

**A mixed methods exploration into the
management of behavioural and
psychological symptoms of dementia in
care homes: care approaches, strategies
and psychotropic medications**

Tamara Backhouse

A thesis submitted in fulfilment of the
requirements for the degree of Doctor of
Philosophy

University of East Anglia
Faculty of Medicine and Health Sciences
January 2014

Abstract

The management of behavioural and psychological symptoms of dementia (BPSD) has gained media and policy attention recently. Antipsychotic medications have been used for these behaviours. Due to the potential risks associated with these medications the Department of Health in England has called for a reduction in their use for people with dementia. Non-pharmacological interventions have been recommended as safer alternatives. The aim of this study was to explore the strategies used in care homes to manage behavioural and psychological symptoms of dementia.

The study used a mixed methods, sequential, two phase design. A postal survey of 747 care homes was conducted. The response rate for the survey was 40% (n=299). This directed purposive sampling for four in-depth case studies in care homes, which included: interviews with 40 care home staff, 384 hours of participant observations, and the mapping of 22 residents' psychotropic medication administration records.

Multiple implicit and explicit care strategies, non-pharmacological interventions, and psychotropic medications were used concurrently in care homes. Twelve percent of care home residents were reported to be prescribed at least one antipsychotic medication. Formal non-pharmacological interventions were predominantly used, and viewed, by staff as activities for all residents and not targeted at the management of behaviours. The risks and impacts of behaviours posed challenges for care staff. Person-centred care was difficult to provide consistently.

This thesis provides an important examination of the strategies that care workers have adopted, developed and implemented to manage behavioural and psychological symptoms of dementia in care homes. The findings portray a gap between rhetoric and practice, with implicit care strategies (some questionable) and perceived usual care approaches employed more than formal non-pharmacological interventions. A theoretical contribution is made by problematising the delivery of person-centred care in communal settings where care workers must constantly negotiate competing demands, risks and organisational constraints.

Contents	Page
Abstract	2
List of Tables	8
List of Figures	8
Table of Abbreviations	9
Acknowledgements	10
Chapter 1: Introduction	11
The increase in dementia and changes in care homes	11
The management of BPSD	13
The knowledge gap: Care home strategies	14
Research questions	15
Methodology and methods: The research approach and design	17
Terminology	18
Personal influence on the study	19
Thesis outline	20
Chapter 2: The management of BPSD in care homes – A scoping review	23
Introduction	23
Definition and terms	23
- <i>Dementia</i>	23
- <i>The term ‘BPSD’</i>	24
- <i>The term ‘management’</i>	27
Aim for the literature review	28
Literature search strategy	29
Search databases	29
Search terms	30
What are BPSD?	30
The policy arena	32
Antipsychotic agents	33
- <i>Prevalence of antipsychotic medications for BPSD</i>	34
- <i>Risks</i>	35
- <i>Efficacy</i>	37
- <i>Class effects</i>	38
<i>Withdrawal of antipsychotics</i>	39
Other psychotropic medications for BPSD	40
Medication use in care homes	41
Non-pharmacological interventions	42
- <i>The term ‘non-pharmacological intervention’</i>	42
- <i>Types and classifications of non-pharmacological interventions</i>	42
- <i>Person centred care</i>	44
- <i>Effectiveness of non-pharmacological interventions for BPSD</i>	46
- <i>Clinical challenges for the use of non-pharmacological interventions</i>	50
Care home factors	52
Care home management of BPSD	53
Discussion	55
Conclusions and knowledge gaps	57

