219/222 (98.6%)	161/164 (98.2%)

Table 5.20 Comparisons from the combined data, between managers and non-managers agreeing or strongly agreeing with fourteen given interventions (* = p<0.0001)

Data from the combined sample for the intervention 'Giving medicines that control behaviour' indicated that 162 respondents (41.8%) strongly agreed or agreed with giving medicines that control behaviour (59/388 (15.2%) strongly agreed, 103/388 (26.5%) agreed). Nearly one third of respondents (127/388 (32.7%)) were neutral, while 99 (25.1%) disagreed or strongly disagreed (67/388 (17.3%) disagreed, 32/388 (8.2%) strongly disagreed).

A comparison of level of agreement (from respondents who strongly agreed or agreed) with the intervention 'Giving medicines that control behaviour', and other respondent demographics is displayed in Table 5.20. Significant differences were found between level of agreement and care worker role, hours worked, and CH registration. Unlike Table 5.9, there was no association between agreement that medicines were useful and: reported use of medicines to control behaviour; or staff role. There was no significant difference found between level of agreement and nursing role.

Comparison		Giving medicines that control BtC (strongly agree or agree)	P Value
CH Registration	Nursing	86/188 (45.7%)	p=0.010
	Non-Nursing	70/190 (36.8%)	
Nursing Role	Nurse	33/73 (45.2%)	p=0.592
	Non-Nurse	129/315 (41.0%)	
Care Worker Role	With Formal Qualification	55/89 (61.8%)	p< 0.0001
	Without Formal Qualification	107/299 (35.8%)	
Hours Worked	Full Time	128/333 (38.4%)	p=0.033
	Part Time	33/53 (62.2%)	

Table 5.21 A comparison of level of agreement with the intervention 'Giving medicines that control behaviour', and respondent demographics

Training

Fewer care staff from method (i) compared to those from method (ii) agreed that training was received (90.6% versus 97.3%), and that training helped (84.9% versus 94.8%). The opposite was found in the proportions reporting that they would like more training (85.0% method (i) versus 76.7% method (ii).

Results of both methods of distribution were similar, but overall training received was reported less frequently by participants responding to the direct distribution method. When the data was combined and tested for a difference between managers' and non-managers' responses to the three training questions, no significant differences were found. On the job training was reported to be the least attended training (23.2% (i) compared with 34.0% (ii)), while face to face training outside the CH was reported to be the most attended training (44.6% (i) compared with 67.7% (ii)). Similarly, on the job training was reported to be the least number of training hours received, while face to face training outside the CH was reported to be the most number of training hours received. Combined data from both methods are displayed in Table 5.21, and reflects the results from separate distribution methods: on the job training was reported to be the least attended training, and face to face within from the CH was reported to be the most attended training. On the job training was reported to be the least number of training hours received (median 3.0 hours), while face to face training away from the CH was reported to be the most number of training hours received (median 10.0 hours).

Training Type	n (%)	Mean number of sessions	n (%)	Median number of hours
Face to Face Away	225 (57.5)	3.31	228 (58.3)	10.0
Face to Face Within	226 (57.8)	4.35	222 (56.8)	6.0
Online	179 (45.8)	2.37	159 (40.7)	2.0
Written	202 (51.7)	2.73	159 (40.7)	6.0
On the Job	129 (33.0)	2.86	94 (24.0)	3.0

Table 5.22 Care staff reported sessions and hours for five given training types to help look after people with dementia who have BtC, over the previous five years

The training experience: A qualitative analysis

The quantitative data in this survey were accompanied by qualitative measures in the form of open questions; this combination of data provided a more comprehensive picture of the opinions and experiences of CH staff. Ninety-nine of the returned postal surveys and seven of the returned direct distribution surveys had comments about the training respondents had received. These comments have been included in this work as they complement the survey data by illustrating respondents' desire to further elaborate on their responses to closed questions. These data were analysed together. The majority of respondents were care workers. The question asked of respondents was:

'Have you any other comments about the training you have received?'

In total, 106 respondents answered. Of these, 68 were managers or nurse-managers, nine were nurses, 18 were care workers with formal qualifications, four were care workers without formal qualifications and seven had other roles. This question gave rise to comments regarding the perceived usefulness of any experienced training. Opinions were largely mixed: while reported positively by a large number of staff, further opportunities were taken to describe their training or offer opinion on the current state of training for care staff. Themes emerging from the data included the positive training experience, training variability, experience versus training, and inadequate training provision. The following section describes each theme in turn, incorporating verbatim transcripts of respondents' answers, to validate the interpretations.

The positive training experience

Fifty four respondents reported a positive training experience. They were generally pleased with the content, duration and support from their training sessions. Staff reported renewing their skills frequently, and reported attending a variety of training, including diploma courses, dementia care mapping, accredited training, e-learning, dementia specific training, Dementia Care Matters, Alzheimer's Society training courses, local council training, National Health Service (NHS) courses and aromatherapy diplomas. Training sessions were well received, with staff commenting that they were '*very good, person specific and realistic*' (Manager), and enabled staff to '*become more knowledgeable and gain more experience to take care of residents*' (Nurse). The majority of respondents reporting positive training experiences suggested that their training was '*constantly ongoing*' (Other), and '*progressing all the time with new evidence*' (Manager). These respondents reported loving *'working in dementia care'* (Manager), '*providing excellent dementia care'* (Manager/Nurse), and providing a '*very high standard*' of '*continuous'* and '*interesting'* dementia training (Manager). One manager reported liking '*any training that will help us to care for our dementia residents better with the dignity and respect they deserve. We will do any training that will help*' (Manager). Respondents also reported acknowledging the importance of training: '*I strongly agree that training for staff to help them cope and understand why there may be challenging behaviour is important'* (Manager), '*I think all staff in all care homes, up and down the country need to do the same training*' (Care Worker with Formal Qualifications), '*training is essential because it help the staff to learn how to face challenging situations'* (Care Worker with Formal Qualifications) and '*training is probably the key to dementia care'* (Other).

Training variability

Five respondents reported a varied quality of experienced training sessions, '*training standards vary considerably between providers and therefore the approach and atmosphere in each home will be different'* (Manager), with some staff reporting initiating training for themselves in order to manage the challenges of their job, '*most of my training has been initiated by myself as I find dementia a fascinating subject'* (Manager). Training was reported to be provided by a variety of sources including outreach teams, mental health teams and even research papers '*receiving new information about recent studies*' (Care Worker with Formal Qualifications).

Experience versus training

Thirteen respondents stated that experience of working with BtC was more beneficial than training, '*all good on paper but (it) depends on the mood of a dementia sufferer; (their) mood changes'* (Manager), and '*every day is a learning curve'* (Manager). The importance of experience was stressed by care staff, particularly hands on, and learning from colleagues: '*the best knowledge…comes from experience and from others, not written courses (or) training'* (Other), and 'a *massive amount of training…doesn't prepare you for what it's like hands on. You build up…knowledge with the experience you have gathered over years*' (Other). The importance of sharing acquired knowledge with colleagues was noted, with respondents stating that they '*try to lead and teach by example, from knowledge and experience'* (Manager/Nurse), and learning '*techniques for dealing with individual people and sharing these with the rest of the team'* (Manager), particularly needing to '*pass on tips on how to manage difficult behaviour'* (Nurse). While some care staff declared on the job training to be '*very helpful'* (Care Worker without Formal Qualifications) and 't*he best way, as you can learn whilst dealing with difficult situations'* (Manager), other staff reported no amount of training being helpful, '*it's all about learning on the job*' (Nurse), and '*no members of staff can work with BtC unless they have had previous experience*' (Other).

Inadequate training provision

Thirty-three staff discussed inadequate training provision. Staff reported finding it '*difficult to access'* (Manager) appropriate training, and obtaining places on training courses: *'I find training difficult to source'* (Manager). Other care staff found it difficult to remember any of the training they had received. One respondent reported that one particular training experience had been a '*complete waste of time…centred around me not being affected by the behaviour rather than management and diffusing the behaviour*' (Manager). Many staff reported experiencing an inappropriately focused training session, '*a lot of training focuses on the earlier stages of dementia and not the very advanced stages with significant behavioural manifestations which our residents experienced*' (Manager/Nurse). Other staff felt training was generic and focused on '*dementia awareness'* (Care Worker) rather than '*specific behaviours that challenge'* (Manager). Training was reported by some respondents to be '*too vague'* (Manager) '*not always appropriate'* (Care Worker with Formal Qualifications), '*very brief'* (Care Worker with Formal Qualifications) and '*not always centred to the service users' needs'* (Care Worker with Formal Qualifications). One member of care staff reported currently reviewing training '*in the field*' (Other), but reported already delivering detailed training sessions, because '*most training concentrates on triggers and not what to do when it happens*' (Other). This was supported by another respondent, reporting '*training often focuses on managing behaviours rather than recognising and preventing (their) onset*' (Manager). Care staff reported being '*too busy'* (Care Worker with Formal Qualifications) for on the job training, rendering it '*inadequate'* (Care Worker with Formal Qualifications).

Other respondents suggested that looking elsewhere for training help was required, either because no bespoke training was readily available, or training by the mental health team was frequently cancelled due to limited resources. Linked to this, respondents reported requiring more funding for training provision, due to tight budgets and CHs struggling *'to pay for good quality training'* (Care Worker with Formal Qualifications). Training was reported to be expensive, and one manager suggested that '*the government must pay a liveable wage for the staff…with no* *funding or incentives we cannot up our staff levels'* (Manager). Four care staff reported wanting more training, that it was needed and would be '*more helpful'* (Nurse), in particular '*we need more insight (into) how a person with dementia sees his or her world'* (Nurse). One respondent felt '*undertrained'* (Care Worker with Formal Qualifications) with regard to BtC, while a manager felt that the CH in which they worked '*DO NOT have the appropriate training*' provided by their company (Manager). Comments such as '*one size does not fit all'* (Manager) and '*each behaviour has a trigger specific to the individual and not easily rectified by a 'one size fits all' training package*' (Manager) describe the difficulties CHs have in providing appropriate and adequate training.

These data suggest that those respondents reporting positive experiences of training acknowledged its importance and received a high standard of well-presented and meaningful training sessions. However, many respondents felt that their training experiences had been inappropriately focused, inadequately funded or inaccessible, and that experience in managing BtC was equally, if not more beneficial than training.

Discussion

This survey aimed to explore the views and experiences of CH staff of BtC through a self-completed survey, therefore creating a picture of the current climate within English CHs with regards to BtC, medicines use and staff perspectives on non-pharmacological interventions. While the low response rate and the required estimation of resident populations by CH staff limit the conclusions that can be drawn, the data obtained has met these aims.

Response rates to varying distribution methods differed: The direct distribution method (i) elicited a greater CH response rate than the postal method (ii) (31.5% CH response rate compared with 24.8%), however a greater proportion of respondents to the postal survey were managers (64.5% of all respondents) compared with the direct distribution (14.3%).

The results from this study have indicated a lower proportion of residents with dementia, who have BtC than other studies in the literature (51% method (ii), compared with 79% BtC in residents with dementia [77], however it is accepted that prevalence estimates vary widely [161]. There is little evidence pertaining to how frequently care staff encounter BtC, however results from this study are in line with Backhouse et al [81], in particular, that physical aggression was most frequently cited as the behaviour CH staff found very difficult to manage. Backhouse et al [81] found that half of CH staff reported experiencing an episode of BtC within the previous week; in this study, nine behaviours were reported by over 50% of care staff to be experienced during every shift. In addition, Backhouse et al [81] stated that NPIs were reported to be used in 87% of CHs. Data from the present study supports this finding, if it is assumed that care staff have used the interventions they reported to find useful in managing BtC. Backhouse et al [81] aimed to determine the prevalence of antipsychotic use in people with dementia living in CHs, and estimated that 73% of CH managers reported having at least one resident with an antipsychotic prescription, and 12% of residents were reported to be prescribed antipsychotic medication. Additionally, Child et al [82] reported that 15.3% of people on the UK dementia register from 59 GP practices were receiving a low-dose antipsychotic, however acknowledged that this may be an underestimation. This study supports both Child et al's and Backhouse et al's findings, with 17.4% of residents reported as being prescribed medicines for BtC. Additionally this study builds on other studies by focusing on 'medicines' as opposed to solely antipsychotic medicines.

Data from this study suggest that there is still a high reported rate of medicines use for BtC in dementia in English CHs. In addition, the opinions of care staff vary, and appear to be related to a variety of factors, including the frequency with which medicines are used. However, it is not clear as to the cause and effect of this relationship. Results highlight that opportunities still exist to optimise medicines management in CHs, given that the reported rates of medicines use appear to be related to the frequency with which medicines are used: further investigation is warranted.

One of the clear findings from this study is that BtC is still very present - and challenging - for care staff in English CHs: the high reported rate with which staff experience BtC suggests this. Moreover, the high reported frequency of such behaviours suggests that care staff are faced with these behaviours on a regular basis, reporting that many behaviours occur during every shift. It is noteworthy that only one behaviour from the list of 25 received an overall rating score of less than 2 for difficulty in managing, which suggests that staff do feel some level difficulty in personally managing BtC in people with dementia. When the data were combined for managers' (n=223) and non-managers' (n=164) ratings of each behaviour, significant differences were found for only five behaviours. Therefore clearly for the majority of behaviours, care staff and their managers report similar challenges. However, the results of the postal distribution survey indicated that for those behaviours experienced every shift, significant differences were found for five behaviours, and the frequencies were all higher in non-manager respondents. This is perhaps unsurprising, given non-managers' resident-facing roles, but is remarkable nonetheless. This is an important issue to address, and could suggest that further training for care staff in managing BtC is necessary to reduce the difficulties felt by staff in this area. In particular, those behaviours with the highest ratings may warrant the most attention in training courses. More in-depth research is required to address why care staff feel that BtC are personally difficult to manage, however that is not within the remit of this study.

Over 90% of total respondents strongly agreed or agreed with seven of the fourteen listed interventions, indicating that care staff believe that a variety of NPIs could be useful in helping people with dementia, exhibiting BtC. It is noteworthy that 41.8% of the total respondents reported strongly agreeing or agreeing with giving medicines that control behaviour to manage BtC, however it was interesting to note the difference between managers' and non-managers' levels of agreement (30.2% managers versus 57.1% non-managers ($p < 0.0001$). This could be due to a number of factors and may warrant further investigation. Indeed, the data suggest that part-time workers, non-qualified staff and those in residential CHs are more inclined towards using medicines to manage BtC. Perhaps more training for non-managers may be beneficial; however conceivably CH managers were overly cautious in answering this question, given that the purpose of the study was to ascertain the number of people being prescribed medicines for behaviour: guidelines state that pharmacological intervention should be attempted only after NPI has been employed.

Certainly when asked about training, 71.4% of managers either agreed or strongly agreed that training had been helpful, compared with 87.0% of non-managers in method (i). For method (ii) 93.5% of managers either agreed or strongly agreed that training had been helpful, compared with 97.3% of non-managers, and 76.8% of both managers and non-managers agreed or strongly agreed that they would like more training. However, there were a higher proportion of managers in the postal sample, so fewer wanted more training in comparison to the direct distribution sample.

It was apparent that a strong level of agreement was reported by care staff both that training had been received and that training had helped staff care for people with BtC, yet over 75% felt they would like more training. One hundred and six CH staff responded to the open questions regarding training. Approximately half of these (50.9%) reported a positive training experience and were generally pleased with the content, duration and support from their training sessions, however approximately one third of these (31.3%) discussed inadequate training provision. Face-to-face training outside the CH was reported to be the most attended training, providing the most number of training hours received, while on the job training was reported to be the least attended training, and was the least number of training hours received. This may suggest that care staff either do not receive 'on the job' training, or do not perceive that they do. This is supported in part by the qualitative data, where some care staff reported being '*too busy*' for on the job training, rendering it '*inadequate*'. However other care staff declared on the job training to be '*very helpful*' and '*the best way',* suggesting that training perceptions and experiences are mixed.

Results suggest that the training of the care workforce is present, and does help care staff to manage BtC in dementia. However, that over three quarters of respondents reported wanting more training raises questions as to the content of the training experienced and its relevance to care staff's everyday needs and encounters with residents: this may warrant further investigation. When commenting on their training experiences, care staff opinions were mixed, and data suggest that care staff experience a variety of standard, frequency and support in their training. Those staff reporting positive experiences of training appeared to deem it important, and reported receiving very good sessions. However, there were many respondents who deemed their training to be inappropriately focused, if it was accessible at all. Funding was reported to be an issue and some respondents felt that experience in managing BtC was equally, if not more beneficial than training.

The data show that CH staff experience difficulty in managing BtC, and additionally that there is a desire for more training by over three quarters of respondents. The data found no significant difference between any of the training-related questions and manager – non-manager roles.

There were some missing data on the returned surveys. This could be due to respondents having a misunderstanding of the question, a reluctance to divulge information, a lack of time, or respondents making an error.

The objectives of this study were to measure CH staff's: experiences of BtC; views on what helps manage BtC; and experiences of training they have received for BtC: the data and its analysis suggest that these objectives have been met.

Strengths and limitations

CH researchers can encounter numerous problems and barriers to their research, not least because the CH population is generally under researched. The care workforce is a busy one, and care staff may not have had the time, or willingness to complete the surveys. The low response rate of 25.1% is reflective of the characteristically low response rates in this kind of research [81, 162, 163]. The data relied upon the self-reporting and estimations of care staff, who may have wished to portray their workplace and job in a particular light. The stigma associated with the overprescribing of antipsychotic medication may have led to inaccuracies in reporting approximate levels of medicines use and there is no way of verifying these data. The survey successfully elicited important information from this population, however, the results must be read cautiously. The input of free text responses on the returned surveys highlight that in part, CH staff appear willing and eager to communicate their opinions with those who are interested in them.

The cross sectional survey enables large numbers of people to be contacted quickly and efficiently, and is easy to standardise since each respondent is asked the same question in the same manner. Therefore I was assured that each participant has answered exactly the same question, increasing the reliability of the survey method. Ethically, while surveys can be used to explore potentially distressing topics, they do not expose individuals to invasive techniques or questioning, and participants are able to remain anonymous and can complete the survey in privacy, increasing the chances of respondents answering more honestly. However, the format of the survey renders the researcher limited in exploring complex issues and opinions in detail, even where open ended questions are included. In addition, the researcher is unable to be absolutely sure that both the respondent filling it in is the required target, and that the respondent has understood the questions properly. In this study, the questionnaire was piloted to avoid the problem that the questions asked meant the same to all respondents. Finally, a low response rate may indicate that only highly motivated participants from the sample responded. An NIHR methods review highlighted potential low survey response rates and difficulties recruiting CH staff to participate in research, and therefore multiple contacts by different means were suggested [132]. Face-to-face contact was cited as the most helpful strategy for gaining research access to American nursing homes [133], and this study supports that notion, with a higher CH response rate using the personalised direct distribution method. However, the data using this method presents real difficulties in calculating the number of residents with dementia, BtC and medicines. There was a wide variation in responses from different staff working in the same CHs. This is a limitation of the data, since it is self-reported data and so may not be accurate, and cannot be verified. In the direct distribution method, inconsistencies in the reported data were noted; in the postal distribution method only one response was received per CH but there may still have been a similar level of variability. The cross-sectional design of this survey method provided us with a snapshot of reported current care practices, and care staff views and experiences, from widely dispersed participants. The respondents are representative of the CH population, and findings can be used to draw conclusions about the CH population. However, the sampling frame chosen for this study was taken from the CQC website, which, given some of the correspondence from non-participating CHs, we now know to hold some factually incorrect data. In addition, CHs in Kent and one in Lewisham were excluded from this study. Additionally, if surveys ask only closed questions, there is very little opportunity for misinterpretation of the meaning of answers, since they can inform us of quantitative measures (in this case, experienced BtC, frequency of BtC, interventions perceived to be helpful, etc.), but can be limited in the information they provide as to why respondents feel the way they do. By introducing open-ended questions, this survey sought to limit this disadvantage where possible. Surveys are generally low in validity since they do not explore complex areas in depth, and as such there is limited scope for respondents to qualify or explain their answers. However, in remaining anonymous, respondents may feel confident in answering questions truthfully, therefore increasing the validity of their responses. In combining data from both postal and direct distribution methods for distributing surveys, the validity of participants’ responses was increased.

Chapter 6 Care in Practice:

An Ethnographic Study

Introduction

Chapter Three outlined the rationale for the design of this phase of the work. This chapter provides: the sampling and development; interview process; data analysis strategy; findings, and a discussion of Phase Three - Care in Practice: An Ethnographic Study. Phase One of this PhD study aimed to explore how different CHs manage BtC, through interviews with CH staff and quantitative measures of the CH environment. Themes emerging from the interviews consisted of 'causes of BtC', 'knowing the resident', 'the CH family' and 'the home-like environment'. These themes were used to inform and develop this third phase of the study, which aims to explore how CHs manage BtC in practice, and an ethnographic approach was chosen. Participant observation was chosen in order to obtain a better understanding of the management of BtC in practice. In addition, personal record data and CH-documented incidents of BtC involving participating CH residents were collected.

Aim and objectives

The aim of this phase of the study was to explore and observe how three CHs manage BtC in practice. The objectives for this phase were:

- To explore the antecedents, behaviours exhibited and consequences of incidents of BtC, exhibited by CH residents with a diagnosis of dementia, occurring in practice, in three CHs.
- To investigate the CH-recorded incidents of BtC exhibited by residents with a diagnosis of dementia.
- To observe and record how staff manage incidents of BtC exhibited by CH residents with a diagnosis of dementia.

Ethical approval

Ethical approval for this phase of work was sought from and granted by the Social Care Institute for Excellence Research Ethics Committee (SCREC). The SCREC reviews social care research in sites in England, social care research involving people lacking capacity to consent and requiring approval under the Mental Capacity Act 2005 [164], and research which uses social science or qualitative methods, and does not involve any change in treatment or clinical practice. The SCREC is recognised by the Secretary of State as an appropriate body for this purpose. Approval from the National Research Ethics Service Research Ethics Committee (NRES) was not chosen for this study since NRES is not constituted to review social care research, and the Health Research Authority is a non-departmental body set up without responsibility to social care. The full protocol and supporting documentation (14-IEC08-0020) is attached as a supplementary booklet (Booklet 1).

Sampling strategy

The initial target population was three CHs previously recruited to Phase One of the study, and this phase intended to recruit three groups from one dementia unit within each CH:

1. **Staff** – patient-facing staff working in the chosen dementia unit at the CH (up to 10 staff (approx. 5 staff per shift))
2. **Residents** – residents living in the chosen dementia unit at each CH (up to 20 residents (all residents in one unit of the CH)):
3. **Consultees of Residents** – Consultees (a person who has a role in caring for the person who lacks capacity or is interested in that person's welfare, but is not doing so for remuneration or acting in a professional capacity) of residents living in the chosen dementia unit at each CH (up to 20 consultees, if required (one consultee per resident)).

Recruitment

The choice of CH settings for this study was purposive, whereby the idea was not to choose settings in order to generalise a whole population; rather to select three CH settings informed by prior knowledge and work from Phase One of this study, which were likely to demonstrate salient features and events or categories of behaviour relevant to the research questions. Three CHs were deliberately selected because they provided three different perspectives, which would allow a contrast and comparison of their approaches to care. Each dementia unit housed approximately 20 residents.

CH Six (CH6) is a dementia specialist private CH with nursing, on a purpose built site, providing multi-disciplinary, 24-hour care. It employs 89 carers and nurses, for its 89 residents, of whom 55 have varying degrees of dementia. Twenty beds are available on the dementia unit, and five staff members, made up of four carers and one nurse, are assigned to the dementia unit per shift. The CH was the largest of the three selected homes, and cares for the most number of people with dementia.

CH Eleven (CH11) is a dementia specialist CH with nursing, formally part of the NHS but now owned by a social enterprise. It provides 24-hour continuing care for all 39 of its residents, who have dementia and high care dependency needs. Forty beds are available over four wings: for my research in this CH, one dementia unit consisted of two adjoining wings of 10 beds per wing. The CH employs 50 staff, with approximately six staff members assigned to a unit per shift. Referral of patients into CH11 is only via the NHS continuing care and funded service.

CH Two (CH2) is a privately owned dementia specialist CH with nursing. It houses a total of 51 residents, all of whom must be over the age of 60 years to be admitted. Thirty-three beds are reserved for dementia nursing, split over two floors. It employs 53 staff, and four or five care staff are assigned to the dementia unit per shift. CH2 adopts a specific programme of care, which is conducted daily. This programme is designed to improve the quality of life for people with advanced dementia and aims to 'honour the spirit within'.

This study aimed to compare and contrast CHs with and without nursing. As such, a CH without nursing was also selected to participate in the study, and the manager agreed to participate. However, the research could not be conducted, since it was not possible to recruit sufficient numbers of CH staff to participate in the study. Additionally, seven other CHs recruited to Phase One of the study were approached to participate and all declined. This is discussed in further detail in Chapter Eight: 'Care Home Recruitment: Obstacles and Outcomes'.

With each CH manager's support, one week prior to the first research visit to each CH, I attended one of the monthly-scheduled staff-consultees-residents meetings, in order for the residents, their consultees and CH staff from the manager-selected dementia unit to meet me, hear about the study, and ask any questions or share any concerns they had. No concerns were expressed at these meetings; however questions were asked which gave me an opportunity to reassure CH staff in particular. At each meeting, individualised participant information sheets and consent forms were available to staff, residents and consultees (Booklet 1, Appendices 1-9).

Methods for obtaining informed consent from CH managers, staff and residents, in addition to the assessment of capacity to consent, are detailed in the study protocol (Booklet 1, p.11-20).

Managers and staff at all three participating CHs were involved in Phase One of this study, and participated in interviews with the researcher, regarding their views and experiences of managing BtC in dementia. As such, both staff and managers at these CHs were prominent in providing their opinions on the design and details of this project, and supporting statements were provided by the manager of each CH. In each CH, one dementia unit made up of approximately 20 residents was selected with the help of the CH manager, in which I could carry out my ‘participant as observer’ research.

Working in the CH

This ethnographic study involved me undertaking voluntary work in three CHs, over a period of between three and five weeks per CH. I was treated by each CH as an unqualified, new member of staff, and was under supervision at all times. As such, I provided care to CH residents in one dementia unit, in accordance with CH protocols for new members of staff. Effectively an employee of the CH, I was bound by their rules and regulations, and had a duty of care to residents in accordance with my own submitted ethical protocol. As a result of this, there was minimal risk to me, the residents and staff. Details of activities and tasks undertaken are described in the findings. It is possible that participant observation can lead to possible conflicts of interest; ensuring participants were aware of my dual role was an important aspect of the study. Therefore I overtly adopted the role of participant as observer to minimise interference with these interactions and activities. For those staff, relatives and residents who did not consent to take part but who were still present in the unit, and who questioned my presence, I openly and honestly informed them that I was a university student, who was working at the CH, specifically to learn and research how CHs look after people with dementia in order to be able to complete my PhD.

Observations

Specific observations

Observations of episodes of BtC were carried out in each CH, over varying shift patterns: these ranged from 8am-2pm, 2pm-8pm and 8pm-7am. The hours worked are discussed in the findings. During the observations, no notes were recorded on site, however at the end of each shift, and at a location away from the CH, I wrote field notes detailing the observations of BtC made over the course of the shift. These notes were a document of the incidents of BtC observed, stating the antecedents, behaviours and consequences (ABC) [165] of the behaviour, in addition to how each behaviour was managed. This involved noting any perceived antecedents to incidences of BtC, as defined by Moniz-Cook [20], the incidents of BtC, and the ways in which staff and residents responded to BtC and finally any interactions that took place involving consenting participants present as a consequence of the BtC.

General observations

In addition to making specific observations, I wrote a reflexive diary entry after every shift, detailing my thoughts and feelings in addition to the work I had done that day. This allowed me to reflect on my experiences and attitudes over the course of the shift, and think about whether incidents of BtC had occurred as a result of an unmet need, frustration or staff approach to behaviour – as suggested by CH staff in the interviews – and finally to think about my contribution to the CH.

Behaviour and personal history records

From the interviews conducted in Phase One of this study, it was identified that CHs keep records of incidents of BtC. During this phase of work, I had limited to access to CH records because of the limitations of my ethical approval. The CHs in this study kept two files for each resident: a care plan file, which detailed the resident's care plans, and a general file, which held the resident's medical records, charts and GP notes, behaviour reports and life histories. As such, I had access only to the general file, and therefore I searched these files for each participating resident, gathering any data pertaining to incidents of BtC as described in residents' notes. In addition to this, I also collected data on residents' biographies through notes taken by the CH, in order to attempt to provide you, the reader, with an overview of the residents I helped to care for, and who were integral to this research. This also allowed me to determine any differences between CHs in how and what they record with regard to residents' personal histories. The collection of these data was carried out throughout the periods of observation, usually at the end of my shifts.

Confidentiality and anonymity

All CHs and participants remained anonymous throughout the course of the study. Staff, residents and relatives participating in the study are associated with the CH that they are involved with, for the purposes of describing the CH as a unique entity.

Each CH was allocated a study number and any personal, identifiable information about residents had names replaced with pseudonyms, so that participants could not be recognised. Participating staff and consultees had names replaced with codes, in order to identify them for analysis purposes. Lists of pseudonyms and codes were written on paper and locked in a filing cabinet. No computer records of these lists were made, and these lists were used only by named members of the research team. These lists were shredded once data analysis was complete. All consent forms were stored in a locked filing cabinet. Study data contained no personal identifiable information and is thus anonymous; however it is possible that staff may recognise their own contribution to the observations identifiable by the work they carry out in any future reports. All data collected was stored on password protected computers and memory sticks. Confidentiality would have been broken if I had identified that residents or others were at serious risk, however this was not necessary.

Data analysis

Observations

Observational research relies on the researcher to act directly as the research instrument, and therefore the quality of observational studies depends more than most methods, on the quality of the researcher, who has a particular responsibility to provide detailed descriptions of data collection and analysis [137]. Field notes of observations contained detailed, highly descriptive accounts of hours of watching, listening and taking part in events, actions and conversations pertaining to incidents of BtC occurring within the dementia unit of three CHs. The analytical process involved sequential analysis, whereby analysis began during the data collection phase, in order for the data to feed into the ongoing data collection.

Chapter Four presented four emergent themes from interviews conducted with CH staff, who discussed their views and experiences in managing BtC. Observed incidents of BtC were analysed using codes: the management strategies used in each incident of BtC were coded with respect to the four themes that emerged from interviews with care staff (Chapter Four):

- Causes of behaviour (C) – that BtC has a cause, and is a consequence of something else. This ‘something’ could be a resident’s inability to express their needs or problems; an illness or pain, like a urinary tract infection, or a headache; a social problem, like not being able to find their handbag, or that someone has taken their newspaper; or worry, or fear, possibly of having personal care, being confused, or just not knowing where they are.
- Knowing the resident (K) - the significance of CH staff knowing who they are caring for, and acknowledging that all residents are different in order to provide individualised and person-centred care.
- The CH family (F) – the CH team, made up of a number of people, including managers, colleagues, receptionists, pets, relatives and often outside support including social services and other local mental health teams.
- The home-like environment (E) – the CH is the residents’ home, in which they feel safe, secure and in a familiar environment.

Behaviour and personal history records

Any notes kept by the CH documenting incidents of BtC involving participating residents were transcribed verbatim. These records were held in residents' individual files, with dates which ranged from March 2013 to January 2015, however not all notes were dated. This varied between CHs, and therefore notes of any kind pertaining to incidents of BtC involving these residents were searched for and recorded. These notes were used to analyse how the CH recorded incidents of BtC, the types of BtC that were recorded, and how staff documented managing BtC. This was compared with my own observations.

Residents' personal history records were used to create resident profiles, which aimed to make the person more alive and present to you, the reader. It also allowed me to illustrate the differences between CHs in how and what they recorded with regard to residents' personal histories. Any notes made by the CH pertaining to residents' personal history were transcribed verbatim into a table created for the purpose of this study, and formatted prior to inserting in this chapter. The table was taken from 'Lifelines: visualising personal histories'[166], and included categories pertaining to residents' medical, financial, education, work, hobbies and legal background.

Case studies

By triangulating findings through combining methodologies from both this phase and Phase One (Chapter Four - Interviews with Care Staff), you, the reader are provided with a synthesis of the data collected from each CH, which, supplemented by my reflexive notes, captures the empirical world of each CH in full complexity [167]. These case studies therefore have developed through a combination of various methods, data collection techniques and reflexivity.

Findings

Twenty-four care shifts were worked in a total of three CHs. Ten shifts were conducted in CH6 between September 2014 and November 2014, eight shifts were conducted in CH11 between December 2014 and February 2015, and six shifts were conducted in CH2 between March 2015 and April 2015. The duration of the shifts ranged from seven hours to 12 hours. A range of shift patterns were chosen in order to observe as many different situations as possible. I worked on different days of the week and at different times of the day, including early mornings, afternoons, evenings and nights. I completed a total of 204 hours of care work over a period of twelve weeks.

Twelve residents were recruited to the study: one resident gave consent, while ten residents' families and one resident's best friend gave assent for their relative/friend to participate. Seventeen staff members were recruited to the study. Participants recruited and working patterns are displayed in Table 6.1.

	Participants			Working patterns				
	Residents	**Staff**	**Consultees**	**Number of Weeks**	**Number of Shifts**	**% Shift Patterns**	**Number of Hours**	**Average Hours**
CH6	7	8	7	5	10	2/3 (66%)	80	16h/week
CH11	3	5	3	4	8	5/5 (100%)	64	16h/week
CH2	2	4	1	3	6	2/3 (66%)	60	20h/week
Total	12	17	11	12	24		204	

Table 6.1 Participants recruited to and working patterns in Phase Three

Participant as observer

Participating in the daily running and work of the CH allowed me to feel less intrusive and able to more easily conduct observations due to often being involved when BtC occurred. I supported CH staff with a variety of tasks, including assisting residents with feeding and drinking, helping to change residents' clothes, assisting CH staff with giving residents a bed bath, serving drinks, tidying the CH, washing up, folding laundry, delivering laundry to residents, assisting residents on trips away from the CH, knitting and other 'activity' related duties, assisting CH staff in taking residents to bed, cleaning and laying tables. By generating close relationships with staff, residents and relatives I was able to bear witness to some of the issues they faced day-to-day, and was sometimes able to assist. There were of course tasks that I was unable to assist with, and these were medicines administration, manual handling and personal care including washing and toileting residents. In completing this research as participant as observer, I acquired real world experience of three CHs: I documented every shift I worked in a reflexive diary; an example entry is displayed in Figure 6.1.

I arrived at the CH at 8am. There was a team briefing, before I chatted to the staff. They seemed unhappy today about the demands on their job, including being underpaid, despite their self-reported wealth of knowledge. They felt unappreciated by management, and mentioned that should they wish to leave, it would be agreed to by the manager, and no incentive would be offered to stay. The staff appeared grateful for my time and efforts in helping and volunteering in the CH and seemed enthusiastic about participating. After briefing I conducted 15 minute observations of seven residents. I felt nervous about doing this because the unit is very high dependency and lots of the residents are unwell. Many stayed in bed until at least 2 pm when I left. After 1 hour I was asked to sit in with a resident who had been forced to stay in bed with the bed rails up because he had tried to get out of bed himself and had fallen. He is on the list as a falls risk. He didn't appear to have injured himself and appeared quite happy in bed although I was warned that he could become aggressive and that I was to persuade him to stay where he was. I had no problems with this resident and chatted to him although he cannot communicate clearly or coherently for the most part, however he did appear to understand some of what I was talking about although he did not appear to retain any information. After the nurse came in to covertly give him his medication I was asked to sit with another resident who was in bed. He is also at increased risk of falling hence I was asked to sit with him until he woke up. This particular resident is able to ambulate slowly supported by a frame. I sat with this resident for 1 hour and he woke and slept intermittently. I watered his plants and sat with him listening to classic FM. He woke and it was clear that he wears a pad in his underpants. He urinated into the pad however the urine leaked down his leg and onto the floor. This appeared to make him uncomfortable by way of his facial expressions - this resident cannot communicate clearly or coherently and does not appear to retain information. The care staff entered the room and I explained that this resident had soiled himself and the floor. They opted to try to change his clothes however they reported that this was not successful and I was informed that he had resisted, therefore the care staff chose to return at a later time. The resident went back to sleep and again I sat with him until he woke up approximately 30 minutes later. When the resident woke up again I was instructed to go and collect the first resident and wheel him into the second resident's bedroom where I sat with both residents. The second resident had, in that time, had a change of clothes. I sat with both residents before taking them into the dining room where we sat by window and talked minimally about varying things including the weather and garden. Much of this conversation was one-sided. This lasted for approximately 1 hour before lunch was served. I wheeled both residents to the table. Resident one was quiet and did not make much effort at conversation or speech during this time. Resident two however was distressed and repeatedly tried to stand up from his wheelchair. He requested to go home, requested to go out and appeared confused about his surroundings and why he was there. One care staff member asked him to tell her a story about 3 bears who ate porridge for breakfast - the resident then became later became distressed calling out that he wanted three bears. When dinner time started both residents ate their lunch: resident one was aided in eating his lunch which was pureed. Resident two was able to eat his lunch himself. Lunch was smoked haddock and mash with peas, with chicken soup to start and apple pie and custard to finish, and a glass of milkshake. Both residents then returned to sit by the window and we had minimal and incoherent conversation before the shift ended at 2 p.m.

Figure 6.1 Reflexive diary entry: CH6, shift 6

Residents' personal profiles

Details of residents' histories recorded by the CHs varied within and between homes: some had copious amounts of detailed information; others had relatively very little, or were specific to one area (medical history, for example). Four examples of these descriptions are included in Figures 5.2-5.4, to show contrasting records. Residents' names have been replaced with a pseudonym.

'Walter'

Walter was born in 1940: he is 75 years old and is married. In 1971 he was diagnosed with paranoid schizophrenia, which was later (1997) diagnosed as schizoaffective disorder and hypomania. In 1980 he underwent a primary repair of an inguinal hernia on his right side. In 1983 he fractured his lower right forearm. In 1992 he suffered a depressive episode. Two years later he underwent a diagnostic arthroscopy of his right knee. In 2000 he was diagnosed with type 2 Diabetes Mellitus, bipolar affective disorder (Section 3) hypomanic state, and had a diagnostic laryngoscopy for moderate dysplasia on his anterior vocal cords. Two years later he had an acute myocardial infarction, (moderate left ventricle function and angiocardiogram conducted diagnosing single vessel disease), tension headaches and chronic daily headaches. In 2005 he was diagnosed with frontal lobe syndrome, and had frequent psychiatric admissions. In 2010, he had a sigmoidoscopy for necrotising enterocolitis and diverticulosis, and haemorrhoids.

Figure 6.2 'Walter': A personal profile; CH6

'Ronald'

Ronald was born in 1929, in Tooting, London: He is 85 years old. He was the fourth eldest of six siblings; he had three brothers and two sisters. Ronald spent time in hospital when he was younger and therefore didn't really like school. He worked as a local trader in fresh fish as his first job, but joined the RAF at age 17, spending the last two years of his RAF career in Karachi, as a Fire Officer. He subsequently took a job in the Central Electricity Generator Board. He married in 1952, living in Mitcham and then Folkestone. Ronald had three children: two sons and a daughter, and a family dog, taking three holidays per year. He has seven grandchildren and eight great grandchildren. Over the last few years he had flying lessons. Ronald was admitted to the CH in 2011, after a stroke in 2007 which caused him to lose his sight in his left eye. He had a second stroke in 2009. Ronald has a diagnosis of vascular dementia. He is allergic to sodium valproate, codeine phosphate, and is highly sensitive to benzodiazepines and haloperidol. Ronald has ischaemic heart disease, pleural aspiration, a left hip problem from an old fracture, cellulitis, and a deep vein thrombosis.

Figure 6.3 'Ronald': A personal profile; CH6

‘Donald’

Donald was born in 1939: he is 75 years old. In 2008 he was admitted to the CH. Donald can’t remember anything about his education, but worked as a projectionist in a cinema, as a cabinet maker and a carpenter. Donald has one brother. He is single, has no children and prior to living in the CH owned a dog. He has one close friend, and enjoyed going to Spain for his holidays. Donald likes being around people and being in the garden. His favourite films are musicals and he enjoys listening to most music. He is allergic to nuts, alcohol and adhesive.

Figure 6.4 ‘Donald’: A personal profile; CH11

‘Vera’

Vera was born in Dublin, in 1922: she is 93 years old. She remembers being a child in Dublin, and her relationship with her mother and father. She is Irish and of Catholic faith. Vera was married however is now widowed. She has four daughters and nine grandchildren; all four daughters visit her. Vera lived in Ireland, Lewisham and Deptford. She was a housewife, however past occupations included being a cook and a domestic cleaner. She was admitted to the CH in 2010, with a history of falls (she fractured the neck of her femur in 2010), hypertension and weight loss. She currently has ‘Alzheimer’s dementia’, anxiety disorder, depression, challenging behaviour and a moderate to dense cataract which was diagnosed in 2012. Vera likes reading, and enjoys a bath or shower. She likes to wear slippers indoors, and shoes outside. She goes to bed between seven o’clock and half past, although she does not sleep well at night: she is fretful and calls out constantly. She likes to have a glass of water beside the bed.

Figure 6.5 ‘Vera’: A personal profile; CH2

In varying degrees of detail, all three CHs documented residents’ medical history, education, work and hobbies, family and marriage, social geography and religion. Each section of the records varied enormously: in Walter’s case only a very detailed medical history and that he was married were recorded, whereas in Ronald’s case, despite living in the same CH, much more personal information was recorded. It is noteworthy that Walter was admitted to the CH halfway through my research placement, and therefore the CH may not have completed his records within the first month of his admission. CH11 documented shorter histories of their residents in general, but the example of Donald included details of his family, his likes and dislikes and social geography in addition to medical, employment or educational records. In Vera’s case, her family, social geography and religion were all recorded in addition to her medical and educational history, and hobbies. CH2 noted more detail regarding Vera’s likes and dislikes, which may have helped them to manage or minimise any incidents of BtC and it is noteworthy that there was a record that she has exhibited BtC. Appendix 12 details the complete records of each resident, including medical, education, work, hobbies and any other notes recorded for each resident.

Observed incidents of BtC

Throughout the 12 weeks of research and care work I conducted, I observed a total of 49 incidents of BtC involving 11 of the 12 participating residents. These incidents included demanding to go out of the unit, wandering, shouting, physical aggression, verbal aggression, hallucinations and crying, and were in line with Moniz-Cook's CBS-defined BtC[20]. These are displayed in Tables 6.3, 6.4 and 6.5. Since 'causes of behaviour' was a key theme from the interviews, it was important to determine whether or not observed incidents of behaviour may have been exhibited as a result of another factor, or trigger. Therefore for the purposes of this study, 'triggers' were noted if there appeared to be a possible reason for BtC occurring. Where no trigger was obvious, 'no trigger apparent' was recorded. The categorised actions of staff in managing the BtC are also recorded in the table (C, K, F, and E).

Resident	Code	Shift	Antecedent	Behaviour	Management	Consequence	C	K	F	E
Ronald	1.1	1	No trigger apparent	Ronald continually shouting "help".	Member of staff (3S) offered Ronald a cup of tea	Ronald agreed to cup of tea and stopped shouting for help. 3S brings him cup of tea.		▨		
	1.2	3	Personal care being conducted	Ronald shouting out incomprehensible words, shouting for help.	Staff (2S&3S) continued to change anyway, while the shouting was going on. They explained they would not put a t-shirt on Ronald because he was 'aggressive'	Ronald had no t-shirt on but was otherwise dressed. Shouting ceased.				
	1.3	4	Ronald incontinent of urine	Ronald shouting out, agitated.	Staff (6S) talks to Ronald while in the bathroom. Staff member shuts door explaining she will assist him.	Ronald leaves bathroom changed and quiet.		▨		
	1.4	5	Ronald is sitting in chair. No trigger apparent	Ronald shouts 'help', and attempts to stand up from his chair. He appears agitated.	Staff (1S) asks Ronald if he would like some dinner or soup. She explains to Ronald that she does not want him to hurt himself or fall over.	Ronald accepts offer of food, and staff member (1S) gives him soup. Ronald sits back in his chair and eats his soup.	▨	▨		
	1.5	6	Ronald is sitting in dining room	Ronald appears agitated, and repeatedly attempts to stand up from his chair, then sits back down. Shouts 'help' and 'mummy' frequently.	Staff (7S) sits with Ronald and holds his hand. She asks him to tell her a story. Ronald says 'what?', 7S says 'about the bears'.	Ronald appears to be less agitated for a few minutes but does not speak with staff (7S). After a few minutes, Ronald shouts 'help, the bears'.	▨	▨		
	1.6	7	Sitting in living room with cup of soup on table in front of him, no trigger identified	Ronald shouting 'help'. Appears very distressed.	Staff (1S) asks 'are you okay?' to Ronald. He responds 'help, please'. 1S asks 'are you hungry?'. Ronald says 'yes'. 1S asks 'would you like some soup?'. Ronald responds 'yes'. 1S says 'it's here', pointing to soup.	Ronald picks up cup of soup and eats soup. Ceases shouting.	▨	▨		

Resident	Code	Shift	Antecedent	Behaviour	Management	Consequence	C	K	F	E
	1.7	7	Sitting in dining room while staff members are preparing dinner	Ronald shouting 'help'. Appears very distressed.	Staff (1S) asks 'are you okay Ronald?' He responds 'help, help me'. 1S asks 'would you like some dinner Ronald? He responds 'yes'. 1S explains that the staff are making his dinner, and that he will be able to eat some in a couple of seconds.	Ronald waits quietly for his dinner while 1S sits with him.	🟪	🟪		
	1.8	7	Sitting in dining room while staff members are preparing dessert	Ronald shouting 'help', 'help'. Appears very distressed.	Staff (1S) asks 'are you okay Ronald?' to resident. Resident takes 1S hand and shouts 'help'. 1S asks 'would you like some dessert? Resident responds 'yes please'. 1S explains that she will go and get some dessert of ice cream and sponge for him and says 'would you like that?'. Resident responds 'yes please'.	Ronald waits for his dessert and eats dessert quietly.	🟪	🟪		
	1.9	8	No trigger apparent. Ronald (on one-to-one observation) sitting in living room.	Ronald attempts to stand up from armchair and is resistive to sitting back down despite one staff member (4S) sitting with him.	Staff (4S) says in loud voice 'you need to sit down Ronald'.	Ronald sits down, however attempts to stand up again every few minutes.				
	1.10	9	No trigger apparent. Ronald is in bed.	Ronald is loudly shouting in the evening. 'Help', 'mummy', 'please'.	Staff (6S) walks into room and says 'what's wrong Ronald?'	Ronald immediately stops shouting but does not answer 6S, who leaves room.				
	1.11	10	Staff (1S) was giving tablets (medicine) for Ronald to take	Ronald threw the two tablets across the room	Staff (1S) explained to Ronald that he must not do that, and that if he took the tablets he would feel better.	Ronald (After three more attempts at explanation) took the tablets.	🟪	🟪		

Resident	Code	Shift	Antecedent	Behaviour	Management	Consequence	C	K	F	E
Betty	1.12	1	Betty walking through the corridor, incontinent of urine	Betty appeared distressed, and shouting to researcher to help	Researcher calls staff member (6S), who talked to Betty while walking her to the bathroom. 6S asked Betty to help her change her, with the help of researcher who collected clean clothes	Betty appeared clean and changed into new clothes. No longer appeared distressed and no longer shouting.	🟪	🟪		
	1.13	2	Bertram has closed all curtains at lunch time	Betty asks in raised voice for him to close the curtains. He closes curtain. Betty gets up and opens it, shaking her head.	Staff (1S) allows this exchange to occur.	Bertram leaves room. Betty finishes lunch.	🟪	🟪		
	1.14	2	Bertram has closed all curtains at lunch time	Betty appears agitated, shaking her head. Shouts that she wants the curtains open.	Staff (1S) asks researcher to open the curtains.	Researcher opens curtains. Betty says 'thank you'.	🟪	🟪		
	1.15	3	Dinner (fish and chips) is served, Betty is sat at table	Betty is shouting, and shouts that they do not want to eat the food.	Staff (7S) in the same room, says to Betty in a loud voice, 'Eat your chips'.	Betty does not respond to 7S. Betty later on shouts that she does not want to eat the food.				
	1.16	6	No trigger apparent	Betty shouting 'oi', and appears agitated.	Staff member (3S) offers Betty a cup of tea.	Betty accepts offer of cup of tea and ceases shouting. Staff member (3S) makes cup of tea and provides Betty with it. Betty says ‘Ta love’.	🟪	🟪		
	1.17	6	Betty sitting in dining room	Betty appears agitated, and shouts 'mummy' and 'oi' repeatedly. Does not	No response from staff (7S, 3S, 4S) who are in the same room	Betty continues to shout 'mummy' and 'oi'.				

Resident	Code	Shift	Antecedent	Behaviour	Management	Consequence	C	K	F	E
				appear to be looking at anyone.						
	1.18	7	Betty is sitting in dining room	Betty appears agitated, and shouting words and sentences: 'no it doesn't', 'well you shouldn't have done that', 'oi', 'what', 'why is it', repeatedly. Does not appear to be looking at anyone.	Staff (7S) says in loud voice, ' Betty, what's the matter?'	Betty does not respond to staff (7S), but ceases shouting. Betty wraps arms around herself.				
	1.19	10	No trigger apparent	Betty is shouting 'oi' repeatedly.	Staff (3S) whispers to Betty (I am unable to hear what). 3S then leaves Betty and explains to researcher that she is leaving to get her to eat her food.	Betty eats food quietly. Ceases shouting 'oi'.		🟪		
Bertram	1.20	2	Bertram finishes lunch in dining room, where other residents are present	Bertram gets up from lunch and closes all the curtains, as he says 'we won't be able to sleep with it being light all night'. Betty shakes her head.	Staff (1S) allows him to close all the curtains.	Bertram finishes closing curtains and says 'goodnight all' and leaves the room. Instigates Betty's BtC (see 1.13; 1.14).	🟪	🟪		
	1.21	2	Bertram enters dining room to see curtains open. Does not appear to remember that he had closed them minutes earlier	Bertram closes all the curtains.	Staff (1S) allows him to close all the curtains.	Bertram finishes closing curtains and says 'goodnight all' and leaves the room. Instigates BtC (see 1.13; 1.14).	🟪	🟪		
Agnes	1.22	4	Agnes is sitting in living room eating lunch, where the window is open.	Agnes shouts 'it's very breezy'.	No response from staff (2S, 3S, 4S, 7S) who are in the same room	Researcher closes the window while residents are eating, and re-opens once residents have left.				

Resident	Code	Shift	Antecedent	Behaviour	Management	Consequence	C	K	F	E
	1.23	5	Agnes is sitting in corridor alone by lift.	Agnes shouts incomprehensible words.	No response from any staff. Agnes continues to shout.	Researcher goes to sit with Agnes, and paints her nails.				
	1.24	6	Agnes sitting in corridor alone by lift.	Agnes shouting incomprehensible words.	No response from staff. Agnes continues to shout. Staff (4S) [in room with researcher] rolls eyes and laughs while serving lunch. Agnes continues to shout.	Researcher goes to talk to Agnes about Liverpool. She stops shouting, and engages in conversation.				
	1.25	8	Agnes sitting in corridor alone by lift.	Agnes shouting incomprehensible words.	No response from staff. Agnes continues to shout.	Researcher goes to sit with Agnes, takes old nail paint off, and files and paints her nails.				
Edwin	1.26	1	Edwin is in bed with rails up to prevent fall, being fed his breakfast.	Edwin attempts to get out of bed, despite rails being up, while being fed breakfast by staff (1S).	Staff (1S) talks to Edwin, asking if he would like some porridge. Staff (1S) explains that she doesn't want resident to get out of bed because he may hurt himself.	Edwin eats porridge, and places his legs back in the bed. Staff (1S) continues feeding Edwin porridge.	🟪	🟪		
	1.27	2	Edwin is sitting with researcher and staff (1S) and appears to be hallucinating	Edwin says 'it's behind you'.	Researcher looks behind, and says 'is it?'. Edwin says 'you don't believe me do you?'. Staff (1S) says 'of course we do', and holds out hand for Edwin. Edwin takes her hand.	A few minutes later, Edwin appears to stop hallucinating and appears to attempt to engage in conversation.	🟪	🟪		
	1.28	3	No trigger apparent. Edwin sitting in living room.	Edwin attempts to stand up from wheelchair, and is resistive to sitting back down despite two staff (3S, 4S) helping.	Staff (3S) holds Edwin by his arms, and keeps talking to him until she states that Edwin is 'out of it'. She explains to researcher that Edwin tends to fall over and this may be a possible seizure.	Edwin is unresponsive to staff members (3S, 4S) for two minutes (approx.). He then appears to listen to them, and sits down in his wheelchair.	🟪	🟪		

Resident	Code	Shift	Antecedent	Behaviour	Management	Consequence	C	K	F	E
	1.29	5	No trigger apparent. Edwin sitting in living room.	Edwin attempts to stand up from wheelchair, and is resistive to sitting back down despite one staff member (4S) sitting with him.	Staff (4S) says in loud voice 'you need to sit down Edwin'.	Edwin does not appear to listen and remains standing up. Edwin is resistive to sitting down.				
Ernie	1.30	7	No trigger apparent. Ernie is sitting alone in bedroom.	Ernie starts to cry loudly. Bedroom door is open and Ernie has head in his hands while sitting in his armchair.	No response from staff (2S, 3S, 4S, 6S) who are in the room opposite Ernie and with whom researcher discusses his crying. They say he often cries.	Researcher goes to talk to Ernie, who says he is 'sad' and he doesn't 'know why'. Researcher holds his hands and talks about Spitfires and Hurricanes. Ernie stops crying after some minutes.				

Table 6.2 Observed incidents of BtC in CH6

Resident	Code	Shift	Antecedent	Behaviour	Management	Consequence	C	K	F	E
Donald	2.1	3	Donald's friend had died	Repeatedly asking to go out, becoming more agitated.	CH staff (1S, 2S, 4S) discussion while Donald was walking up and down corridor, as to how best to control situation. Decided to distract him by telling him they would take him out later in the day. CH staff (2S) put arm around Donald, talking gently with him.	Donald said he wanted to go out soon, but took off his coat. Appeared to become less agitated and walked with staff (2S) to his room.	■	■	■	
	2.2	3	Donald's friend had died	Wanted to be let out the building to find someone he knew.	CH staff (1S, 2S, 3S) debated about asking Donald if he would like a beer. Staff (3S) asked resident if he would like to join him in having a beer, before they went out.	Donald accepted, and staff (3S) escorted him to lounge, where he had a beer.	■	■	■	
	2.3	3	Donald's friend had died	Confusion and appeared agitated. Became verbally aggressive	CH staff (1S, 2S, 4S) discussion that Donald was verbally aggressive potentially due to learning of friend's death. CH staff (1S, 2S, 4S) talked to Donald, asking him what the matter was, if he wanted to come with them and that they would sort something out for him 'in a minute'.	Donald engaged in conversation but was clearly agitated. Was unsure why he was being kept in the CH and suggested that he did not know anybody. When offered a cup of tea with company of staff (2S) he accepted and walked to his room.	■	■	■	
	2.4	4	No trigger identified	Walked out of bedroom with coat on and expressed need to go to the bank.	CH staff (6S) explained that it would be too difficult to go to the bank at that moment, because it would be shut. Explained that he was going in the morning, and would knock for Donald before he left.	Donald was surprised bank was shut, however took his coat off, and asked whether he should go to his room. Staff (6S) answered if he wanted to it was probably a good idea. Staff (6S) took Donald back to room.		■		
	2.5	5	No trigger identified	Donald is running in the corridor	CH staff (2S) said 'How are you doing today Donald?'	Donald stopped running, and answered staff (2S) that he was fine thank you. He asked		■		

Resident	Code	Shift	Antecedent	Behaviour	Management	Consequence	C	K	F	E
						2S how they were, and walked on.		■		
	2.6	5	Joan was shouting in her mobile armchair	Donald threw cup of juice over resident shouting.	CH staff (5S) immediately came over and said in a firm voice ‘no Donald, you must not do that. It is not kind to Joan’.	Donald walked away. CH staff (5S) cleaned up Joan in chair while asking another member of staff to watch where Donald went.	■	■		
	2.7	6	No trigger identified	Waking and wandering through the suite at night looking for ‘it’	CH staff (3S) talked quietly to Donald and escorted him back to his room.	Donald remained in his room for the next two hours.	■	■		
	2.8	6	No trigger identified	Wandering in the night, looking for ‘it’	CH staff (3S) talked quietly to Donald and escorted him back to his room.	Donald remained in his room until morning.	■	■		
	2.9	7	No trigger identified	Crawling on the corridor floor	CH staff (2S, 3S) watched Donald from the lounge, while serving lunch. 2S asked him if he would like to have some lunch.	Donald accepted offer of lunch and crawled all the way to the lounge, where he stood up and came to sit down to eat his lunch.		■	■	
	2.10	7	Another resident eating at the dining table.	Donald shouted 'you dirty sod', 'you're a dirty sod' at resident eating his dinner.	CH staff (5S) said ‘Donald, that’s not kind. He loves you, you know’, to which Donald replied ‘oh, does he?’. 5S says ‘yes’. Donald says ‘oh, I’m sorry’.	Donald continues eating dinner until finished, without shouting at other resident.	■	■	■	
	2.11	7	No trigger identified	Donald is crawling on the floor of the corridor.	CH staff (4S) sitting with researcher watching him from the sofa in the corridor, while talking to another resident. 4S asks how Donald is, Donald replies he is ‘fine thanks’.	Donald continues to crawl on floor, then gets to the end of the section of the corridor and stands up, then walks on.		■		

Resident	Code	Shift	Antecedent	Behaviour	Management	Consequence	C	K	F	E
	2.12	8	No trigger identified	Donald moved furniture around the suite, blocking doors.	CH staff (2S) watches resident move furniture, and tells me she thinks it is because he wants to be able to watch the television on his own. Once Donald has moved the furniture, he sits down in front of the telly (cricket is on). 2S asks him if she can move the chair because it might hurt someone. She then asks if she can sit with him.	Donald sits quietly and tells CH staff (2S) she can move the chair and come and sit with him. 2S and Donald sit watching the television together.	▨	▨		
	2.13	8	No trigger identified	Donald had his coat on and repeatedly expressed wanting to go out to town, while becoming increasingly agitated.	CH staff (1S, 2S, 5S) discussed being able to take Donald into the garden. 1S asked Donald if he could come and help him identify a bird in the garden, because he didn't know what it was. 2S explained to me that Donald was very good at identifying birds.	Donald agreed, and went hurriedly with 1S into the garden, where they stayed for approximately 30 minutes. Donald and 1S were brought a cup of tea by 3S.	▨	▨	▨	▨
Joan	2.14	5	No trigger identified	Joan shouting in her mobile armchair 'mummy, mummy'.	CH staff (1S) walks to Joan and asks whether she would like a cup of tea and a piece of cake. Joan accepts.	Joan ceases shouting, and 1S brings her a cup of tea and piece of cake, which she consumes.	▨	▨		
	2.15	7	No trigger identified	Calling out in her room, incomprehensible words	CH staff (6S) goes into room saying 'hello Joan, now tell, what's the matter?' 6S engages in conversation with Joan for approximately five minutes with the door open, asking about Joan's husband and whether she is going out today. 6S asks Joan if she would like to come to the lounge. Joan declines.	6S leaves room, and Joan is no longer calling out.	▨	▨		

Table 6.3 Observed incidents of BtC in CH11

Resident	Code	Shift	Antecedent	Behaviour	Management	Consequence	C	K	F	E
Vera	3.1.	2	No trigger identified	Shouting incomprehensible words while sitting in the living room amongst other residents. Increasingly agitated looking round.	CH staff (1S) calls from open-plan dining room ‘are you okay Vera?’ Vera does not answer but continues shouting. 1S walks into living room and takes Vera by the hands, sitting next to her.	Vera ceases shouting and smiles at 1S. Attempts to engage in conversation with 1S although words are incomprehensible to me.	▨	▨		
	3.2	3	No trigger identified	Shouting incomprehensible words while sitting in the living room amongst other residents.	CH staff (3S) sits with Vera and holds her hands, asking if she would like a hand massage.	Vera ceases shouting and smiles at 3S. Vera has hands massaged with hand cream.	▨	▨		
	3.3	4	No trigger identified	Shouting incomprehensible words while sitting in the living room amongst other residents.	CH staff (1S) calls from open-plan dining room ‘are you okay Vera?’. Resident does not answer. 1S asks Vera how she is today, while carrying cups of tea into the living room for other residents. She asks Vera if she would like a cup of tea and a biscuit. Vera stops shouting and smiles.	Vera ceases shouting and sits smiling. She is brought a cup of tea and a biscuit by 1S which she consumes. 1S finishes bringing tea in to other residents and then sits holding Vera’s free hand.	▨	▨		
Edna	3.4	2	No trigger identified	Edna shouting 'Where's my son? I want to see my son'. Appeared to be getting increasingly agitated.	CH staff (3S) explains to Edna that her son is coming later that afternoon, because he is at work at the moment. She asks Edna if she would like to call her son while having a cup of tea and a biscuit.	Edna declines the offer to call her son, but accepts the offer of a cup of tea and biscuit. She is brought tea and biscuits with a newspaper by 3S and sits in her chair quietly turning the pages of the newspaper.	▨	▨		

Table 6.4 Observed incidents of BtC in CH2

Overview of Observed BtC

In total, 49 incidents of BtC were observed throughout the 24 shifts. The most incidents occurred in CH6, (30 incidents), 15 incidents occurred in CH11, and four in CH2.

While it is to be expected that the home in which I spent the longest time observing elicited the most number of incidents, it is important to note that CH6 also had the most number of residents.

More residents were recruited from CH6 than CH11 and CH2, which may also help to explain why there were more incidents observed. However, is interesting to note that CH11's Donald was observed exhibiting the most BtC (13 incidents), which may suggest that he was a particularly challenging resident to manage. However only two residents from CH11 were observed exhibiting BtC, unlike CH6, where six residents were observed. This may suggest that staff in CH11 were more adept at minimising BtC than staff in CH6. Certainly their approaches to incidents of BtC differed.

Observed incidents of BtC appeared to be primarily managed by staff's knowledge of the resident, in addition or sometimes separately to, attributing a cause to the behaviour. Staff in CH11 often used their colleagues to help with incidents of BtC, particularly in discussing how to manage the behaviours, however staff in the other two CHs did not appear to do this. The environment was rarely used in managing behaviours: only once in CH11 was the garden used, when a resident expressed a need to go out. Despite the existence of sensory rooms in all CHs, and indeed it being documented in some ABC charts that they were used, this was not observed in practice. From Chapter Four, CH staff posited that the best methods of managing incidents of BtC include understanding that BtC has a cause, knowing the resident, using colleagues and the CH family to support managing the incidents, and using the environment to manage or minimise BtC. It would appear from the observations of BtC in three CHs, that some incidents were potentially inappropriately managed, or not managed at all, according to CH staff's own recommendations. Of the 49 incidents of BtC that were observed 74 actions taken by staff in 37 incidents could be categorised into one of the four themes identified in Chapter Four, with 30 categorised into 'causes of behaviour', 37 categorised into 'knowing the resident', 6 categorised into 'the CH family' and one categorised into 'home-like environment'. However for 12 incidents, all in CH6, no category was identified which suggests the potentially inappropriate management of BtC.

Causes of behaviour

Understanding that incidents of BtC are a consequence of something, was a theme identified from interviews with CH staff, discussed in Chapter Four. In 30 incidents, causes of behaviour were illustrated. Observed incidents of BtC appeared to be frequently managed by attributing a cause to the behaviour, with staff communicating to residents about their needs (1.6, 1.7, 1.8, where staff had identified that Ronald's hunger may be causing BtC), initiating calm (2.7, 2.8, 3.2), intimate conversation with residents (2.15) and asking about their welfare (2.5, 2.11, 3.1, 3.3). All incidents of BtC from CH2 appeared to be managed by staff identifying what the causes of the behaviours were. In CH11 all but four incidents were managed using the same identification of a trigger, or cause of behaviour. One staff member from CH6 took the opportunity to explain to residents why their behaviour was causing a problem: to Ronald who refused his medicines, explaining that it may make him feel better resulted in him successfully taking his medicines (1.11); to Edwin who was attempting to leave his bed but was at risk of falling, explaining that getting out of bed may cause him injury resulted in him calmly placing his legs back in the bed (1.26).

By contrast, sometimes not communicating with residents and allowing them to make their own choices triggered BtC from other residents: in one case, Bertram closed all the curtains at lunch time, explaining that it was getting late and he was going to bed (1.20). This prompted Betty to shout, and demand the curtains to be open (1.13, 1.14). At the time of observation, it appeared that the staff member knew that Bertram was going to close the curtains, understanding that his BtC had a cause (he was tired, and thought it was time for bed), however subsequently, Betty presented with BtC as a result of Bertram's actions. In this case, Betty was settled by me opening the curtains once Bertram had left the room, as directed by the member of staff.

Knowing the resident

In Chapter Four, CH staff talked about the importance of knowing who they were caring for, knowing their likes and dislikes, and being able to tailor their care provision as a result of this. Along with identifying what the causes of BtC were, during observed episodes of BtC, CH staff appeared to regularly manage incidents by using their knowledge of individual residents to diffuse situations. In 37 incidents, knowing the residents was illustrated. In CH11 and CH2, every observed incident appeared to be managed using some element of knowledge about the resident in question, however this strategy was adopted to a lesser extent during incidents observed in CH6 (six incidents occurred in CH6 whereby no action was taken at all, despite residents exhibiting BtC. In analysing these incidents, in addition to a further six incidents, no categorisation could take place). Knowing that residents enjoyed cups of tea (1.1, 2.13, 2.14, 3.3, 3.4), biscuits and cake (2.14), beer (2.3), and reading newspapers (3.4) for example, allowed CH staff to manage and diffuse incidents of BtC that could potentially have worsened. In CH11 and CH2, every incident of

BtC appeared to be managed successfully, with no further exhibition of BtC by the individual residents in the following twenty minutes. Understanding that the same resident, Donald for example, required reassurance in some circumstances (putting an arm around him, when he was confused and agitated (2.1)), and responded to admonishment in others (stating firmly that it was neither acceptable nor kind to throw a drink over another resident, or that it was not kind to call someone a ‘dirty sod’ (2.6, 2.10)) appeared to be a key component of the successful management of BtC exhibited by residents, particularly in CH11 and CH2. In CH6, a staff member who was caring for Ronald clearly knew that if she offered him food, he would accept, and therefore when he was shouting and appearing agitated at dinner time, explaining to him that his dinner would be arriving shortly as well as offering him a dessert afterwards, quickly lessened his distress (1.6, 1.7, 1.8). Similarly, in CH2 when Vera was becoming agitated and calling out incomprehensible words, a staff member kept her company, held her by the hands, and in one instance, gave her a hand massage (3.1, 3.2, 3.3). This immediately placated Vera, who began to smile. Knowing how to diffuse different situations involving different residents is a skill that many CH staff in this study appear to have acquired.

The CH family

From their interviews in Chapter Four, CH staff talked at length about the relationship built between colleagues who helped manage incidents of BtC, either through identifying and sharing new methods of managing BtC for specific residents, or liaising with managers and other staff members to determine the most effective management strategies. As such, they rely on their CH family of colleagues and residents’ relatives, in day to day practice. In six incidents, the CH family was illustrated. In this study, no evidence of the use of the CH family was present in CH6 or CH2, however while incidents of BtC were occurring in CH11, on five occasions two or more staff were present to observe, discuss and manage the behaviour (2.1, 2.3, 2.5, 2.9, 2.13). In observing the staff liaise with each other, it was clear that they relied upon each other to establish the best way of diffusing sometimes very difficult situations. In the case of Donald, his friend had died and he was clearly very upset by this news. He became agitated, and this appeared to exacerbate his confusion as to why he was staying in the CH, and why he was not allowed to go outside. The staff were discrete in their discussions about Donald and his behaviour, all the while observing him closely, and allowing him to ask them questions, albeit with frustration. They answered his questions, and provided sympathy and reassurance to him, while ensuring that each member of staff involved in his care at that time, was aware of the strategies to be adopted in managing Donald through his grief, agitation and confusion. This scenario played frequently over the course of one particular day, and CH staff were present every time, discussing previous strategies and ideas for future strategies, should the situation arise again. Each time Donald's behaviour became more challenging it appeared to be successfully and calmly managed (2.1, 2.3, 2.5).

The Home-like environment

In Chapter Four, CH staff discussed the importance of residents being in a familiar environment, similar to the home they no longer lived in, where they felt safe and secure. Staff explained that the use of the care environment had the potential to help in managing incidents of BtC. In CH11, a nurse reported that residents had access to the unit kitchen, in which they were allowed to help care staff make tea, or washing up for example. In only one incident observed, the use of the home-like environment was illustrated. No evidence of the use of the environment to manage episodes of BtC was present in CH6 or CH2, however in one instance in CH11, the garden was used as a distractor when Donald became agitated, wanting to go out to town (2.13). Donald had previously had a bird feeder gifted to him at the CH on his birthday, in addition to a book about garden birds which he often enjoyed reading in the afternoons, therefore he was eager to help the staff member with his 'endeavour' to identify a bird in the garden. Whether there was an unidentified bird in the garden remains unknown, however the situation was diffused and Donald appeared to forget his need to go out to town.

Summary

The incidents of BtC that I observed were most commonly managed by CH staff's knowledge of each resident, often alongside their understanding that the behaviour had a cause. There were observed instances when the CHs responded differently to the same behaviours: staff in CH6 were observed ignoring residents shouting or crying (1.17, 1.22, 1.23, 1.24, 1.25, 1.30), whereas this did not happen during any incident of BtC in CH11 or CH2. In CH6, all of Agnes's and Ernie's BtC were ignored. While there were only two residents recruited from CH2, CH staff adopted the same strategy for similar behaviours in the same resident; that is, they provided her with their company, and touch. CH11 appeared to treat many incidents of BtC as a problem that required solving: solutions were reached as a (often multidisciplinary) team. The CH environment was used infrequently to manage BtC, despite evidence to the contrary documented in residents' BtC records in the general files kept by each CH. For example, CH11 (the only CH to use the environment to manage BtC) used the garden in one instance. It is noteworthy that during the periods of observation, it was not always appropriate weather to be outdoors, and this may have impacted on the frequency with which the gardens were used. Additionally, despite documenting in their BtC records, that the sensory room was often used to manage episodes of BtC, this was not observed throughout the duration of research. Additional rooms and activities in the CH were not observed being used to manage incidents of BtC, rather to engage residents who were not showing signs of BtC.

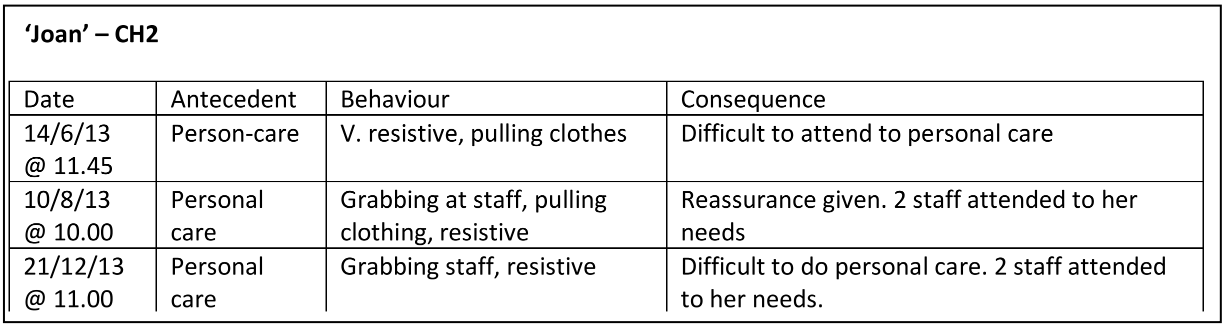
While 49 incidents were observed, it is of importance to reiterate that there were only 12 recruited residents to this study, and therefore any incidents of behaviour involving any resident or staff member not consenting to participate could not be recorded. This omits a large number of incidents I observed but could not record. Additionally, incidents of BtC occurred when I was sitting with residents (painting Agnes' nails for example), or assisting residents with food in their rooms. Whilst I frequently overheard what was almost certainly incidents of BtC, I was not in the vicinity to observe these, and therefore could not include them in this study. As such, these findings represent a partial snapshot of the incidents of BtC occurring in each CH.

CH documented incidents of BtC

Similarly to the personal profiles, the recording of incidents of BtC and their detail varied within and between CHs. CH11 completed each record of BtC using 'ABC' [165] documents, noting the Antecedent (A), Behaviour (B) and Consequence (C). CH6 did not appear to be following any recognised or consistent BtC record-keeping documentation; incidents of BtC were recorded on non-headed paper and placed in individual residents' files. The two participating residents in CH2 did not appear to have any records of BtC in their individual files, and therefore it is not clear whether CH2 kept records of BtC or not. Incidents of BtC directly transcribed from CH6 and CH11 records of BtC are provided in Figures 6.6 and 6.7. All incidents of BtC recorded by the CHs were directly transcribed and displayed in Tables 6.6 and 6.7: where these data refer to observed incidents, a cross-reference to the shift and observed incident is provided.

'Bertram' – CH1
16/6/14
Can become increasingly anxious and confused, and subsequently violent verbally and physically, when not allowed to get out of the unit. Can use walking stick to threaten.
Observation, PRN medicines, distraction. Only allow him to use stick when unsteady. Engage in activities he likes. Shorter visits from family.

Figure 6.6 Transcribed incident of BtC, 'Bertram', CH6



'Joan' – CH2

Date	Antecedent	Behaviour	Consequence
14/6/13 @ 11.45	Person-care	V. resistive, pulling clothes	Difficult to attend to personal care
10/8/13 @ 10.00	Personal care	Grabbing at staff, pulling clothing, resistive	Reassurance given. 2 staff attended to her needs
21/12/13 @ 11.00	Personal care	Grabbing staff, resistive	Difficult to do personal care. 2 staff attended to her needs.

Figure 6.7 Transcribed incidents of BtC, 'Joan', CH11

Resident	Reference	Reported Incidents of BtC	
Ernie			No incidents reported
Bertram		*1*	15/7/14 – wandering up and down the unit, looking for food. Eventually retired to his room.
		2	16/6/14 – can become increasingly anxious and confused, and subsequently violent verbally and physically, when not allowed to get out of the unit. Can use walking stick to threaten. Observation, PRN medicines, distraction. Only allow him to use stick when unsteady. Engage in activities he likes. Shorter visits from family.
Agnes		*3*	Undated handwritten ABC Chart – A: Fire alarm set off; B: Became lost, confused, disorientated. Smashed hands on door frames; C: Severe skin tears on arms and hands. Was assisted to wash/change and helped to bed.
Betty		*4*	9/4/14: 18:10 – Walking back from dining room, assisting X back to her room. As I was walking with X on the left side so my left hand was under her right arm. She became walking towards the wall which then I became squashed between the wall as I explained to X I'm just about to let go so I can put my hand under your left arm. She grabbed my right side and scratched me. I told X it was hurting me and to let go but she wouldn't I had to get X's hand off me as she wouldn't. Asked another carer to walk X back to her room.
Ronald	Shift 7 (1.6)	*5*	15/10/14 – Refusing meals. Offered regular snacks/meals. Use pictures of food if helps. Formal monitoring of food intake.
	Shift 3 (1.2)	*6*	3/10/14 – behaviour started to change dramatically and now displaying physical and verbal aggression. Agitated, calling out most of the time. No strategies tried so far are helping de-escalate. When agitated, member of staff required to sit with him. On 15-minute observations or 1-2-1.
		7	1/9/14 – Events of anxiety more frequent.
		8	15/8/13 – Waking up other residents by going into rooms shouting. Walked back to room with member of staff and offered cup of tea. Use of PRN medication
Edwin		*9*	9/11/14 – Aggressive, removed pad and bed clothes. Refused medication. One-to-one imposed. Calm 2-4 hours later.
		10	2/6/14 – marked improvement in presentation with reduced symptoms.
		11	1/6/14 – covert medication request sent, and given.
		12	No date: refusing medication. 1/6/14 – covert medication request sent, and given.2/6/14 – marked improvement in presentation with reduced symptoms.
		13	4/3/13 – "freezing" (episodes of rigidity). → Stop, calming, tell him to think what he wants to do, plan how to do that, and do it. Avoided moving resident forward.
		14	No date: refusing medication.
		15	No date: Reduce frequency of falls → nurse resident on 2 mattresses (resident regularly falls off the bed when attempting to get out).
		16	No date: restless, wandering, other rooms when he can't find the toilet: Note to 'intervene and document on ABC chart', but no chart found.
Walter			No reported incidents of behaviour

Table 6.5 CH6 documented incidents of BtC

Resident		**Date**	**Antecedent**	**Behaviour**	**Consequence**
Donald	17	8/1/15 @ 3pm	No Triggers	Tried to strangle one of the residents who was sitting in chair. No phys contact.	Separated X1 (other resident) and reassured
	18	5/1/15 @ 630am	Unsettled at night, trying to punch staff	Aggressive towards staff. Trying to punch staff	Observed one to one. Went to SR for a few mins
	19	31/12/14 @ 630am	Unsettled, aggression early hours AM.	Aggressive towards staff	Went to sensory room for few minutes. Observed one to one
	20	29/12/14 @ 6pm	Very unsettled late PM. Signs of aggression, to residents	Pushed down one of the female residents who was wandering in corridor	Diverted his attention. Assisted him to the sensory room where he was observed one to one
	21	23/12/14 @545pm	Tried to punch staff and crawl on floor	He was running in the corridor most of the evening	Diverted his attention and keep followed him
	22	21/12/14@ 530pm	Grabbed some sani cloth from assisted toilet.	Suddenly put them in a female residents mouth/face	Staff immediately intervened and escorted to sit in lounge on close observation. Settled.
	23	11/12/14 @1pm	No trigger	Physical aggression, towards female resident	One to one care given. Prescribed medicines given
	24	10/12/14@ 8.15pm	No trigger	Went in to residents room and poking his chest. Grabbed staff member by arms.	Removed from resident's room and told it was not nice
	25	10/12/14@ 7.33pm	No trigger	Tried to punch one of female residents in face	Was asked to go to his room, and when he sat there he still attempted to hit her
	26	7/12/14 @8-930am	No trigger. Wandering, became restless. Went upstairs twice	Crawling on floor, started to become agitated.	Reassurance given. Nurse in sensory room 121.
	27	30/11/14 @3-430pm	No trigger/restless, swearing at staff	Attempt to hit other residents	Reassured, advised not to do so. Nurse in SR til 345pm. Settled afterwards.
	28	21/11/14 @2pm	No trigger/restless, agitated	Attempted to hit/punch other resident.	Reassured, advised not to do so. Nurse in SR til 345pm. Settled afterwards.
	29	18/11/14 @720pm	No trigger/Trying to strangle staff member.	Stopped him before he could get his hands on staff member throat.	
	30	15/11/14@ 10-1230am	No trigger.	Climbing upstairs trying to hit and punch staff when offering assistance. Try to hit another resident. When offered breakfast tried to throw bowl.	Reassured and medicines given but to no avail. Time given to settle in SR with close supervision.
	31	14/11/14 @11am	No trigger, trying to kick a member of staff	Shouting	121 care given, told him not to be aggressive to staff

Resident		Date	Antecedent	Behaviour	Consequence
	32	12/11/14@11am	No trigger.	Throw a cup of tea at member of staff	Was told his behaviour was unacceptable.
	33	8/11/14@ 815pm	No trigger	V unsettled running in the corridor	Prescribed medicines given. 121 care given.
	34	7/11/14 @2pm	Was in SR as v agitated. Supported 121	Verb and phys aggression to staff and residents	121 care given. Told that behaviour was unacceptable.
	35	6/11/14@740pm	No trigger. Verbally and physically aggressive towards staff and residents.	121 care given. Prescribed medicines given.	
	36	4/11/14 @1230pm	Was in SR as v agitated. 121	Upon leaving SR, approached resident and bent resident's arm backwards	Staff intervened. On 121. Remains unsettled.
	37	3/11/14@6pm	Walking along corridor with staff, 121 obs	Grabbed hold of a mop and hit staff on chest	Other staff intervened. 121 continued. Was brought to SR
	38	2/11/14@657pm	No trigger. Has been calm most PM.	At teatime he punched one of agency staff in face.	We assisted him to room for residents' safety
	39	1/11/14@230pm	Was sitting in the chair and shouting. No trigger.	He punched resident	Resident was reassured and moved away from him. Was explained to that behaviour was not acceptable.
	40	30/10/14@3pm	Was increasingly restless. Visitors opened door and he managed to go through first door. Staff tried to stop him going out while letting visitors in.	Kicked staff on right knee. He was lying on floor when he kicked staff.	Staff was limping due to knee being kicked. Other staff came to intervene.
Joan	41	21/12/13 @ 11.00	Personal care	Grabbing staff, resistive	Difficult to do personal care. 2 staff attended to her needs.
	42	10/8/13 @ 10.00	Personal care	Grabbing at staff, pulling clothing, resistive	Reassurance given. 2 staff attended to her needs
	43	14/6/13 @ 11.45	Person-care	V. resistive, pulling clothes	Difficult to attend to personal care
Myrtle		No reported incidents			

Table 6.6 CH11 documented incidents of BtC

In total, 43 incidents of BtC were recorded. In CH6, 16 incidents were recorded and 27 incidents of BtC were recorded in CH11. It is noteworthy that over a period of 19 months, 16 incidents of BtC were recorded in CH6; in the same CH with the same number of residents, over a separate period of five weeks, I observed 30 incidents of BtC. Similarly in CH11, over a period of 18 months, 27 incidents of BtC were reported; over a separate period of four weeks, I observed 15 incidents of BtC. In total I observed 49 incidents of BtC over a period of 13 weeks of observations, an average of 3.8 per week.

For each resident, the number of recorded incidents, along with the number of my observed incidents are displayed in Table 6.8. An overlap is indicated where my dates of observation overlapped with recorded incidents of BtC. Study observed incidents which were recorded in patient records are recorded as: 'N/A' if no incidents were observed; 'No' if observed incidents were not recorded, or incident was undated, and 'Yes' if an observed incident was recorded (it would be expected that all incidents should be recorded).