Research questions	58
Chapter 3: Methodology and study design	60
Introduction	60
Finding the right approach for this study	61
Philosophical and methodological debates	61
Adopting a pragmatic approach	63
Study design: Mixed methods	65
Study design	67
Rationale for postal survey: Phase 1	69
Rationale for case studies: Phase 2	71
Unstructured observations	74
In-depth interviews	75
Psychotropic medication mapping	77
Data analysis: The Framework Approach	77
Methodological challenges	78
Rigour and trustworthiness	78
Researcher influence on study design	79
Assumptions	81
Summary	82
Chapter 4: Postal survey	83
Introduction	83
Objectives for Phase 1	83
Sampling frame development	84
Survey development and questionnaire design	86
Data sorting and analysis	89
Ethical considerations	90
Results:	90
- <i>Survey responses</i>	91
- <i>Antipsychotic use</i>	93
- <i>Behaviours & related issues care home staff found difficult to manage</i>	94
- <i>The use of non-pharmacological interventions</i>	95
- <i>Additional free text responses</i>	96
Discussion: Contextualising the findings	99
Limitations of Phase 1: using the postal survey method to care homes	101
Conclusions	102
Chapter 5: Case studies: Methods and processes	104
Introduction	104
Phase 2: Research questions	104
Sampling strategy: Case studies	105
Negotiation process	108
Case studies	109
Ethical considerations	110
Participant sampling	111
Recruitment: Obtaining informed consent and consultee declarations	112

Observations and the researcher role	116
Times and spaces	120
Freedom and trust	120
Note taking	121
Researcher approach	121
Data access	122
Interviews	123
Data management	126
Anonymity and confidentiality	126
Data Analysis: qualitative data	127
- <i>Analysis process</i>	127
Medication mapping	128
Limitations of Phase 2	129
Summary	129
Chapter 6: Care Home dynamics	131
Introduction	131
Aims for Phase 2	131
Introduction to the cases	132
- <i>Bullace View</i>	133
- <i>Gage Hill</i>	135
- <i>Mirabelle Way</i>	136
- <i>Cherry-Plum</i>	137
Care home dynamics and Organisational factors	138
- <i>Ownership and management of the case study care homes</i>	138
- <i>Care home admissions</i>	141
- <i>Moving residents on</i>	144
- <i>Environmental effects</i>	146
Staff team characteristics	149
- <i>Caring for residents with BPSD</i>	149
- <i>Knowledge, experience and training</i>	150
- <i>Staff teams</i>	155
- <i>Staff role blurring</i>	155
- <i>Confidence/adherence to social norms</i>	158
Support and Resources	160
- <i>External agencies</i>	160
- <i>Funding</i>	162
People as resources	163
Conclusions	163
Chapter 7: Medication use	166
Introduction	166
Medication use in care homes	166
Medication mapping findings	167
Observation and interview findings: Medication use	177
- <i>Knowledge of psychotropic medications</i>	177
- <i>Instating and reviewing medications for BPSD</i>	178

-Staff monitoring of medications	182
-Perception of psychotropic medications	184
-Administering medications	185
-Pro re nata (as required) medications	188
-General administration practices	194
Conclusions	195
Chapter 8: The use of non-pharmacological interventions and strategies	197
Introduction	197
Survey responses	197
Activities and non-pharmacological interventions	199
Person centred care (PCC)	211
Lack of person centred care	214
Routines and flexibility	216
The placement of residents	217
Staff approaches	223
Monitoring	224
Communication: techniques used by staff when talking to residents	225
Distraction	226
Moving residents on	227
Conclusions	227
Chapter 9: Issues and Tensions in the Management of BPSD	230
Introduction	230
An illustrative example	231
Monitoring and surveillance of residents	234
-Communication between staff team members about residents	234
-Documentation	236
-Technology for surveillance	237
Security and safety: restriction versus resident autonomy of movement	240
Forceful restraint	243
A balance between neglect and forced care	247
Impact of behaviour on self (person with BPSD)	251
The problems delivering person centred care in care home settings	252
-Competing demands	252
- <u>Divergent wishes of residents</u>	252
- <u>Resident conflict</u>	253
- <u>Organisational responsibilities</u>	254
- <u>Constant attention required</u>	255
- <u>Interrupted work</u>	256
- <u>Mitigating risk or impact as the priority at the time</u>	256
-Not knowing a resident	257
The concept of person centred care	258
Conclusions	259
Chapter 10: Discussion	262
Introduction	262

Central findings	262
Key findings	264
Addressing the research questions	264
- <i>Psychotropic medications</i>	265
- <i>Non-pharmacological interventions/Activities</i>	266
- <i>Staff approaches</i>	267
- <i>Resident placement and segregation</i>	268
- <i>Surveillance</i>	268
- <i>Forced care or restraint</i>	269
- <i>Moving residents on from the care home</i>	270
- <i>Resources and support</i>	270
Unexpected findings	272
- <i>Risk and impact on others</i>	272
Theoretical contribution: Person centred care problematised	273
Methodological findings	275
- <i>Using the Framework approach for data analysis</i>	276
- <i>Triangulation</i>	277
Contribution to the wider field of knowledge	277
- <i>The dichotomy between rhetoric and practice</i>	279
Hindsight: If I conducted the study now	279
Areas of interest for future research	280
Summary	281
Chapter 11: Conclusions	282
Introduction	282
Methodological Triangulation	282
Critical evaluation	284
Conflict between policy and practice	285
Implications for practice	286
Contribution to knowledge	287
References	290
Appendices	304
Appendix A: List of non-pharmacological interventions	304
Appendix B: Questionnaire for postal survey	307
Appendix C: Categorised free text responses	309
Appendix D: Indicative observation guide	312
Appendix E: Indicative interview topic guide	314
Appendix F: Medication mapping form	315
Appendix G: Survey cover letter to care home managers	317
Appendix H: Aging & Mental Health publication	319
Appendix I: Negotiations with care homes for case study phase	332
Appendix J: Interview and interviewee characteristics	334
Appendix K: Framework for analysis	336
Appendix L: Example excerpt of an indexed interview	338
Appendix M: Example of charting analysis phase	342

List of Tables	Page
Table 4.1: Original sample and response sample figures by care home characteristics	91
Table 4.2: Care home factors by home type (Nursing includes dual-registered)	92
Table 4.3: The frequency of reported difficult to manage behaviours and related issues by care home	95
Table 4.4: Non-pharmacological interventions used by care home	96
Table 5.1: Survey response categories and relevance for case studies	106
Table 5.2: Sample exclusion process and rationale	107
Table 5.3: Sampling subgroups for case studies and CHs in the final sample	108
Table 5.4: Breakdown of generated care home data	110
Table 5.5: Tasks undertaken as part of the observer as participant role	117
Table 6.1: Care home characteristics	133
Table 6.2: External sources of support for care homes	161
Table 7.1: Antipsychotic prescription levels from participating case study care home survey responses	167
Table 7.2: Medication mapping across participating case study care homes: residents' psychotropic prescriptions	169-170
Table 7.3: Medication mapping across participating case study care homes: psychotropic regular doses	174
Table 7.4: Medication mapping across participating case study care homes: psychotropic PRN doses	175
Table 8.1: Survey responses from case study CHs: NPIs and behaviours	198
Table 8.2: Activities/NPIs observed at the case study care homes	201
Table 8.3: Activity staff and hours by care home	202
List of Figures	
Figure 3.1: Model of study design and interactions	69

Abbreviations

BPSD	Behavioural and Psychological Symptoms of Dementia
PRN	Pro re nata (as required)
CB	Challenging Behaviour
CH	Care Home
MH	Mental Health
PCC	Person Centred Care
NPI	Non-pharmacological Intervention
CVAE	Cerebrovascular Adverse Events
GP	General Practitioner
CQC	Care Quality Commission
BNF	British National Formulary
MAR	Medication Administration Record
UK	United Kingdom
PWD	People With Dementia
NICE	National Institute for Health and Care Excellence

Acknowledgments

The study depended entirely on participant involvement. I am grateful to the care home managers who responded to the survey questionnaires. I would particularly like to thank the four care home managers who allowed me to enter their homes and the many staff, residents, family members and visitors that made up the care home communities who welcomed me so warmly. These participants, and non-participants, kind-heartedly accepted my presence in their homes and work places. I would like to thank those who participated for their interest, openness and enthusiasm, without which this study would not have been able to obtain the rich findings that it did.