	Resident	**Incidents recorded by CH**	**Incidents observed**	**Observed incidents recorded by CH**
CH6	Ernie	0	1	No
	Walter	0	0	N/A
	Betty	1	8	No
	Agnes	1	4	No (Undated)
	Bertram	2	2	No
	Ronald	4	11	Yes – 2 recorded
	Edwin	9	4	No
CH11	Donald	24	13	No
	Joan	3	2	No
	Myrtle	0	0	N/A
CH2	Vera	0	3	No
	Edna	0	1	No
Total		**44**	**49**	**2**

Table 6.7 Comparing CH-recorded and observed incidents of BtC

Only two observed incidents of BtC were recorded, in Ronald's notes. Of the 49 observed incidents of BtC observed, only two were recorded, by CH6. Neither CH11 nor CH2 recorded any observed incidents. Both incidents recorded by CH6 refer to Ronald (5, 6), firstly refusing meals, where a formal monitoring system was put in place, and secondly displaying physical and verbal aggression. The 'staff member required to sit with him', was usually me, when on shift. This means that 47 of the 49 observed incidents of BtC went unrecorded, unless they were documented somewhere other than the designated file, and therefore prominence must be given to the underreporting of incidents of BtC. I was on shift for 204 hours over 12 weeks, giving an average of 17 hours per week – this equates to approximately 50% of a full time week. Therefore, it can be postulated that these 49 observed incidents only represent half of the actually-occurring incidents of BtC. It is also important to note that these observed incidents were only reflective of the participants and care staff who chose to participate in the study, therefore this estimate is almost certainly an underestimation. The nature of the incidents observed and documented by the CH were similar in severity, and while it is plausible that care staff did not deem the incidents observed challenging enough to report, there appeared to be no criteria noted or discussed by care staff used to document some incidents over others. For example, I observed BtC including physical aggression and verbal aggression, both of which were also documented in other incidents. I believe there to be little difference in severity of BtC. As such, this supports the notion incidents of BtC are under-reported.

In CH6, records were noted from March 2013 in the case of Edwin, to as recently as October 2014 for Ronald. Edwin had the most recorded incidents of BtC, having been involved in eight incidents, while both Ernie and Walter had no incidents of BtC recorded. In line with findings from Chapter Four, CH staff appeared to attribute Bertram's verbal and physical violence to a cause, namely his increasing anxiety and confusion in not being able to leave the unit (16/6/14). Management strategies included observation, medicines and engagement in activities, although it was not clear whether these were carried out.

Both Agnes and Betty had only one incident of BtC recorded. While Agnes was reported to be challenging (no date recorded), no apparent management strategy was noted, except washing and changing her clothes after tearing her skin on glass. Betty was reported to have scratched a member of CH staff while being escorted back to her room: the carer adopted a management strategy alluded to by many CH staff in Chapter Four, and asked another member of staff to assist Betty back to her room.

Both Ronald and Edwin had more records of BtC than any of the other residents. Ronald's BtC were shouting, verbal and physical aggression and refusing food. It was noted that he was becoming increasingly agitated and anxious although there was no corresponding note as to why. Management strategies for Ronald included a cup of tea, PRN medicines and one-to-one observations: a role that I often undertook as a volunteer. Edwin's episodes of BtC involved him refusing medicines, being aggressive, attempting to get out of bed and wandering. Management strategies for Edwin involved giving convert medicines, the use of one-to-one observation and nursing him on mattresses on the floor.

It is apparent from the records kept, that staff in CH6 experienced a variety of BtC. The emergence of physical violence or aggression appeared to be managed by observations and/or medicines, sometimes covertly, although the cause of this type of behaviour was not always noted. It is interesting to note that while Agnes 'smashed [her] hands on [the] door frames' and severely tore her skin after a fire alarm had sounded, it was not noted as aggressive behaviour. It appeared that there was a difference in how the incidents of BtC were reported in each CH, with CH6 possibly adopting an approach wherein they attempt to foresee and avoid the possibility of criticism, particularly when staff or residents acquired injuries (3, 4), when medication was refused (9, 12, 14), falls were reported (15), meals were refused (5) and when staff were threatened (2). Additionally, 'improvements' are reported (10). This study suggests that incidents of BtC appear to be underreported throughout, and therefore this may explain why CH6 adopted this approach when documenting incidents of BtC.

Of the three residents in CH11, Donald had by far the most reported incidents of BtC, being involved in 24 of the 27 incidents recorded. Donald's BtC varied: he was reported to be predominantly physically aggressive, towards CH staff and residents. Reporting staff attempted to identify a trigger for every behaviour recorded, however often it could not be identified. When triggers were identified, they included being restless and agitated. Management strategies for Donald's aggression included separation from other residents, diversion (often with escort to a sensory room), medicine (Donald was given medicine in three of the 24 incidents), reassurance and often explanation that his behaviour was inappropriate. Joan's three reported incidents of BtC occurred during personal care, which she was reportedly resistive to. CH staff reported giving reassurance to Joan, while asking an additional staff member to assist. Care staff in CH11 appeared to attempt trigger identification when noting incidents of BtC, although their formal monitoring paperwork may have aided this. Similarly to Betty in CH6, it is again interesting to note that while Joan was also reportedly 'grabbing' at care staff, in CH11 two staff members aided Joan, however in CH6, the staff member walking with Betty was replaced by another member of staff.

It is noteworthy that in the 27 incidents recorded in CH11, medicines were reported to be administered on only three occasions. Indeed, in the total 43 incidents recorded, medicines were reported to be administered on only three occasions.

Case studies

The following case studies are syntheses of data collected from CH6, CH11 and CH2. They describe each CH based on interviews with CH staff in Chapter Four, my observations, records kept and reflexive diary entries. It is hoped that generating this material from a variety of sources will provide a comprehensive picture of each home, illuminating the challenges and successes of care they provide to their residents. Each case study begins with a brief description of the CH, before moving on to describe and illustrate the different aspects that make each home unique. All three CHs are dementia specialist CHs with nursing, which provide 24-hour care to between 39 and 89 residents.

CH6

> *'It [BtC] can affect the staff, umm, in terms of stress levels. When they feel that they're not being able to fix it…And that's I think, a big thing around expectations of what we are here to do in terms of behaviours, and again goes back to the approach. So I think people become worried that they're not getting their tasks done, and you go back to task orientated pressure, whereas that's not what we're about here, it's more about the person-centred approach and giving people choices. But also then having a balance between not just always saying 'they don't want it', 'they won't let me so I haven't done anything', we've got a duty of care so it's getting that balance right really' – Manager, CH6*

CH6 is a large purpose-built CH situated in a residential area on the outskirts of a Kent town. There is a large front car park, and a smaller secure back garden. The residents share the living areas, which consist of a quiet lounge, a TV lounge and a dining room. My reflexive diaries note that the leadership in the home appeared excellent, with an 'open-door office policy', certificates adorning the walls and, for a large part of my time, a present manager, and deputy manager. The ethos of the CH comprises of a personal approach to care, and states that the provision of recreational and therapeutic activity is available to all its residents. At the time of submitting this thesis (November 2015), the service had not been inspected and no CQC report was available.

Despite the manager's assurances that the home delivers a person-centred approach, there were many instances where CH staff were purely task-orientated. Very often, it appeared that they were under pressure to have every resident awake, dressed and fed by ten thirty, regardless of residents' choices. As such, I was able to spend time with residents, attempting to engage them in conversation, placate them, listen to their stories or paint their nails, when staff were too busy. I observed only one instance when a member of CH staff sat down and asked Ronald to tell her a story (1.5); however Ronald had been becoming increasingly agitated, and no other interventions were attempted. The CH staff I worked alongside were not complimentary about their job, or their management, and one member of staff felt he would be more appreciated elsewhere. I felt there was a high level of stress amongst the team of care workers and nurses, and many occasions when staff appeared to have no time to complete tasks such as daily care plan updates, while ensuring residents were safe. It was unclear to me whether this was as a result of a lack of staff, or whether care staff were conducting their completing their tasks in the wrong way. This was recognised by one staff member in an interview, when asked what he would change:

> *'Umm, probably the staffing levels. Because then you could spend a bit more time with each resident, and not have to sort of rush it… Even just one more. Because then one person could just, for the whole thing, just do drinks. Or just help with fluids or meals or whatever, and the other four just carry on with care. It just means that there's someone always floating around somewhere settling people, or if someone's shouting find out what they want. It just gives you an extra pair of hands to, or an extra pair of eyes anyway, especially for the ones who are wandering, you always know where everyone is then.' (6CW5)*

However in the interview with the CH manager, she identified that care staff may revert to task when worried that they do not have enough time:

> *'So I think people become worried that they're not getting their tasks done, and you go back to task orientated pressure, whereas that's not what we're about here, it's more about the person-centred approach and giving people choices' (6M)*

During the interviews, staff talked about a sensory room, in which agitated residents could relax with a member of staff:

> *'Our sensory room, it's really good…Especially with people with quite severe dementias, if they become anxious, we can sort of say would you like to come along to our room, and nine times out of ten they will come. And we'll sit with them for a while and chat with them, or just hold their hand, and you can guarantee somebody that has been very agitated or anxious, will, nine times out of ten drift off to sleep, and have a quiet little snooze.' (6CW1)*

> *'They've got a sensory room, on our floor as well, which has got sort of lights, a couple of sofas, relaxing music. Its dark as well, so If they're really agitated we can, just sort of sit down with them in there with a cup of tea, and normally that just chills them out a bit. It's quite quiet so you can close a couple of sets of doors, so you can get it so it's completely silent in there, and then it'll help them calm down a little bit as well' (6CW5)*

Throughout the ten shifts I worked at CH6, I neither used nor saw anyone use the room, which is regrettable given that some residents were observed displaying agitation, which was documented by the CH.

One to one care was discussed in the interviews with CH staff.

> *'If somebody, very often if somebody here, if somebody is very, very anxious and there is, especially if there is likelihood that they could cause themselves harm, they will be put on a one to one basis with somebody…until the agitation subsides, yeah. And we also do umm, charts, umm, a fifteen minute obs [observation] charts…to observe how that person is throughout, you know throughout the time that they are anxious. So we know exactly where they are, exactly how they're feeling, if there's been any triggers, anything like that.' (6CW1)*

By and large, my role in CH6 was to do the majority of one-to-one care, involving two residents who were at risk of falls. This mostly took place in their bedrooms, while they were in bed or sitting in a chair (Shift 8), although on some occasions both residents were in the quiet lounge (Shift 4). However I was not asked to carry out observation charts during this time and was not made aware that anybody else would be doing them. Additionally, residents who were bed bound were described by a member of staff as being hoisted into recliner chairs in order for them to be engaged in the home.

> *'We've got a few residents who are bed bound, and we hoist them into recliner chairs, so they can come out. The recliner chairs look out of the windows, so they can sit in the recliner chair and look out the window' (6CW5)*

I did not observe this during the ten shifts.

I spent a large amount of my time with two particular residents, both of who attempted to be ambulant but were at risk of falling. My role was to prevent them from falling and encourage them to remain seated, or in bed. One of these residents had bed rails in place, to prevent him from falling out of bed. The manager had discussed the use of bed rails as a form of restraint in the interview

> *'The only kind of restraint that could ever be seen as restraint would be bed rails, but we wouldn't use those if somebody was agitated or demonstrated challenging behaviours because it increases the risk of harm' (6M)*

Despite the manager's assertions that bed rails would not be used if a resident demonstrated BtC, these bed rails were used for the resident who, in CH6, exhibited the most BtC. The resident attempted on one occasion (1.26) to climb over the bed rails while he was being fed breakfast in bed. Consequently, over the course of my time at CH6, his bed was removed and he was nursed on a mattress on the floor. On more than one occasion his wife discussed this with me personally and communicated her unhappiness about this situation.

The organisation of CH6, compared with both CH11 and CH2 was the poorest of the three homes. Not all residents had the same, consistently completed records. MAR charts were often printed with additional hand-written entries, many of which were spelt incorrectly. These are discussed in depth in the next chapter, ‘Care in Practice: Medicines Use in Care Homes’. Residents’ records noting any incidents of BtC involving them were all different, with no consistent method of documentation. Residents’ personal history records varied from resident to resident, and were inconsistent on the level of detail included (Walter versus Ronald, for example). In one of my reflexive diary entries (Shift 8),

‘Social services had also been called for a resident as a ‘routine check’, however the resident’s notes had not been updated, and work was apparently needed to update these. The nurse said that although it was ‘fine’ that the notes needed updating, she was not being given any time to complete the updating, and this was causing her some stress.’

This level of stress was apparent throughout the home, on more than one occasion.

Staff appeared frustrated (Shift 1, Shift 3, Shift 8, Shift 10) about the quantity and content of their work. Sometimes they were frustrated with their management (Shift 1); at other times they were frustrated at having to deal with residents who they felt, were beyond their control (Shift 3, Shift 10). At least once during every shift I witnessed care staff talking amongst themselves, in the same room as residents who sat alone, disengaged. This happened most frequently when staff wrote daily updates to residents’ care plans in their care plan files. Where possible in these situations, I attempted to sit with residents, however given that staff were otherwise engaged, there were less ‘hands on deck’, and frequently I was needed elsewhere, either to assist with retrieving residents’ clothes when they were being toileted, ensuring residents had drinks, or making sure the two residents at risk of falls were safe.

When triangulating the data collected from interviews and observations, it appeared that CH staff and managers are acutely aware of the different methods they could use to potentially prevent, and manage incidents of BtC. The CH provided the facilities, and yet they were not observed in use. In some cases, BtC were ignored (1.22, 1.23, 1.25, 1.30). Notes documenting incidents of BtC were not recorded in the same manner as they were observed: this may be due to a lack of time perhaps, or CH staff not deeming certain behaviours challenging enough to warrant documenting. The staff in this CH reported wanting more staff on their unit, as an extra pair of hands: I suspect that this research benefited the home by providing them with that for the duration of the observations, and that care staff's ability to provide the same level of care without an additional person, would have been compromised.

CH11

> *'If people are given the freedom to move, aggression goes down. Because they can walk off the aggression, they can um, they're not being told what to do, I think trying to keep people in a small space and telling them to sit down and not do that, obviously people think 'I want to do that'. But if they've got that freedom that they can wander as much as they want, um, we've found that aggression really comes down. And I think that's one of the best things about [CH11] is they've got room to move. We take a lot of people from other nursing homes, and generally, they come from the nursing homes because they can't cope with them and they're really aggressive. But when they come here, because they've got that room to move, it might be as basic as endorphins – exercise makes you feel better.' (11M)*

CH11 is the smallest of the CHs, and is a purpose-built home situated in a residential street. There is a large front car park, and a reasonably large and secure back garden. The residents share the living areas, which consist of a lounge, a kitchen, a dining room and often during my time there, the offices. The home feels busy but relaxed, and staff are regularly engaged in conversation with, or about, a resident. At the time of submitting this thesis (November 2015), the service had been inspected by the CQC and was found to require improvement in the recruitment and effectiveness of CH staff. Other standards were fully complied with.

Referral of patients into CH11 is only via the NHS continuing care and funded service, and therefore it felt different to the other two homes on first visit. The protocols (signing in and out, hand sanitisation, for example) were much more strictly enforced, staff rotas were present in every unit and there were posters displaying the day, date and weather on both floors. Medicines administration and meal times aside, there appeared to be much less of a morning routine in CH11: those residents who were able, went to bed and got up at their leisure. Residents ambulated through the units, and had access to lounges, dining rooms and offices. Care staff did not class 'wandering' as challenging, and this was evidenced in their interviews.

> *'It's down to each individual…we have three or four wanderers. They just do, they just wander. They're in no trouble…I don't find them a challenge unless they're being aggressive with it' (11AC)*

> *'You can't stop them from wandering, because it's down to them. You can't block them in a room and say they're not going anywhere. Wandering is what people do…Its fine to wander. If something happens then there's people here who are going to stop that' (11CW1)*

Unlike CH6 and CH2, residents also had access to the unit kitchen, in which they were allowed to help care staff, as alluded to in the interviews and my reflexive diary (Shift 2).

> *'They're very caring and concerned for us…the tea trolley, they're really frail, and they say 'would you like me to help you dear?'… Was it today or yesterday…she really wants to go into the kitchen, I said… 'I think she wants to help you, just ask her to do some washing up', and she did…don't…discard them because they have dementia…But of course, maybe if they want a cup of tea, you still do the hot water, but if she can put the sugar in, by all means, and then stir, that's fine' (11N)*

The CH prided itself on its corridor design – as the manager alluded to in the interview, there was certainly plenty of room for ambulation, and many residents were able to maximise that. Those residents on the ground floor walking between units must walk past the reception desk – as such there were often residents talking to the receptionists. The home has two cats that seemed to enjoy sitting on the living room chairs (and on the residents, who are sitting on the chairs). The home felt relaxed and calm, if a little overwhelming at first given the extent of the BtC witnessed (2.9, 2.11, 7/12/14).

During all of my eight shifts, residents appeared mostly content. When incidents of BtC occurred, they were always managed as a priority, often by more than one member of care staff. Staff spent the majority of their time engaging the residents, sitting talking to them while they had their hair cut (Shift 3), making them tea and cake (every shift) and even singing gospel music with them (Shift 2, Shift 5, Shift 7).

Staff (and residents) were very welcoming to me, and appeared content. Their professionalism in handover struck me as a key component in their management of, and approach towards residents: every resident was meticulously discussed during the handover, which I sat in during every shift. Any issues arising from previous shifts were declared and talked through.

My time in CH11 was varied. I spent hours talking to residents, drawing with them, discussing the war, talking about their families and making them cups of tea and cake. On one occasion I assisted staff in conducting personal care to a particularly frail resident when he was upset, by holding his hand and talking with him: he kissed me on the hand and asked me not tell his wife (Shift 7). I had dinner with one resident and his friend, and spent time talking to staff about their jobs.

I was able to complete a night shift at CH11, and it was a pleasure to experience. Throughout the night residents awoke, and were comforted by care staff. It was during the night shift that I was struck by the real care and compassion that is required to successfully look after CH residents with dementia: I was surrounded by staff who, even at three o clock in the morning after the fourth resident was awake, up, and wanting to go out to the shops, were dedicated to looking after someone else, and comforting them enough so that they went back to bed. It was wonderful to watch.

The CH staff I worked alongside were complimentary about the CH, and the managers were present, and engaged in the same work as their staff. It appeared that the home wanted to work towards the same goal – person-centred care. Staff were knowledgeable about dementia and in interviews talked about having copious amounts of training. Similarly to CH2, I felt there was a high level of companionship and comradery amongst the team of care workers and nurses on my unit, who were all compassionate and caring towards, and in talking about, their residents. It was, on the whole, a very enjoyable unit in which to work.

'You got so much training before you started working here, it was unreal. All different types, there was so much training. It was good' (11CW1)

'I find this fascinating Charlotte. You know they can be really confused. But you see three men or three…females, and they're having a laugh. You're either sitting with them, or you…try to overhear their conversation and the conversation…is going nowhere. But then there's that connection between them…I will always say 'are you the three kings or the three cheeky monkeys?' And what I love about them, they never cease to surprise us' (11N).

The organisation of CH11 was similar to that of CH2. All residents had the same, consistently completed records. MAR charts were printed. Notes on incidents of BtC could be found in the same place in every resident's file, and were consistently filled in on the same documents. Residents' personal history records were detailed on the same documents, and were reasonably consistent on the level of detail included. My reflexive diary entries for CH11 were very positive, and on reflection I clearly relished the opportunity to be witness to the care provided.

When triangulating the data collected from interviews and observations, it appeared that CH staff and managers were acutely aware of the different methods they could use to potentially prevent, and manage incidents of BtC, and according to the observations, were successful in doing so.

In contrast to CH6, I did not feel as though I was the valuable ‘extra pair of hands’ in CH11 that CH6 required. While I suspect that this research benefited the home by providing them with an additional person to talk to the residents, my participation gave staff members an opportunity to spend time with residents. As such, I believe that without me present, for the duration of the observations, the care staff’s ability to provide the same level of care would not be in any way compromised.

CH2

> *‘With this programme what we found, the staff find time to spend time with the residents…because if you don’t pay much attention to residents – we are busy, working – that is not [what] residents want. Residents want…to sit with them and talk to them more, to find out what is their problem or whether they have any difficulty, or whether they are not able to express their problem, and how you…can identify the problem. So staff really need the time to spend with the residents to find out what, how, whether they are facing any difficulty or not. So this programme really helped, staff got the time to sit with them, spend time with them, more interaction…and also that makes the residents more calmer and comfortable also, we noticed that.’ (2M)*

CH2 is a fairly large purpose-built CH situated in a London borough, in a residential area. There is a small side car park and the CH is accessed by the front door. There is a small but secure back garden. The residents share the living areas, which consist of an open plan lounge and dining room. The registered manager of the CH is now well into her eighties, and stewards her deputy manager in championing her ethos, ‘Namaste’. A Hindu term, Namaste translates to ‘honour the spirit within’, and seeks to engage people with advanced dementia through sound, touch, smell and taste. All the CH staff, who are mainly of South Asian origin, are required to deliver the Namaste programme, and appear adept at doing so. They are attentive, tactile and not least, compassionate. The home feels quiet, and at times spiritual, particularly during periods of Namaste care. At the time of submitting this thesis (November 2015), the service had been inspected and the CH complied fully with the essential standards.

The routine of CH2 was primarily centred on their Namaste programme of care. During all of my six shifts, residents were largely calm and appeared content. Care staff were very warm to me, with happy dispositions. The large part of their time was spent with the residents, talking to them or engaging in massage, feeding and reading (the daily newspapers, predominantly). Care staff appeared to work in a very person-centred manner, and were able to talk to residents about their families with what appeared to be, accurate knowledge, particularly with regard to residents' children's type and location of employment (Shift 2).

The majority of my time was spent talking to residents, making them cups of tea and cake, and assisting them with their food. I observed four incidents of BtC from the two participating residents, and in all cases, residents were placated and the behaviour appeared to be managed (3.1, 3.2, 3.3, 3.4). The CH staff I worked alongside were complimentary about the CH, and I saw numerous examples of the elderly home manager talking to residents, discussing CH staff roles and generally being present around the home. As a result of this, I felt there was a high level of companionship and comradery amongst the team of care workers and nurses on my unit, and it was on the whole, a very enjoyable unit in which to work. Care staff appeared to be knowledgeable about the purpose and ethos of the Namaste programme, and this was evidenced by their interviews,

> *'Namaste it's a care, a particular activity for those people whose life has been compromised. For those people who doesn't know who are they, where they live, or what were they before…So for those who have got capacity, they can engage in many activities, like that. But those people who has [dementia] or in the end stage of life, they need some activities rather than sitting beyond the TV and sleeping all the day. So this Namaste is mainly the power of gentle touch, the power of touch. So Namaste involves the whole sense joined together' (2CW5)*

The organisation of CH2 was similar to that of CH11. However additionally, care plans were computerised and as such, appeared to make it easier for staff to find any lingering issues with residents that had not been dealt with. All residents had the same, consistently completed records. MAR charts were printed. No notes on incidents of BtC could be found, however these may have been computerised in residents' care plans and as such, I did not have ethical approval to search for them. Residents' personal history records were detailed on the same documents, and were consistent on the level of detail included. My reflexive diary entries for CH2 were all positive, with no witness of stressful or difficult situations in which staff found themselves. On the contrary, I was invited on each day to eat lunch with the deputy manager and different members of the care team, who all ate a prepared meal together.

Care staff appeared compassionate towards their residents, showing compassion to the person with dementia, and this was evident in their interviews, as well as in their management of BtC (3.1, 3.2, 3.3, 3.4).

'Because the dementia we know that there is no cure for…this disease, so the only thing, umm, just to make the day more comfortable and quality for them, as much we can…And sometimes, I think of my grandmother, how she, she was…a patient for two, three years and my mother was taking care of her. So I think of them, you know, so I don't miss any of my chance to give care to them' (2CW1)

'So what I have felt with experiences that whenever we are dealing with those with challenging behaviour we need a personal approach that will change their mind. A personal touch or something that they like, offering a cup of tea, cup of coffee or a talk with them. Rather than 'hey, hello…wake up its time for a shower, it's time for breakfast, come on'. Rather than that, if you talk to them, offer them something… So personal approach, how we communicate, a personal touch, a gentle stroke, has managed so far' (2CW5)

When triangulating the data collected from interviews and observations, it appeared that CH staff and managers were acutely aware of the different methods they could use to potentially prevent, and manage incidents of BtC, and adopted a unique approach to doing so. The Namaste programme has received acclaim from the media (Alzheimer's Society's 'Living with Dementia' magazine, February 2015[168]), and the staff consistently championed the programme, and credited it with enabling them to provide good quality care.

Similarly to CH11, I did not feel as though I was the valuable 'extra pair of hands' in CH2 that CH6 required. Staff indicated in the interviews that they felt there was an adequate staffing level: it is noteworthy that the three members of staff described had increased to four or sometimes five care staff while I was observing. Additionally, one member of staff talked about the importance of staff quality over quantity.

'We have three [staff on the unit], three during the day time and two during the night time. Yeah it's enough' (2CW2)

'Let me see, the number of staff versus the residents. You see, whatever the number of staff, if the staff doesn't know the residents, then what is the use in the number of staff proportional to the resident? So the quality of staff is proportional to the resident, rather than the number of care staff. So what I am saying is rather than the large number of staff, that staff who knows the

resident well… is enough to deal with a resident who has challenging behaviour, who knows that resident…how to approach the resident' (2CW5)

I suspect that this research benefited the home by providing them with an additional person to talk to the residents; when I was assisting with feeding for example, it gave a staff member the opportunity to sit and engage in conversation with other residents, rather than need to be elsewhere. As such, I believe that without me present, for the duration of the observations, the care staff's ability to provide the same level of care would not be in any way compromised.

Discussion

This phase of the study has provided an insight into how three CHs manage BtC in practice. The data support those findings of Chapter Four, that CH staff experience BtC amongst their residents and attempt to use philosophies of attributing BtC to a cause, and knowing the resident to manage these. Indeed, I personally witnessed 49 incidents of BtC from all 12 residents. These incidents included demanding to go out of the unit, wandering, shouting, physical aggression, verbal aggression, hallucinations and crying. While the observational and CH recorded data suggest that there is no explicit, consistent method of management in practice, CH staff did adopt similar strategies to manage similar behaviours, explaining to the resident why it would be beneficial for him to take his medicines, for example. All three of the CHs observed in this study were different from each other, and adopted different practices to manage BtC: CH11 relied heavily on its team of staff to observe, discuss and manage incidents of BtC for example, while CH6 and CH2 did not.

This work supports the findings of Barber et al [49], that CHs do not keep the same records, or keep them in the same place, however the CHUMS study refers to medicines management records. This study adds to the body of literature surrounding CH records by suggesting that CHs do not keep the same BtC or life history records, and do not keep these data in the same place. Additionally, the CHs in this study used different terminology for these records, and the information within them varied within and between homes. As such, the challenge of identifying personal history and BtC records was present in each CH, because no CH kept the same records.

There appears to be a difference between how CH staff perceive themselves to manage BtC, and how this is done in practice. Staff from all three CHs stated (Chapter Four) that distraction and emotional reassurance were used, and the data from observations confirmed this. However, the strategies used to minimise BtC (ensuring residents are either stimulated, or relaxed, often engaging in activities), were not observed. As such, there appears to be a divergence between policy (using NPIs), and practice (using distraction and emotional reassurance).

It is clear from this study that underreporting of incidents of BtC occurs, and this happened in all three CHs. In estimating the extent to which this occurs, it is suggested that the observed incidents make up only 50% of actual incidents, recruitment rates and ethical limitations notwithstanding. This is a concerning finding, and warrants further investigation as to why care staff are not reporting incidents of BtC. Data from the survey suggest that CH staff recognise and frequently experience BtC, therefore questions are raised as to why incidents go unreported.

In some instances, I was able to calm residents down when the care staff declined to attempt to do so. This suggests that simply by finding out about the resident from reading their records, it is sometimes possible to identify the best way in which to diffuse a situation. This also highlights the importance of accurate, up-to-date and accessible records.

The findings of this phase of the study are limited by the number of self-selected CHs participating, and cannot be generalised, however they provide a small yet valuable insight into care in practice, which may apply to the wider CH community. In line with the findings from Chapter Four, the three CHs which took part in this study 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, CH staff often responded quickly, and carefully. The data support Pulsford et al [88], and suggest that CH staff act in such a way that would infer that they view BtC as causal, often deriving, in this study, from interactions with others. Despite the findings from Chapter Four suggesting that a familiar, home-like environment is a key facilitator in minimising behaviours, the CH environment was infrequently used as a strategy to manage BtC, however it was noted from records in CH11 that a sensory room was used: this was not observed in practice. CH staff have previously discussed the importance of knowing who they were caring for: their life history; their family; their personality and their behaviours. This was frequently observed in practice, and throughout my time within each CH it was clear that CH staff had some knowledge about residents' histories. Despite the sharing of ideas (Chapter Four) being acknowledged as a way of passing on management strategies to other colleagues, this was only observed in CH11, in staff meetings and during incidents of BtC.

It is noteworthy that medicines use was rarely observed as a strategy to manage incidents of BtC. It was also used only three times in 49 recorded incidents. This finding may suggest that medicines use in CHs is controlled, however this warrants further investigation, and must be taken with caution, particularly since it is clear that incidents of BtC are underreported.

This work has attempted to identify an evidence base for what CH staff are doing in practice to manage BtC. It also has attempted to be the first study to investigate how CH staff manage BtC through synthesising structured observational data and CH records data.

Strengths and limitations

This study brings together observational and CH recorded data of managing BtC in practice. A major strength of this phase of work is the novel method utilised. No published studies exist using ethnographic participant observation in a CH setting, and this study has allowed an insight into what happens in practice. Moreover, it has highlighted a difference between what CH staff say they do, and what they actually do. This ethnographic approach and limitation to one geographical area of England were used to explore this topic area, and inform and develop future work.

The self-selected CHs and care staff participating in this study were likely to think that they were doing a good job, and therefore the study is not representative of the wider population of CHs, particularly since the majority of CHs from Phase One declined to participate in this phase. I suggest that a CH manager who had concerns about the level of care they provided would have declined to have their care observed and documented. Therefore a limiting factor in this research is that the practice observed and recorded was likely to have been 'good' in comparison with other CHs throughout Kent and the London Borough of Lewisham. While it is difficult to generalise the findings of this study, given the relatively small number of homes and participants recruited, they do provide a number of substantial conclusions. The data has provided only a snapshot of care in practice, given that I had limited shifts in which to observe practice. In addition, ethical limitations resulted in being unable to gain access to full care records – something which future studies could build on. While no incentives were used in this phase of work, by providing an 'extra pair of hands', the CHs would have received some benefit, and therefore the three CHs may have been more likely to participate. However, given that seven of the 11 CHs from Phase One did not choose to participate in this phase, the 'extra pair of hands' incentive may not be valid. It is likely that those CH staff participating were interested in dementia, and in the care of their residents. While there did not appear to be any coercion from CH managers on their staff to participate, I cannot be absolutely confident that none occurred prior to my visit, or while I was absent from the CHs.

Chapter 7 Care in Practice: Medicines Use in Care Homes

Introduction

Chapter Three outlined the rationale for the design of this phase of the work. This chapter provides: the data analysis strategy; findings, and a discussion of Phase Four: Medicines Use in CHs. Polypharmacy is defined as the concurrent use of multiple medication items by one individual, and is described as 'appropriate' or 'problematic' [169]. Appropriate polypharmacy has been defined as 'prescribing for complex and sometimes multiple conditions where medicines use is optimised and where prescriptions adhere to best evidence'[169]. Problematic polypharmacy on the other hand is defined as 'the prescription of multiple medicines inappropriately or where the anticipated benefit of the medicine is not realised'[169]. In frail elderly people, the risk of significant morbidity and mortality is increased [170], and there are key considerations that must be taken into account when prescribing for this population. As such, a number of tools have been developed to aid practitioners in decision making with regard to prescribing or stopping medicines. Frail, elderly people are likely to be receiving several medicines, therefore it is important that these medicines are identified, and that medicines reviews are undertaken to identify any issues [169] . A cross-sectional analysis of a UK primary care database examined prescribing in CHs [171]. The study found that CH residents were more likely to receive medicines of concern, compared to their community-dwelling counterparts. These included benzodiazepines, anticholinergic antihistamines, loop diuretics and antipsychotics. Elderly people are at increased risk of adverse drug reactions (ADR) [172], and despite this, the use of central nervous system (CNS) drugs among older people is common. In people with dementia, who may already be taking numerous medicines, prescriptions of CNS drugs are more common [173]. Anticholinergic medicines in particular increase experiences of ADRs such as constipation, urinary retention, dry mouth/eyes, sedation, confusion, delirium, photophobia, falls and reduced cognition [43, 174]. Additionally, there is a possible association with increased mortality [43]. Antipsychotic drugs can be beneficial in treating symptoms of dementia; however severe side effects are associated with their long-term use, including blood clots, stroke and increased risk of mortality [25]. Additionally when used short term, antipsychotic drugs generate a state of apathy and inhibited initiative[30]. A 2009 report by the Department of Health[1] raised significant issues regarding the prescription of antipsychotic drugs for people with BtC, in particular quality of care and patient safety. While medicines can certainly prolong life-expectancy in this population, and improve quality of life, their benefits must be considered alongside the risks [175]. Research into polypharmacy in CHs has suggested approaches to medicines management that may improve resident safety and quality of prescribing within CHs [49, 50]. One suggested approach is the continual review of the use and accuracy of medicine administration records. It is therefore relevant to examine and critique MAR charts in the three CHs involved in Phase Three.

Aim and objectives

The aim of this phase of the study was to explore the medicines prescribed and administered to residents, in three CHs. The objectives for this phase were:

- To investigate the appropriateness of the medicines prescribed for CH residents with a diagnosis of dementia
- To assess the mechanisms of recording medicines administration in three CHs

Ethical approval

Ethical approval for this phase of work was sought from and granted by the SCREC, as described in Chapter Six. The full protocol and supporting documentation (14-IEC08-0020) is attached as a supplementary booklet (Booklet 1).

Sampling

The participants in this phase of work had consented (or their relatives had given assent) to participate in the ethnographic phase of this PhD study. Recruitment of these participants is described fully in Chapter Six – Care in Practice: An Ethnographic Study.

Collecting medicine records

The primary medicines record used in CHs to record the medicines prescribed and administered to each resident, is the Medicine Administration Record (MAR), often referred to as a MAR chart. The MAR chart documents the medicines list for each resident, and facilitates the administration and recording of this, each chart usually lasting for a four-week cycle per resident. MAR charts can be provided to the CH by a pharmacy, printed, or can be produced as hand-written documents by the CHs themselves. There can be other documents pertaining to medicines information in CHs, such as medicines on admission, treatment advice from out-patient clinics, and resident profiles, which may include medicine allergies, for example. However, these documents vary by CH, and some may not keep this information at all [49]. In order to identify the medicines prescribed and administered, for each participating resident the previous 1-month MAR chart was anonymised, reviewed and copied by hand, under supervision from a member of staff, and notes were made as to residents' current medicines, dosage, commencement of treatment and indication, if available. In this study, medicines were defined as any item printed or hand-written on a resident's MAR chart.

Data analysis

A preliminary analysis of all the items prescribed to each resident was undertaken by the research team, including my pharmacist supervisors. The data were first combined into an appendix (Appendix 13), and a preliminary analysis was undertaken by categorising the medicines according to their British National Formulary (BNF) classification [176]. The BNF provides up-to-date guidance on prescribing, dispensing and administering medicines. Further details were documented pertaining to each recorded medicine's likely name, dose in accordance with the BNF, likely indication and whether that indication was present on residents' medical records. The research team considered potential ways of analysing the data, which I completed as a first analysis. This included using the STOPP[177] tool, the Anticholinergic Drug Scale (ADS)[178] and the Anticholinergic Cognitive Burden Scale[189] to analyse the data. Following this preliminary analysis, a Medicines Analysis Tool (MAT: Appendix 14) was developed and formalised for use by my primary supervisor, before I applied it to the medicines data. This was checked by my supervisor. Seven steps were undertaken to achieve this. These are outlined below and explained in the MAT:

1. Add resident's name, medical problems (as identified in CH record), record of medication prior to admission
2. List medicines obtained from resident's MAR chart and record medicine name, dose, indication and administration instructions
3. Complete Summary of Medicines tables for each resident
4. Use BNF to record BNF section, likely medication and likely indication
5. Identify Potentially Inappropriate Medicines (PIMs) [Potentially Inappropriate Medication – Indication (PIM-I), STOPP criteria[177], Preventative medicines (PIM-P), Oral Nutritional Supplements (PIM-ONS), Other (PIM-O)]
6. Calculate anticholinergic scores for each medicine
7. Identify MAR chart errors

The PIMs are discussed below.

Potentially inappropriate medicine – indication (PIM-I)

The STOPP criteria identified any medicine prescribed without an evidence-based indication clinical indication as potentially inappropriate [177]. This study found only very limited medical information in the CH records and did not involve data collection from other sources, for example, GP records. As such, this lack of detailed information in the CH records is likely to have augmented the identification of potentially inappropriate medicines. In order to minimise inaccuracies, different categories of 'indication' were generated in the MAT: Indication present, self-limiting indication, unlicensed indication, PIM-I, and non-medicinal product. The review of MAR charts enabled potentially inappropriate medication because of a lack indication to be identified.

Potentially inappropriate medicine – STOPP (PIM-STOPP)

Certain medicines are considered inappropriate or potentially inappropriate in elderly people due to increased risk of intolerance associated with 'adverse pharmacodynamics or pharmacokinetics or drug-disease interactions' [179]. The Screening Tool for Older People's Prescriptions (STOPP), first published in 2008 and updated in 2014 due to the expanding therapeutics evidence base [177], was used to provide an indication of potentially inappropriate medicines (PIM-STOPP) for each participant. The authors posit that STOPP criteria have been shown to be significantly associated with adverse drug events in elderly people, unlike other criteria attempting to identify PIMs [180-183]. There is evidence that using these criteria as an intervention in single-centre randomised controlled trials significantly improves the appropriateness of medicines, and reduces the incidence of adverse drug reactions, compared with normal pharmaceutical care [184]. The lack of definitive clinical information about each resident limits the application of all 65 STOPP criteria. Therefore, it was necessary to make some assumptions when undertaking this analysis, and a list of 12 STOPP criteria which could be applied were used to review residents' MAR charts for the purpose of identifying PIM-STOPPs.

Potentially inappropriate medicine – Preventative medicines prescribed (PIM-P)

New evidence and shifting guidelines may affect the appropriateness of using a specific medicine. Indeed, most medicines do not need to be used for life [169]. Therefore, where the risks of medicines use are greater than the benefits in an individual, it is necessary to conduct a review of the medicine in question [169]. Various questions have been suggested to aid clinicians in stopping medicines[170], particularly since preventative treatments can become less beneficial in old age, and the journey towards palliative care ensues complete with prescribing challenges [185]. The Scottish Government's Polypharmacy Guidance aims to 'address the issues resulting from the use of multiple medicines in the frail and elderly population' [186]. The guidance considers severe dementia as constituting frailness, and therefore it is relevant to this study. The 'number needed to treat' (NNT) is a measure used in evaluating the effectiveness of a particular medication. It calculates the average number of patients who need to be treated in order for one to benefit to occur. The ideal NNT is 1, which means every person improves with treatment. As such, the higher the NNT, the less effective the treatment in terms of the likely positive outcome for any one individual. For medicines treating hypertension, (cerebrovascular morbidity and mortality > 80 years), the NNT to avoid one cerebrovascular event per year is 122 [187]. Similarly, for medicines treating osteoporosis, the NNT to prevent further hip fractures in people over 80 years is 105 [188]. Therefore the guidelines suggest that these preventative therapies in elderly, frail people should be withdrawn. As such, in this study, medicines prescribed for the purpose of preventing an event occurring in the future rather than for treating a current medical condition were identified and analysed.

Potentially inappropriate medicine – Oral Nutritional Supplements (PIM-ONS)

The NHS has produced guidelines for the appropriate prescribing of ONS which specifically state that as ONS should not be used as a substitute for the provision of food, 'care homes should provide adequate quantities of good quality food so that the use of unnecessary nutrition support is avoided' [189]. As such, residents prescribed ONS were identified for each resident and analysed.

Potentially inappropriate medicine – Other issues (PIM-O)

Any additional issues concerning potentially inappropriate medicines identified from the initial BNF review which could not be grouped into one of the four other categories were categorised as 'Other'.

Anticholinergic scores

Fox and Maidment's systematic review determined the effects of drugs with anticholinergic properties on relevant health outcomes, and identified that anticholinergic medicines have a significant adverse effect on cognitive and physical function [43]. Thus anticholinergics should not be used in patients with dementia. Section D8 of the STOPP Criteria suggests that a prescription of anticholinergic medicines in patients with dementia is potentially inappropriate, due to a risk of exacerbation of cognitive impairment [43]. The Anticholinergic Cognitive Burden Scale[190] categorises medicines into three scoring groups, and this has been widely adopted for use in practice. A score of 3 or more is considered clinically relevant. However, the ACB scoring scale contains some anomalies whereby not all medicines in similar classes are listed and some medicines with known anticholinergic activity are missing. The Anticholinergic Drug Scale[177], which was used to develop the ACB, provides are more wide-ranging list of medicines. The ADS score is calculated by totalling the scores for all of the anticholinergic medicines per resident. For each resident, those medicines with anticholinergic activity were identified and scored. An anticholinergic score was calculated using both the ACB and ADS.

MAR chart errors

Inaccuracies on the MAR charts that could cause errors were identified, and analysed. These included incorrect spellings of medicines, incorrect dose of medicines, therapeutic duplication, PRN medicines with no instructions and regular medicines not administered.

Findings

The details of all residents' medicines and errors identified are displayed in Appendix 13, and the data refer to this.

General findings

Errors were noted on residents' medical problems identified from their CH records, however, these errors ('thyrotoxicism' and 'hyomanic' for example) were ignored for the purpose of this analysis, as they were deemed to be unlikely to affect MAR chart errors. These can be found in Appendix 13, where they have been transcribed verbatim.