Sincere thanks go to my supervisors: Anne Killett and Bridget Penhale at the University of East Anglia, Richard Gray at the University of West England and Diane Burns at the University of Sheffield. Their tireless commitment to providing encouragement and support while simultaneously questioning and challenging my thought processes has enabled me to develop considerably as a researcher and thinker. The varied perspectives and experience the collective supervisory team provided have worked to enhance this study and my understanding of this complex subject area.

I would especially like to thank my husband, Alan, who has been an immense source of support throughout my studies. His patience, encouragement, and ability, at times, to endure a second place position to the PhD have been essential to the completion of this thesis. I would also like to thank my three children: Emily, Warren and Gus who have supported me in numerous ways; most of all, their vivacity and sense of fun has kept me going throughout my studies.

I am grateful to my PGR colleagues who have been invaluable for providing motivation and reassurance throughout this study.

I gratefully acknowledge the financial support I received from the University of East Anglia through a three year studentship, which provided both, tuition fees and a stipend.

Chapter 1: Introduction

The increase in dementia and changes in care homes

Dementia is a broad term used to describe a progressive decline in cognitive functioning; it can present differently with each person affected. Due to the worldwide ageing population, the global prevalence of dementia is likely to increase greatly over the coming years (Alzheimer's Disease International, 2009; Prince et al., 2013a). It is estimated that 36 million people were living with dementia worldwide in 2010 and that, by 2030, this figure will rise considerably to around 76 million (Prince et al., 2013b). In the United Kingdom (UK) there are currently estimated to be over 821,000 people with dementia (PWD), a figure also set to rise significantly over the coming years; 37% of these are estimated to be living in long term care settings (Knapp et al., 2007; Luengo-Fernandez et al., 2010). Increasing levels of dementia are likely to intensify the current societal challenges of diagnosis, care, social stigma and cost associated with this disease (Alzheimer's Disease International, 2009; Luengo-Fernandez et al., 2010). With the potential scale of the future challenges dementia may pose, it is unsurprising that the care for PWD is currently receiving rising global attention (Alzheimer's Disease International, 2009).

Adjacent to the increase in the prevalence of dementia there has been a decrease in care home (CH) provision in the UK. The National Health Service and Community Care Act 1990 was a policy imperative, which allowed people needing long term care to be supported and receive care while either living in their own homes or in residential care settings (National Health Service and Community Care Act, 1990), but with an emphasis towards people being enabled to remain living at home for as long as possible. This, along with the financial pressures on care settings stemming from the introduction of the national minimum wage (National Minimum Wage Act, 1998) and the national minimum care standards (Care Standards Act, 2000) led to many CH closures around the turn of the twenty first century (Lievesley et al., 2011; Netten et al., 2002). There has also been a significant shift in CH ownership from the public to the private sector over the last few decades (Johnson et al., 2010). As a consequence

of these changes, and as the role of Government has changed from provider to procurer, the character of CHs in the UK has changed in recent decades. Individuals with specialist, acute and complex needs, not able to be catered for in the community, are most often those now admitted to CHs. Therefore, profiles of populations in CHs are different to those frequently found for community-dwelling populations. CHs are increasingly used as a final option instead of as retirement homes. Additionally, due to the complex needs of many residents, the division between qualified nursing care and residential care is blurring, with the medical model becoming increasingly prominent as individuals often require more medical and/or nursing interventions to meet their needs (Lievesley et al., 2011).