MAR charts varied between CHs: CH6 used a mixture of pharmacy-printed MAR charts and hand-written charts, on which CH staff wrote residents' drug names, doses and additional information. There were errors in drug names and omissions of doses on both the printed and hand-written charts, particularly where printed MAR charts were added to by hand. CH11 and CH2 had MAR charts printed by the pharmacies dispensing residents' medicines: there were no errors in drug names, and no omissions of doses. The MAR charts for each participating resident in CH11 had additional information on when each drug was commenced, and documented pre-admission medicines prescriptions for all three of their participating residents. Residents were prescribed an average of 9 medicines. At least one medicines related issue was found for all twelve (100%) residents in this study.

Resident-related findings

Potentially inappropriate medicine – indication (PIM-I)

This study did not seek to investigate whether an indication was present in a resident, rather, whether or not a documented indication was present in residents' medical records. As such, it is likely that the medical record keeping was inaccurate, and therefore it is important to reiterate that this analysis identifies potentially inappropriate medicines. Table 7.1 displays a summary of the PIM-I identified from residents' records.

	No of residents	**No (%) prescribed PIM-I**
CH6	7	7 (100%)
CH11	3	3 (100%)
CH2	2	1 (50%)
Total	12	11 (92%)

Table 7.1 PIM-I identified from residents' records.

Eleven (92%) of the 12 residents in this study were prescribed at least one PIM without a documented indication present in the list of medical conditions. In total, 40 medicines were prescribed without a documented indication. These are detailed in Appendix 13. The CH records held very limited medical information, and this study did not collect data from other sources, which may have provided clarity.

Potentially inappropriate medicine – STOPP (PIM-STOPP)

Table 7.2 displays a summary of the PIM-STOPP identified from residents' records.

	No of residents	**No (%) prescribed PIM-STOPP**
CH6	7	5 (71%)
CH11	3	2 (67%)
CH2	2	1 (50%)
Total	12	8 (58%)

Table 7.2 PIM-STOPP identified from residents' records

Of the 12 residents, eight (66%) were prescribed at least one PIM according to the STOPP criteria. Two or more PIM-STOPPs were prescribed for four (33%) residents. Two (16%) residents were prescribed six or more PIM-STOPPs (Walter – six PIM-STOPPs, Donald – 10 PIM-STOPPs). CH6 had the highest proportion of residents with PIM-STOPPs (5/7 residents (71%)).

One third of the residents were prescribed a potentially inappropriate benzodiazepine or Z-drug: three residents were prescribed lorazepam, one resident was prescribed diazepam and three residents were prescribed zopiclone. Regular and prolonged use of these medicines should be avoided in the elderly because of the risk of tolerance to effects, dependence and an increased risk of adverse effects [176].

Only two of the 12 participating residents received an antipsychotic medicine: these were haloperidol and risperidone. Despite Walter's diagnosis of psychosis on his medical record, his prescription of the antipsychotic medicine risperidone was potentially inappropriate due to the increased risk of falls in the elderly that antipsychotics cause. Additionally, Walter was neither observed nor recorded exhibiting BtC. Donald's prescription of haloperidol was potentially inappropriate, particularly because there is no indication of schizophrenia, however given that he exhibited BtC (observed and documented in Chapter Six), it is likely that it was prescribed for BtC, and is therefore an unlicensed indication. STOPP guidelines suggest that antipsychotics are 'only to be used for BPSD if symptoms are severe and all other NPI have failed'[177]. Additionally NICE and SCIE guidelines recommend using pharmacological intervention to manage BtC as a second-line treatment after NPIs have been attempted[21]. While there is ample evidence that Donald did exhibit BtC, there was no evidence that all other NPIs have been used and failed, however this may not be realistic given that Donald lived in a CH only accepting referrals and continuing care residents. In the 13 instances where Donald was observed exhibiting BtC, no NPIs were observed being implemented; rather he was distracted and/or reassured. In the 24 instances where Donald was recorded as having exhibited BtC by the CH, prescribed medicines were administered on three occasions. On the other occasions, he was reassured, reprimanded or nursed in the sensory room.

Potentially inappropriate medicine – Preventative medicines prescribed (PIM-P)

Table 7.3 displays a summary of the PIM-P identified from residents' records.

	No of residents	**No (%) prescribed PIM-P**
CH6	7	3 (25%)
CH11	3	1 (33%)
CH2	2	1 (50%)
Total	**12**	**5 (42%)**

Table 7.3 PIM-P identified from residents' records

Of the 12 residents, five (42%) were prescribed PIM-Ps. Ronald, Myrtle and Edna were all prescribed simvastatin. Ronald was prescribed three PIM-Ps: alendronic acid, calcium carbonate and simvastatin. One resident (Myrtle) was prescribed a total of three medicines, all of which were preventative (losartan potassium, felodipine and simvastatin). Myrtle's medicines were prescribed for hypertension: while hypertension increases the risk of dementia, and so treatment is beneficial to cognitive function[190], there is no evidence that treating hypertension in established dementia improves cognitive or cardiovascular outcomes [191]. Indeed, blood pressure is reduced as dementia progresses [192].

Potentially inappropriate medicine – Oral Nutritional Supplements (PIM-ONS)

Table 7.4 displays a summary of the PIM-ONS identified from residents' records.

	No of residents	No (%) prescribed ONS	PIM-ONS prescribed
CH6	7	4 (57%)	• Ensure® liquid (Ernie and Ronald) • Ensure® plus fibre liquid (Edwin) • Forticreme® Complete (Bertram)
CH11	3	0 (0%)	
CH2	2	0 (0%)	
Total	**12**	**4 (33%)**	

Table 7.4 PIM-ONS identified from residents' records

Four (33%) of the 12 residents were prescribed oral nutritional supplements, and these were all from CH6. The NHS PrescQIPP guideline stating that 'care homes should provide adequate quantities of good quality food so that the use of unnecessary nutrition support is avoided'[189], clearly suggests that these supplements are unnecessary and inappropriate, and this raises questions as to the reasons behind prescribing ONS for 57% of the participating residents from CH6.

Potentially inappropriate medicine – Other issues (PIM-O)

Table 7.5 displays a summary of the PIM-O identified from residents' records.

	No of residents	No (%) prescribed PIM-O
CH6	7	5 (71%)
CH11	3	1 (33%)
CH2	2	0 (0%)
Total	**12**	**6 (50%)**

Table 7.5 PIM-O identified from residents' records

Of the 12 residents, six (50%) were prescribed medicines with ‘other’ issues. These issues comprised of unsuitable prescribing (Ferrograd, Bertram and Edwin - a product deemed unsuitable for prescribing by the BNF), doses outwith the BNF (clotrimazole 1% applied four times daily, Agnes), inappropriate use of dabigatran etexilate (Ronald, see below), inappropriate pain relief (buprenorphine patch when only prescribed paracetamol as alternative pain relief, Ronald), unrealistic expectation of administration instructions (alendronic acid and calcium carbonate, Ronald - medicines to be swallowed whole while sitting or standing upright and for at least 30 minutes after because of risk of oesophageal reactions), co-prescription of laxatives and codeine, when codeine is prescribed for diarrhoea (Edwin), unclear duration of course (amorolfine, Edwin; clopidogrel, Walter), and inappropriate duration (domperidone, Donald - should be used at the lowest effective dose for the shortest duration, and normally should not exceed one month).

Ronald’s prescription of dabigatran etexilate was identified as inappropriate due to its long-term use, for a deep vein thrombosis (DVT). His medical records did not state when Ronald’s DVT occurred. The BNF (Section 2.8.2) states that ‘Duration of treatment should be determined by balancing the benefit of treatment with the bleeding risk; shorter duration of treatment (at least 3 months) should be based on transient risk factors i.e. recent surgery, trauma, immobilisation, and longer duration of treatment should be based on permanent risk factors, or idiopathic deep-vein thrombosis or pulmonary embolism’ and side effects include haemorrhage, excessive bruising and chest pain [176]. It is noteworthy then, that during my time at CH6, I was frequently asked to watch Ronald one-to-one, and noted in my reflexive diary on a number of occasions contusions to his head, arms and legs. Dabigatran is an anticoagulant; therefore any bleeding in a patient taking dabigatran is suggestive of an adverse effect. Hence it is important that dabigatran is only taken for the required duration. Additionally on two occasions, Ronald became distressed, intermittently pointing to and clutching his chest (Shift 6, Shift 8): if Ronald was feeling chest pain, it is possible that this may have been a side effect of his medicine.

Anticholinergic scores

Of the 12 residents, 10 (83%) were prescribed medicines with anticholinergic activity. The scores for each resident are detailed in Table 7.6.

Resident	Number of Anticholinergic Medicines (Score)
Ernie	1 (3)
Bertram	1 (1)
Agnes	1 (1)
Betty	1 (1)
Ronald	0 (0)
Edwin	1 (1)
Walter	5 (8)
Donald	6 (9)
Joan	2 (2)
Myrtle	0 (0)
Vera	2 (2)
Edna	1 (1)

Table 7.6 Number of anticholinergic medicines and total scores calculated for each resident

Twenty-one medicines were prescribed which had an anticholinergic score, calculated according to the MAT. The prescribed anticholinergic medicines with a score of 1 or higher were: lorazepam, sertraline, furosemide, procyclidine hydrochloride, valproic acid, carbamazepine, chlorphenamine, codeine and diazepam. ACB scores for each resident ranged from 1 – 9. Of the 10 residents, five (50%) had an ACB score of 1, two (20%) residents had a score of 2, one (10%) resident had a score of 3, one (10%) resident had a score of 8 and one (10%) resident had a score of 9. In this study, three of the 10 residents (33%) were prescribed one anticholinergic with ACB Score 3 (Ernie, Donald and Walter), and two of these residents were co-prescribed an anticholinergic with ACB Score 2 (Donald and Walter), the only two residents prescribed a Score 2 medicine. For 20 (95%) of these anticholinergic medicines prescribed, other issues relating to PIM were identified, suggesting that there is a potential for unnecessary anticholinergic burden. Indeed, in 11 (52%) of these medicines prescribed, a PIM-I was identified, suggesting that it may be possible to cease their prescription as a result of lack of indication.

MAR chart errors

Of the 12 residents' MAR charts, five (42%) had errors in some form. There were a total of 12 errors, made up of spelling and dosing errors. Drugs were spelt incorrectly on three MAR charts ('furosimide', for example), and some names of medicines had to be presumed ('Phenaymethylpeniciles' was presumed to be phenoxymethylpenicillin, for example). Four charts had errors in the dose written (40mcg of Tamsulosin, instead of 400mcg, for example) or an unspecified dose. Two residents (Bertram and Walter) had three misspelled medicines on each MAR chart. It is noteworthy that these spelling and dosing errors only occurred in CH6, where MAR charts were a mixture of printed and hand-written charts.

CNS medicines

Of the 12 residents, 10 (83%) were prescribed medicines which act on the CNS. Bertram, Agnes, Betty, Ronald, Edwin, Walter, Donald, Joan, Vera and Edna were all prescribed these medicines. It is noteworthy that nine of these 10 residents were observed exhibiting BtC. Those incidents of BtC observed and recorded together with each resident's CNS medicines are displayed in Table 7.7. Residents are ordered from greatest to least total number of incidents of BtC observed and recorded by the CH. For full details, please refer back to Chapter Six, Table 6.2 for observed incidents of BtC and Tables 6.5 and 6.6 for CH-documented incidents of BtC.

Resident	Number of CNS Medicines	Observed incidents of BtC	CH Recorded incidents of BtC	Total incidents of BtC
Donald	7	13	24	37
Ronald	3	11	4	13 (2 observed incidents recorded)
Edwin	4	5	8	13
Betty	1	9	1	10
Agnes	4	4	1	5
Bertram	5	3	2	5
Vera	3	3	0	3
Joan	3	2	0	2
Walter	6	0	0	0
Edna	1	1	0	0

Table 7.7 CNS medicines and total number of incidents of BtC observed and recorded

From the data, Donald had the most CNS medicines prescribed, and also the highest total number of incidents of BtC. However, there is no clear pattern emerging from the data, which is unsurprising given the small numbers. It is interesting to note that of the seven CNS medicines Donald was prescribed, five (lorazepam, zopiclone, haloperidol, co-codamol and carbamazepine) were identified according to the STOPP criteria as PIMs. His prescription of mirtazapine for major depression was appropriate according to the STOPP criteria, however the MAT suggests that mirtazapine is not an anticholinergic medicine within this study.

One resident (Vera) was prescribed trazodone hydrochloride for anxiety (50mg, one in the morning and one at night, with an additional 50mg once daily dose, as required, when 'in an extreme anxious state'). According to her MAR chart, Vera was administered 50mg once in the morning, and once at night, with an 'as required' dose given as shown in Table 7.8. Analysis of the prescribing pattern suggests that trazodone hydrochloride was likely to be being used to manage BtC. However, a Cochrane review[193] studying the use of trazodone to manage agitation in dementia found insufficient evidence to recommend the use of trazodone as a treatment for BtC in dementia.

Dose given	MAR chart day
Double PRN dose given	Day 4 (morning and afternoon)
PRN dose given	Day 1 –Day 12 (consecutively, inclusive)
PRN dose given	Day 16-Day 17 (consecutively, inclusive)
PRN dose given	Day 22

Table 7.8 As required administration of trazodone hydrochloride: Vera, CH2

While no CH-documented BtC records were found in CH2, it was noted in Vera's personal history record that she 'Does not sleep well at night: fretful and calls out constantly'. Vera was also observed on three occasions exhibiting BtC.

Pre-admission medicines

Three residents (Donald, Joan and Myrtle) had notes documented about their medicines prior to their admission to CH11.

Prior to his admission, Donald was prescribed carbamazepine 300mg BD, co-dydramol QDS, lactulose 15-20mls BD, thiamine BD, haloperidol 2mg BD, furosemide OD and quetiapine 12.5mg BD. It appears from Donald's MAR chart that quetiapine was stopped since his admission to the CH, a positive step given that he was also prescribed another antipsychotic medicine, and it is inappropriate to prescribe two antipsychotic medicines simultaneously. However, zopiclone, lorazepam and mirtazapine may have been initiated during his stay in CH11, given that he was admitted on 13/10/2008 and these medicines were started on 14/12/2009, 11/07/2013 and 10/06/2013 respectively.

Prior to her admission, Joan was prescribed trazodone, diazepam, spironolactone, lactulose, senna, lorazepam, clonazepam, zopiclone, paracetamol and procyclidine. It is encouraging that procyclidine (an anticholinergic for which there appeared to be no indication, although it is likely to have been given with an antipsychotic in the past to prevent or treat extrapyramidal effects), zopiclone and lorazepam were no longer being prescribed, as well as spironolactone, which is potentially dangerous, especially in the elderly unless potassium levels are monitored carefully. Prior to her admission, Myrtle was prescribed amisulpride, felodipine, losartan and simvastatin. It is encouraging that amisulpride was no longer being prescribed, given that it is an atypical antipsychotic medicine.

Overall in CH11, there is evidence that, in three patients, two antipsychotics and an anticholinergic were stopped since admission, suggesting that medicines were reviewed after admission in relation to both dementia and BtC. Reviews of medicines on admission were limited to CH11 however, where previously good practice was identified (Chapter Six). No information on pre-admission medicines was available in the other two CHs, to enable a similar analysis to be undertaken.

Discussion

This study aimed to explore the medicines prescribed and administered to residents, in three CHs in Kent and the London Borough of Lewisham. It builds on other recent studies by synthesising CH residents' MAR chart data, without limiting medicines data to solely antipsychotic prevalence and use or medication errors.

While regulations and guidelines do exist (Commission for Social Care Inspection (CSCI), now CQC and Royal Pharmaceutical Society of Great Britain (RPSGB)), there is no single model of medicines management in CHs [49]. The three CHs in this study all used different types of medicines records, and within one CH the level of consistency in maintaining these records was poor. This is potentially problematic in ensuring residents receive the correct medicines at the correct dosage.

Of the 12 participating residents, all (100%) had at least one potential medicines-related issue. Barber identified one or more medication errors in 69% of 256 residents from 55 English CHs [49], while Szczepura et al[194] found that 90% of 345 residents from 13 English CHs were exposed to at least one error.

Most CH residents take several long-term medicines and this study found that residents took an average of 9 medicines, in line with Szczepura et al [194], and similar to Barber's [49] and Shah's [171] analysis of 8 medicines per CH resident. This illuminates the complexity of the clinical conditions of CH residents. As such, this provides assurance that the population in this study was similar to that of other studies, and therefore further investigation utilising the specially-developed MAT is warranted.

The findings from this study illuminate the importance of reviewing CH residents' medicines. In line with two studies suggesting that over half of nursing homes residents were prescribed at least one potentially inappropriate medicine [181, 195], this study found that 58% of participants were prescribed one or more PIMs according to the limited number of STOPP criteria which could be applied. This is higher than Shah's findings of 33% of residents who received a PIM [171]. In addition, 33% of residents in this study were prescribed two or more PIMs and one (8%) was prescribed six

PIMs. One third of the residents were prescribed potentially inappropriate benzodiazepines or Z-drugs, regular and prolonged use of which should be avoided [176]. I suggest that the MAT gives a broader approach to medicines review, and therefore the identifying of PIM in CH residents warrants further and more in-depth investigation using this tool.

Twenty-one medicines with anticholinergic activity were prescribed to 83% of residents. For 20 (95%) of these anticholinergic medicines prescribed, other issues relating to PIM were identified, suggesting that there is a potential for unnecessary anticholinergic burden. Indeed, in 11 (52%) of these medicines prescribed, a PIM-I was identified, suggesting that it may be possible to cease their prescription as a result of lack of indication. It is imperative that the question of whether anticholinergic medicines are indicated is asked for every resident, particularly because of their side-effect profile and association with increased mortality. Anticholinergic medicines worsen dementia, therefore in this population this question is of utmost importance. In addition, whether or not the medicine can be replaced with an alternative that is without anticholinergic burden, is important to consider. An older study in 1983, by Blazer et al, surveyed 5902 CH residents for drug administration and drug quantity [196]. Of these, 60% received drugs with anticholinergic properties. There are no recent studies investigating the use of anticholinergic medicines in CH residents, and therefore further research in this area is warranted.

Half of the residents were prescribed medicines which act on the CNS, and all of these residents were observed exhibiting BtC. The resident with the highest number of prescribed medicines acting on the CNS was the resident with the greatest number of observed and recorded incidents of BtC. As such, whether an association between medicines acting on the CNS and incidents of BtC exists requires exploration.

It would appear even from this small study that different CHs have different views towards ONS, which were prescribed more freely in one CH compared to the others. There is little published evidence on the prevalence or appropriateness of ONS in CH residents. A study conducted in Helsinki suggested that malnutrition was associated with female gender, a longer stay in the CH, functional impairment and dementia, stroke, constipation and dysphagia. In this study however, the residents prescribed ONS were male, of whom, one had had a stroke (Ronald), and two were the most recently admitted residents. Four of the seven residents in CH6 received an ONS, yet none of the other two CHs' residents were prescribed them. This raises questions as to the reasons behind their prescription. While the nutritional risk of the participants in this study was not calculated, PrescQIPP guidelines state that 'CHs should be able to provide adequately fortified foods and snacks and prepare homemade milkshakes and smoothies, which should negate the need to prescribe ONS in the majority of cases'[189]. It is also suggested that food fortifying care plans are introduced into residents' care plans to instruct care staff regarding food fortification. This study did not receive ethical approval to extract data from residents' care plans. It is noteworthy that the majority of residents from CH6 participating in this study were prescribed ONS where other CHs' residents were not, and as such it is evident that CHs have different views towards ONS.

Barber's study identified that 14% of residents were exposed to incorrect dosing errors [49], a figure lower than the 33% that this study found. This study also found spelling errors in 25% of MAR charts.

The results of this study illuminate the errors and issues relating to the use of medicines in CHs. It appears that regardless of the methods used to categorise problems relating to medicines use in CHs, problems are found. This in particular is a limitation of most studies investigating medicines use in CHs, in that they adopt only one method of identifying problems, and therefore this raises questions as to what additional issues may have been missed. It is crucial that residents' medicines and symptoms are reviewed, which may in turn lead to the possible discontinuation of inappropriate and unnecessary medicines and a reduction in polypharmacy in this population. This could result in better adherence to medicines by residents who are reluctant to take several medicines, an improved quality of life, a reduction in BtC and an overall improved quality of care.

Strengths and limitations

This study brings together a current picture of medicines use in CHs. Although limited to one geographical area of England and three CHs, the data collected allowed a more in-depth exploration this area of research than any previously conducted, and may inform and develop future work. The MAT specially developed for this study drew on a wide range of published guidelines and prescribing information. Similarly to Chapter Six, the CHs and care staff participating in this study were likely to think that they were doing a good job, and therefore the study is not representative of the wider population of CHs. Moreover, it is likely that those CHs participating were interested in dementia, and the care of their residents. It is difficult to generalise the findings of this study, given the small number of homes and participants recruited, however a number of important findings have been made.

Chapter 8 Relatives: The Alternative Perspective

'And I said, can't you remember then girl? She said, no'.

Introduction

It is important to describe the experience of living with dementia from the perspective of those who have experienced just that: this includes those people who care for their loved ones with dementia, whose voices are often unheard in research. The above quote comes from a husband I interviewed within this phase of work, and it describes the morning his wife had gone to her GP with a headache complaint, only to get there and forget why she had gone. This was the moment he realised there was something wrong with his wife, who was later diagnosed with dementia. It justified to me why this perspective was included in the study, and how important it is to be inclusive in this research, allowing relatives an opportunity to share their stories and experiences.

Chapter Three outlined the rationale for this study design. This chapter provides: the sampling and development; interview process; data analysis strategy; findings, and a discussion of, Phase Five, Relatives: The Alternative Perspective.

While residents' experiences of this care are not directly examined in this thesis, relatives' perspectives can illuminate the reality of living with and caring for a loved one with dementia, and this chapter attempts to do that. A qualitative focus group discussion was initially chosen for Phase Five, however due to poor recruitment and an inability to select dates and times mutually beneficial to all participants, single interviews were conducted with three consenting participants. Data collected from ethnographic observations described in Chapter Six informed the qualitative focus group discussion schedule chosen for Phase Five, and this was re-written as an interview schedule, which required revised ethical approval from the SCREC. The views and experiences of CH residents' family, friends, visitors and/or any person(s) who had been involved (though not in a professional capacity) in the care of residents living in the chosen dementia unit at each CH were sought in order to gain an alternative perspective of the reality of living with and caring for a loved one with dementia.

Aim and objectives

The aim of this phase of the study was to seek an alternative perspective of dementia care, by exploring the views and experiences of relatives of residents living in three CHs.

Objectives for this phase of the study were:

1. To explore relatives' 'dementia journeys'
2. To explore relatives' views and experiences of BtC
3. To explore relatives' views and experiences of CHs

Ethical approval

For this study phase, favourable ethical opinion was granted by the SCREC. The participant information sheets were designed to include all of the information that potential participants required in order to decide whether to participate or not. Informed consent was provided by completion of the consent form. On the basis of poor recruitment and a lack of mutually convenient dates and times for all participants, focus groups could not be conducted, and therefore an amendment was sought and obtained to the ethical approval for transforming the focus group discussion into an interview schedule (refer to protocol in Booklet 1, Appendix 13 for focus group schedule). All transcribed interviews were coded to maintain CH and participant anonymity, and this is discussed further in the protocol, within Booklet 1.

Sampling strategy

The initial target population for this study consisted of CH residents' family, friends, visitors and/or any person(s) who has been involved (though not in a professional capacity) in the care of residents living in the chosen dementia unit at each of the three CHs studied in Chapter Six. Participants were identified with the help of care staff, and were limited to those people already visiting the CH. None of the three homes could agree to provide me as researcher with a list of contacts, but instead suggested I could approach potential participants directly, when they visited the home. This limited my ability to recruit participants, however six consenting spouses (two in each CH) were successfully recruited. As two was an insufficient number for a focus group, it was decided by the research team to conduct single interviews instead. Unfortunately, three of the consented participants were unsure about participating in a recorded interview, and despite my reassurances, subsequently declined to participate. I felt it would be unethical to pursue them further, but left the offer of participation open to them while I remained conducting observational research at the CH. The three remaining relatives consented to participate in an interview.

Interview schedule development and design

There is little published research exploring the views and experiences of relatives, friends and visitors of CH residents, and therefore the interview schedule was designed to be as broad as possible. The interview schedule began with a grand tour question asking about the interviewee's shared dementia journey, to allow them to set the course of the interview. Questions then followed the leads that participants provided, returning to the scheduled questions after pursuing those leads. The following areas were included:

- Scene setting and story sharing of participants' 'dementia journey' (Grand Tour)
- Participants' perceptions of BtC prior to and post CH admittance
- Participants' perceptions of staff views that 'relatives can be a barrier'
- The shared dementia journey

Conduct of interviews

Once participants had consented to take part in the study, the researcher made arrangements for conducting each interview at a convenient time for the relatives: this tended to be whenever they next visited the CH. Interviews took place in the living rooms of the CHs, since participants wanted to remain sitting with their spouses. The advantage of these locations was the familiarity that participants had with them, and in particular, the addition of sitting with their spouses may have added some comfort, and potentially provided a feeling of inclusion of the resident, by their spouse.

A digital audio recorder was used to record the interviews, which lasted approximately twenty minutes and were conducted according to the interview schedule (Appendix 15). Informed consent was obtained in writing prior to the interview and again verbally, immediately before the conversation. Before the interview, an opportunity was given for participants to ask any questions, or decline to participate.

Each interview began with the same question, 'If you are willing, it would be lovely if you could first of all share your stories by telling me about [name of friend/relative who has dementia], and your shared dementia journey', and depending on the responses given, the following question was asked, 'Can you tell me your opinions on the use of the term 'challenging behaviour', and what challenging behaviour means to you?'. A copy of the interview schedule in the format used during the interviews is included in Appendix 15. Once I was satisfied that all the areas of the interview schedule had been covered, interviewees were asked if there was anything they felt had not been covered, or if there was anything they would like to add, before the interview was concluded.

Data analysis

Each audio file was saved onto a password protected computer, before being transcribed verbatim by the researcher. Transcription of the interviews assisted my immersion in the data, by listening to the transcripts repeatedly. A thematic analysis was used to develop a coding framework, from which themes emerged. The initial analysis was performed by reading through the transcripts and highlighting portions of text that assisted in the coding process, because they illustrated individual participants' views. The analysis process comprised six phases, identified by Braun and Clarke [155], as described in Chapter Four.

Findings

Three interviews were conducted between July 2014 and February 2015. The duration of the interviews ranged from 15 to 33 minutes. Saturation was not reached due to a poor level of recruitment. Codes were sometimes disparate because of the small number of interviews, each discussing a unique person. Three CHs yielded three interviews; one participant was female and two were male.

Emergent themes

Three principal themes emerged. These were: worsening of behaviours, lack of formal support and the CH transition. These themes are further detailed in Table 8.1, together with sub-themes for each.

Themes	**Sub-Themes**
Worsening of behaviours	Lack of awareness, attribution to old age , perception of BtC term, experience of BtC
Lack of formal support	Nowhere to turn, changing support
The CH transition	CH admission, BtC, processes, CH family

Table 8.1: Themes and associated sub-themes identified following analysis of spouses' interview transcripts

The following section describes each theme in turn, and quotes from the interviews will be used to validate the meanings contained within the themes. The section ends with quotes pertaining to relatives' views of research.

Theme 1: Worsening of behaviours

Relatives' dementia journeys were unique in many ways, but also incredibly similar. Relatives talked at length about their experience of living with their spouse's dementia, and it was clear that caring for them at home, often alone, became increasingly difficult as time went on. All three interviewees reported being unprepared for the diagnosis of dementia, despite knowing that unusual behaviours were increasingly occurring. These behaviours were sometimes attributed to other things, including old age and stress, and sometimes ignored all together.

> *'In hindsight the symptoms were there a long time ago. But being ignorant of it, we put it down to other things, or just getting on with it, things of that nature… I thought [her] lack of cognition I suppose for want of a better word, was umm, shook me… And I thought crikey, there's something really wrong here' (Relative 1).*

> *'I thought she was stressed out…having a nervous breakdown…they said she's got Alzheimer's. I just couldn't believe it' (Relative 2)*

> *'I suppose I knew really, and I think we probably lived with it for such a long time. His mum had it you know. I suppose I ignored it was ever there to begin with. I don't really know if he knew (Relative 3)'.*

Relatives were asked about their perceptions of the term 'challenging behaviour', and asked whether they felt it was an inappropriate term to use, when conducting research with people with dementia and their families. All of the interviewees supported the term, and showed understanding and empathy towards those people managing it.

> *'It [BtC] sounds a bit naughty, but it's ok. I've got a practical background so I call a thing what it is. A spade's a spade' (Relative 1).*

> *'I don't find it offensive. Because you see here what happens to some of them, and they are challenging. Some of the staff here they end up with orange juice all down them, they're abused, hit. You can understand why they use that term' (Relative 2)*

> *'Not at all. It can be challenging, I can understand why really. That one lady, poor thing, she just sits and shouts that she wants to go home. All day. All night. And all day again, poor love.' (Relative 3)*

Relatives had experienced BtC personally while caring for their spouses at home, and this is often what forced the transition to CH, or in one case, hospital prior to moving to a CH. A number of

BtC were experienced; in two cases, this took the form of aggression and in one, dangerous behaviour. Relatives talked of the toll this had on them personally, including lack of sleep, panicking when their spouses tried to wander off, having to orientate their spouses when they awoke confused in the night, not allowing them to cook in case the gas was left on and being unable to leave them in the house alone.

'I think she was frightened of him [doctor] and um, on at least one occasion she wanted to get out the place when she realised where she was. And I had to block the door and she was hammering on my chest, so I thought oh dear' (Relative 1).

'She was getting up in the night and moving all the furniture around, and walking around the house in the nude, and she'd put the gas stove on and nothing on top of it…I just used to bite my lip like, because you knew, she couldn't help it' (Relative 2).

'He lived at home for a long time before he had to go into the care home. When I knew, was when he turned the car lights off when he was driving us home…at night. Down a country lane and he just went and turned them right off. And I knew' (Relative 3)

Theme 2: Lack of formal support

One of the main topics discussed by relatives when talking through their dementia journey was the lack of formal support they and their spouses received after diagnosis and before the transition to the CH. They talked about their lack of knowledge, and sometimes being passed from pillar to post, because of staffing levels, staff difficulties in managing behaviours and frequent changes to staff within care provision services resulting in repeated changes of 'care managers'. One participant remembered her frustration in no one understanding her situation, and feeling that no one cared. Admiral Nurses are specialist dementia nurses, who provide support for both the individual with dementia and their family. They were introduced as a result of the experience of family carers, relatively recently. To family carers, they provide emotional, practical and psychological support to enable the individual with dementia to remain living at home. It is important to note that they may not have been in place when the relatives' residents were living at home, being cared for by their spouses. One participant discussed the knowledge imparted by an Admiral Nurse, but felt it was provided at too late a stage.

'I only wish when it happened, they'd put us in touch with the admiral nurse. Because it took two years to learn for me, how people [care for their loved ones], have you done this, have you done that? The admiral nurse come in…and everything that had taken me two years to learn she told me in half an hour…That's what they should do, put you straight in touch' (Relative 2)

> *'We went there [respite centre] for, some time I suppose. Many months. And then they said she will need to go under a different care manager or something I think, or some changes going on. So we had this other woman, I call her the poisoned dwarf. She was absolutely useless…As far as I was concerned she wanted to cure her, but that's the problem.' (Relative 1)*

> *'The GP was lovely with him, really lovely. But there wasn't really anywhere we could find information. I did try to get him to go to a day centre once but it was so confusing and, I can't remember now really, it wasn't helpful. At all. Mind you, we tried to get a blue badge for him so I could take him to the shops more easily…terrible, terrible process. No one understood. No one cared I suppose.' (Relative 3)*

Theme 3: The CH transition

Once relatives had accepted, or decided that their loved one could no longer live at home, they talked emotively about the difficulties in either getting into a CH, or even staying in one. Relatives had very contrasting views of different CHs, and CH staff attitudes and willingness to cope with BtC. One relative spoke of the three attempts it took to get his wife admitted to a CH, and how each time, his wife was refused on the basis of her having BtC. It is noteworthy that this assessment of her having BtC was made in one visit. He went on to remark how wonderful the current CH was with regard to her BtC, and why.

> *'They tried to get us in one down by the river…big posh place about six or seven acres…but um, they said it was too much of a handful…he interviewed her there in my absence. Fortunately, he decided there and then that he couldn't take her on and she was too, restless you know…And her record by then was getting naughty. She's been to [a different CH] earlier; she could be wandering in and out of rooms. So they said they couldn't take her on as permanent. They'd take her on temporary like, two weeks or something.' (Relative 1)*

> *'We were shown one…oh gosh it was, can't imagine it. It was an old ruin of a garden, like an old monastery or something like that. But…they took two carers to escort her…When they came back they said they weren't very happy because she needed two people to watch her…Anyway the upshot was because they said they needed too many carers to look after her, they couldn't take her.' (Relative 1)*

> *'They calmed her down. She calmed down pretty quickly within a matter of weeks of being here…In hindsight, because these people care what they're doing. They're very good, very patient.'*
>
> *(Relative 1)*

Another relative recounted with distress, an assessment that his wife was required to pass, in order to continue receiving her continuing care package. He was clearly displeased with the CH and its assessment process; however he praised the other residents and their relatives, and talked about how they impacted on his life.

'The only way they can justify their jobs is by moving people on…from the home. I mean two year ago they put ten of us through hell. Two hour assessments and all that…for our loved ones…continuing care package…' (Relative 2)

'I feel like they're my friends as well. I know the families…what's happening in their lives…which takes your mind off of what's going on with yours.' (Relative 2)

One relative talked of her desperation for her husband not to be in a CH, but also of her exhaustion from caring for him at home. She visited her husband daily, and was particularly praising of the CH staff and environment.

'Well I went every day you see. And sat with him, did the crossword, you know. I'd say the CH staff were wonderful, they worked so hard. And I know that it was the right place for him to be, but I hated seeing him there, like that. Wanting to come home with me…I wish I could've just said yes dear. But I couldn't, well you can't can you? But you know, they let us take him out, and they had beautiful garden, lots of flowers. He loved the garden. But the girls were just wonderful' (Relative 3).

Relatives' views of research

Two of the relatives talked about their view of research, one having experienced a research study previously with her husband. I believe their comments are particularly pertinent to this study, and warrant inclusion.

'All the research [is] on the earlier stages and not the later stages. Alright prevention's better than cure, but we've got a heck of a lot of people suffering, their relatives and everything else, their independence as well. So research could be on the other end…it'd be better. It'd make a lot of us a lot happier.' (Relative 1)

'He did take part in some research at the beginning, a drugs one, and it was lovely. But yes I would fully support anything that helps, especially in care homes yes. Well it's so important isn't it? There are all these people, and we've got to get better at knowing how to look after them properly. Of course.' (Relative 3)

Discussion

This chapter has provided an insight into the lives and experiences of relatives of CH residents, and the reality of living with and caring for a loved one with dementia. This phase confirms that relatives of residents living in CHs can provide an important alternative perspective on dementia care and therefore should be included in future research studies. Relatives have experience of BtC, including dangerous and aggressive behaviour, and in this study were able to discuss the unusual behaviours occurring. In retrospect they may have realised it was dementia, however they did admit to attributing the behaviours down to other factors including old age and stress, or being in denial about a potential diagnosis. It is possible that this could have perhaps been avoided had more information or support been more widely available. With the Dementia Strategy[15] only being introduced in 2009, it is possible that there was a lack of support and information at that time. Indeed one of the Strategy's key themes was early diagnosis and support (Objectives 3 and 4: Good-quality information for those with diagnosed dementia and their carers; providing people with dementia and their carers with good-quality information on the illness and on the services available, both at diagnosis and throughout the course of their care. Enabling easy access to care, support and advice following diagnosis; a dementia adviser to facilitate easy access to appropriate care, support and advice for those diagnosed with dementia and their carers). Relatives were understanding, and empathetic to the use of the term BtC, and this may be useful knowledge in conducting any future research with relatives of people with dementia. Chapters Four and Six showed that the CHs in this wider study are attempting to provide support for residents' families, as proposed by the National Dementia Strategy [15], however it is clear that this support is not provided across all healthcare services, particularly prior to admission to a CH. Indeed, this study revealed that being admitted into a CH may not be a straightforward process, particularly where BtC is present. This study supports the findings of Chapter Four, which reported the acknowledgement of CH managers that residents' families required their care and support, when struggling with unusual behaviours, consequences of a dementia diagnosis and the CH transition. Indeed, the relatives in this study felt that they required much more support than they received, and wished they had had it. Relatives were praising of the CH in which their spouses were cared for, and talked highly of the staff, and in one case, the environment. Finally, it is noteworthy that two relatives discussed participation in research, and their wish to contribute. In particular they suggested that more research should be focused on caring for people with late stages of dementia, not just on preventing deterioration.

Strengths and limitations

This study brings together the views and experiences of relatives of CH residents on dementia, BtC and CHs. Three relatives from three CHs in one geographical area of England were used to explore and contribute in a small way to this under-researched area. The findings of this phase of the study are limited by the number of participants, and cannot be generalised, however they provide a small yet important insight into an alternative perspective in CH research, which may apply to the wider CH community. CHs were self-selected, as described in Chapters Four and Six. Potential participants were suggested by CH staff members, on the basis that they visited the CHs. Therefore, it is likely that those relatives who visited frequently and so were more familiar with the CH consented to participate. Data saturation could not be reached in this phase. Additionally, two interviewees had very positive views about research, and therefore this may have influenced their decision to participate: as such, a bias existed as a result of their positivity toward research. Three relatives declined to participate on the basis of having to be interviewed individually by the researcher, and eleven relatives declined participation in both focus group discussions and interviews.

Implications for practice and research

The number of people living with dementia in the UK is increasing, and in 2013, was estimated to be 815,827 [4]. Additionally there are approximately 670,000 people in the UK who act as primary family carers for people with dementia [3]. When the transition from own home to CH occurs, these thousands of primary family carers become a lost statistic, yet they can still make a unique and valuable contribution to research. Health and social care services should routinely involve service users and their informal carers in service evaluations [197], and while carers' opinions are included in the evaluation of services [198], the literature review did not find any studies investigating the experiences of relatives in dementia care research. The relatives of CH residents do not currently have a voice in healthcare research, and there is no published work on their views and experiences of the dementia journey. One study exists[100] which interviewed relatives of people with dementia being cared for in CHs and hospitals, however they were asked about their perceived role and who they approached with concerns or questions. The study's main focus was including people with dementia as research subjects. This study highlights the need for and potential benefit of inclusion of relatives' experiences and perspectives in dementia research.

Chapter 9 Care Home Recruitment: Obstacles and Outcomes

Introduction

Conducting research in CHs is not without its challenges [133]. During this PhD study I have witnessed first-hand the challenges of providing care to CH residents with dementia who exhibit BtC, and it is clear that this topic urgently requires further investigation. Ensuring that CH residents receive good, safe care is a priority in current health planning, however those individuals entering care establishments are increasingly older, requiring care for both chronic illness and reduced functional abilities [199]. Research within community care establishments is a requirement of addressing these challenges in order to ascertain how best to deliver care to vulnerable older people [200].

Since commencing this PhD study, Enabling Research in Care Homes (EnRiCH), a joint venture between the Centre for Research in Primary and Community Care, the University of Herefordshire, University College London, King's College London and the Dementias and Neurodegenerative Diseases Research Network (DeNDRoN), began developing a resource to support researchers, CH staff, residents and relatives in the delivery of research in CHs (http://www.enrich.nihr.ac.uk). It initially recruited 40 CHs across 4 'local networks' in England to form the EnRiCH CH network. By 2014, 141 CHs had been recruited to this network. While this appears to have been a success, it is clear that there is still a huge amount more to do: there are currently 16,898 CHs in England, therefore 0.8% English CHs belonged to the EnRiCH network in 2014. None of the CHs included in this PhD study were recruited to the EnRiCH network.

This chapter aims to provide a description of obstacles and outcomes of the recruitment process experienced throughout the duration of my PhD study. In particular it describes the approach to recruitment, the problems encountered, how these problems were addressed, and finally provides recommendation for future researchers.

Recruitment Approach

This study consisted of five phases: interviews with CH staff and environmental observations; multi-method distribution of a cross-sectional survey; ethnographic observations of care in practice; an investigation of medicines use in CHs and interviews with residents' relatives. Each phase brought its own challenges in recruiting eligible participants, and difficulties were encountered in attempting to recruit CHs (and managers), CH staff, CH residents, CH residents' consultees, and CH residents' relatives. The following is a brief outline of the recruitment approach in each phase:

- Pilot and Phase One: a face to face visit was made with 11 CH managers, to discuss the study. Managers who provided consent for their CH to participate were provided with recruitment packs to deliver to CH staff, consisting of a participant information sheet and informed consent form.
- Phase Two: 2520 surveys were distributed across England (n=1170 direct distribution survey (i), n=1350 postal distribution survey (ii)). Consent was provided through completion and return of the questionnaire.
- Phases Three: all previously participating CH managers from Phase One were contacted to discuss any potential interest in participating in the next phases of the study. Meetings to discuss the project further were organised with interested CH managers, and four managers provided consent for their CH to participate. Thereafter, meetings were held with CH staff, residents and relatives to discuss the study. Interested potential participants were provided with a participant information sheet and informed consent form to complete and return at their leisure.
- Phase Four: all CH managers consenting to participate in Phase Three were aware that they were also consenting to Phase Four, since both phases were covered in one participant information sheet and informed consent form. Similarly, all residents or consultees were aware that by consenting/assenting to Phase Three, they would be consenting/assenting to Phase Four.
- Phase Five: individual discussions about the final phase of the study were held with residents' relatives at a time convenient to them. If interested, they were provided with a participant information sheet and informed consent form to complete and return.

Table 9.1 details the numbers of CHs and participants that were contacted, those who responded, those who were willing to participate, and those who were ultimately recruited.

	Method	Invitation	Invited to participate	Responding to contact	Willing to participate	Research completed
Phase One: Pilot CHs (Lewisham)	Interview	Letter to manager	12	0 (0%)	1 (8%)	1 (8%)
Phase One: Pilot CHs (Kent)	Interview	Letter to manager	130	32 (24.6%)	1 (0.8%)	1 (0.8%)
Phase One: CHs Kent	Interview	Telephone call	198	87 (43.9%)	9 (4.5%)	9 (4.5%)
Phase Two: CHs England	Questionnaire	Direct and postal distribution	1404	371 (26.4%)	352 (25.1%)	352 (25.1%)
Phase Three: CHs	Observations	Telephone call	11	11 (100%)	4 (36.4%)	3 (27.3%)
Phase Three: Staff	Observations	Face to face	34	34 (100%)	19 (55.9%)	17 (50.0%)
Phases Three and Four: Residents	Observations	Face to face	1	1 (100%)	1 (100%)	1 (100%)
Phases Three and Four: Consultees (assented residents)	Observations	Face to face	57	11 (19.3%)	11 (19.3%)	11 (19.3%)
Phase Five: Relatives	Interviews	Face to face	16	16 (100%)	6 (37.5%)	3 (18.8%)

Table 9.1: Participants approached and recruited to Phases One, Two, Three, Four and Five

In the Pilot study of Phase One, a 1.4% response rate occurred, from two CHs out of a possible 142.

In Phase One, this study experienced a 4.5% response rate to invitations distributed to managers of 198 CHs in Kent. Additionally three CHs from Phase One were recruited from one company.

For Phase Two, 391 of 2520 surveys were returned (15.5%), of which, 56 (4.8% response rate) were from 17 (31.5% CH response rate) CHs (method (i)) and 335 (24.8% response rate) were from 335 CHs (method (ii)). In total 352/1404 (25.1%) CHs responded.

In Phase Three, four of the 11 CHs involved in Phase One reported being willing to participate, however research was only conducted in three (27%) homes. Additionally, 17 out of 34 (50%) CH staff gave their consent to participate, and 12 from a possible 58 residents (21%) were recruited.

In Phase Five, three out of a possible 16 (19%) relatives consented to be interviewed.

Details of the characteristics of the homes which agreed to the various phases of the study in Phases One and Three (CH1-CH11) and Phase Two, compared to those which did not are displayed in Table 9.2. The total numbers of residents in each CH varied (see Table 9.2), however there were differences in the actual number of residents as reported by CHs, and the data held online (www.carehome.co.uk). Therefore data pertaining to the numbers of residents in each CH has not been recorded for non-participating CHs.

There does not appear to be any location bias, although it is unsurprising that CHs were recruited were in Medway, and may have heard of the Medway School of Pharmacy. The study recruited proportionately more CHs with nursing than CHs without nursing, in comparison to the actual distribution; therefore there is a bias towards CHs with nursing in this study.

	CH with Nursing	**CH without Nursing**	**Number of Residents (as stated by CH)**	**Local Authority District Areas**
Phases One, Three, Four and Five CH1-11 **(Total sample=199)**	8 (11.6%)	3 (2.3%)	28-112	London Borough of Lewisham (1) Ashford (1) Canterbury (1) Dartford (1) Maidstone (2) Medway (3) Shepway (1) Tunbridge Wells (1)
Non-participating homes	61 (88.4%)	127 (97.7%)	Not recorded	Ashford (87) Canterbury (171) Dartford (277) Dover (160) Gravesham (157) Maidstone (175) Medway (307) Sevenoaks (248) Shepway (125) Swale (179) Thanet (126) Tonbridge and Malling (236) Tunbridge Wells (102)
Total	69 (34.7%)	130 (65.3%)		
Phase Two CHs (Total sample=1350+54) (missing data for 7 CHs)	164 (29.9%)	181 (21.1%)	Range 20-750	Yorkshire and The Humber (29) North East (18) North West (38) East Midlands (39) West Midlands (35) East of England (40) London (23) South East (62) South West (67)
Non-participating homes	384 (70.1%)	675 (78.9%)	Unknown	Yorkshire and The Humber (115) North East (59) North West (143) East Midlands (97) West Midlands (127) East of England (152) London (114) South East (146) South West (117)
Total	548 (50.7%)	856 (73.9%)		

Table 9.2: Details of CHs which agreed to the various phases of the study (CH1-CH11), compared to those which did not

Obstacles Encountered

Assessing online data

Information pertaining to the numbers of beds and residents in the homes, whilst provided online (www.carehome.co.uk), was not always accurate or evident. In one case, a CH who ultimately declined to participate was recorded to have 130 beds, however on telephoning the CH, I was informed that the home was made up of three individual CHs housing 40, 50 and 40 residents. When I checked this online, these CHs were all stated to have 130 beds, creating an inaccuracy of 260 beds. As such, it is difficult to compare those CHs which agreed to the studies with those which did not.

Contacting and recruiting CHs

As described in Chapters Four, Five and Six, successfully recruiting CHs was not an easy task. The first challenge encountered was in piloting Phase One: learning that postal invitations to participate in research were not received by their intended addressee. Of the 12 invitations posted first class directly to the named manager, on telephoning, not a single CH reported receiving the invitation. In following postal invitations up by telephone call, being able to speak with the managers of CHs directly was frequently unsuccessful. Relatively few CHs had a receptionist (or designated, consistent person responsible for answering the telephone), and therefore it was particularly difficult to speak to the same person each time, even on occasions where I had previously asked for the most suitable time to call back. CHs were contacted multiple times (as many as eleven phone calls before getting through to the manager in one case, who then ultimately declined to participate). Multiple contacts ended with the person answering the telephone saying ‘She’s not available, sorry’. When asked when she would be available, the answer was often ‘I don’t know’. This was recorded as ‘Contact made, manager unavailable, no further help’. Other times, staff would encourage me to call back or ask me to call back at a specific time. This was recorded as ‘Contact made, please call back’. Table 9.3 details the number and outcome of every contact made to each home in the pilot study, after the initial postal invitation was sent. The picture was similar, if worse, in the main Phase One study, however given that there were 198 homes, all with multiple contacts, the total contact data have not been included.

Contact	1	2	3	4	5	6	7	8	9	10	11
CH A	🟪	🟪	🟦								
CH B	🟪	🟪	🟪	🟪	🟦						
CH C	🟥	🟨	🟥	🟥	🟨	🟨	🟥	🟥	🟨	🟥	🟦
CH D	🟦										
CH E	🟦										
CH F	🟦										
CH G	🟪	🟪	🟪	🟪	🟪	🟪	🟪	🟪	🟪	🟦	
CH H	🟨	🟨	🟪	🟥	🟥	🟪	🟥	🟪	🟪	🟦	
CH I	🟨	🟥	🟥								
CH J	🟥	🟥	🟨	🟨	🟥	🟪	🟥	🟥	🟦		
CH K	🟨	🟪	🟪	🟪	🟪	🟪	🟩				
CH L	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟪	🟦		

Table 9.3: Outcome of contacts made to Phase One Pilot CHs throughout recruitment attempt

Key	
🟥	Telephone not answered
🟨	Contact made, manager unavailable, no further help
🟪	Contact made, please call back
🟦	Contact made, manager available, meeting declined
🟩	Contact made, manager available, meeting agreed

In Phase Three of the study, seven CHs declined to participate, citing reasons such as ‘it would be too much’, ‘it is quite invasive’ and ‘we are a bit too busy right now’, despite my reassurances. At the time of recruitment it would have been unethical to pursue their declinations further, however I believe that these issues warrant further investigation.

Recruiting CH staff (Phases One, Two and Three)

For Phase One of this study, CH managers were provided with recruitment packs to deliver to CH staff. As such, it was not possible to gauge whether managers had persuaded staff to participate or briefed them in what to say. Of the 30 CH staff interviewees, all appeared willing and enthusiastic to participate, however due to the nature of interviewing in a designated room, I was unable to directly ask any other members of staff if they would like to participate: as such I assumed that all willing staff were interviewed, and equally that all interviewed staff were willing.

In Phase Two, 19 surveys were returned unanswered. Seven were returned by the Royal Mail, with either an inaccessible address, 'addressee gone away' marked or with no reason for return. Five were returned with notes identifying themselves as non-dementia homes, or as private residences, highlighting the errors present in the current CQC database of registered CHs. Seven further surveys were returned blank with personal messages stating homes were unable to assist with the study. A total of 12 out of 170 (7.06%) in this survey either had an invalid postal address or were not CHs caring for people with dementia. This highlights errors within the current CQC database, however there was a period of four weeks between downloading the database and sending the questionnaires, which may have accounted for some of the errors.

Phase Three of this study illuminated the real issues in recruiting CH staff to research studies, particularly in the one CH where the research could not be conducted despite the manager's consent to participate. This is described in a case study later in this chapter. CH staff from the three successfully recruited CHs appeared generally relaxed and open about participating in the study, and did not have any questions after reading the information sheet.

Recruiting CH residents' relatives

Only one resident had the capacity to consent to participating in Phases Three and Four, and her consent, and ongoing consent was straightforward. She was a resident who was willing and interested in participating in research, and lived in a CH which dedicated a lot of its time to engaging in academic research studies. Obtaining assent from residents' consultees however was more challenging.

Staff helped me to identify residents' relatives, where they existed, however this was limited to those people already visiting the CH. None of the three homes could agree to provide me with a list of next of kin to call, but instead suggested I approach residents' relatives directly, when they visited the home. While talking to relatives when they were visiting the CH was not challenging in itself, I felt on many occasions that taking up their time while they had come to see their relatives was morally difficult to justify, particularly when there was a lot to explain, both for being a consultee and also for agreeing to be interviewed. Most relatives were unable to commit to a specific time and date to conduct interviews, because of work or other commitments, and three originally consenting relatives declined to participate when the focus group discussion changed to interviews, on the basis that they did not want to be interviewed separately. As such, only three relatives were interviewed.

Overcoming the Obstacles

Assessing online data

In order to ensure that online data is correct, it was most beneficial to telephone individual care providers and cross-check the data provided. While this was time consuming, and not always effective (see 'Contacting and recruiting CHs' below), it was the only way to ensure data accuracy.

Contacting and recruiting CHs

Once contact had been established, building a rapport with receptionists, where available, was a valuable tool in obtaining access to the management teams, however this took time and multiple contacts.

Through piloting, as well as learning from other research [133] it became clear that the approach that was most beneficial in gaining access to CHs in Kent was face to face contact. In arranging a meeting with each manager, once telephone contact had finally been established, I was able to discuss the project in depth and face to face with each gatekeeper, and therefore answer any questions or reservations they had. Those managers willing to arrange a meeting were all keen to participate in Phase One of the project. They were all confident that recruitment of their staff would not be a difficult task, and were happy to pass on recruitment packs to the CH staff on my behalf. In one case, the owner of a CH company was contacted through a personal network, and they agreed that I could pursue the recruitment of three of their CHs, via three CH managers. As such, there are benefits of personal networks and contact in the recruitment process. The process of recruiting CH managers once a meeting had been established was comparatively easy: managers were knowledgeable about the study, enthusiastic, and all signed the consent forms having read the CH recruitment pack prior to my arrival. They were happy to arrange the first interview date, and I left the initial recruitment meeting in all 11 CHs with a signed consent form and a date on which to begin interviewing.

Recruiting CH staff (Phases One, Two and Three)

In Phase One, since 11 CH managers were provided with recruitment packs to deliver to CH staff, I had no direct contact with CH staff until they were interviewed. As such I had to assume that all willing staff were able to participate.

In Phase Three, I was able to complete a period of volunteer work at each CH prior to starting research work, which allowed me to demonstrate my willingness to be immersed in CH routine, as well as build relationships with CH staff, residents and relatives. This period of time allowed me to 'settle in' to my role, while allowing CH staff to get used to me being around, and learning my capabilities, and limitations. I believe this also enhanced recruitment rates, since a number of CH staff signed up to the Phase Three study during my volunteer week. However it is important to note that this approach was unsuccessful in one CH (refer to Case Study: Unsuccessful staff recruitment).

Recruiting CH residents' relatives

Instead of asking relatives to give up their time while they had come to see their relatives, I opted to ask the relatives whether I could have five minutes with them at a time convenient to them: this was often in the lounges when their relative was sleeping, watching TV, or taking part in an activity. Given that most relatives were unable to commit to a specific time and date to conduct interviews, because of work or other commitments, the focus group discussion was amended to an interview.

Recommendations for future research

As this chapter has shown, there are numerous obstacles in conducting successful research studies with the CH population, including gaining access to CHs, recruiting CHs and their staff, residents and relatives, getting to know the staff and residents (and obtaining consent from them), and organisational barriers to practical work. The following provides recommendations for future research.

Gaining access to CHs

Arguably the most problematic barrier in CH research is being granted access to the CHs in the first instance. However, arranging face to face meetings with managers appears to be the most successful method of gaining access to CHs. Having patience in telephoning CHs and building rapport with receptionists is also essential.

Getting to know the staff/residents/relatives

Taylor and Bogdan[201] suggest that at the point of saturation, leaving the field may be more difficult than gaining initial entry; it may mean 'breaking attachments and sometimes even offending those one has studied, leaving them feel betrayed and used'. As such, they recommend tapering off, that is, 'gradually cutting down on the frequency of visits and letting people know that the research is coming to an end'. Therefore, at the end of each period of research, I undertook a ‘wind down’ week, tapering off the visits at the manager’s discretion, where I conducted no research, and simply volunteered. Ethically, this was important in order to not leave the CH, its staff and residents immediately after my purpose of being there was fulfilled, but also it gave me an opportunity to leave the CH having spent some quality time with residents and staff, outside of the research study. Similarly, I chose to also do this prior to commencing any research, undertaking a week of ‘volunteering’ work. This allowed me to get to know, and be trusted by, the staff and residents of the CH, and as researcher, adjust to new practices, new approaches to care, and new management hierarchies. It allowed me to engage with staff without feeling any pressure to be observing residents’ behaviours and staff management strategies, and it also gave CH staff the opportunity to get to know me, and observe my capabilities and limitations, as well as the chance to ask informally about the project and my research. I believe this facilitated recruitment in Phase Three, however it is important to note that this was unsuccessful in one CH. As a result of my experiences, I would encourage future researchers to spend a set period of time at a study site prior to commencing research, during which they are able to build relationships with management, staff, residents and any visiting relatives, and also investigate the processes and documentation involved in the area of interest. It is possible that this informal time will increase interest in the research, and positively affect recruitment rates.

Organisational recommendations

CHs are predominantly not run by the NHS, and are increasingly moving away from being owned and managed by local councils, to being owned by private companies. CHs are usually owned, and therefore managed by many different companies, who each run their business in different ways. As such, maintaining consistency as a researcher across 11 different CHs was a challenge. Each CH was unique in its channels of communication between managers and staff, and whereas some managers had open door policies, others did not. As such, trying to relay messages to CH staff through the management teams was more challenging in some CHs than others, particularly where recruitment was concerned. Once a meeting has been established, as a result of my experiences I would recommend discussing these communication channels and policies with CH managers, in order to assess how best to recruit CH staff within each CH.

Case Study: Unsuccessful staff recruitment

This case study portrays the unsuccessful staff recruitment in a CH already recruited to Phase Three of this PhD. The home was a large CH without nursing, located in Kent. The manager and staff had been interviewed as part of Phase One, and the manager had consented to the home participating in Phase Three.

Despite the CH manager’s assurances that ethnographic research would be welcome and successful at this CH, only two out of a possible fifteen members of CH staff consented to participate in the study. One of these staff members was the ‘suite manager’, the most senior member of staff on the unit in which I was observing, while the other was an activities co-ordinator for the CH. The activities co-ordinator does not work solely on the one unit, but instead works between all six units of the home.

The manager had promised to conduct a staff meeting before I began, whereby she would introduce the project, discuss it and ‘promote’ the project from the home’s perspective, explaining why it was important. When I turned up for the first volunteer day, the manager had forgotten this was promised, and explained it had not been done. Whether this was subsequently done, is unclear, however when she later alluded to her ‘chain of command’, it appeared that she may have passed this duty on to a care manager, who may have passed it on to the suite managers, or may not have discussed the project at all.

During the first volunteer week, I spoke both individually and in pairs, to every member of care staff working on the unit where the project was explained, the benefits were discussed, and the impact of their participation [i.e. that it would be beneficial to me and to the research study, but there was absolutely no obligation (or repercussion) if they did not want to participate]. Each person was given an information sheet and consent form, and asked to deposit completed forms in a box at reception, if they wished to participate. At this point, both the suite manager and activities co-ordinator consented to participate. During three of these meetings, staff did not appear enthusiastic about participating in the study, and at times said they may feel uncomfortable. All of the staff however said they would think about participating, when asked. No staff members declined to participate at this point.

By the end of the second week, one week after these meetings, no further consent forms had been completed. During the third week, after discussion with the research team, I spoke again to every individual member of staff, in order to confirm whether they were a ‘definite yes’, ‘definite no’ or a ‘maybe’, with regard to their participation. By the end of that week, ten staff members were a ‘definite no’, and three were undecided.

Reasons for declining to participate varied: CH staff expressed concerns about being judged, they were worried it would alter the way they did their job, they did not wish to be ‘observed’ in what they were doing and said they did not want people watching. Despite my reassurances about the observations, and asking gentle questions about their reservations, staff either suggested that they did not know why they didn't want to participate, or said nothing. One member of staff who appeared positive at the initial meeting, explained she had persuaded another staff member to consent, however both members ultimately declined to participate. Ethically I felt it was inappropriate to continue attempting to recruit these staff members, and therefore recruitment came to a halt.

At the beginning of the fourth week, I attempted to contact the CH manager but was advised by a receptionist to send an email explaining the difficulties of proceeding with the study. It was also agreed with the suite manager that the researcher would no longer work on the suite, but would work as a volunteer (in order to ascertain the three still-undecided staff members' opinions). On Tuesday of week four, I worked as a volunteer with the activities co-ordinator, and had a meeting with the manager to discuss the problems with the study. The manager was surprised to hear that participation by staff had been too little to proceed with the study, and could not guarantee that her message about participating in the study had successfully been transferred through her 'chain of command'. She also suggested that perhaps the care staff did not understand what the project was about, and that one must 'use simple words with them'. She was concerned that there may be a problem with the care being delivered on the chosen unit, and suggested that if staff were confident and competent, they should have no problems in consenting to participate in the study. I explained to the manager that there must be no repercussions on the care staff of the chosen unit as a result of the study. She was unaware of who did and did not consent to participate, as well as how many staff members consented. Finally, the manager said that she was pleased to have had me volunteer in the CH, and expressed thanks for attempting to conduct the study and getting involved in running of the day-to-day home. She felt this lack of participation may lead to a significant piece of research involving her CH, however she declined to comment on what, or who that research may involve.

Discussion

It is clear from this project that obstacles to research are inherent in CH environments; however the current paucity of research conducted in CHs in addition to CH managers' and staff's apparent unfamiliarity with participating in healthcare research studies does not make this surprising. There is very little evidence referring to recruitment of CHs in research studies: only one American study exists [133]. These authors reported the research issues and recruitment barriers experienced by their team, during an investigation of the education and learning needs of nursing home nurses in central Illinois. Telephone recruitment was largely unsuccessful due to messages not being passed on by CH administrators, or potential participants declined, citing a lack of information. They reported that there was no ‘shared understanding’ between the research team and CH facilities, particularly since recruitment and retention of staff to the study was also challenging. While their study had no ethical dilemmas, the authors warn of the potential risk that abuse of residents may be seen and reported to ‘the licensing agency’ (Care Quality Commission in the United Kingdom) and this should be discussed as part of the recruitment process. They encourage face-to-face contact in recruiting CHs to research studies, in addition to networking with CH companies, and liaising with CH administrators. The dearth of research consequently leaves little foundation on which to build. While EnRiCH appears to have been successful in its recent efforts to recruit CHs to its network, it is clear that there is still a huge amount more to do: only 0.8% English CHs belonged to the EnRiCH network in 2014, and excluding Phase Two, none of the CHs included in this PhD study were recruited to the network.

Studies reviewed as part of this PhD project experienced varying recruitment rates. Backhouse et al [81] experienced a 40% response rate to a postal survey distributed to managers of 747 CHs in four English counties. In contrast, Pulsford et al [88] experienced a 70% response rate from CH staff completing questionnaires, however the study was conducted in four purposively selected CHs owned by the same company, and only 36 CH staff participated. In contrast with this PhD study, three CHs from Phase One were recruited from one company, which illustrates the importance of being known to, and trusted by CH contacts. It is possible that there is a greater influence of higher organisational management in recruitment. Randomised controlled trials in dementia research contain little to no information regarding the recruitment of their participants [74, 75, 94]. Similarly, there are no recommendations for, or criticisms of recruitment of CHs in any of the reviews included in the review of the literature [57, 58, 83]. In addition, there is little to no information regarding recruitment of participants in dementia research in but not limited to CHs[92]. Child et al[82] obtained a 98.3% recruitment rate of GP surgeries to their pharmacy-led programme, suggesting that recruitment of GP surgeries may be more successful than CHs. This was a Primary Care Trust-led audit however, and there may have been an expectation that GP surgeries would participate. Additionally, the high recruitment rate was likely due to incentives (as part of a Prescribing Incentive Scheme).

Recruitment rates to this study may have been low due to the nature of the study (investigating BtC), and because CHs may not be familiar with participating in research, and are worried about the implications of poor practice, if identified. CH staff, although incentivised, may not have been willing to share their opinions and experiences of their work, particularly in a one-to-one environment, where they were being recorded. In particular, the incentive may have appeared small in comparison to any fears about losing their job, should they disclose anything they perceived to be poor practice. Care staff are generally very poorly paid, and therefore the incentive may not have been enough to allay any fears about participating. They may also have felt that they would have been unable to say anything that portrayed the home in a negative light, particularly when the interviews were conducted on site. At the time of recruitment, CHs were portrayed in an extremely negative manner by the media, and this very possibly affected recruitment of CHs and staff to the study, who may not have been familiar with engaging in research studies. CHs which declined to participate in the ethnographic phase of this study offered varied reasons as to their unwillingness to contribute to the research, however with limited ethnographic studies in CHs published, in combination with recent negative media portrayals of covert observations in CHs uncovering bad practice, it is unsurprising, but disappointing.

There are several issues arising from this study, which align with those of Garcia et al [133]: participating CHs were self-selected, and therefore were not typical or representative of the CH population. However, this is almost certainly true of all studies recruiting CHs to health services research, and in particular likely to be the case for any which use participant observation: the literature search did not identify any published studies which have adopted an ethnographic approach to observe the real-world experiences of CH residents and staff. In particular, the recruitment for this study raises potential questions regarding the practices ongoing in CHs who firmly do not wish to be participants in research. Due to the low recruitment rates and small sample sizes, there is a lack of generalisability and lack of transferability to other CHs, however this study does add to the existing body of work.

Future CH research teams are urged to build and develop networks with gate keepers prior to discussing their research. In particular, researchers attempting to undertake ethnographic studies are encouraged to acculturate themselves with the CH and its management, staff, residents, and visiting relatives, and involve themselves where possible into the practices and daily functioning of the CH and its community. More could be done to provide support for researchers and CHs who wish to participate in research studies, and ventures such as EnRiCH have the potential to do this, providing they evolve to fully acknowledge the needs of researchers and CHs alike, and commit to supporting the research process.

Chapter 10 Discussion

Introduction

The primary aims of this study were to explore how BtC in elderly people with dementia are managed by staff in CHs, and how that translates to care in practice. A pragmatic approach was employed for this study in order to best answer varied research questions: therefore the data were collected using a mixed methods approach and from multiple sources.

Data elicited from Phase One of the study provided an overview of how different CHs in Kent manage BtC, therefore establishing the current situation within CHs locally and gaining insight into how CH staff perceive and claim to manage BtC. Phase One also provided evidence of the CH environment and its design, captured as photographs, and highlighting the differences in the design of English CHs. Phase Two of the study utilised a cross-sectional survey to provide a broader dataset spanning a range of CH practices, and as such captured a picture of the current CH climate throughout England at the time of data collection. Phase Three of the study presented an ethnographic approach to CH research; data elicited from the study provided a narrower, but more in-depth insight into how BtC are actually managed in practice, in three CHs. It explored the antecedents, behaviours, management strategies and consequences surrounding incidents of BtC, both recorded by the CH and observed, and Phase Four investigated the medicines prescribed and administered to the residents observed in these homes. Phase Five of the study provided an alternative angle on the dementia journey and managing BtC, from the perspective of residents' relatives.

Over the past six years there has been increasing interest in both dementia and the best ways to care for people with BtC, from the Government and the academic world. Dementia is a complex medical condition, with no absolute cure. Recommendations and strategies for care have been established, however research in this area is limited and often of poor quality. The lived experiences of the CH populations, including staff, residents and their families are largely ignored within published research. The management of BtC in people with dementia is often assumed in research studies which focus on a single management strategy, to be a panacea; a 'one-size fits all' approach. All national guidelines stress the importance of multiple, interlinked treatments focusing on the individual, but these are based on the results from RCTs either of individual and not interlinked treatments, or which are only tested against usual care, and have a limited evidence base. Current published research tends to focus on the clinical management of dementia, (for example, RCTs in 'controlled' populations showing that one drug or intervention is better than another) and it is clear from the literature that there is not a clear, multi-dimensional solution to managing BtC in dementia. Systematic reviews are yet to provide a strong evidence base on which to build recommendations, and for the vast majority of NPIs, the evidence is inconclusive. Indeed, the majority of studies investigating NPI efficacy has opted to investigate or observe environmental, staff, pharmacological and non-pharmacological approaches as separate entities in the treatment plans for individuals with dementia. Little is known about the effects of combining interventions in practice, especially in CHs, which are already under researched. As such, it is difficult to make rigorous and unified practice or policy recommendation.

Those people on the front line, CH staff, have a crucial role to play in the implementation of quality care, but their voices are not often heard in research studies. Consequently there is very little published data which has investigated the management strategies adopted by CH staff, and their opinions on whether these strategies are effective. A literature search identified two main studies which sought to investigate how CH staff manage BtC, both of which have limitations. Pulsford's study investigated a small number of CHs all owned by the same company[88], while Backhouse's study[81] focused on CHs in the East of England only.

The search of the literature found limited studies which had involved observations of care in practice using ethnographic methods. One paper described problems with a study using participant observation to explore dementia care in nursing home wards but the author 'did not fully participate'[202]. It appeared that no previous research in this area had assumed an 'insider' approach[203]. The present study therefore sought to fill the gaps identified from the literature by conducting a mixed, multi-method study, consisting of qualitative investigations of CH staff through exploring how CH staff perceive and manage BtC. A quantitative study of English CHs built on the work of Backhouse and Pulsford, expanding the investigated population to a national level. Building on the data collected from CH staff during their interviews, the ethnographic phase of this study illustrated the work of care staff in practice, and an investigation into the medicines prescribed to CH residents with BtC illuminated the issues present in medicating this frail and elderly population. Finally, obtaining relatives' perspectives sought to provide an alternative viewpoint of care, and showed that they can make an important and valuable contribution to research studies. This study appears to be the first which has attempted to investigate how CH staff manage BtC through synthesising observational and CH recorded data, and is also the first study to conduct an in-depth analysis of CH MAR chart data which goes beyond simply reporting antipsychotic prevalence and use or medication errors.

These contrasting methods have enabled all the research questions to be fully answered. This chapter summarises the principal findings, before describing how the study has provided answers to each research question in turn.

Principal Findings

The principal finding of this study is that there is no one way to manage BtC in dementia. CH staff do not believe that one size fits all, and observations showed that the management of BtC changes from day to day and from person to person. CH 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 CHs 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, CH staff often responded quickly, and thoughtfully.

A further important finding from this research study is that BtC is common and is experienced by every CH 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. By and large, numerous and varying approaches were used in CHs 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 CHs 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[57, 83]. 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 CH staff observed being used to manage BtC when they did occur were predominantly distraction and emotional reassurance and were employed by CH staff routinely, often regardless of behaviour.

The data collected from self-reported and CH recorded antipsychotic use showed that the level of antipsychotic use was lower than anticipated based on previous studies (33%-43%) [76-78] indicating that there has been some progress in better managing BtC in people with dementia since the 2009 Banerjee report, however there was extensive use of other medications which were found to be questionable, (the survey investigated CHs use of ‘medication to control behaviour’) indicating that perhaps the problem of managing BtC, and for caring for this population in general, is still very much present. The dementia journey is challenging, not just for CH staff, but also for relatives of people with dementia, who have valuable experience and opinion, and who are not involved by CH staff as much as they perhaps should be. These experiences and opinions must not be overlooked, either by future researchers, or by CH managers and staff.

Answering the Research Questions

The overarching research question in this study was:

What strategies exist to manage BtC in people with dementia in English CHs and how are these strategies used in practice?

This was broken down into four sub-questions, which I will now answer.

How are residents cared for during incidences of BtC?

There were important findings about how CH residents are cared for during incidences of BtC from the interviews with CH staff in 11 homes, national survey involving 391 homes and from the observations of a small sample of residents from only three homes. The survey findings support Backhouse et al’s survey of CHs in East Anglia[81] which also found that a number of strategies were reported to be implemented by CHs and their staff to minimise and manage BtC, including both non-pharmacological and pharmacological approaches.

Data from the interviews suggest that where BtC are exhibited, CH staff need to read the situation, often quickly, and apply various techniques to restore calm. The findings from these interviews support Pulsford’s finding that CH staff viewed BtC as causal, deriving from the environment, situation or interactions with others[88]. In addition, the interviewees discussed the importance of knowing who they were caring for: their life history; their family; their personality and their behaviours. This knowledge helped staff to manage episodes of BtC, and enabled them to share strategies with other colleagues. The sharing of new ideas and successful interventions was reported widely, and managers often praised their ‘family’ of staff.

Analysis of the CH recorded incidents of BtC in the small sample of only 12 residents demonstrated that there appears to be no explicit, consistent method of management in practice, and this was supported by observational data.

There appears to be a difference between how CH staff perceive themselves to manage BtC, and how this is done in practice. CH staff stated that distraction and emotional reassurance are used, and the data from observations confirms this. However, the strategies staff stated they used to minimise BtC (ensuring residents are either stimulated, or relaxed, often engaging in activities), were not observed. This may be because this study recorded and observed the management strategies adopted during incidents of BtC, rather than observing those strategies used to minimise BtC. As such, espoused practice (from the survey and interviews) varied from actual practice.

The current guidelines commissioned by NICE and SCIE [21] advise that individually tailored care plans that help both staff and carers should be developed, recorded and regularly reviewed, prior to any form of pharmacological intervention. These care plans should be dependent on the individual's preferences, skills and abilities as well as the treatment availability, and should be delivered by a variety of health and social care professionals and volunteers. In particular, they include non-pharmacological interventions such as aromatherapy, multi-sensory stimulation, therapeutic use of music and/or dancing, animal assisted therapy and massage. From the records included within the ethical remit of this study, no such plans were documented, however this study did not have ethical approval to explore or document residents' care plans, and as such it is not possible to state whether these tailored plans were in place. From the data elicited from interviews, survey and analysis of a small sample of residents from three CHs, these NPIs were not used to manage BtC, rather to minimise BtC and engage or relax the residents. Instead, CH staff use distraction and emotional reassurance to care for residents during incidents of BtC. It appeared that their skills in knowing the residents they were caring for in addition to understanding that the behaviour had a cause enabled them to most effectively manage incidents of BtC. As a result of the absence of intent to manage incidents of BtC by using these NPIs, this finding conflicts with clinical guidance [21]. However, it is important to note that while the absence of intent was observed, it was not within the ethical limits of this study to analyse residents' care plans, and therefore such plans may have been drafted.

What different strategies are adopted by CHs to manage BtC?

There were important findings about the different strategies that are adopted by CHs to manage BtC from the interviews, survey and from the analysis of a small sample of residents from only three homes. The survey findings support Pulsford's findings of CH staff's experiences of aggressive behaviour[88]. Data from the interviews and survey suggest that using distraction or reassurance, in addition to knowledge of the resident and the help of their colleagues was often

CH staff’s best strategy to diffuse potentially difficult situations. These strategies have similarities to the behaviour management interventions (distraction, communication) identified by Dickson et al[57] to have the most reliable evidence base. The strategies used also had similarities to some strategies used in research studies (validation therapy, functional analysis and the use of stepped frameworks). The interviews CH staff talked about a variety of activities routinely provided by their home, in order to keep residents engaged. Most CHs had an activity co-ordinator, responsible for a set programme of daily activities for all residents. One CH adopted a ‘Namaste Programme’ of care, which sought to improve the quality of life for people with advanced dementia, by conducting a wide range of practices and activities every day, at certain times. Other CHs reported using designated activity co-ordinators to provide regular activities including singing, knitting, crafts, reminiscence and sensory games.

Analysis of the observed incidents of BtC in this small sample of only 12 residents, demonstrated that CH staff appear to do a great deal to minimise potentially difficult behaviours. This study also found that that simply by finding out about the resident from reading their records, it is sometimes possible to identify the best way in which to diffuse a situation.

There is a developing evidence base for the use of NPIs in reducing incidences of BtC, however there is a dearth of high quality literature investigating their efficacy in the management of BtC. Dickson’s synthesis of current evidence surrounding the efficacy of NPIs for BtC in dementia found that the evidence pertaining to the effectiveness of NPIs to manage BtC is disparate and inconclusive[57].

With regard to the effect of non-pharmacological management on BtC, it is generally acknowledged that such treatment must be tailored to the individual [21]. However, the National Audit Office’s report, Improving Services and Support for People with Dementia, suggests that in practice this is not adhered to [23]. The data elicited from the observed incidents of BtC support this.

Clinical guidelines produced by NICE and SCIE [21] suggest that people with dementia who exhibit BtC should ‘be offered an assessment at an early opportunity to establish the likely factors that may generate, aggravate or improve such behaviour’. I suggest that this is what care staff may be informally doing in practice each time an incident of BtC occurs, but they call it ‘knowing the resident’. As stated previously, individual care plans were not explored as part of this study, and therefore it remains unclear as to whether CH staff formally use this strategy to create tailored care plans. Clear and concise guidelines regarding the implementation of non-pharmacological methods of managing BtC are non-existent and instead, a range of non-pharmacological interventions are suggested by NICE and SCIE: aromatherapy, multi-sensory stimulation, therapeutic use of music and/or dancing, animal assisted therapy and massage [21]. However, NICE and SCIE suggest that care staff use these interventions to 'address' the BtC, which leaves ambiguity as to whether these interventions are for prevention or management of such episodes.

What training and support do care staff have to manage BtC?

Little is known about the attitudes of CH staff and their impact on BtC, despite a report by the Department of Health that they are often the least trained, with little support and are subject to stressful and emotional working practices[1]. The interviews and survey with CH staff and managers sought to illuminate this subject area.

The literature in this area is primarily limited by small sample sizes. By conducting a national survey which sought to illuminate the views and experiences of CH staff on managing BtC, the data from the survey provide a snapshot of the views of care staff on potentially effective practices to manage BtC. Thus it goes further than any previously published studies, which have been limited to specific geographical areas, or by small sample sizes.

Both the interviews and survey elicited important findings about the level of training and support received by CH staff to manage BtC; it appears that training of the care workforce does take place, and does help CH staff to manage BtC in dementia. The survey findings support the findings of Train and Nurock [100], since a strong level of agreement was reported by care staff both that training had been received and that training had helped staff care for people with BtC. However, the survey also found that over 75% of care staff felt they would like more training, which has not been previously reported. This raises questions as to the content of the training experienced and its relevance to care staff's everyday needs and encounters with residents. Banerjee's 2009 report recommends a need for care staff to develop appropriate skills in order to implement NPIs for BtC in dementia. However, CH staff are an under-researched population, and Banerjee acknowledges that implementing these changes takes time[1].

Data from the interviews suggest that CH managers were encouraging of staff training, and offered a wide range of programmes. However no single training programme was consistent across all homes and managers often led sessions themselves. Contrasting opinions were evident regarding the quality and efficacy of training; therefore it is likely that this area warrants further research. CH staff in this study reported receiving training, however not all staff reported receiving dementia specific training, a finding which may add to the growing evidence that the delivery of dementia specific training to CH staff is low. These data may be explained by the findings of Ervin et al[86] , which identified that staff were aware of BtC but lacked understanding of what resources were available to them. Indeed, perhaps the fact that no consistent training programme exists across the CH population, makes understanding the resources available to manage BtC more problematic for staff.

Findings from the CH survey revealed that 'on the job training' was reported to be the least attended training, and was the least number of training hours received. This may suggest that care staff either do not receive 'on the job' training, or do not perceive that they do.

NICE and SCIE guidelines implore health and social care managers to provide access to dementia care training and skill development and the data from interviews with CH staff and the survey suggest that this access is limited. In 2007 the National Audit Office identified that only a small proportion of acute care staff receive dementia care training, and in the United Kingdom approximately one third of CHs with specialist dementia services have no explicit dementia training for their staff [23]. This was echoed in the data elicited from interviews with CH staff. Since most long-term residential care is for individuals with dementia, the training and education of staff should be widely available and specifically address managing BtC, however data from the survey suggests that training can be inaccessible, and CH staff have limited power to change this. The joint report between the WHO and ADI stresses that there is an urgent need for dementia care training for the residential care workforce [2], however findings from interviews and the survey suggest that CH staff require more accessible training to care for their residents with dementia.

What do different CH environments look like and what impact may these differences have on BtC?

The interviews and environmental observations conducted in Phase One provided an important and unique perspective on what different care environments look like. These observations support Hiatt, Skolaski, Peppard, Rauma and Gignoux[105-109] in that views on what constitutes the ideal care environment are complex and often contradictory. Indeed, opinions regarding the best practices for orientating residents within CHs were mixed.

Data from the interviews suggest that signs and resident photographs on bedroom doors in the CHs were both advocated and criticised by staff and managers, and the environmental observations supported this. However furnishings such as photographs within rooms, and posters depicting relevant scenes allowed staff to initiate conversations, which added to their knowledge of residents. The findings from the interviews suggest that a familiar, home-like environment is a key facilitator in minimising BtC, but there is very little research which supports or refutes this. However, differences in opinion on specific aspects of the care environments, such as signposting, showed that CHs adopt approaches that work for them, often after a trial and error process.

Analysis of the CH recorded and observed incidents of BtC, although using a small sample of only 12 residents, revealed that the CH environment could be used as a strategy to manage BtC, however analysis of the observed incidents of BtC in this sample found that the CH environment was in fact infrequently used to manage BtC – in particular, the sensory rooms.

Very little is known about the impact of the CH environment on BtC and there is minimal support for CHs in how to design an optimal environment. A review of the literature found only one study which suggested that the environment alone does not reduce BtC in people with dementia[110]. The data from the environmental observations illustrate the differences in care environments between CHs, and are the first sources of photographic data which allow an insider view of CHs and their facilities. Combined with the data from interviews and observations, the findings suggest that the environment is seldom used for either minimising or managing BtC. However, staff's use of the kitchen and the availability of the outside space were both useful in managing individual incidents of BtC.

The King's Fund's tool, 'Enhancing the Healing Environment' has proved that it is possible to enhance the quality of life of people with dementia staying in hospital, by changing the environment around them to a more dementia-friendly design[159]. CHs can utilise this tool to assess the quality of their care environments, enabling them to create more dementia-friendly homes, however, it is likely that the changes required in some CHs would be significant and potentially costly. In contrast, making changes to the care environment may not enable residents to fully engage with the facilities, as Cohen Mansfield suggests[111].

What medicines are prescribed and administered to residents with dementia living in CHs?

In 2009 Banerjee suggested that antipsychotics were being excessively used to manage BtC in people with dementia [1], particularly in CHs where manifestations of BtC can be challenging for formal carers[71]. Recent studies have sought to investigate the prevalence of antipsychotic prescribing in the CH population. There were important findings about the use of medicines in CHs from both the survey and from the analysis of medicines use in a small sample of residents from only three homes. The survey findings support both Child's pharmacy-led analysis of medicines use from 59 primary care information systems in Kent[82], and Backhouse's limited survey of self-reported medicines use in CHs in East Anglia[81], with survey respondents reporting that an estimated 17.4% of residents were being prescribed medicines for BtC. This finding is supported by data from the investigation of medicines use, which also suggests that antipsychotic use is low (two (17%) of the 12 residents were prescribed an antipsychotic), compared to previous estimates, which estimated prevalence ranges of between 33 and 43%.

While the data from both the survey and observations thus suggest that medicines are still being used for BtC in dementia in English CHs, the survey found that both medicines use and the opinions of care staff towards medicines vary, and that the frequency with which medicines are used may be related to staff opinions. However, it is not clear as to the cause and effect of this relationship. Additionally, there was a significant difference between managers and non-managers in agreement with giving medicines that control behaviour to manage BtC; this novel finding warrants further investigation.

In-depth analysis of the MAR charts in this small sample of 12 residents illustrated the range of problems beyond antipsychotic use which could be found relating to medicines. All of the residents had at least one issue with their medicines, which covered the prescription of inappropriate, preventative and anticholinergic medicines, the use of oral nutritional supplements and errors in dose and spelling of prescribed medicines on MAR charts. This small study also found considerable differences in the quality of recording of medicines in CHs, and the differences between CHs which printed records and CHs which had printed and hand-written records went some way to explaining the errors in dosing and spelling of medicines. Consequently this suggests that the work of the CHUMS study[49], which looked only at medication errors in CHs, requires expansion to explore other issues in this population.