The rising prevalence of dementia also impinges on the change in the characteristics of populations in CHs. Most PWD experience behavioural and psychological symptoms of dementia (BPSD), such as wandering, repeated questioning, psychosis, anxiety, agitation or aggression, at some point during the illness (Savva et al., 2009). These behaviours can diminish quality of life, they have been reported to be difficult for carers to cope with and can increase caregiver burden (Onishi et al., 2005), making BPSD justifiable targets for intervention. This is particularly so since BPSD are distressing and difficult to manage for both PWD and their caregivers; making them an important cause for the earlier than expected admission of PWD into care (Banerjee et al., 2003; Lopez et al., 2013; O'Donnell et al., 1992). Consequently, these symptoms are often found in CHs, where many residents now have higher and more complex needs relating to cognitive impairment than ever before (Banerjee, 2009); meaning that care providers are having to adapt to cope with the increasing challenges with which they are faced. There is also the possibility of CH life causing further instances of BPSD. With the projected increase in the prevalence of dementia over the next few decades, coping with the challenges posed by residents experiencing BPSD is likely to be a long term issue for CHs.

The management of BPSD

Antipsychotic medications¹ have been prescribed for those experiencing BPSD; yet, only risperidone is licensed to be used for these symptoms, making the use of other types of antipsychotics 'off label'. Antipsychotic medications can have limited efficacy and have been found to be associated with multiple side effects along with serious adverse events such as stroke and death (Ballard et al., 2009b; Ballard & Howard, 2006; Schneider et al., 2006a). Due to the risk/benefit balance, the Department of Health in England acted on a Government commissioned report (Banerjee, 2009) and in 2010 pledged to reduce the use of antipsychotic medications for all PWD. A Dementia Action Alliance was formed and together the members called for an antipsychotic prescription review (Dementia Action Alliance, 2011). However, the move to reduce antipsychotics for PWD has intensified the long standing problem of how best to care for people with BPSD.

Non-pharmacological interventions (NPIs), such as, aromatherapy, massage, animal therapy and music therapy, have been recommended by the National Institute for Health and Care Excellence (NICE) as alternative first line treatments for BPSD, with the use of antipsychotic medications only as a last resort (NICE and SCIE, 2006, revised 2012). However, although the focus of much encouraging research, as yet, the evidence base for many of these varied interventions is in its infancy. There can also be problems with the accessibility of NPIs (Ballard et al., 2009a); they can be context specific (meaning the surrounding conditions can affect their delivery), costly to implement and often time consuming with restricted availability (Kolanowski *et al.*, 2010). Care approaches, such as person centred care (PCC) or seeking to identify and

¹Antipsychotics (sometimes called 'neuroleptics') are a group of medicines that come under the umbrella of psychotropic medications. Psychotropic medications include hypnotic, anxiolytic, antidepressant, antipsychotic, atypical antipsychotic, and antimanic drugs. They all alter chemical levels in the brain to change mood or behaviour (British National Formulary. (2013). *British National Formulary*. BMJ and Pharmaceutical Press.).

address unmet needs, are also viewed as helpful in the prevention and management of BPSD (NICE and SCIE, 2006, revised 2012).

At present, there is no one singular clear, evidenced strategy, intervention or approach that stands out as the most appropriate for the management of BPSD. This situation leaves those caring for people experiencing BPSD with the responsibility to decide which approach to adopt or strategy to use to try to manage these behaviours. There is also the issue of whether it is the management of symptoms or individuals that occurs, or is needed.

The knowledge gap: Care home strategies

The literature review revealed that both the social policy and biomedical perspectives conceptualised caring for people with BPSD as predominantly a top down management problem. These standpoints valued research with treatments and interventions at the focus (for example, randomised controlled trials researching the efficacy of medications or NPIs). Conversely, psychological and social stances advocated personhood, PCC and a bottom up approach (see, for example, Kitwood, 1997). In this approach behaviour would be understood as an expression of emotions or needs. Person centred approaches to care would be seen as a way of meeting psychological needs. The majority of research related to the management of BPSD comes from a biomedical stance with a focus on formal interventions. Other research has explored family caregiver experiences of caring for relatives with dementia and micro level care strategies, such as, types of communication with PWD.