The current guidelines commissioned by NICE and SCIE [21] state that for individuals with all types and severities of dementia presenting with BtC, pharmacological approaches should only be offered as a first-line treatment if the individual is severely distressed, or there is an imminent risk of harm, either to the person, or those around them. From the observed and CH-recorded incidents of BtC, there were examples where individuals were far from severely distressed, yet were prescribed (and MAR-recorded administered) medicines to control their behaviour. One resident in particular was prescribed trazodone hydrochloride, to be administered once in the morning, and once at night, with an ‘as required’ dose given. Analysis of the prescribing pattern suggested that trazodone hydrochloride was possibly being used to manage BtC. No CH-documented BtC records existed, however it was noted in the resident’s personal history record that she called out constantly at night.

Thus, regardless of the methods used to categorise problems relating to medicines use in CHs, problems are found. This in particular is a limitation of most studies investigating medicines use in CHs, in that they adopt only one method of identifying issues, and therefore this raises questions as to what additional issues may have been missed. By analysing all medicines prescribed for a small sample of CH residents in three homes, this study illustrates the diversity of issues which can be found, thus it goes further than any previously published studies, which either focus on solely on antipsychotic medicines or on medication errors.

What are residents' relatives' experiences of the dementia journey?

(What are their preferences for care? Are these preferences met by the CH in which their relative resides?)

There were important findings about how CH residents' relatives experience the dementia journey, from the interviews with staff and interviews with relatives. There is little published work on the relatives' experiences of the dementia journey, and therefore this study has contributed to a small body of research. The three interviewed relatives had experience of BtC, including dangerous and aggressive behaviour, which are found difficult to manage by CH staff. As such, it may be useful for CH staff, some of whom reported relatives could be a barrier to managing BtC, to engage with relatives in determining how to manage certain behaviours.

Data from interviews suggest that more information or support should be more widely available for relatives. The relatives in this study felt that they required much more support than they received, and wished they had had it. In addition, relatives were understanding, and empathetic to the use of the term BtC, and this may be useful knowledge in conducting any future research with relatives of people with dementia.

Analysis of the CH staff interviews confirmed that CHs in this wider study are attempting to provide support for residents' families, but this level of support is not provided across all healthcare services, particularly prior to admission to a CH. Admission to CHs is not straightforward, particularly where BtC is present, however the relatives interviewed in this small study were praising of the CH in which their relatives were cared for.

This phase of work confirmed that relatives of residents living in CHs can provide an important alternative perspective on dementia care and therefore should be included in future research studies.

Implications for research and practice

There are a range of stakeholders interested in dementia, including policy makers, regional, national and international agencies, academic researchers, practitioners and people with dementia and their carers, for whom the findings of this study may have differing implications[204].

There are implications for policy makers because of their focus on evidence of effective practice leading to improved policy making. The findings of this thesis suggest that there is conflict between clinical guidance issued by policy makers, and practice. The vague language used in policy documents ('address' BtC, rather than 'manage' or 'prevent', for example) adds to this. By engaging policy makers in new and original research studies like this one, it is possible that revisions of policy and clinical guidance could be undertaken and as a consequence CH staff and managers would feel listened to, trusted and valued as the front-line, experienced teams that they are. In his Prime Minister's Challenge on Dementia 2020 rhetoric, David Cameron stated that by 2020, he would like to see more research being conducted in, and disseminated through, CHs, and a majority of CHs signed up to the EnRiCH network[205]. As discussed in Chapter Nine of this thesis, the recruitment process for this study was challenging, and there was little support from outside agencies such as EnRiCH. As such, the recruiting difficulties are relevant to agencies such as EnRiCH, who could provide more structured and specific support to CH researchers in the future, and help to build the CH research community that the government has spoken about.

There are implications for international, national and regional agencies because they seek to ensure good practice and improve standards. The WHO recognises dementia as a public health priority, aiming to strengthen efforts to improve care and support on a national and international level[2]. One of the aims of the first Ministerial Conference on Global Action Against Dementia in March 2015[206], supported by both the Organisation for Economic Co-operation and Development (OECD) and the UK Department of Health was to provide a better understanding of governments' primary role and responsibility in the dementia challenge. This research study has provided a picture of the current practices reported by CH staff to be effective in managing BtC, as well as CH staff's experiences and views regarding managing BtC in practice. It has illustrated the work of care staff through direct observation, and demonstrated that there appears to be no explicit or consistent method of managing BtC. The absence of intent by CH staff to use NPIs to manage episodes of BtC warrants further investigation, particularly where policy and clinical guidance are not applied in practice. A possible consequence of a lack of support, this issue must be better understood in order to improve resident care: as such, the responsibilities of governments and policy makers are added to. As the independent regulator of all health and social care services in

England, it could be expected that the CQC maintain a current database of these services. However data elicited from the CQC website exposed inaccuracies with CH provision and registration, and problems like this can hinder the progress of good quality research. Identifying these issues in research studies is important not just to the research team, but is also relevant to the agencies concerned.

The work is of interest to academic researchers who seek to add to the evidence base and research outcomes. This novel research study utilised a mixed methods, pragmatic approach and the findings justify the importance of adopting such a style, using triangulation to create a more complete picture. The findings of this research raise important questions, which warrant further investigation, but which were not included within the scope of this study. These include exploring the dichotomy between managers' and non-managers' opinions regarding medicines use to manage BtC, further exploration into the content, quality and feasibility of staff training, and investigating medicines administration in CHs using more in-depth methods. As mentioned above, academic researchers have the potential to influence policy makers. Adding to this specialist body of research can therefore facilitate a transformation in the way that individuals with dementia are perceived and cared for.

Practitioners can gain through the evidence the study provides about knowledge of effective practices to improve care. A number of groups of healthcare practitioners may benefit from this research study, including CH staff, GPs and pharmacists. Given the findings from the investigation into medicines use in CHs, regular medication reviews in CHs could assist CH staff, GPs and pharmacists in finding the appropriate balance for each resident. The implementation of a multi-disciplinary team would allow potentially untrained CH staff to utilise the MAT developed and formalised for use in this study, to identify problems with medicines use. This data could then be appropriately disseminated to qualified colleagues. Alternatively, the appointment of a pharmacist within CHs is a potential solution to some of the problems identified by Phase Four of this study, and could work alongside designated GPs to ensure the safe and appropriate prescription and administration of medicines to elderly residents with dementia. Specifically, the literature review identified no recent studies investigating the use of anticholinergic medicines in CH residents, and therefore further research in this area is warranted.

There are a number of findings from this study which are relevant to CH staff. In triangulating data from interviews and the survey, CH staff were clear about the strategies they adopted to manage BtC, however they also alluded to a lack of accessible and dementia-specific training, and three quarters of care staff wanted more training. Therefore, I suggest that ensuring CH staff are able to build relationships and understand the numerous causes of BtC, while encouraging them to learn about the people that they care for and spend their time focusing on these skills, may be an appropriate approach to training regimes. It is noteworthy that contrasting opinions were evident regarding the quality and efficacy of current training and as such this area warrants further research. The difficulties in recruiting CH staff to this research study must not be ignored. As discussed above, organisations such as the EnRiCH network aim to increase the participation levels of CHs in research studies, however in-depth explorations as to why CH staff may not wish to participate, or why CHs decline participation are required, and may positively influence future recruitment rates.

This research study has set out to explore how BtC in people with dementia are managed by CHs, and observe how they are managed in practice. As such, people with dementia are the foundation of this entire body of research. The policy makers, governments, international, national and regional agencies, academic researchers and practitioners are all committed to creating a better quality of life and improved quality of care for people with dementia and their carers. This study has recognised the importance of quality of life, for residents, staff and family, while maintaining a person-centred approach; the research was conducted in a manner wherein the resident remained the primary focus. The findings of this study do not depict a smooth or especially pleasant journey for people with dementia and their carers, and care has been observed to be variable, both within and between CHs. The CQC does not hold a complete dataset for all CHs in England, making the potentially difficult transition from home to CH even more challenging. Relatives are a valuable source of knowledge and experience to the CH in which their loved one resides, and CHs should ensure the inclusion of relatives within research, policy and practice. For the person with dementia, for Ernie, Bertram, Agnes, Betty, Ronald, Edwin, Walter, Donald, Joan, Myrtle, Vera and Edna, it is probable that this research study will not be of benefit, except during my day-to-day hand holding, listening and storytelling. However this research may influence the decisions of those millions of people who are in the early stages of dementia and their carers, in terms of helping make informed, evidence-based decisions about the CHs in which they may reside and the manner in which they wish to be treated.

I am hopeful that by creating an awareness in the academic world of the difficulties in recruiting CHs to research studies, of the challenging and very present nature of BtC in CHs, of the divergence of policy and practice in CHs, of the novel but appropriate ethnographic methodologies utilised in CH research, of the variation in care within and between CHs, of the necessary further investigation and regulation of medicines use in CHs, and of the importance and value of including residents' relatives in CH research, I may succeed in influencing those decisions.

Consistency of methodological findings

The findings from each phase of this study were consistent in some cases but not in others. The results of the survey and medicines use exploration found that antipsychotic use in CHs is consistent, but reduced, compared to other estimations. However, while the use of NPIs was espoused in both the survey and interview phases, this was found to a lesser extent during the observation phase. Data from the interviews concluded that NPIs were widely used across CHs, and data from the survey reported that CH staff perceived NPIs to be useful in managing BtC. In contrast however, the observation phase saw little use of NPIs in practice, and concluded that the activities described as NPIs were used in CHs regardless of whether residents were exhibiting BtC or not, and were in fact used primarily to minimise, or prevent incidents of BtC rather than to manage them. This is an interesting finding in itself, and points to a divergence between what CH staff say they do, and what they are observed doing in practice. It also reinforces the importance of utilising different methods and a pragmatic approach to answer similar research questions, and shows how differing methods can influence findings, which triangulate to create a more comprehensive picture. As such, the value of situating oneself outside the constraints of philosophical ontologies allows the importance of each method to be acknowledged.

Contribution to knowledge

The number of people with dementia worldwide is growing rapidly. In 2013, there were reported to be 815,827 people living with a form of dementia in the United Kingdom, and this number is estimated to increase to one million by 2025[4], if current trends continue. Dementia is a complex, multi-faceted illness that is often poorly managed, particularly given co-morbidities that are frequently present alongside it. It is associated with numerous complex requirements, including the management of distressing symptoms that can be challenging to carers.

Dementia can be a devastating diagnosis, not only for the person themselves, but also their loved ones, and so a change in the way that people with dementia are perceived and cared for is a matter of priority. At least two thirds of CH residents have dementia[53] and caring for them is challenging, involving time, energy and physical exertion and because of the long-term support they require to manage their condition and associated beahviours[3, 19]. Thus care systems need to tackle this significant requirement of help required by individuals with dementia and their relatives. As such, it is enormously important that CHs are available for the people that need them.

Banerjee's report[1], in addition to NICE and SCIE guidance[21], implored healthcare providers to reduce antipsychotic prescribing to manage BtC and use NPIs as a first-line treatment instead. A review of the literature revealed a lack of evidence regarding the efficacy of NPIs as treatment strategies, and very few studies have observed the day-to-day routine of CH staff managing BtC. Therefore, this study has added to current knowledge about the management of BtC by exploring and observing the day-to-day challenges faced by front-line CH staff, and the practices they use to manage BtC. Indeed, the findings from this study have begun to fill the gaps identified in the literature review:

- The survey provided an estimate of medicines use by CHs in England, building on the existing literature by examining the use of these medicines on a national level.
- The survey and interviews provided a picture of the current practices reported by CH staff to be effective in managing BtC, and CH staff's experiences and views regarding managing BtC in practice.
- The environmental observations have added to a scant body of literature which has attempted to describe the care environment, by endeavouring to provide a true depiction of real care environments, and highlight the differences between these.
- The exploration of medicines use added to the literature by examining more than just antipsychotic medication use or medication errors in CHs, and provided a synthesis of CH MAR chart data in the current climate.
- The ethnographic study illustrated, through observations and data collection, the work of care staff: specifically how they manage BtC in practice, and who they care for. The data demonstrated that there appears to be no explicit or consistent method of managing BtC.
- Interviews with relatives' residents highlighted that they are an important component of research into CHs – in this study they had a wealth of knowledge regarding their family member and the CH transition, since they can provide a valuable alternative viewpoint of care, but were often overlooked by CH staff. This study highlighted the difficulties in recruiting family members to focus group discussions, and therefore alternative methods of recruitment could be attempted in future studies.

Strengths and Limitations

Although it is inevitable that I have influenced this study from the topic to the design, data collection, analysis and interpretations, my lack of care experience and therefore lack of underlying assumptions leave little room for bias. The continued input from and discussion with my supervisors has added to this.

The study has several limitations, but also many strengths, which are set out clearly at the end of each research Chapter (Chapters Four to Eight).

The major strength of this PhD study is the use of multiple methods, some of which were highly novel, resulting in a contribution to both knowledge and methodological development. The study contributes new information about the management of BtC in people with dementia living in CHs. There are no published studies which have conducted an ethnographic participant observation methodology, in CHs, to explore this. The biggest limitation of this PhD study, is the recruitment bias: CHs 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. Therefore it is difficult to suggest that the findings are fully generalizable to the wider population of CHs. Chapter Nine is dedicated to stating and exploring the difficulties encountered during recruitment throughout this study, and proposes recommendations for future researchers.

In Phase One, (Chapter Four), the sample size of 11 CHs was limiting, however interviewing 42 participants allowed for a diversity of experiences, and a robust analysis. Although the 11 independent CHs made it possible for findings to be transferable to other sites, collecting data from more sites may have elicited new data.

In Phase Two, (Chapter Five), the survey data relied on the self-reporting of CH managers and staff, who may have wished to portray their workplace and job in a particular light and the interpretations of questions were subjective. The CH response rate of 25.1% was low, yet similar to other studies. This phase supports the notion that direct distribution of surveys elicits a higher response rate than postal distribution, however, the data using this method presented difficulties given the wide variation in responses from different staff working in the same CHs – the data must be read cautiously. Nevertheless, the data yielded some interesting results, providing a national picture of how CH staff perceive and reportedly manage BtC – the first study to do so.

In Phase Three (Chapter Six), a novel methodology was utilised with some success. Using an ethnographic participant observation in a CH setting, allowed an insight into what happens in practice. Moreover, it highlighted a difference between what CH staff say they do, and what they actually do. It is difficult to generalise the findings from this phase, given the relatively small number of homes involved and participants recruited. Furthermore, a major ethical limitation of this phase was the inability to search all care records. While the findings from this phase represent only a snapshot of care practice, they are valuable nonetheless.

In Phase Four (Chapter Seven), a current picture of medicines use in CHs was established. Limited to one geographical area of England, and with only a small number of homes and participants recruited, the findings are limited. However, the study builds on other recent studies by synthesising CH residents' MAR chart data, using a specially-developed MAT, which it was demonstrated revealed a wide range of medicine-related issues, going beyond any previous studies.

In Phase Five (Chapter Eight) the views and experiences of relatives of CH residents on dementia, BtC and CHs were sought, from three relatives. The findings of this phase of the study are limited by the number of participants, however they provide a small yet important insight into an alternative perspective in CH research, which may apply to the wider CH community. Most importantly, this phase showed the need for and value of including relatives' experiences and perspectives in dementia research.

Due to the exploratory nature of the study and its wide ranging investigation of views, experiences, observed practice, and medicines use, the literature pertinent to many of the findings was not originally systematically explored in the literature review (the use of relatives in research, for example). However, relevant literature was retrieved and reported in each chapter, to which findings were related.

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 CHs can be improved is by exploring, and improving the quality of care these homes provide. This thesis, which utilised novel methods to undertake such exploration, has implications for a range of organisations and health professionals about how care is currently provided. It focused on how CHs in England are managing BtC exhibited by their residents with dementia. The lack of existing knowledge surrounding care in practice underpins the study, which explored the use in practice of non-pharmacological interventions in managing BtC, an area of research which has been largely neglected. It has provided a picture of how care is delivered to people with dementia in CHs, particularly during incidents of BtC. It has demonstrated some of the ways in which people with dementia are cared for during incidents of BtC, and has found that, rather than adhering to current guidelines, knowing the resident, understanding causes of BtC and the occasional use of the CH environment play a vital role in enabling staff to manage these behaviours. Future observational research, involving staff and relatives more frequently, is required to investigate staff practices and training, as well as medicines use in dementia more robustly. Studies are needed which aim to establish more clearly what constitutes ‘knowing the resident’ and the use of the environment in managing incidents of BtC, before efficacy studies are conducted in these areas.

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APPENDICES

Appendix 1 – Literature searches, terms and paper selection

Medical Subject Headings (MeSH) and key-words were identified by consideration of relevant past articles on BtC in dementia.

The following words have been used as search terms: *Dementia (MAJR), Alzheimer Disease (MAJR), nursing homes (MeSH), care homes, behavior (MeSH), intervention, attitude of health personnel (MeSH), non-pharmacological (MeSH), antipsychotic agents (MeSH) and environment (MeSH).* The MeSH terms were exploded to include all categories within them. The databases searched were: EBSCO Host Electronic Database (MEDLINE, PsycINFO, and CINAHL Plus with Full Text) and PubMed**.**

Search 1

#	Searches	Results
1	Dementia	103249
2	Alzheimer Disease	56514
3	1 OR 2	103249
4	Nursing homes	33101
5	Care homes	97017
6	4 OR 5	120683
7	Behavior	1281574
8	Intervention	408076
9	3 AND 6 AND 7 AND 8	224
10	Attitude of health personnel	127392
11	9 AND 10	11
12	Kept by title	10
13	Kept by abstract	8
14	Included in review	8

Search 2

#	Searches	Results
1	Dementia	103249
2	Alzheimer Disease	56514
3	1 OR 2	103249
4	Nursing homes	33101
5	Care homes	97017
6	4 OR 5	120683
7	Behavior	1281574
8	Intervention	408076
9	3 AND 6 AND 7 AND 8	224
10	Non-pharmacological	46198
11	9 AND 10	0
12	(9) Kept by title	207
13	Kept by abstract	94
14	Included in review	83

Search 3

#	Searches	Results
1	Dementia[MAJR]	103249
2	Alzheimer Disease	56514
3	1 OR 2	103249
4	Nursing homes	33101
5	Care homes	97017
6	4 OR 5	97017
7	Behavior	1281574
8	Intervention	408076
9	3 AND 6 AND 7 AND 8	224
10	Antipsychotic agents	43577
11	9 AND 10	5
12	Kept by title	4
13	Kept by abstract	4
14	Included in review	4

Search 4

#	Searches	Results
1	Dementia	103249
2	Alzheimer Disease	56514
3	1 OR 2	103249
4	Nursing homes	33101
5	Care homes	97017
6	4 OR 5	97017
7	Behavior	1281574
8	Intervention	408076
9	3 AND 6 AND 7 AND 8	224
10	Environment	965012
11	9 AND 10	6
12	Kept by title	5
13	Kept by abstract	4
14	Included in review	3

Appendix 2 – Concept indicator framework

This concept indicator framework displays the research sub-questions of this study series, and points to the phases in which each question is answered. By displaying the questions in this way, it is possible to see the potential for triangulation across phases, and ensures that each question is answered.

Sub-Questions	Phase 1	Phase 2	Phase 3	Phase 4	Phase 5
How are residents cared for during incidences of BtC?	Questions 2, 3 and 9	CH survey	Ethnographic observations	Exploration of MAR Chart	
What different strategies are adopted by CHs to manage BtC?	Questions 1, 2, 3, 4 and 9	CH survey	Ethnographic observations	Exploration of MAR Chart	
What training and support do care staff have to manage BtC?	Question 6	CH survey	Ethnographic observations		
What do different CH environments look like and what impact may these differences have on BtC?	Question 5 Observations of care environments	CH survey	Ethnographic observations		
What medicines are prescribed and administered to residents with dementia living in CHs?	Question 8	CH survey		Exploration of MAR Chart	
What are residents' relatives' experiences of the dementia journey?					Grand Tour
What are their preferences for care?	Question 7				Key Questions
Are these preferences met by the CH in which their relative/friend resides?					

Appendix 3 – Letter of Ethical Approval (Phase One)

medway school of pharmacy

1st February 2013

Dear Charlotte

Your application for ethical approval for the project **Managing challenging behaviours in dementia: making alternatives to medication work in practice, Phase 1** has now been considered on behalf of the Medway School of Pharmacy School Research Ethics Committee (SREC).

I am pleased to inform you that the project has been approved with the following conditions;

- An off campus risk assessment is completed
- That within your protocol you must state that you as the researcher will access student counselling services if you are affected or need to discuss any issues that have arisen as a result of visiting these care homes for your research project; student counselling medwaycounselling@kent.ac.uk Gillingham G013

I must remind you of the following:

1. that if you are intending to work unaccompanied with children or with vulnerable adults, you will need to apply for a CRB check; the project must be conducted under the supervision of someone who has an up-to-date CRB check; you must not be in the presence of children alone except if you have completed a CRB check;
2. that you must comply with the Data Protection Act (1998);
3. that you must comply throughout the conduct of the study with good research practice standards;
4. If you are completing this project off site, you must obtain prior approval from relevant authorities and adhere to the MSOP off site protocol.
5. to refer any amendment to the protocol to the School Research Ethics Committee (SREC) for approval.
6. You are required to complete an annual monitoring report or end of project report and submit to j.mowbray@kent.ac.uk

Yours sincerely

SHCorlett

Dr Sarah Corlett

Appendix 4 – Pilot recruitment pack (Phase One)

Letter of Invitation

25th March, 2013

Dear Matron**,**

How do nursing homes manage challenging behaviour in dementia?

Have your say.

As part of my PhD project at the Medway School of Pharmacy, I am exploring how different nursing homes in Kent manage challenging behaviour in people with dementia. I am currently recruiting care homes to participate in a pilot study for the project.

This pilot study will involve:

- Providing some basic information about your care home
- 3 visits, where I **will**:
    - Have one interview with the Matron;
    - Interview some of your staff members;
    - Observe the environment of the care home.

I **will not**:

- Observe your residents
- Interfere in the care provided to your residents
- Access any information about your residents

'Why should our care home take part?'

- Very little is known about the best ways to manage challenging behaviour. This project aims to **inform future practice in caring for people with dementia**;
- **Have your say.** This project will give you an opportunity to tell us what problems you face looking after people with challenging behaviour and share any good ideas you have which you find successful;
- We recognise that your time is precious. Therefore, we will reimburse every interviewee with a **£10 Marks and Spencer voucher**.
- As a thank you for your participation, we will also provide the opportunity to win a specially designed workshop run by Bright Shadow, a Kent-based company providing performance workshops for older people with dementia.

I would be really grateful if you could help by participating in my project. I will telephone you in the next few days to discuss any questions that you may have. If you would like to contact me before then, please do not hesitate: the details are below.

Yours Sincerely,

Charlotte Mallon

Managing Challenging Behaviours in Dementia – A Holistic Approach

Project Team: Charlotte Mallon (Lead Researcher), Professor Janet Krska, Dr Shivaun Gammie

💻cm559@kent.ac.uk ☎**01634 202920**

Participant Information Sheet for Matron on behalf of Nursing Homes

A study exploring how nursing homes manage challenging behaviour in people with dementia.

Name of researcher(s): Charlotte Mallon, Dr Shivaun Gammie, Professor Janet Krska

You are being invited to take part in a study. This study is being carried out by researchers at the Medway School of Pharmacy. Before you decide if you want to participate, you must understand why the study is being done and what it involves. Please take time to read the following information. Take time to decide if you want to take part or not.

1. Why is this study being done?

The study is designed to explore staff perspectives and the environmental impact on the behaviour of residents of nursing homes, who have a diagnosis of dementia.

2. Why have I been asked to take part?

The study explores how different nursing homes in Kent manage challenging behaviour in people with dementia. The study seeks to examine the personal experiences and opinions of the staff as well as the environment of the nursing home. Your nursing home has been invited to take part in order to consider these factors. This is because your nursing home is located in the county of Kent and cares for individuals with dementia.

3. Do I have to take part?

No. It is up to you to decide whether or not you wish for your nursing home to take part. Even if you agree to take part, you can change your mind at any time without giving any reason.

4. What will happen to me if I take part?

As part of this study, your nursing home will be used to explore how challenging behaviour in dementia is managed. This study has three phases. Firstly, it will involve a **single, in-depth interview with the Matron, or designated nurse in charge**. This interview will involve an audio-recorded conversation with the researcher about different aspects of your nursing home that you believe may impact on challenging behaviour, including methods of managing challenging behaviour, your staff, and the nursing home environment. The interview will last approximately one hour and will take place outside of working hours at a mutually convenient time. Secondly, it will involve **up to nine audio-recorded interviews with your nurses and carers**, in order to obtain their views on managing challenging behaviour, the environment, staff training and the barriers they face. Staff interviews will last approximately thirty minutes and will take place outside of working hours at a mutually convenient time. Finally, an **observation of the nursing home environment** will be carried out. This will involve measuring space, identifying interior decoration, measuring noise levels, and photography to capture the feel of the nursing home environment. It is important to note that the researcher will not observe the residents, interfere in the care provided to the residents or access any information about residents. If you consent to your nursing home take part, you will be asked to sign a consent form and return it to the researcher. Please note that consenting to participate does guarantee your care home will be selected.

5. Are there any risks involved?

This study involves an interview, therefore any risks are minimal. The researcher has undergone a full CRB check, and has a duty of care to the residents of the nursing home. Anything you say to the researcher is entirely confidential, however, you are reminded that the researcher has a legal and ethical duty of care which may override this anonymity should disclosures be made that may significantly compromise patient safety. The interview may bring up difficult areas. Where you feel uncomfortable, you will be given an option of not answering the question, or suspending the interview. If you choose to disclose any information that may compromise patient safety, you will be encouraged to discuss this with the Responsible Individual. Matron interviews will last approximately one hour, while staff interviews will last approximately thirty minutes. Participants will be required to be interviewed outside of their working hours, so as not to compromise patient care.

6. Are there any benefits of taking part?

Yes, there are some benefits to taking part. If you take part, it will help us to learn how nursing homes manage challenging behaviour in dementia, and this may help us to develop future programmes for managing challenging behaviour. This is your opportunity to tell us what challenges you face working with individuals with dementia in care homes, and we will listen.

We recognise that your time is precious. As a thank you for your time, every participant will receive a **£10 Marks and Spencer voucher**. Each care home will also have the opportunity to win a specially designed workshop run by Kent-based theatre company 'Bright Shadow', who provide performance workshops for older people with dementia in care homes.

7. What will happen to the results?

Anything said during interviews with the researcher will remain anonymous and will be put together with the comments of all the different participants in the study. The results of the interviews and observations will be included in reports we write about the research, but no one will know who made the comments.

8. Who will know that I have taken part?

If you decide to take part, you will be providing consent for your nursing home to be a part of this project. Therefore it is likely that your staff, residents and their relatives will know that you are taking part. Members of the study team will also know that you are taking part, however your information and participation will not be divulged to any other parties.

9. What should I do if I change my mind?

You can withdraw from the study at any time without giving a reason, by contacting the researcher below.

10. Can I get a copy of the study results?

Yes. A summary of the study results will be sent to all participating nursing homes and their Responsible Individual.

Who should I contact if I have any questions or problems?

Miss Charlotte Mallon
Medway School of Pharmacy
Chatham Maritime
Kent ME4 4TB
Phone: 01634 202920
Email: cm559@kent.ac.uk

Please keep a copy of this information leaflet

CONSENT FORM for NURSING HOME

Name of researchers: Miss Charlotte Mallon, Dr Shivaun Gammie, Professor Janet Krska

I have read and understand the information provided about the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	Initial here
I understand that participation is voluntary and that the nursing home is free to withdraw at any time, without giving a reason and that this will not affect legal rights.	Initial here
I understand that the nursing home's details will be retained securely, used only for maintaining contact and will be destroyed after the study finishes.	Initial here
I agree to give a single, in-depth interview, which will last approximately one hour. I understand that the interview will be audio-recorded. I understand that a legal and ethical duty of care exists that may override any confidentiality agreement made.	Initial here
I agree to provide information from the staff roster. I agree to the nursing home staff being approached and asked to participate in this study by undertaking an interview with the researcher, and I understand that they are free to decline.	Initial here
I agree to the nursing home environment being observed, and understand that the researcher will not observe the residents, interfere in the care provided to residents or access any information about residents.	Initial here
I give consent for the nursing home to be a part of the study.	Initial here

Name of Matron/designated nurse in charge, on behalf of nursing home:

Signature: Date:

Name of researcher:

Signature: Date:

Appendix 5 – Main recruitment pack CHs (Phase One)

Letter of invitation

September 2013

Dear Matron**,**

How do nursing homes manage challenging behaviour in dementia?

Have your say.

Thank you for agreeing to meet with me on [INSERT DATE] at [INSERT TIME].

As part of my PhD project at the Medway School of Pharmacy, I am exploring how different nursing homes in Kent manage challenging behaviour in people with dementia. I am currently recruiting care homes to participate in the project.

This study will involve:

1. Providing some basic information about your care home
2. 3 visits, where I **will**:
    - Have one interview with the Matron;
    - Interview some of your staff members;
    - Observe the environment of the care home.

I **will not**:

- Observe your residents
- Interfere in the care provided to your residents
- Access any information about your residents

'Why should our care home take part?'
Very little is known about the best ways to manage challenging behaviour. This project aims to **inform future practice in caring for people with dementia**;
Have your say. This project will give you an opportunity to tell us what problems you face looking after people with challenging behaviour and share any good ideas you have which you find successful;
We recognise that your time is precious. Therefore, we will reimburse every interviewee with a **£10 Marks and Spencer voucher**.
As a thank you for your participation, we will also provide the opportunity to win a specially designed workshop run by Bright Shadow, a Kent-based company providing performance workshops for older people with dementia.

Please feel assured that after the meeting you are under no pressure or obligation to participate, however I would be really grateful if you could help by participating in my project. If you would like to contact me before our meeting, please do not hesitate: the details are below.

Yours Sincerely,

Charlotte Mallon

Managing Challenging Behaviours in Dementia – A Holistic Approach

Project Team: Charlotte Mallon (Lead Researcher), Professor Janet Krska, Dr Shivaun Gammie

💻cm559@kent.ac.uk ☎**01634 202920**

Participant Information Sheet for Matron on behalf of Nursing Homes

A study exploring how nursing homes manage challenging behaviour in people with dementia.

Name of researcher(s): Charlotte Mallon, Dr Shivaun Gammie, Professor Janet Krska

You are being invited to take part in a study. This study is being carried out by researchers at the Medway School of Pharmacy. Before you decide if you want to participate, you must understand why the study is being done and what it involves. Please take time to read the following information. Take time to decide if you want to take part or not.

1. Why is this study being done?

The study is designed to explore staff perspectives and the environmental impact on the behaviour of residents of nursing homes, who have a diagnosis of dementia.

2. Why have I been asked to take part?

The study explores how different nursing homes in Kent manage challenging behaviour in people with dementia. The study seeks to examine the personal experiences and opinions of the staff as well as the environment of the nursing home. Your nursing home has been invited to take part in order to consider these factors. This is because your nursing home is located in the county of Kent and cares for individuals with dementia.

3. Do I have to take part?

No. It is up to you to decide whether or not you wish for your nursing home to take part. Even if you agree to take part, you can change your mind at any time without giving any reason.

4. What will happen to me if I take part?

As part of this study, your nursing home will be used to explore how challenging behaviour in dementia is managed. This study has three phases. Firstly, it will involve a **single, in-depth interview with the Matron, or designated nurse in charge**. This interview will involve an audio-recorded conversation with the researcher about different aspects of your nursing home that you believe may impact on challenging behaviour, including methods of managing challenging behaviour, your staff, and the nursing home environment. The interview will last approximately one hour and will take place outside of working hours at a mutually convenient time. Secondly, it will involve **up to nine audio-recorded interviews with your nurses and carers**, in order to obtain their views on managing challenging behaviour, the environment, staff training and the barriers they face. Staff interviews will last approximately thirty minutes and will take place outside of working hours at a mutually convenient time. Finally, an **observation of the nursing home environment** will be carried out. This will involve measuring space, identifying interior decoration, measuring noise levels, and photography to capture the feel of the nursing home environment. It is important to note that the researcher will not observe the residents, interfere in the care provided to the residents or access any information about residents. If you consent to your nursing home take part, you will be asked to sign a consent form and return it to the researcher. Please note that consenting to participate does guarantee your care home will be selected.

5. Are there any risks involved?

This study involves an interview, therefore any risks are minimal. The researcher has undergone a full CRB check, and has a duty of care to the residents of the nursing home. Anything you say to the researcher is entirely confidential, however, you are reminded that the researcher has a legal and ethical duty of care which may override this anonymity should disclosures be made that may significantly compromise patient safety. The interview may bring up difficult areas. Where you feel uncomfortable, you will be given an option of not answering the question, or suspending the interview. If you choose to disclose any information that may compromise patient safety, you will be encouraged to discuss this with the Responsible Individual. Matron interviews will last approximately one hour, while staff interviews will last approximately thirty minutes. Participants will be required to be interviewed outside of their working hours, so as not to compromise patient care.

6. Are there any benefits of taking part?

Yes, there are some benefits to taking part. If you take part, it will help us to learn how nursing homes manage challenging behaviour in dementia, and this may help us to develop future programmes for managing challenging behaviour. This is your opportunity to tell us what challenges you face working with individuals with dementia in care homes, and we will listen.

We recognise that your time is precious. As a thank you for your time, every participant will receive a **£10 Marks and Spencer voucher**. Each care home will also have the opportunity to win a specially designed workshop run by Kent-based theatre company 'Bright Shadow', who provide performance workshops for older people with dementia in care homes.

7. What will happen to the results?

Anything said during interviews with the researcher will remain anonymous and will be put together with the comments of all the different participants in the study. The results of the interviews and observations will be included in reports we write about the research, but no one will know who made the comments.

8. Who will know that I have taken part?

If you decide to take part, you will be providing consent for your nursing home to be a part of this project. Therefore it is likely that your staff, residents and their relatives will know that you are taking part. Members of the study team will also know that you are taking part, however your information and participation will not be divulged to any other parties.

9. What should I do if I change my mind?

You can withdraw from the study at any time without giving a reason, by contacting the researcher below.

10. Can I get a copy of the study results?

Yes. A summary of the study results will be sent to all participating nursing homes and their Responsible Individual.

Who should I contact if I have any questions or problems?

Miss Charlotte Mallon
Medway School of Pharmacy
Chatham Maritime
Kent ME4 4TB
Phone: 01634 202920
Email: cm559@kent.ac.uk

Informed Consent Form

How do different nursing homes manage challenging behaviour in people with dementia?

CONSENT FORM for NURSING HOME

Name of researchers: Miss Charlotte Mallon, Dr Shivaun Gammie, Professor Janet Krska

I have read and understand the information provided about the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	Initial here
I understand that participation is voluntary and that the nursing home is free to withdraw at any time, without giving a reason and that this will not affect legal rights.	Initial here
I understand that the nursing home's details will be retained securely, used only for maintaining contact and will be destroyed after the study finishes.	Initial here
I agree to give a single, in-depth interview, which will last approximately one hour. I understand that the interview will be audio-recorded. I understand that a legal and ethical duty of care exists that may override any confidentiality agreement made.	Initial here
I agree to provide information from the staff roster. I agree to the nursing home staff being approached and asked to participate in this study by undertaking an interview with the researcher, and I understand that they are free to decline.	Initial here
I agree to the nursing home environment being observed, and understand that the researcher will not observe the residents, interfere in the care provided to residents or access any information about residents.	Initial here
I give consent for the nursing home to be a part of the study.	Initial here

Name of Matron/designated nurse in charge, on behalf of nursing home:

Signature: Date:

Name of researcher:

Signature: Date:

Appendix 6 – Main recruitment pack CH staff (Phase One)

Participant Information Sheet for Staff

A study exploring how nursing homes manage challenging behaviour in people with dementia.

Name of researcher(s): Charlotte Mallon, Dr Shivaun Gammie, Professor Janet Krska

You are being invited to take part in a study. This study is being carried out by researchers at the Medway School of Pharmacy. Before you decide if you want to participate, you must understand why the study is being done and what it involves. Please take time to read the following information. Take time to decide if you want to take part or not.

1. Why is this study being done?

The study is designed to explore staff perspectives and the environmental impact on the behaviour of residents of nursing homes, who have a diagnosis of dementia.

2. Why have I been asked to take part?

The study explores how different nursing homes in Kent manage challenging behaviour in people with dementia. The study seeks to examine the personal experiences and opinions of the staff as well as the environment of the nursing home. Your nursing home has been invited to take part in order to consider these factors. This is because your nursing home is located in the county of Kent and cares for individuals with dementia. You have been asked to take part because you are a clinical staff member in your nursing home.

3. Do I have to take part?

No. It is up to you to decide whether or not you wish for your nursing home to take part. Even if you agree to take part, you can change your mind at any time without giving any reason.

4. What will happen to me if I take part?

As part of this study, your nursing home will be used to explore how challenging behaviour in dementia is managed. If you participate, you will undergo **one audio-recorded interview**, in order to obtain your views on managing challenging behaviour, the nursing home environment, staff training and the barriers you face. The interview will last approximately thirty minutes and will take place outside of working hours at a mutually convenient time. Also, an **observation of the nursing home environment** will be carried out. This will involve measuring space, identifying interior decoration, measuring noise levels, and photography to capture the feel of the nursing home environment. It is important to note that the researcher will not observe the residents, interfere in the care provided to the residents or access any information about residents. The researcher is also not observing you, as a staff member. If you consent to take part, you are required to sign a consent form and return it to the researcher. Please note that consenting to participate does not guarantee that you will be selected for interview.

5. Are there any risks involved?

This study involves an interview, therefore any risks are minimal. The researcher has undergone a full CRB check, and has a duty of care to the residents of the nursing home. Anything you say to the researcher is entirely confidential, however, you are reminded that the researcher has a legal and ethical duty of care which may override this anonymity should disclosures be made that may significantly compromise patient safety. The interview may bring up difficult areas. Where you feel uncomfortable, you will be given an option of not answering the question, or suspending the interview. If you choose to disclose any information that may compromise patient safety, you will be encouraged to discuss this with the Responsible Individual. Your interview will last approximately thirty minutes. You will be required to be interviewed outside of your working hours, so as not to compromise patient care.

6. Are there any benefits of taking part?

Yes, there are some benefits to taking part. If you take part, it will help us to learn how nursing homes manage challenging behaviour in dementia, and this may help us to develop future programmes for managing challenging behaviour. This is your opportunity to tell us what challenges you face working with individuals with dementia in care homes, and we will listen.

We recognise that your time is precious. As a thank you for your time, every participant will receive a **£10 Marks and Spencer voucher**. Each care home will also have the opportunity to win a specially designed workshop run by Kent-based theatre company 'Bright Shadow', who provide performance workshops for older people with dementia in care homes.

7. What will happen to the results?

Anything said during interviews with the researcher will remain anonymous and will be put together with the comments of all the different participants in the study. The results of the interviews and observations will be included in reports we write about the research, but no one will know who made the comments.

8. Who will know that I have taken part?

If you decide to take part, you will be providing consent for your nursing home to be a part of this project. Therefore it is likely that your staff, residents and their relatives will know that you are taking part. Members of the study team will also know that you are taking part, however your information and participation will not be divulged to any other parties.

9. What should I do if I change my mind?

You can withdraw from the study at any time without giving a reason, by contacting the researcher below.

10. Can I get a copy of the study results?

Yes. A summary of the study results will be sent to all participating nursing homes and their Responsible Individual.

Who should I contact if I have any questions or problems?

Miss Charlotte Mallon
Medway School of Pharmacy
Chatham Maritime
Kent ME4 4TB
Phone: 01634 202920
Email: cm559@kent.ac.uk

Please keep a copy of this information leaflet

Informed Consent Form

How do different nursing homes manage challenging behaviour in people with dementia?

CONSENT FORM for STAFF

Name of researchers: Miss Charlotte Mallon, Dr Shivaun Gammie, Professor Janet Krska

I have read and understand the information provided about the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	Initial here
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason and that this will not affect my legal rights.	Initial here
I understand that my personal details will be retained securely, used only for maintaining contact and will be destroyed after the study finishes.	Initial here
I agree to give an interview to a researcher who will ask me about my experiences and opinions of my job, and to the interview being audio-recorded. I understand that the interview will last approximately thirty minutes.	Initial here
I understand that anything I say during my interview with the researcher is confidential, however I understand that a legal and ethical duty of care exists that may override any confidentiality agreement made.	Initial here
I give my consent to take part in the study.	Initial here

Name of participant: Signature: Date:

Name of researcher: Signature: Date:

Appendix 7 – Interview schedules for CH managers and CH staff (Phase One)

Managers: Opening

Before we start the interview, I would like to remind you that it will focus on your opinions and experiences of managing challenging behaviour in dementia, including issues such as your staff and the nursing home environment. Firstly, I want to check the information from the Baseline Data Questionnaire we did on the telephone.

Interviewer to refer to BDQ for care home (copy of Appendix 4)

Question 1 **Can you tell me about your experiences of challenging behaviour?**

Interviewer prompts

Have you experienced patients who are aggressive?

Have you experienced patients who wander?

Have you experienced patients who have delusions or hallucinations?

How does this affect you? Your staff? Your residents? Visitors?

If a resident is wandering/shouting/other (not mentioned), would you call that challenging?

Question 2 **How do you manage challenging behaviours?**

Interviewer prompts

Can you tell me more about X?

Approximately how often do you use X?

Interviewer to tick when mentioned (and at end ask *)

Restrictive practice	☐
Antipsychotics	☐
Other drugs	☐
Reminiscence therapy	☐
Orientation therapy	☐
Music therapy	☐
Aromatherapy	☐
Massage	☐
Bright light therapy	☐

Interviewer prompts ***Have you any experience of X? (not ticked above)?**

Question 3 **Are there any ways of managing challenging behaviours that you would like to use more often?**

Interviewer prompts **Can you tell me why?**

Question 4 **Are there any ways of managing challenging behaviours that you**

	would prefer not to use?		
	Interviewer prompts	**Can you tell me why?**	
Question 5	**How do you think the Care Home environment affects challenging behaviour?**		
	Interview prompts	**Can you tell me more about X?**	
		How often do you use X?	
		Different rooms for different purposes:	
	Interviewer to tick when mentioned	**Corridors**	☐
		Living room	☐
		Dining room	☐
		Sensory room	☐
		Activity room	☐
		Gardens	☐
		Different decoration:	
	Interviewer to tick when mentioned	**Signs**	☐
		Colour	☐
		Different sounds:	
	Interviewer to tick when mentioned	**Noise level**	☐
		Music	☐
	Interviewer prompts	**Have you any experience of X? (not mentioned above)**	
Question 6	**How do you think your staff cope when managing challenging behaviour?**		
	Interviewer prompts	**Can you tell me more about X?**	
	Interviewer to tick when mentioned	**Staff numbers**	☐
		Staff training	☐
		Staff mix	☐
Question 7	**What are the barriers you face when managing challenging behaviour?**		
		Support	☐
		Facilities	☐
		Budgets	☐
		Relatives	☐

Interviewer prompts **Can you tell me a little more about your experiences of staff training?**

Question 8 **This background to this project is about appropriate prescription of medication. Are you aware of the current drive to reduce antipsychotic prescribing in people with dementia?**

Interviewer prompts **What effect has this had in your home?**

Do you think that it is important?

Do you think antipsychotics should be prescribed for challenging behaviour at all? When?

Question 9 **What three things, are the most important aspects of managing challenging behaviour?**

Thank you for taking part in this interview.

Next, I would be really grateful if you could show me the staff roster, so I can send out the staff invitations to participate. Each staff member will be given an information sheet and a consent form that they can sign and send back to me in the pre-paid envelope, if they want to take part.

If it's appropriate now, I would like to start some observations of the environment.

Thank you.

CH Staff:

Opening

This project is exploring how different nursing homes manage challenging behaviour. Everything you say is confidential, although after reading the information sheet you know that if you choose to disclose any information that may compromise patient safety, you will be encouraged to discuss this with the Responsible Individual. I have a legal and ethical duty of care that may override this confidentiality. If you feel uncomfortable at any time, you have the option of not answering a question, or suspending the interview altogether. Before we start the interview, I want to remind you that it will focus on your opinions and experiences of managing challenging behaviour in dementia as well as the nursing home environment. Shall we start?

Question 1 **Can you tell me about your experiences of challenging behaviour?**

Interviewer prompts

Have you experienced patients who are aggressive?

Have you experienced patients who wander?

Have you experienced patients who have delusions or hallucinations?

How does this affect you? Your residents?

Question 2 **How do you manage challenging behaviours?**

Interviewer prompts

Can you tell me more about X?

Approximately how often do you use X?

Interviewer to tick when mentioned

Restrictive practice	
Antipsychotics	
Other drugs	
Reminiscence therapy	
Orientation therapy	
Music therapy	
Aromatherapy	
Massage	
Bright light therapy	

Interviewer prompts

Have you any experience of X? (not ticked above)?

Question 3 **How do you think the care home environment affects challenging behaviour?**

Interview prompts	**Can you tell me more about X?**	
	How often do you use X?	
	Different rooms for different purposes:	
Interviewer to tick when mentioned	**Corridors**	☐
	Living room	☐
	Dining room	☐
	Sensory room	☐
	Activity room	☐
	Gardens	☐
	Different decoration:	
Interviewer to tick when mentioned	**Colour**	☐
	Signs	☐
	Different sounds:	
Interviewer to tick when mentioned	**Noise level**	☐
	Music	☐
Interviewer prompts	**Have you any experience of X? (not mentioned above)**	

Question 4 **What makes it difficult for you to manage challenging behaviour?**

Interviewer prompts	**Can you tell me more about X?**	
Interviewer to tick when mentioned	**Staff numbers**	☐
	Staff training	☐
	Staff mix	☐
	Support	☐
	Facilities	☐

Budgets

Interviewer prompts **Can you tell me a little more about your experiences of staff training?**

Question 5 **What three things, that if you could, would you change about managing challenging behaviour?**

Thank you for taking part in this interview.

Appendix 8 – Observation chart (Phase One)

CARE HOME:

Date: Time started: Time finished:

Room/corridor:

Measurements:

Description:

Photograph references:

Appendix 9 – Letter of Ethical Approval (Phase Two)

medway school of pharmacy

25th October 2013

Your application for ethical approval for the project *Behaviour that challenges – the views and experiences of staff working in Care Homes* has now been considered on behalf of the Medway School of Pharmacy School Research Ethics Committee (SREC).

I am pleased to inform you that the project has been approved with immediate effect.

I must remind you of the following:

1. that if you are intending to work unaccompanied with children or with vulnerable adults, you will need to apply for a CRB check; the project must be conducted under the supervision of someone who has an up-to-date CRB check; you must not be in the presence of children alone except if you have completed a CRB check;
2. that you must comply with the Data Protection Act (1998);
3. that you must comply throughout the conduct of the study with good research practice standards;
4. If you are completing this project off site, you must obtain prior approval from relevant authorities and adhere to the MSOP off site protocol.
5. to refer any amendment to the protocol to the School Research Ethics Committee (SREC) for approval.
6. You are required to complete an annual monitoring report or end of project report and submit to j.mowbray@kent.ac.uk

Yours sincerely

Dr Sarah Corlett

Appendix 10 – Cover letter and participant information sheet (Phase Two)

medway school of pharmacy

The Universities of Kent and Greenwich at Medway, Central Avenue, Chatham Maritime, Kent ME4 4TB

Tel: +44 (0)1634 883145 Fax: +44 (0) 1634 883927

XX October 2013

Dear Colleague

We are 4th year students studying Pharmacy at Medway School of Pharmacy and are writing to ask for your help with our final year project which aims to explore care staff views and experience of behaviour that challenges in people with dementia living in Care Homes. We are working under the supervision of Dr Shivaun Gammie who is a pharmacist at Medway School of Pharmacy.

We would be grateful if you would participate in our project by completing the enclosed questionnaire, and returning it to us in the FREEPOST envelope provide by **XX November 2013**. The questionnaire should take you around XX minutes to complete. The information that you provide on the questionnaire is **anonymous** and **strictly confidential**. A questionnaire number has been included only so that we can follow up any non-responding Care Homes.

By completing and returning this questionnaire, you are giving your consent to be part of this project and for your data to be used as described in this letter and the Participant Information Sheet which can be found overleaf.

We would like to take this opportunity to **thank you** for your time. We appreciate how busy you are and are really grateful for your help with our student project.

Yours sincerely

<table>
<tr><td></td><td></td><td></td><td></td></tr>
<tr><td>Cynthia Amponsah</td><td>Haval Aziz</td><td>Stephen Mathew</td><td>Mohamed Omar</td></tr>
</table>

<table>
<tr><td></td><td></td><td></td></tr>
<tr><td>Anita Obese- Acquaah</td><td>Avni Patel</td><td>Eric Ssemakadde</td></tr>
<tr><td colspan="3"><i>4th year Pharmacy Research Students</i></td></tr>
</table>

Dr Shivaun Gammie (Project Supervisor)

Pharmacist, Clinical Lecturer, Medway School of Pharmacy

PARTICIPANT INFORMATION SHEET

Title of Project: Behaviour that challenges – the views and experiences of staff working in Care Homes

You have been invited to join this project because you work in a Care Home registered with the Care Quality Commission as providing care for people with dementia. This information sheet provides more details about the project and what is involved if you take part. Please take time to read it and decide if you want to take part.

1. Why is this study being done?

There is a lot of attention on the best way to care for people with dementia who have behaviour that challenges. However, little is known about the views and experiences of care staff working in Care Homes. Therefore, it is important to find our more from care staff.

2. What will I need to do if I take part?

Complete the enclosed questionnaire and return it in the FREEPOST envelope enclosed.

3. Are they are any risks or benefits to taking part?

All your responses will be anonymous. Therefore, although there will be an inconvenience to you as it will take time to complete the questionnaire there are no anticipated risks. By taking part your views will contribute to what is known about managing behaviour that challenges.

4. Who will know that I have taken part?

The questionnaire has been sent to your Care Home. No-one will know that you have participated in this project. The information that you provide on the questionnaire is **anonymous** and **strictly confidential**. A questionnaire number has been included only so that we can follow up any non-responding Care Homes.

5. What will happen to the results?

The results of your questionnaire responses will be combined with those from all the Care Home staff who participate and analysed as part of seven final year pharmacy student projects. Each student will prepare a report for their final degree and the results may be published in academic journals.

6. Can I get a copy of the study results?

Yes. If you would like a short summary of the results once the project is completed please contact Dr Shivaun Gammie, the Project Supervisor (contact details below). We will retain your contact details until the report is drafted and destroy them after we have sent the summary to you.

7. Who should I contact if I have any questions or problems with this project?

Dr Shivaun Gammie, Pharmacist, Clinical Lecturer, Medway School of Pharmacy.

Phone: *01634 883145* E-mail: *s.m.gammie@kent.ac.uk*

Address: *Medway School of Pharmacy, The Universities of Kent and Greenwich at Medway, Central Avenue, Chatham Maritime, Kent ME4 4TB*

Please keep a copy of this information leaflet.

Appendix 11 – Questionnaire (Phase Two)

medway school of pharmacy

Behaviour that challenges

This questionnaire seeks care staff's views and experiences of working with people with dementia who have behaviour that challenges. There are no right or wrong answers so please tell us about the experiences YOU have gained whilst working in Care Homes. Anyone who works in a Care Home providing care to residents is welcome to complete this questionnaire.

The information that you provide on the questionnaire is **anonymous** and **strictly confidential**. A questionnaire number has been included only so we can follow up any non-responding Care Homes.

The questionnaire is divided into FOUR sections

- Section 1 – Your views and experiences of behaviour that challenges
- Section 2 – Your experience of what helps behaviour that challenges
- Section 3 – Training for behaviour that challenges
- Section 4 – About you and the Care Home you work in

Instructions for participants

- All questions relate to your work in Care Homes
- Please answer all sections of the questionnaire
- Please answer the questions by ticking the appropriate box or writing in the space provided, unless otherwise instructed. If you do not wish to answer a particular question or do not know the answer, please leave it blank and continue to the next question
- If the box provided for your response is too small, please continue on a separate sheet of paper.
- Please return your completed questionnaire in the Freepost envelope provided.

Thank you for your help

Acknowledgement: This questionnaire uses The Challenging Behaviour scale developed by Professor Esme Moniz-Cook (Moniz-Cook E et al. The Challenging Behaviour Scale (CBS): Development of a scale for staff caring for older people in residential and nursing homes. *British Journal of Clinical Psychology* 2001; 40: 309-322).

Questionnaire Number

This number will only be used to follow-up non-responding Care Homes

University of Kent

UNIVERSITY of GREENWICH

Section 1 – **Your views and experiences of behaviour that challenges**

Qu. 1 Below is a list of behaviours that residents may exhibit. Please

A. Indicate (***by ticking the appropriate box***) if you have experienced each behaviour whilst at work. If you haven't experienced the behaviour move down to the next behaviour on the list leaving columns B and C blank.

B. Indicate (***by ticking the appropriate box***) approximately how often you experience residents with this behaviour whilst at work.

C. Rate (***by writing a number in the box***) how challenging ***you personally*** find each behaviour using a scale where
1 = I **do not** find this behaviour challenging
and
5 = I find this behaviour **very** challenging

If you don't know how challenging you find the behaviour, please write "0"

	A		**B**				**C**
Behaviour	**I have experienced this behaviour**		**I experience this behaviour**				**Rate how you find this behaviour on a scale of 1 – 5** ***(see above)***
	Yes	**No**	**Every shift I work**	**At least once a week**	**At least once a month**	**Less than every month**	
Physical Aggression (hits, kicks, scratches, grabbing, etc.)	☐	☐	☐	☐	☐	☐	
Verbal Aggression (insults, swearing, threats, etc.)	☐	☐	☐	☐	☐	☐	
Self Harm (cuts/hits, refuses food / starves self etc.)	☐	☐	☐	☐	☐	☐	
Shouting	☐	☐	☐	☐	☐	☐	
Screaming / Crying out	☐	☐	☐	☐	☐	☐	
Perseveration (constantly repeating speech or actions, repetitive questioning or singing)	☐	☐	☐	☐	☐	☐	
Wandering (walks aimlessly around home)	☐	☐	☐	☐	☐	☐	

Restlessness (fidgets, unable to settle down, pacing, "on the go", etc.)	☐	☐	☐	☐	☐	☐	

Question 1 continued

	A		B				C
Behaviour	**I have experienced this behaviour**		**I experience this behaviour**				**Rate how you find this behaviour on a scale of 1 – 5**
	Yes	**No**	**Every shift I work**	**At least once a week**	**At least once a month**	**Less than every month**	
Lack of motivation (difficult to engage, shows no interest in activities, apathy, etc.)	☐	☐	☐	☐	☐	☐	
Clinging (follows / holds on to other residents / staff, etc.)	☐	☐	☐	☐	☐	☐	
Interfering with other people	☐	☐	☐	☐	☐	☐	
Pilfering or Hoarding (Possessions, rubbish, paper, food, etc.)	☐	☐	☐	☐	☐	☐	
Suspiciousness (accusing others, etc.)	☐	☐	☐	☐	☐	☐	
Manipulative (Takes advantage of others, staff, etc.)	☐	☐	☐	☐	☐	☐	
Lack of Self Care (hygiene problems, dishevelled, etc.)	☐	☐	☐	☐	☐	☐	
Spitting	☐	☐	☐	☐	☐	☐	
Faecal Smearing	☐	☐	☐	☐	☐	☐	
Inappropriate Urinating (in public, not in toilet, etc.)	☐	☐	☐	☐	☐	☐	
Stripping (removes clothes inappropriately, flashes, etc.)	☐	☐	☐	☐	☐	☐	

Inappropriate sexual behaviour (masturbates in public, makes inappropriate "advances" to others, etc.)	☐	☐	☐	☐	☐	☐	

Question 1 continued

	A		B				C
Behaviour	**I have experienced this behaviour**		**I experience this behaviour**				**Rate how <u>you</u> find this behaviour on a scale of 1 – 5**
	Yes	**No**	**Every shift I work**	**At least once a week**	**At least once a month**	**Less than every month**	
Sleep Problems (waking in night, insomnia, etc.)	☐	☐	☐	☐	☐	☐	
Non-compliance (deliberately ignores staff requests, refuses food, resists self care help, etc.)	☐	☐	☐	☐	☐	☐	
Dangerous Behaviour (causes fires or floods, etc.)	☐	☐	☐	☐	☐	☐	
Demands Attention	☐	☐	☐	☐	☐	☐	
Lack of Occupation (sits around doing nothing, etc.)	☐	☐	☐	☐	☐	☐	

Qu. 2 Are there any other behaviours that you find challenging? **Yes** ☐ **No** ☐
(please tick)

Qu. 3 If yes, please write in the space below and then rate the behaviour as in question 1.

	A		B				C
Behaviour	**I have experienced this behaviour**		**I experience this behaviour**				**Rate how <u>you</u> find this behaviour on a scale of 1 – 5**
	Yes	**No**	**Every shift I work**	**At least once a week**	**At least once a month**	**Less than every month**	

	☐	☐	☐	☐	☐	☐	
	☐	☐	☐	☐	☐	☐	
	☐	☐	☐	☐	☐	☐	

Section 2 – **Your experiences of what helps behaviour that challenges**

Qu. 4 For each intervention listed below please indicate (***by ticking the appropriate box***) your level of agreement or disagreement with the statement *“**The intervention helps people with dementia who have behaviour that challenges**”*

Intervention	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
Assessing each resident to find out the factors that cause them to have behaviour that challenges	☐	☐	☐	☐	☐
Having clear signposting in the home to help residents find their way around the home	☐	☐	☐	☐	☐
Having enough room for residents to walk around	☐	☐	☐	☐	☐
Having separate rooms for different activities	☐	☐	☐	☐	☐
Having activities involving music and / or dancing	☐	☐	☐	☐	☐
Having brain stimulating activities e.g. reading, reminiscing	☐	☐	☐	☐	☐
Aromatherapy	☐	☐	☐	☐	☐
Massage	☐	☐	☐	☐	☐
Having activities that stimulate all the senses	☐	☐	☐	☐	☐
Having time to talk to people with dementia	☐	☐	☐	☐	☐
Giving medicines that control behaviour	☐	☐	☐	☐	☐
Making sure that the resident is free of pain	☐	☐	☐	☐	☐
Having animals for the residents	☐	☐	☐	☐	☐
Treating each resident as an individual	☐	☐	☐	☐	☐

Qu. 5 In your own words, describe the best way to help residents with behaviour that challenges you

Section 3 – **Training for behaviour that challenges**

Qu. 6 Please read the following statements and indicate (***by ticking the appropriate box***) your level of agreement or disagreement with the statement

Statement	**Strongly Agree**	**Agree**	**Neutral**	**Disagree**	**Strongly Disagree**
I have received training to help me care for people with behaviour that challenges	☐	☐	☐	☐	☐
The training I received has helped me to care for people with behaviour that challenges	☐	☐	☐	☐	☐
I would like more training to help me care for people with behaviour that challenges	☐	☐	☐	☐	☐

Qu. 7 If you have received training to help you care for people with behaviour that challenges, please answer the questions below. If you have not received training, go to the next page.

Type of training	**In the last 5 years, approximately how many**		**How would you rate this training?**		
	a) training sessions have you attended	**b) hours of training have you received**	**Excellent**	**Good**	**Poor**
Face to face training at a venue away from the Care Home			☐	☐	☐
Face to face training in a training room within the Care Home			☐	☐	☐
On-line training			☐	☐	☐
Written training materials (e.g. training pack/ booklet/ manual, hand outs, assignments)			☐	☐	☐
"On the job training" from experienced members of staff			☐	☐	☐
Other *(please specify)*			☐	☐	☐

Qu. 8 Have you any other comments about the training you have received?

Section 4 – **About YOU and the Care Home you work in**

Finally, please tell us a little bit about yourself and where you work. Remember, all information that you provide will be analysed anonymously.

Qu. 9 Is your Care Home? ***(please tick all boxes that apply)***

Care Home with Nursing	☐	Care Home without Nursing	☐

Qu. 10 How many residents live in the Care Home that you work in?	
Qu. 11 Approximately how many residents have dementia?	
Qu. 12 Approximately how many residents have behaviour that challenges?	
Qu. 13 Approximately how many residents are prescribed medicines to control their behaviour that challenges?	

Qu. 14 What is your role within the Care Home that you work ***(please tick all boxes that apply)***

Manager	☐	Care Worker with a formal qualification e.g. NVQ	☐
Nurse	☐	Care Worker without a formal qualification	☐
Other	☐	***Please specify….***	

Qu. 15 Do you work? ***(please tick all that apply)***

Full-time	☐	Day shifts	☐
Part-time (20 hours or more a week)	☐	Night shifts	☐
Part-time (less than 20 hours a week)	☐	Weekend shifts	☐

Qu. 16 Approximately how long have you worked in Care Home(s)?

	In this Care Home	In any Care Home

Less than 3 months	☐	☐
3 months – 1 year	☐	☐
More than 1 year but less than 5 years	☐	☐
More than 5 years but less than 20 years	☐	☐
20 years or more	☐	☐

Thank you for completing this questionnaire, please return it in the envelope provided.

Appendix 12 – Resident Personal Record Data

Resident	Medical	Education	Work	Hobbies	Other
Ernie CH6 Born: 1924 Admitted: 02/2014	None in recent significant history. Ileostomy and catheter – UTI stoma since 18y. Ileostomy due to large prostate. History of falls with UTI. Moderate level of dementia, some lucid moments. No aggression noted, not particularly extrovert. NKDA. Short term memory very impaired. Transfers independently but prone to falls with UTI. DNR		Chief clerk in an insurance office. Job is a job.	Likes relaxing. Not a music man. Can play mouth organ. Invite to activities daily. Church of England. Enjoys looking smart and has strong sense of pride in appearance. Enjoys family visits, enjoys garden.	*Family*: Married, with 2 sons. *Social geography*: Lived Maidstone. No community involvement. *Other*: Fully clothed. Non-smoker. Normal diet, no nuts. Likes tea/coffee. Would like meals in his room or dining room. Afternoon naps when wanted. Small appetite.
Bertram CH6 Born: 1927, London Admitted: 20/1/14	Allergic to bendroflumethiazide. 1/9/96 – essential hypertension. 28/1/11 – Vit B12 deficiency. 14/6/13 – Depression 25/11/13 – H/O splenectomy after fall 26/11/13 – Laparotomy High levels of anxiety/confusion. DNR	School in Westminster	War years spent in the army. London taxi driver.	Likes light ale, enjoys going to the pub for a beer. Likes quizzes, especially on TV. Enjoys reading, watching the TV – challenge channel.	*Family*: Widowed in February 2013. *Religion*: Jehovah's Witness.
Agnes CH6 Born: 1917, Liverpool Admitted: 27/2/13	DNR. Dementia, registered blind, diabetes, stroke (24/10/12). Thryotoxicism. Spoonfed one tablet at a time (10/11/14).	School in Anfield.	Housewife but used to help father with bookshop/window cleaning.	Likes bowls and knitting. Likes dogs. Would like visit from vicar.	*Family*: One brother in Wales. No visiting family. 4 granddaughters. Some grandchildren and great grandchildren. Married 40+ years to G. He died 1990. *Social geography:* Lived in Liverpool and Eastbourne (1972) and very recently Kent. *Religion*: She is Christian *Other:* Likes a quiet environment whilst eating.
Betty CH6 Born: 1927, Barking Admitted: 4/11/13	'V limited medical history as no family'. Eczema.	"A little backward" at school	A domestic help, mainly. Worked in the fields as a Land Girl. Mother was always at home.	No hobbies or interests. Likes wildlife, shopping. Does not like TV.	*Family*: Youngest in the family. 1 brother and 1 sister. Wonderful childhood, very spoiled. No significant relationships. Walked in the park with family to listen to bands when young. No living relatives, no one close.

					Religion: Always went to church with family *Other*: No significant life events. “I feel out of place”. Widowed
Ronald CH6 Born: 1929, Tooting Admitted: 16/4/11	1st stroke 2007. Lost sight in left eye. Allergies: sodium valproate, codeine phosphate, highly sensitive to benzodiazepines, haloperidol. 4th eldest of 6 siblings, 3 brothers and 2 sisters. Stroke 2009. Ischaemic heart disease, pleural aspiration, Left hip problem (old fracture), cellulitis, DVT, Vascular dementia	Spent time in hospital when he was younger therefore didn’t really like school.	Worked as a local trader in fresh fish as his first job. Joined RAF at 17y, and spent the last 2 years of RAF in Karachi, as a Fire Officer. Took a job in Central Electricity Generator Board.	3 holidays per year. Had flying lessons over the ‘last few years’.	*Family*: Married in September 1952. 3 children, 2 sons and a daughter. 1 dog. 7 grandchildren and 8 great grandchildren. *Social geography*: Lived in Mitcham, then Folkestone.
Edwin CH6 Born: 1934, Camberwell Admitted: 24/1/13	Orthostatic hypertension, vascular dementia, Parkinson’s, depression. Allergies: Penicillin Doesn’t take medicines frequently due to profound cognitive impairment and confusion. Therefore has covert medication. DNR	Woolwich Grammar School	National Service – army. Ran motorcycle garage. Butcher. Estate agent. Property development.	Singing, dancing, spending time with family. Rugby. Enjoys air shows. Painting, drawing. Likes Bee gees and Elvis, as well as classical music. Likes to get up at 9am. Bed between 7-8pm.	*Family*: 3 cats, 1 dog. 1 daughter, 1 son. 3 grandchildren and 1 great-grandchild. *Religion*: When he was younger, he attended the local Methodist church, but is no longer practising. *Other*: Non-smoker. Charity fundraiser, member of the rotary club.
Walter CH6 Born: 1940 Admitted: 23/10/14	Diabetes, arthritis. NKDA. Mental health history of schizophrenia and bipolar disorder (schizoaffective disorder), and frontal lobe dementia. 25/10/10: Sigmoidoscopy NEC diverticulosis and haemorrhoids 05/05: frontal lobe syndrome MRI-frequent psychiatric admissions 02/02: Tension type headache, chronic daily headache 11/02: MI-acute ant-lat with moderate LV function and angiocardiogram: single vessel disease				*Family*: Married

	04/00: Diagnostic laryngoscopy-mod dysplasia ant vocal cords 01/00: Bipolar Affective Disorder Section3 Hyomanic state 2000: Type 2 DM 1994: Diagnostic arthroscopy of knee (R) foreign body 1992: Depressive episode 1983: Fracture (closed) of forearm, lower end NOs R radius 1980: Primary repair of inguinal hernia R 1971: Paranoid schizophrenia admission (later diagnosed as SAD & Hypomania, 1997)				
Donald CH11 Born: 1939 Admitted: 13/10/08	Allergic to nuts, alcohol and adhesive.	Can't remember	Employment – projectionist in cinema. Cabinet maker and carpenter.	Likes being around people. Likes being in the garden. Favourite film- musical films and most music.	*Family*: Single. One brother. One dog. Close friend. No children. *Social geography*: Spain for holidays.
Joan CH11 Born: 1943, London Admitted: 29/1/07	Advanced stages of early onset dementia. Epilepsy (chair bound @ 27/6/14)	No school/ childhood memories	Secretary in office in London.	No favourite TV /Film. Enjoys jazz. Enjoys gardening. Enjoyed many holidays & Australia was a place she visited often. Enjoys being outside gardening and going for walks	*Family*: 1 brother and 1 sister. No pets. Married. Many friends but 2 closest are female
Myrtle CH11 Born: 1938, Chatham Admitted: 21/01/09	Previous medicines: amisulpride, losartan, felodipine, simvastatin. NKDA.	Went to Glencoe School.	Worked in ragtrade. Worked in Sainsburys as a cashier for 25 years.	Favourite film/TV: Seven brides for seven brothers, Morecambe and Wise, Two Ronnies. Favourite music: Nana MouseViverie, Shirley Bassey. Enjoys walking, badminton, cycling, cross	*Family*: No brothers or sisters. Had dogs and goldfish. Married husband in 1984 at St John's Church, Chatham. No children and no grandchildren. *Social geography:* Childhood memories were going on holiday with her parents. Holidayed to Austria, Crete, Holland,

				stitch. Enjoyed being outside and walking.	Athens and Isle of Wight.
Vera CH2 Born: 1922, Dublin Admitted: 2010	History of falls-fractured neck of femur (2010) Hypertension, weight loss. Has 'Alzheimer's dementia', anxiety disorder, depression, challenging behaviour and moderate to dense cataract (2012).		Housewife, however past occupations included being a cook and a domestic cleaner.	Reading, enjoys a bath or shower. Likes to wear slippers indoors, and shoes outside.	*Family*: Being a child in Dublin, and her relationship with her mother and father. Was married, now widowed. Four daughters, nine grandchildren. Visited by all daughters.
					Social geography: Lived in Ireland, Lewisham and Deptford.
					Religion: She is Irish and of Catholic faith.
					Other: Goes to bed between 7-730pm. Does not sleep well at night: fretful and calls out constantly. Likes to have a glass of water beside the bed.
Edna CH2 Born: 1934, Aldridge Admitted: 2014	History of hypertension, high cholesterol and arthritis. Currently has hypertension, rheumatoid arthritis, high cholesterol and reduced mobility. DNR.			She enjoys knitting, embroidery, sewing, reading, gardening and lace-making.	*Family*: Married and had no children, however is now a widow.
					Social geography: Essex, Birmingham, London.
					Religion: Church of England.

Appendix 13 – Medicines Data Table (Phase Four)

Medicines Data Analysis – 'Ernie'

Medical problems (identified in Care Home record):

None in recent significant history. Ileostomy and catheter – UTI stoma since 18y. Ileostomy due to large prostate. History of falls with UTI. Moderate level of dementia, some lucid moments. No aggression noted, not particularly extrovert. NKDA. Short term memory very impaired. Transfers independently but prone to falls with UTI. DNR

Medication Prior to Admission: Not recorded

Summary of medicines on MAR chart:	Total number of items on MAR chart	6	Number of medicinal products on MAR chart	5	Number of CNS medicines (Chapter 4 of BNF)	0

Previous 1-month MAR Chart:

	Exact Copy of MAR Chart				**BNF Validation of MAR Chart**			**Analysis of potentially inappropriate prescriptions**		
BNF Chapter	**Medicine**	**Dose**	**MAR Chart Indication**	**MAR Administration**	**Likely Medicine**	**Dose in line with BNF?**	**Likely Indication**	**Appropriate indication identified?**	**Category**	**Further information**
5.1	Nitrofurantonin	50mg QDS	UTI	QDS for 12 days	Nitrofurantoin	Yes	Treatment of acute uncomplicated urinary tract infection	Indication present	MAR error	Drug name spelt incorrectly
5.1	Trimethoprim susp 50mg/5ml	2 5ml at night	UTI	2.5ml at night 22.00	Trimethoprim	Yes	Prophylaxis of UTI	Indication present		
7.4	Vesicare	10mg OD		1 in morning 09.00	Solifenacin succinate (Vesicare®)	Yes	Urinary frequency, urgency and urge incontinence	PIM-I (indication is inappropriate as catheter is in situ)	PIM-STOPP Section I1	I1 (catheter in situ)
									PIM-I	Catheter in-situ
									Anticholinergic	MAT Score 3
7.4	Tamsulosin MR	40mcg OD		1 capsule in the morning, swallow whole 09.00	Tamsulosin Hydrochloride	400mcg OD	Benign prostatic hyperplasia	Indication present	MAR error	Incorrect dose stated (40 mcg instead of correct 400mcg)
9	Ensure liquid	250ml		As directed (twice a day at 9am, 10om)	Ensure Liquid	Yes	Oral nutritional supplement	Non-medicinal product	PIM-ONS	ONS

(13)	Cavilon 339IE Durable Cream 28g			Apply to affected area OD		Cavilon Durable Barrier Cream	Yes	Skin damage associated with incontinence	Self-limiting indication		

Medicines Data Analysis – ‘Bertram’

Medical problems (identified in Care Home record):

Allergic to bendroflumethiazide.
1/9/96 – essential hypertension.
28/1/11 – Vit B12 deficiency.
14/6/13 – Depression
25/11/13 – H/O splenectomy after fall
26/11/13 – Laparotomy
High levels of anxiety/confusion. DNR

Medication Prior to Admission: Not recorded

Summary of medicines on MAR chart:	Total number of items on MAR chart	12	Number of medicinal products on MAR chart	10	Number of CNS medicines (Chapter 4 of BNF)	5

Previous 1-month MAR chart

	Exact Copy of MAR Chart					**BNF Validation of MAR Chart**				**Analysis of potentially inappropriate prescriptions**	
BNF Chapter	**Medicine**	**Dose**	**MAR Chart Indication**	**MAR Administration**		**Likely Medicine**	**Dose in line with BNF?**	**Likely Indication**	**Appropriate indication identified?**	**Category**	**Further information**
3.1	Ventolin	100 mcg PRN		1-2 puffs QDS		Salbutamol (Ventolin® Inhaler)	✓	Asthma/other condition associated with recurrent airway obstruction	PIM-I No respiratory indication listed in medical conditions	PIM-I	
4.1	Zopiclone	3.75mg	N/A			Zopiclone	✓	Insomnia	PIM-I Insomnia not	STOPP - Section K4	Hypnotic Z drugs

		PRN							listed in medical conditions	PIM-I	
										CNS drug	Chapter 4 (BNF)
4.1	Lorazepam	1mg PRN	N/A	½ tablet TDS given daily.		Lorazepam	✓	Anxiety	Indication present	STOPP Sections D5 and K1	Benzodiazepines for ≥ 4 weeks and Benzodiazepines (sedative, may cause reduced sensorium, impair balance)
										Anticholinergic	MAT Score 1
										CNS drug	Chapter 4 (BNF)
4.3	Mirtazapine	30mg	N/A	1 tablet at night		Mirtazapine	✓	Major depression	Indication present	CNS drug	Chapter 4 (BNF)
4.7	Paracetamol	500mg PRN		2 tabs up to QDS		Paracetamol	✓	Mild to moderate pain, pyrexia	Self-limiting indication	CNS drug	Chapter 4 (BNF)
4.11	Donepizil	5mg	N/A	1 tablet at night		Donepezil Hydrochloride	✓	Mild to moderate dementia in Alzheimer's Disease	Assumption that resident has dementia, although no indication in medical records	MAR error	Incorrect spelling of medicine
										CNS drug	Chapter 4 (BNF)
5.1	Phenaymethyl-peniciles	250mg		2 in AM, 2 in PM		Phenoxymethlypenicillin	✓	Infection	PIM-I No infection listed in medical conditions	PIM-I	
										MAR error	Incorrect spelling of medicine
9.1	Ferrous Sulfate MR	325mg		1 in AM before food		Ferrograd (Ferrous Sulfate 325mg)	✓	Iron deficiency, anaemia	PIM-I Anaemia not listed in medical conditions	PIM-I	
										PIM-O	BNF lists Ferrograd® as a product less suitable for prescribing
11.8	Celluvisc	0.5% C 4ml PRN	N/A	5 x day to affected eye		Carmellose Sodium (Celluvisc®)	✓	Dry eyes	Self-limiting indication		
13.2	Dermol Cream	QDS	N/A			Dermol Cream	✓	Dry/ pruritic skin conditions	Self-limiting indication		
13.2	Batheem Cream	BD	N/A			Balneum	✓	Dry/pruritic skin conditions	Self-limiting indication	MAR error	Incorrect spelling of medicine
A2.2	Forticreme Complete			1 pack BD		Forticreme Complete		Nutritional Supplement	Non-medicinal product	PIM-ONS	ONS

Medicines Data Analysis – 'Agnes'

Medical problems (identified in Care Home record):
DNR. Dementia, registered blind, diabetes, stroke (24/10/12). Thryotoxicism. Spoonfed one tablet at a time (10/11/14).

Medication Prior to Admission: Not recorded

Summary of medicines on MAR chart:	Total number of items on MAR chart	13	Number of medicinal products on MAR chart	12	Number of CNS medicines (Chapter 4 of BNF)	4

***citalopram = 1 item, 1 medicinal product, 1 CNS medicine**

Previous 1-month MAR chart

	Exact Copy of MAR Chart				**BNF Validation of MAR Chart**				**Analysis of potentially inappropriate prescriptions**	
BNF Chapter	**Medicine**	**Dose**	**MAR Chart Indication**	**MAR Administration**	**Likely Medicine**	**Dose in line with BNF?**	**Likely Indication**	**Appropriate indication identified?**	**Category**	**Further information**
1.6	Micralax Enema			Use 1 every 6h PRN (none given)	Sodium Citrate (Rectal)	✓	Constipation	Self-limiting indication		
1.6	Senna	7.5mg		2 at bedtime	Senna	✓	Constipation	Self-limiting indication		
1.6.4	Laxido			1 sachet twice a day 9am, 1700	Macrogol Osmotic Laxative	✓	Constipation	Self-limiting indication		
2.9	Aspirin	75mg		1 in AM	Aspirin	✓	Antiplatelet	Indication present	PIM-P	Secondary prevention of cardiovascular disease
4.1	Zopiclone	3.75mg		1 at night 2200 PRN (26/11-3/12)	Zopiclone	✓	Insomnia	PIM-I Insomnia not listed in medical conditions	STOPP section K4	Hypnotic Z drugs
									CNS drug	Chapter 4 (BNF)
									PIM-I	

4.1	Lorazepam BD	½ tab		BD PRN (none given)		Lorazepam	✓	Insomnia/ anxiety	PIM-I Anxiety nor insomnia not listed in medical conditions	STOPP Section K1	Benzodiazepines (sedative, may cause reduced sensorium, impair balance)
										Anticholinergic	MAT Score 1
										PIM-I	
										CNS drug	Chapter 4 (BNF)
4.3	Citalopram	10mg		1 in AM		Citalopram	✓	Depressive illness/ panic disorder	PIM-I Depression/panic disorders not listed in medical conditions	PIM-I	
4.3	Citalopram	20mg		1 in AM (total 30mg daily)						CNS drug	Chapter 4 (BNF)
4.8	Lamotrigine	100mg		1AM		Lamotrigine	✓	Seizures and bipolar disease	PIM-I Seizures/bipolar disease not listed in medical conditions	PIM-I	
										CNS	Chapter 4 (BNF)
5.1	Cefalexin	250mg		1 at night		Cefalexin (Cefaclor®)	X 250 mg every 8 hours, doubled for severe infection; max. 4 g daily	Infection	PIM-I Infection not listed in medical conditions	PIM-I	
										MAR Error	Dosage error
9.1	Ferrous Fumerate	322mg		1AM		Ferrous Fumarate	✓	Iron-deficiency anaemia	PIM-I Anaemia not listed in medical conditions	PIM-I	
										MAR error	Incorrect spelling of medicine
13.2	Sudocream	125g		Apply to affected areas BD 0800, 2200		Sudocrem	✓	Rash or pressure sores	Self-limiting indication	MAR error	Incorrect spelling of medicine
13.10	Clotrimazole 1%	20g		Apply to affected area 4 x day, daily for duration (9, 12, 1800, 2200)		Clotrimazole	X Apply 2–3 times daily	Fungal infection	PIM-I No infection listed in medical conditions	PIM-I	
										PIM-O	Treatment where a specific duration is recommended in the BNF but it was not clear from the MAR chart how long the medication was being used
A2.5	Thick and Easy	225g		PRN (every day, 9, 12, 1800, 2200)		Thick and Easy™ instant food thickener	✓		Non-medicinal product		

Medicines Data Analysis – ‘Betty’

Medical problems (identified in Care Home record): ‘V limited medical history as no family’. Eczema.

Medication Prior to Admission: Not recorded

Summary of medicines on MAR chart:	Total number of items on MAR chart	3	Number of medicinal products on MAR chart	2	Number of CNS medicines (Chapter 4 of BNF)	1

Previous 1-month MAR chart

	Exact Copy of MAR Chart				**BNF Validation of MAR Chart**				**Analysis of potentially inappropriate prescriptions**	
BNF Chapter	**Medicine**	**Dose**	**MAR Chart Indication**	**MAR Administration**	**Likely Medicine**	**Dose in line with BNF?**	**Likely Indication**	**Appropriate indication identified?**	**Category**	**Further information**
3.4	Fexofenadine Tabs	120mg		0900 Take one in the morning	Fexofenadine Hydrochloride	✓	Chronic idiopathic urticaria	Eczema		
4.3	Sertraline Tabs	50mg		Take half of a tablet in the morning	Sertraline	✓	Depressive illness	PIM-I Depression not listed in medical conditions	PIM-I	
									Anticholinergic	MAT Score 1
									CNS drug	Chapter 4 (BNF)
13.2	Doublebase Gel			Apply when required as directed (applied every morning)	Doublebase Gel	✓	Eczema	✓		

Medicines Data Analysis – ‘Ronald’

Medical problems (identified in Care Home record):
1st stroke 2007. Lost sight in left eye.
Allergies: sodium valproate, codeine phosphate, highly sensitive to benzodiazepines, haloperidol. Stroke 2009. Ischaemic heart disease, pleural aspiration, Left hip problem (old fracture), cellulitis, DVT, Vascular dementia

Medication Prior to Admission: Not recorded

Summary of medicines on MAR chart:	Total number of items on MAR chart	12	Number of medicinal products on MAR chart	11	Number of CNS medicines (Chapter 4 of BNF)	3

Previous 1-month MAR chart

	Exact Copy of MAR Chart				**BNF Validation of MAR Chart**				**Analysis of potentially inappropriate prescriptions**	
BNF Chapter	**Medicine**	**Dose**	**MAR Chart Indication**	**MAR Administration**	**Likely Medicine**	**Dose in line with BNF?**	**Likely Indication**	**Appropriate indication identified?**	**Category**	**Further information**
1.3	Lansoprazole Orodispersible Tablets	15mg		1 in AM	Lansoprazole	✓	Reflux oesophagitis Ulcer	PIM-I No gastrointestinal indication listed in medical conditions	PIM-I	
1.6	Lactulose Solution	15ml		Twice a day	Lactulose Solution	✓	Constipation	Self-limiting indication		
2.8	Dabigatran etexilate Capsules	110mg		1 in AM 1 in night	Dabigatran etexilate	✓	Treatment of DVT (no date given)	Indication present	PIM-O	Used to treat a DVT would normally be expected to be prescribed for 6 months
2.12	Simvastatin Suspension	40mg/ 5ml SF		One spoonful at night	Simvastatin	✓	Prevention of CV events	Indication present	PIM-P	Secondary prevention of cardiovascular disease

4.7	Paracetamol	500mg PRN		2 x 500mg tabs QDS		Paracetamol	✓	Pain	Self-limiting indication		
4.7	Butrans Patch	10mcg/ hr		1 patch every seven days as directed		Buprenorphine	✓	Pain	PIM-I Pain not listed in medical conditions	PIM-I	
										PIM-O	Identified from the BNF as generally not recommended because may antagonise the analgesic effect of previously administered opiates.
										CNS drug	Chapter 4 (BNF)
4.11	Memantine	10mg/ 1ml oral solution SF		Take 1ml (2 pumps) in AM		Memantine Hydrochoride	✓	Moderate to severe dementia in Alzheimer's disease	Indication present. Dementia listed as a medical condition	CNS drug	Chapter 4 (BNF)
6.4	Finasteride Tablets	5mg		1 in AM		Finasteride	✓	Benign prostatic hyperplasia	PIM-I. Prostatic hyperplasia not listed in medical conditions	PIM-I	
6.6	Alendronic Acid Tablets	70mg		1 once a week in AM on Thursday		Alendronic Acid	✓	Secondary prevention of fractures	Indication present. Old hip fracture listed in medical conditions	PIM-P	Prevention of hip fractures.
										PIM-O	Unsuitable for prescribing in patients with swallowing problems
9.5	Adcal-D3 tablets chewable lemon			Take 2 in evening		Calcium Carbonate	✓	Prevention of fractures	Indication present. Old hip fracture listed in medical conditions	PIM-P	Prevention of hip fractures.
										PIM-O	Unsuitable for prescribing in patients with swallowing problems
13.2	Generic Dermol Cream	100mg		Apply to affected		Dermol Cream	✓	Dry/ pruritic skin conditions	Self-limiting indication		
9	Ensure Liquid	250ml		One pack daily		Ensure Liquid	✓	Nutritional supplement	Non-medicinal product	PIM-ONS	ONS

Medicines Data Analysis – 'Edwin'

Medical problems (identified in Care Home record):
Orthostatic hypertension, vascular dementia, Parkinson's, depression.
Allergies: Penicillin
Doesn't take medicines frequently due to profound cognitive impairment and confusion. Therefore has covert medication. DNR

Medication Prior to Admission: Not recorded

Summary of medicines on MAR chart:	Total number of items on MAR chart	16	Number of medicinal products on MAR chart	15	Number of CNS medicines (Chapter 4 of BNF)	4

***co-beneldopa = 1 item, 1 medicinal product, 1 CNS medicine**

Previous 1-month MAR chart

	Exact Copy of MAR Chart				**BNF Validation of MAR Chart**				**Analysis of potentially inappropriate prescriptions**	
BNF Chapter	**Medicine**	**Dose**	**MAR Chart Indication**	**MAR Administration**	**Likely Medicine**	**Dose in line with BNF?**	**Likely Indication**	**Appropriate indication identified?**	**Category**	**Further information**
1.4	Codeine phosphate	15mg PRN		None supplied	Codeine Phosphate	✓	Acute diarrhoea or pain	Self-limiting condition	PIM-O	Treatments for diarrhoea and constipation prescribed concurrently
									Anticholinergic	MAT Score 1
1.6	Lactulose Solution	3.1-3.7g/5	Constipation	Supplied one day, BD	Lactulose Solution	✓	Constipation	Self-limiting indication	STOPP Section A3	Duplicate drug class prescription

		ml PRN									
1.6	Lactugal Solution	5ml PRN		3 x 5ml spoonful BD		Lactulose Solution	✓	Constipation	Self-limiting indication	MAR Error	Therapeutic duplication -2 products containing lactulose
4.6	Betahistine	16mg		1 in AM 1 in Lunch 1 in PM		Betahistine Dihydrochloride	✓	Menieres Syndrome.	PIM-I Menieres Syndrome not listed in medical conditions	PIM-I CNS	Chapter 4 (BNF)
4.7	Paracetamol	500mg PRN	Pain in back, pain in left arm	1 or 2 up to QDS		Paracetamol	✓	Pain	Self-limiting indication	CNS	Chapter 4 (BNF)
4.9	Rasagiline	1mg				Rasagiline	✓	Parkinson’s Disease	Indication present	CNS	Chapter 4 (BNF)
4.9	Madopar	50mg/ 200mg		250mg: 1 at 0700, 1 at 1100, 1 at 1400, 1 at 1700		Co-Beneldopa	✓	Parkinson’s Disease	Indication present	CNS	Chapter 4 (BNF)
4.9	Co-Beneldopa	25mg/ 100mg		1 at night							
6.3	Fludrocortisone	100mcg	Falls clinic advised	2 AM and 2 evening		Fludrocortisone Acetate	✓	Orthostatic hypotension (unlicensed)	Unlicensed indication		
6.1.5 unlic-ensed	Midodrine	5mg		2 tabs, TDS		Midodrine Hydrochloride	✓	Orthostatic hypotension	Unlicensed indication		
9.1	Ferrous sulphate	325mg		None supplied		Ferrograd (Ferrous Sulfate 325mg)	✓	Iron deficiency anaemia	PIM-I Anaemia not listed in medical conditions	PIM-I PIM-O	BNF lists Ferrograd® as a product less suitable for prescribing
9.1.2	Folic Acid	5mg		None given		Folic Acid	✓	Anaemia	PIM-I Anaemia not listed in medical conditions	PIM-I	
9.6	Colecalciferol Vit D	10,000 unit		1 in AM on Monday		Colecalciferol	✓	Osteoporosis	PIM-I Osteoporosis not listed in medical conditions	PIM-I	
13.2	Doublebase Gel Pump	500g		4-6 x day		Doublebase Gel Pump	✓	Dry/pruritic skin conditions	Self-limiting indication		
13.5	Silkis ointment	3mcg/g 100g		Apply BD		Calcitriol	✓	Mild to moderate plaque psoriasis	Self-limiting indication		

13.10	Amorolfine medicated nail lacquer	5%	Fungal nail infection	(Applied twice weekly throughout chart– duration unclear)		Amorolfine	✓	Fungal nail infection	PIM-I Infection not listed in medical conditions	PIM-I	
										PIM-O	Treatment where a specific duration is recommended in the BNF but it was not clear from the MAR chart how long the medication was being used
	Ensure plus fibre liquid	200ml		1 pack BD		Ensure Liquid	✓	Nutritional supplement	Non-medicinal product	PIM-ONS	ONS

Medicines Data Analysis – 'Walter'

Medical problems (identified in Care Home record):

Diabetes, arthritis. NKDA. Mental health history of schizophrenia and bipolar disorder (schizoaffective disorder), and frontal lobe dementia.
25/10/10: Sigmoidoscopy NEC diverticulosis and haemorrhoids
05/05: frontal lobe syndrome MRI-frequent psychiatric admissions
02/02: Tension type headache, chronic daily headache
11/02: MI-acute ant-lat with moderate LV function and angiocardiogram: single vessel disease
04/00: Diagnostic laryngoscopy-mod dysplasia ant vocal cords
01/00: Bipolar Affective Disorder Section3 Hyomanic state
2000: Type 2 DM
1994: Diagnostic arthroscopy of knee (R) foreign body
1992: Depressive episode
1983: Fracture (closed) of forearm, lower end NOs R radius
1980: Primary repair of inguinal hernia R
1971: Paranoid schizophrenia admission (later diagnosed as SAD & Hypomania, 1997)

Medication Prior to Admission: Not recorded

Summary of medicines on MAR chart:	Total number of items on MAR chart	17	Number of medicinal products on MAR chart	14	Number of CNS medicines (Chapter 4 of BNF)	6

Previous 1-month MAR chart

	Exact Copy of MAR Chart					**BNF Validation of MAR Chart**				**Analysis of potentially inappropriate prescriptions**	
BNF Chapter	**Medicine**	**Dose**	**MAR Chart Indication**	**MAR Administration**		**Likely Medicine**	**Dose in line with BNF?**	**Likely Indication**	**Appropriate indication identified?**	**Category**	**Further information**
1.6.4	Laxido orange SF oral powder			One to be taken daily		Macrogol Osmotic Laxative	✓	Constipation	Self-limiting indication		

2.2	Furosimide Tablets	40mg		One to be taken in the morning		Furosemide	✓	Heart failure (moderate LV function)	Indication present	MAR error	Incorrect spelling of medicine
										Anticholinergic	MAT Score 1
2.2	Spirinolactone tablets	25mg		One to be taken in the morning		Spironolactone	✓	Moderate to severe heart failure	Indication present	STOPP Section B12	Aldosterone antagonists with concurrent postassium-conserving drugs without monitoring of serum potassium.
										MAR error	Incorrect spelling of medicine
2.5	Ramipril Capsules	2.5mg		One to be taken daily		Ramipril	✓	Heart failure likely because of furosemide and spironolactone	Indication present		
2.9	Clopidogrel	NO DOSE		Take one 75mg tablet daily		Clopidogrel	✓	Prevention of atherothrombotic events	Indication present	PIM-P	Secondary prevention of cardiovascular disease
										PIM-O	Patients with a history of ischaemic events such as myocardial infarction would normally be expected to be prescribed for no more than 12 months
2.12	Simvastatin Tablets	40mg		One to be taken at night		Simvastatin	✓	Prevention of cardiovascular events	Indication present	PIM-P	Secondary prevention of cardiovascular disease
4.1.1	Pizocyclidine tabs	5mg		Take one twice a day		Procyclidine Hydrochloride	✓	Parkinsonism OR drug-induced extrapyramidal symptoms	PIM-I. Parkinsonism OR drug-induced extrapyramidal symptoms not listed in medical conditions	PIM-I	
										STOPP Section M1	Concomitant use of anticholinergic
										STOPP Section D7	Used to treat extra-pyramidal side-effects of neuroleptic medications (risk of anticholinergic toxicity)
										CNS drug	Chapter 4 (BNF)

										Anticholinergic	MAT Score 3
										MAR error	Incorrect spelling of medicine
4.2	Depakote Tablets	250mg		One taken twice a day		Valproic Acid	✓	Mania in bipolar disorder	Indication present	Anticholinergic	MAT Score 1
										CNS drug	Chapter 4 (BNF)
		500mg								STOPP Section M1	Concomitant use of anticholinergic
4.2	Risperidone Tablets	2mg		One to be taken twice a day		Risperidone	✓	Psychosis	Indication present	STOPP Section K2 and M1	Neuroleptic drugs (may cause gait dyspraxia, Parkinsonism), and Concomitant use of anticholinergic
										Anticholinergic	MAT Score 1
										CNS drug	Chapter 4 (BNF)
4.7	Paracetamol tablets	500mg		Two to be taken four times a day when required (9 am doses given daily)		Paracetamol	✓	Pain	Self-limiting indication	CNS drug	Chapter 4 (BNF)
4.8	Pregabalin Caps	75mg		One to be taken at night		Pregabalin	✓	Epilepsy? Neuropathic pain?	PIM-I Epilepsy nor neuropathic pain listed in medical conditions	PIM-I	
										CNS drug	Chapter 4 (BNF)
4.8	Carbamazepine	200mg		One to be taken twice a day		Carbamazepine	✓	Bipolar disease or neuropathic pain	Indication present	Anticholinergic	MAT Score 2
										STOPP Section M1	Concomitant use of anticholinergic
										CNS drug	Chapter 4 (BNF)
6.1	Novomix 30 penfill insulin	20 units am, 10 units pm		(Given as directed)		Insulin Aspart (Novomix®)	✓	Diabetes Mellitus	Indication present		
7.4	Tamsulosin hCl mr capsules	400 mcg		One taken daily		Tamsulosin Hydrochloride	✓	Benign prostatic hyperplasia	PIM-I Benign prostatic hyperplasia not listed in medical conditions	PIM-I	
9.1.2	Folic Acid Tablets	5mg		One to be taken		Folic Acid	✓	Anaemia	PIM-I Anaemia not	PIM-I	

				daily					listed in medical conditions		
A5	Softelix lancets	0.4mm /128g		Use as directed		Softclix Lancets	✓	Diabetes Mellitus	Non-medicinal product		
	Comfort point pen needles	8mm /31g		Use as directed					Non-medicinal product		
	Aviva testing strips for routine [*blood glucose?] use weekly use but more frequently when blood sugar control is poor			None signed for		Aviva Testing strips	✓	Diabetes Mellitus	Non-medicinal product		

Medicines Data Analysis – 'Donald'

Medical problems (identified in Care Home record): Allergic to nuts, alcohol and adhesive.

Medication Prior to Admission:

Carbamazepine 300mg BD	Co-Dydramol TT QDS	Lactulose 15-20mls BD	Thiamine BD
Haloperidol 2mg BD	Furosemide OD	Quetiapine 12.5mg BD	

Medication Prior to Admission: Not recorded

Summary of medicines on MAR chart:	Total number of items on MAR chart	20	Number of medicinal products on MAR chart	13	Number of CNS medicines (Chapter 4 of BNF)	7

Previous 1-month MAR chart

	Exact Copy of MAR Chart					**BNF Validation of MAR Chart**				**Analysis of potentially inappropriate prescriptions**	
BNF Chapter	**Medicine**	**Dose**	**MAR Chart Indication**	**MAR Administration**		**Likely Medicine**	**Dose in line with BNF?**	**Likely Indication**	**Appropriate indication identified?**	**Category**	**Further information**
1.3	Omeprazole g-r capsules (56)	20mg		One twice daily (@8am and		Omeprazole	✓	Prevention of NSAID-induced GI symptoms	PIM-I NSAID-induced GI symptoms not	PIM-I	

				5pm daily) (from16/10/14)					listed in medical conditions		
1.6.4	20 Laxido orange oral powder s-f orange (sachet(s)).			Take 1 daily (@8am daily, from 10/8/11)		Macrogol Osmotic Laxative	✓	Constipation	Self-limiting indication		
2.2	Furosemide tablets (28)	40mg		Take one each morning (8am daily)		Furosemide	✓	Oedema or liver failure	PIM-I Oedema or liver failure not listed in medical conditions	PIM-I	
										STOPP Section B7	Loop diuretic for dependent ankle oedema with clinical, biochemical evidence or radiological evidence of heart failure, liver failure, nephrotic syndrome or renal failure (leg elevation and / or compression hosiery usually more appropriate).
										Anticholinergic	MAT Score 1
3.4	Piriton tabs (112)	4mg		1 x 4d PRN (from 22.12.14)		Chlorphenamine Maleate (Piriton®)	✓	Symptomatic allergy relief	Self-limiting indication	STOPP Section D14	First generation antihistamines. Safer, less toxic antihistamines are now widely available)
										Anticholinergic	MAT Score 3
										STOPP Section M1	Concomitant use of anticholinergic
4.1	Lorazepam tablets (28)	1mg		1 tablet daily (@5pm) (from 11/7/13)		Lorazepam	✓	Anxiety or insomnia	PIM-I Anxiety or insomnia not listed in medical conditions	PIM-I	
										STOPP Sections D5 and K1	Benzodiazepines for ≥ 4 weeks (Prescribed since 2013 and

											administered daily), Benzodiazepines (sedative, may cause reduced sensorium, impair balance)
										Anticholinergic	MAT Score 1
										STOPP Section M1	Concomitant use of anticholinergic
										CNS Drug	Chapter 4 (BNF)
4.1	Zopiclone tablets (28)	7.5mg		One at night (@10 pm daily, from 14/12/09)		Zopiclone	✓	Insomnia	PIM-I Insomnia not listed in medical conditions	PIM-I	
										STOPP Section K4	Hypnotic Z drugs
										CNS Drug	Chapter 4 (BNF)
4.2	Haloperidol oral solution sugar free 10mg/5ml			Take 1ml at 8am and 1ml at 12noon and 1ml at 17h (all daily, from 3/2/14)		Haloperidol	✓	Schizophrenia, psychoses	Unlicensed indication (BtC)		Only to be used for BPSD if symptoms are severe and all other NPI failed. Lots of incidents of BtC but no evidence of using NPIs observed
										STOPP Sections K2 and M1	Neuroleptic drugs (may cause gait dyspraxia, Parkinsonism), Concomitant use of anticholinergic
										Anticholinergic	MAT Score 1
										CNS Drug	Chapter 4 (BNF)
4.3	Mirtazapine orodispersible tabs	45mg		1 at night (10pm every day) (from 10/6/13)		Mirtazapine	✓	Major depression	PIM-I Major depression not listed in medical conditions	PIM-I	
										CNS	Chapter 4 (BNF)
4.6	Domperidone tablets (28)	10mg		One to be taken three times		Domperidone	✓	Nausea relief	PIM-I Nausea not listed in medical	PIM-I	

				daily PRN Take 30-60 minutes before food (@8,12 and 5 daily) (from 31/12/14)					conditions	PIM-O	Should be used at the lowest effective dose for the shortest duration (normally should not exceed one month)
										CNS	Chapter 4 (BNF)
4.7	Co-codamol tablets (200)	8mg + 500mg	For pain	One or two tablets four times a day for pain. Do not take more than two at any one time or more than 8 in 24 hours (@8,12,5&10 every day) (from 2/9/14)		Co-codamol	✓	Pain	Self-limiting indication	Anticholinergic	MAT Score 1
										STOPP Section M1	Concomitant use of anticholinergic
4.8	Carbamazepine (84 tabs)	200mg		One to be taken at 8am, noon and 10pm (from 11/6/12)		Carbamazepine	✓	Prophylaxis of bipolar disorder	PIM-I Bipolar disorder not listed in medical conditions	PIM-I	
										Anticholinergic	MAT Score 2
										STOPP Section M1	Concomitant use of anticholinergic
										CNS drug	Chapter 4 (BNF)
9.6.2	Thiamine tablets (56)	100mg		One twice a day (@8am and 5pm daily) (from 2/11/09)		Thiamine	✓	Alcoholism – thiamine deficiency	Indication present		
10.1	Naproxen tabs (28)	250mg		1 at 12 noon. Take with or just after food, or a meal (1@12 every day) (from 10/6/13)		Naproxen	✓	Acute musculoskeletal disorder OR gout	PIM-I Acute musculoskeletal disorder or gout not listed in medical conditions	PIM-I	
										STOPP Section H2	NSAID with established hypertension (risk of exacerbation of hypertension) or heart failure (risk of exacerbation of heart failure.
13.2	Epaderm cream			As directed. None supplied		Epaderm® Cream	✓	Dry skin	Self-limiting indication		

				this cycle (from 16/4/12)							
13.2	E45 (500g)	500g		Apply twice a day @8am (only 8 days, once a day, from 10/6/13)		E45®	✓	Dry skin condition	Self-limiting indication		
A5.2.4	Aquacel ag dressing 10cm x 10cm			As directed. None supplied this cycle (from 21/5/14)		Aquacel®			Non-medicinal product		
A5.8	20 Profore #1 layer padding 10cm x 3.5cm			As directed. No signatures, from 25/9/14)		Profore®			Non-medicinal product		
A5.8	Profore Latex-free layer 1 natural orthopaedic padding 10cm x 3.5cm			As directed. None supplied this cycle (from 14/4/14)		Profore®			Non-medicinal product		
A5.7.1	1 Dressit sterile dressing pack with M/L gloves as directed			No signatures, from 9/4/14		Dressit®			Non-medicinal product		
A5.8.7	Actico short stretch compression bandage 10cm x 6cm (dressing(s)) as directed			No signatures, from 22/12/14		Actico®			Non-medicinal product		

Medicines Data Analysis – ‘Joan’

Medical problems (identified in Care Home record):
Advanced stages of early onset dementia. Epilepsy (chair bound @ 27/6/14)

Medication Prior to Admission:

Trazodone	Diazepam	Lepripctone (Spironolactone?)	Lactulose	Senna
Lorazepam	Clonazepam	Lopiclone (Zopiclone?)	Paracetamol	Procyclidine

Medication Prior to Admission: Not recorded

Summary of medicines on MAR chart:	Total number of items on MAR chart	5	Number of medicinal products on MAR chart	5	Number of CNS medicines (Chapter 4 of BNF)	3

Previous 1-month MAR Chart

	Exact Copy of MAR Chart					BNF Validation of MAR Chart				Analysis of potentially inappropriate prescriptions	
BNF Chapter	**Medicine**	**Dose**	**MAR Chart Indication**	**MAR Administration**		**Likely Medicine**	**Dose in line with BNF?**	**Likely Indication**	**Appropriate indication identified?**	**Category**	**Further information**
1.6.4	Laxido Orange oral powder sugar free orange sachet(s)	Take 1 when required		(taken at 12 noon daily) (28)		Macrogol Osmotic Laxative	✓	Constipation	Self-limiting indication		
4.1	Diazepam	2mg		1 at 6pm (29)		Diazepam	✓	Anxiety OR insomnia?	PIM-I Anxiety or insomnia not listed in	PIM-I	

									medical conditions	STOPP Sections D5 and K1	Benzodiazepines for ≥ 4 weeks, Benzodiazepines (sedative, may cause reduced sensorium, impair balance)
										Anticholinergic	MAT Score 1
										CNS drug	Chapter 4 (BNF)
4.3	120ml Trazodone Oral Solution Sugar free 50mg/5ml	Take 2 5ml spoon-fuls		6pm (16/4/13)		Trazodone Hydrochloride	✓	Depression OR anxiety	PIM-I Depression or anxiety not listed in medical conditions	PIM-I	
										Anticholinergic	MAT Score 1
										CNS drug	Chapter 4 (BNF)
4.8	Sodium Valproate Modified Release Tablet	200mg		1 twice a day (8am and 5pm) Started 24/3/09 (56)		Sodium Valproate		Epilepsy	Indication present	CNS drug	Chapter 4 (BNF)
	Resource thicken up clear thickening powder			As directed (None supplied this cycle)		Resource® Thicken Up™	✓		Non-medicinal product		

Medicines Data Analysis – ‘Myrtle’

Medical problems (identified in Care Home record): Previous medicines: amisulpride, losartan, felodipine, simvastatin. NKDA.

Medication Prior to Admission:

Amisulpride	Felodipine
Losartan	Simvastatin

Summary of medicines on MAR chart:	Total number of items on MAR chart	3	Number of medicinal products on MAR chart	3	Number of CNS medicines (Chapter 4 of BNF)	0

Previous 1-month MAR Chart

	Exact Copy of MAR Chart					**BNF Validation of MAR Chart**				**Analysis of potentially inappropriate prescriptions**	
BNF Chapter	**Medicine**	**Dose**	**MAR Chart Indication**	**MAR Administration**		**Likely Medicine**	**Dose in line with BNF?**	**Likely Indication**	**Appropriate indication identified?**	**Category**	**Further information**
2.5.5.2	Losartan	50mg		Once per day		Losartan Potassium	✓	Hypertension	PIM-I Hypertension not listed in medical conditions	PIM-I	
										PIM-P	Secondary prevention of cardiovascular disease. Hypertension is a risk factor for CV disease rather than a disease itself

2.6.2	Felodipine	2.5mg		Once in the morning		Felodipine	✓	Hypertension, prophylaxis of angina	PIM-I Hypertension not listed in medical conditions	PIM-I	
										PIM-P	Secondary prevention of cardiovascular disease. Hypertension is a risk factor for CV disease rather than a disease itself
2.12	Simvastatin	20mg		Once at night		Simvastatin	✓	Prevention of cardiovascular events	PIM-I Hypertension not listed in medical conditions	PIM-I	
										PIM-P	Secondary prevention of cardiovascular disease. Hypertension is a risk factor for CV disease rather than a disease itself

Medicines Data Analysis – 'Vera'

Medical problems (identified in Care Home record):
History of falls-fractured neck of femur (2010) Hypertension, weight loss. Has 'Alzheimer's dementia', depression, challenging behaviour and moderate to dense cataract (2012).

Medication Prior to Admission: Not recorded

Summary of medicines on MAR chart:	Total number of items on MAR chart	4	Number of medicinal products on MAR chart	4	Number of CNS medicines (Chapter 4 of BNF)	3

Previous 1-month MAR Chart

	Exact Copy of MAR Chart				**BNF Validation of MAR Chart**				**Analysis of potentially inappropriate prescriptions**	
BNF Chapter	**Medicine**	**Dose**	**MAR Chart Indication**	**MAR Administration**	**Likely Medicine**	**Dose in line with BNF?**	**Likely Indication**	**Appropriate indication identified?**	**Category**	**Further information**
1.6	Senna syrup	10ml		25/2 - 12 noon 8/3 10am for constipation	Senna	✓	Constipation – prescribed regular opiate (codeine)	Self-limiting indication		
4.3	Trazodone	50mg caps		Take 1 in AM and 1 at night (takes 1 am, 1 pm)	Trazodone Hydrochloride	✓	Anxiety	PIM-I Anxiety not listed in medical conditions	PIM-I	Prescribing pattern suggests it is being used to manage BtC
				One to be taken when in extreme anxious state when required in addition to		✓			Anticholinergic	MAT Score 1

				regular dose (takes OD for 3d, BD (N.T) for 1d, OD for 8d, 3d off, OD for 1d, 4d off, OD for 1d, 6d off.						CNS drug	Chapter 4 (BNF)
4.7	Paracetamol	500mg		Take 2 tabs up to four times daily (takes QDS, daily)		Paracetamol	✓	Mild to moderate pain, pyrexia	Self-limiting indication		
4.7.2	Codeine phosphate	15mg		Take 1 or 2 max. 3 times a day for pain when required. Causes nausea, drowsiness and constipation. (Takes TDS daily)		Codeine Phosphate	✓	Pain	Self-limiting indication	Anticholinergic	MAT Score 1
										STOPP M1	Concomitant use of anticholinergic

Medicines Data Analysis – 'Edna'

Medical problems (identified in Care Home record):
History of hypertension, high cholesterol and arthritis. Currently has hypertension, rheumatoid arthritis, high cholesterol and reduced mobility. DNR.

Medication Prior to Admission: Not recorded

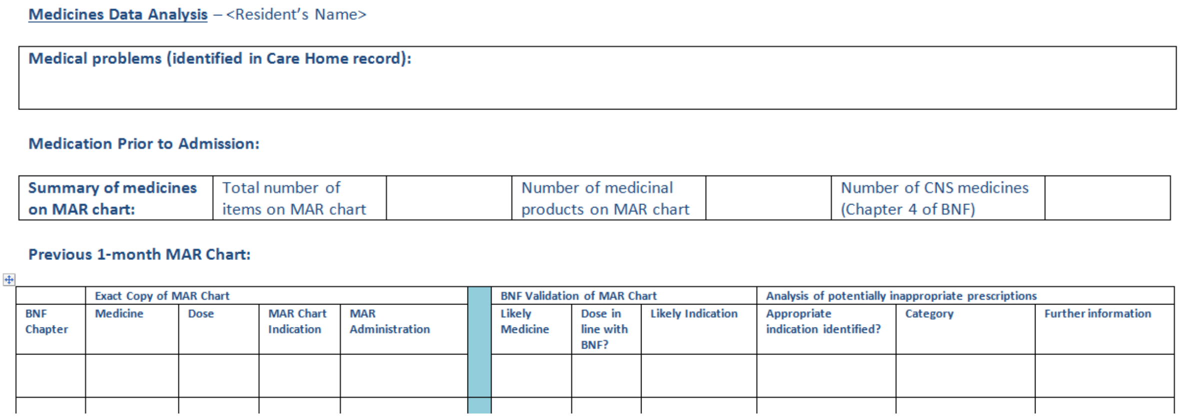
Summary of medicines on MAR chart:	Total number of items on MAR chart	3	Number of medicinal products on MAR chart	3	Number of CNS medicines (Chapter 4 of BNF)	1

Previous 1-month MAR Chart

	Exact Copy of MAR Chart					**BNF Validation of MAR Chart**				**Analysis of potentially inappropriate prescriptions**	
BNF Chapter	**Medicine**	**Dose**	**MAR Chart Indication**	**MAR Administration**		**Likely Medicine**	**Dose in line with BNF?**	**Likely Indication**	**Appropriate indication identified?**	**Category**	**Further information**
1.4	Codeine phosphate	15mg		Take one when required three times a day in 24h. None given		Codeine Phosphate	✓	Pain or diarrhoea	Self-limiting indication	Anticholinergic	MAT Score 1
2.12	Simvastatin Tablets	40mg		Take one at teatime (Takes one at 'T' daily)		Simvastatin	✓	Prevention of cardiovascular events	Indication present	PIM-P	Secondary prevention of cardiovascular disease
4.7	Paracetamol	500mg		Take 2 tabs up to four times daily (takes 2 QDS, daily)		Paracetamol	✓	Mild to moderate pain	Self-limiting indication		

Appendix 14 – Medicines Analysis Tool (Phase Four)

This Medicines Analysis Tool was developed following analysis of the medicines data by CM and pharmacist supervisors (SG, JK), formalised for use by SG, applied to the medicines data by CM and checked by SG.



Medicines Data Analysis – <Resident's Name>

Medical problems (identified in Care Home record):

Medication Prior to Admission:

Summary of medicines on MAR chart:	Total number of items on MAR chart		Number of medicinal products on MAR chart		Number of CNS medicines (Chapter 4 of BNF)	

Previous 1-month MAR Chart:

	Exact Copy of MAR Chart					BNF Validation of MAR Chart			Analysis of potentially inappropriate prescriptions		
BNF Chapter	Medicine	Dose	MAR Chart Indication	MAR Administration		Likely Medicine	Dose in line with BNF?	Likely Indication	Appropriate indication identified?	Category	Further information

Step 1 – Add resident's name, medical problems (as identified in Care Home record), record of medication prior to admission

Step 2 – List medicines obtained from resident's MAR chart and record the following

- Medicine name
- Medicine dose
- Indication for medication as specified on the MAR chart (MAR Chart Indication)
- Administration instructions as specified on the MAR chart (MAR Administration) – This included details of any medication that had not been administered.

Step 3 – Complete summary of medicines on MAR chart

- Total number of items on MAR chart
- Number of medicinal products. This includes medicines listed in chapters 1 – 14 of the BNF but excludes dietary supplements, dressings, lancets, needles and blood testing strips used in the management of diabetes.

Step 4 – Use BNF (ref) used to record

- BNF section
- Likely medication (where a drug name wasn't clear the likely medication was determined, with input from pharmacist (SG) as appropriate)

- Likely indication – The BNF list of indications was compared with the resident's list of medical conditions to determine the likely indication for the medication.

Step 5 – Identify **Potentially Inappropriate Medication (PIM)** *(see below for further detail)*

- Potentially Inappropriate Medication – Indication (PIM-I)
- STOPP criteria (Ref O'Mahony, 2014)
- Preventative medicine
- Oral Nutritional Supplements (ONS)
- Other

Potentially Inappropriate Medication – Indication (PIM-I)

STOPP(ref) has identified any drug prescribed without an evidence-based indication clinical indication as potentially inappropriate. The present study found only very limited medical information in the Care Home records and did not involve data collection from other sources, for example, GP records. However, the review of MAR charts suggested potentially inappropriate medication because of a lack indication.

For each medicinal product on the MAR chart, complete the "appropriate indication identified" box using the table below

Category	**Description**	**Examples**
Indication present	Indication for medication present in resident's clinical record	Lorazepam for anxiety Sertraline for depression Trimethoprim for Urinary Tract Infection
Self-limiting indication	Medicines available without prescription for common, self-limiting conditions that a patient living at home may purchase for themselves (paracetamol, oral laxatives, barrier creams, tear substitute eye drops)	Paracetamol Laxatives (lactulose, macrogol, senna) Barrier creams (Sudocrem, Emollients (Balneum, Doublebase®, Dermol®, E45®, Epaderm®) Tear substitute eye drops (Celluvisc®)
Unlicensed indication	Suspected unlicensed indication for a medication where an indication for the medication is present in the resident's clinical record	Midodrine and fludrocortisone for orthostatic hypotension
PIM - I	**Potential inappropriate medication because no indication identified**	

Non-medicinal product	Dietary supplements, dressings, lancets, needles and blood testing strips used in the management of diabetes.	

Potentially Inappropriate Medication – STOPP (PIM-STOPP)

Apply the following STOPP criteria (0’Mahony, 2014, Supplementary data, accessed on-line 24/7/2015)

Code	System	Description
B7	Cardiovascular System	Loop diuretic for dependent ankle oedema with clinical, biochemical evidence or radiological evidence of heart failure, liver failure, nephrotic syndrome or renal failure (leg elevation and / or compression hosiery usually more appropriate).
B12		Aldosterone antagonists (e.g. spironolactone, eplerenone) with concurrent postassium-conserving drugs (e.g. ACEIs, ARBs, amiloride, triamterene) without monitoring of serum potassium (risk of dangerous hyperkalaemia i.e. . 6.0 mmmol/L – serum K should be monitored regularly, i.e. at least every 6 months).
D5	Central Nervous System	Benzodiazepines for ≥ 4 weeks (no indication for longer treatment; risk of prolonged sedation, confusion, impaired balance, falls road traffic accidents; all benzodiazepines should be withdrawn gradually if taken for > 2 weeks as there is a risk of causing a benzodiazepine withdrawal syndrome if stopped abruptly).
D7		Anticholinergics / antimuscarinics to treat extra-pyramidal side-effects of neuroleptic medications (risk of anticholinergic toxicity)
D9		Neuroleptic antipsychotic in patients with behavioural and psychological symptoms of dementia (BPSD) unless symptoms are severe and other treatments have failed (increased risk of stroke)
D14		First generation antihistamines (safer, less toxic antihistamines now widely available)
H2	Musculoskeletal System	NSAID with established hypertension (risk of exacerbation of hypertension) or heart failure (risk of exacerbation of heart failure
I1	Urogenital System	Antimuscarinic drugs for overactive bladder syndrome with concurrent dementia or chronic cognitive impairment (risk of increased confusion, agitation) or narrow-angle glaucoma (risk of acute exacerbation of glaucoma), or chronic prostatism (risk of urinary retention)
K1	Drugs that predictably	Benzodiazepines (sedative, may cause reduced sensorium,

	increase the risk of falls in older people	impair balance)
K2		Neuroleptic drugs (may cause gait dyspraxia, Parkinsonism)
K4		Hypnotic z-drugs (e.g. zopiclone, zolpidem, zalepon) (may cause protracted daytime sedation, ataxia)
M1	Antimuscarinic / anticholinergic drug burden	Concomitant use of two or more drugs with antimuscarinic / anticholinergic properties (e.g. bladder antispasmodics, intestinal antispasmodics, tricyclic antidepressants, first generation antihistamines) (risk of increased antimuscarinic/ anticholinergic toxicity) **Note:** See Anticholinergic Score criteria below

Note: The lack of definitive clinical information about each resident limits the application of the STOPP criteria. Therefore, it will be necessary to make some assumptions when undertaking this analysis. Refer to pharmacist (SG, JK) for guidance.

Potentially Inappropriate Medication – Preventative medicines prescribed (PIM-P)

Identify where patients are prescribed medication where the purpose is to prevent an event occurring in the future rather than treating a current medical condition

PIM-P	Description
Secondary prevention of cardiovascular disease	Statin e.g. simvastatin Hypertension e.g. losartan, felodipine Antiplatelet e.g. aspirin, clopidogrel
Prevention of hip fractures	Alendronic acid / calcium and vitamin D

Potentially Inappropriate Medication – Oral Nutritional Supplements (PIM-ONS)

Identify any patients prescribed ONS as NHS (Prescqipp ref) has identified that Care Homes should provide adequate nutrition for their residents and should not use ONS as substitutes for the provision of food.

Potentially Inappropriate Medication – Other (PIM-O)

Identify other issues from BNF review. The following examples have been identified from preliminary work:

◪ Preparation considered by Joint Formulary Committee (BNF ref) to be less suitable for prescribing.

Buprenorphine patches identified from the BNF(Ref) as generally not recommended because may antagonise the analgesic effect of previously administered opiates.

Alendronic acid identified as unsuitable for prescribing in a patient with swallowing difficulties. BNF(ref) counselling instruction – "Tablets should be swallowed whole with plenty of water while sitting or standing; to be taken on an empty stomach at least 30 minutes before breakfast (or another oral medication); patients should stand or sit upright for at least 30 minutes after taking the tablet.

Treatments for diarrhoea and constipation prescribed concurrently.

Treatment where a specific duration is recommended in the BNF but it was not clear from the MAR chart how long the medication was being used (or where it was clear that the recommended duration had been exceeded). For example,

- dabigatran used to treat a DVT would normally be expected to be prescribed for 6 months
- clopidogrel used to prevent atherothrombotic events in patients with a history of ischaemic events such as myocardial infarction would normally be expected to be prescribed for no more than 12 months
- amorolfine used to treat a nail infection would normally be expected to be prescribed for 6 months (finger nail infections) or 9 – 12 months (toe nail infections)
- domperidone used to treat nausea and vomiting should be used at the lowest effective dose for the shortest duration (normally should not exceed one month)

Step 6 – Calculate **Anticholinergic score**

Calculate anticholinergic scores using the **Anticholinergic Cognitive Burden (ACB) score** (Ref Boustani et al, 2008) with reference to the Anticholinergic Drug Scale (ADS) (Ref Carnahan et al, 2006) as specified.

Note: Boustani et al promoted the use of the Anticholinergic Cognitive Burden (ACB) scoring which has been widely adopted for use in practice. This list contains some anomalies whereby not all drugs from a similar class are listed and some drugs with known anticholinergic activity are missing. The ADS, which was used in the development of the ACB scoring, provides a more extensive list of drugs with 4 levels of anticholinergic drugs (level 3 approximates to an ACB score of 3, level 2 approximates to an ACB score of 2, level 1 approximates to an ACB score of 1 and level 0 denotes no anticholinergic activity).

Use the following ACB scores (Ref Boustani et al, 2008)

ACB score = **1**	ACB score = **2**	ACB score = **3**
codeine diazepam furosemide haloperidol risperidone trazodone	carbamazepine	chlorphenamine procyclidine

Additionally, use the following scores

Drug	**Score Allocated**	**Explanation**
Solifenacin	3	Not included on ACB or ADS but BNF (Ref) lists solifenacin as a newer anticholinergic drug similar to oxybutynin and tolerodine which have a ACB score of 3
Lorazepam	1	Lorazepam is included as a level 1 anticholinergic drug in ADS. Diazepam (also a benzodiazepine) has an ACB score of 1 and is listed as a level 1 anticholinergic drug in ADS.
Sertraline	1	Sertraline is included as a level 1 anticholinergic drug in ADS. Paroxetine (an SSRI which) has an ACB score of 1 and is listed as a level 1 anticholinergic drug in ADS.

The following drugs were not allocated an anticholinergic score

Mirtazepine – not listed in ABC and is a level 0 anticholinergic drug in ADS. The SPC (Ref mirtazapine SPC) states mirtazapine has "practically no anticholinergic activity."

Citalopram – unlike paroxetine (another SSRI, ABC score of 3, level 1 ADS), citalopram (level 0, ADS, SPC [ref] states citalopram has "no affinity or very low for muscarine cholinergic receptors) Therefore, citalopram was not allocated an anticholinergic score.

Ramipril – unlike captopril (another ACE inhibitor, ABC score of 1, level 1 ADS) ramipril is not listed in the ACB score and was included at level 0 of ADS. Therefore, ramipril was not given an anticholinergic score.

Step 7 – Identify any **MAR chart errors**

Category	**Description**	**Examples**
Drug name spelt incorrectly	Name on MAR chart does not match spelling in BNF	Phenaymethylpeniciles believed to be phenoxymethlypenicillin
Incorrect dose stated	Dose specified on MAR chart differs to that stated in the BNF	Tamsulosin MR 40 mcg stated on MAR chart, BNF product tamsulosin MR 400 micrograms Clotrimazole cream 4 times a day on MAR chart, BNF dose 2 – 3 times a day
Therapeutic duplication	Two or more products containing the same drug listed on the MAR chart	Lactulose 5 mL BD (supplied one day) and Lactugal (lactulose) 3 x 5 mL BD
PRN – no instructions	No instructions provided for PRN medication	"Codeine phosphate 15 mg PRN" – no indication of what it is taken for e.g. diarrhoea / pain and no indication of frequency provided
Medication (regular) not given	Where a medication has been written on the MAR chart to be given regularly but signatures denoting administration are not present.	

July 2015

SG / CM

Appendix 15 – Interview schedule (Phase Five)

Relatives Interview

Hello and thank you all for coming today. My name is Charlotte and I am a PhD student at the Medway School of Pharmacy: you may have seen me working around [NAME OF CARE HOME]. Before we begin, it would be great if I could mention a couple of things:

Firstly, I will be recording the interview because I don't want to miss any of your comments, but don't worry, everything you say will be anonymised. Just to remind you, the data collected including the recording will be stored securely and kept for one year after the study has ended.

Secondly, I want to really explore your opinions on challenging behaviours today, but please only talk about what you're comfortable with. If you are not happy, don't forget that you are free to stop the interview at any time.

Introduction:

So, let's start. Can I check that you are happy for me to turn the recorder on?

Scene Setting (Grand Tour):

If you are willing, it would be lovely if you could first of all share your stories by telling me your own experiences of living with your relative/friend and your shared dementia journey.

Question: Challenging Behaviours:

My study looks at something we call 'challenging behaviours' in people with dementia. The term 'challenging behaviour' is an umbrella term that includes unusual behaviours like shouting, wandering, biting, agitation and waking at night. In a nutshell, it describes any behaviour by people that is deemed to be dangerous or antisocial.

Can you tell me your opinions on the use of the term 'challenging behaviour', and what challenging behaviour means to you? (What are your experiences of the behaviours we have talked about?)

Key Questions:

How did you feel about these behaviours before you came to this care home?

How do you feel about these behaviours now you relative/friend is living at [CARE HOME NAME]?

Other studies suggest that some care home staff members think that occasionally relatives can be a barrier to being able to care for their residents, because of differing opinions on how best to look after them. How do you feel about this?

Ending Questions:

Of all the issues discussed today, which is the most important to you?

Hopefully, I have explored your opinions and experiences on the care given to your relatives/friends at [CARE HOME NAME]. From the issues we have talked about, can you think of anything else of importance, or anything that I have forgotten?

Conclusion:

Is there anything you would like to add?

Finally, thank you so much for your time today.