Care homes are caught in the middle of these perspectives; trying to negotiate policy, evidence and care approaches. There is often an assumption that institutions such as CHs are capable of managing the varied and complex needs of residents with BPSD. Yet, many provisions have made only slight adaptations over the last two decades to address the general increase in CH residents' morbidity and requirements, and are presently ill equipped to cope with existing resident profiles (Banerjee, 2009). Furthermore, although CH staff are on the front line of dementia care they are often the least trained and have to directly negotiate the multiple divergent needs of

residents (Hussein, 2010). The Department of Health in England's pledge to reduce antipsychotic use is in the shadow of a supposition that this medication is used profusely in CHs to manage BPSD.

Although there is a recent move to find better evidenced interventions for BPSD, there remains a paucity of knowledge about the problems these symptoms create for CH staff. The organisational factors of care settings have been found to influence care practices (Killett et al., 2013) therefore, exploring how BPSD are managed within the CH context is of great interest. Little is known about care staff perceptions of the situation and about the strategies they actually use to work with individuals experiencing BPSD on a day-to-day basis. Therefore, this exploratory study was designed to contribute to the understanding of the management of BPSD specifically in CHs. The study's focus was directed at the front line of dementia care within CHs. By exploring the current situations in CHs the formal and informal strategies used and the issues and tensions present could be identified and examined. This information contributed knowledge to address the gap found in the literature: the present status of the management of BPSD in CHs. Therefore, this thesis makes a contribution to knowledge by illuminating, and examining the use of, the multiple strategies used in CHs to manage BPSD. The findings develop the existing literature in several ways (set out in detail in Chapter 10). For example, although multiple strategies are used in CHs to manage BPSD, formal NPIs are predominantly used and viewed as activities for all residents rather than directed at behaviours. Additionally, the findings show it is not always possible to deliver PCC to all residents at all times. These findings are contrary to the current rhetoric surrounding the management of BPSD, which focuses on formal NPIs and PCC as first line care strategies.

Research questions

The literature review established that, until now, the care practices and interventions employed by CH staff to manage BPSD have been little explored. Therefore, the central aim of this research was to gain understanding about the formal and informal strategies used to manage BPSD in CHs. The use of the term strategies in this thesis refers to the decision-making and actions (including care practice related actions and

medication use) that care workers have developed, employed and/or adopted in response to the management of the BPSD within the contextual constraints of the CHs. The organisational, pharmacological, care team and individual care staff level strategies were all of interest. By focusing on CH strategies this study starts to address the current lack of knowledge about the day-to-day management of BPSD in these settings.

The focus of this thesis is on care approaches and strategies; this is not a study of residents with dementia or, directly of BPSD. Therefore, the care of residents experiencing BPSD is explored and examined and not the residents' experiences. The person with dementia is not irrelevant to this study, their participation in the research allowed closer observations of care practices and the interactions with residents illuminated the fieldwork. Additionally, the focus of the study may not include residents' perspectives and experiences, yet the findings touch on issues of personhood, PCC, human rights and freedom; areas of fundamental importance to all residents.

By focusing the research on care approaches rather than resident experiences a deep understanding of the factors that help or hinder CH staff in looking after people with BPSD, including their concerns and the difficulties involved in their work, could be explored. The study gained knowledge to illuminate the current state of care for people with BPSD in CHs, providing an understanding of current practice from which to move dementia care in care settings forward. The research questions were:

Research Questions:

- 1) What are the formal and informal strategies used to manage BPSD in CHs?
 - a) Why and how are they used?
- 2) How do various strategies work?
 - a) And for whom?
- 3) What resources and sources of support are available to assist CH staff to cope with BPSD?
 - a) How are they used?
- 4) What is the prevalence of antipsychotic medication use in CHs?

Methodology and methods: The research approach and design

A pragmatic approach was adopted and used to guide the research design for this exploratory study. The logic of pragmatism is that the methods perceived to be the most appropriate to answer the research questions, regardless of inherent epistemological or ontological assumptions, can be employed and combined (Morgan, 2007; Onwuegbuzie & Leech, 2005). Recognising the complexity of the management of BPSD, a mixed methods design was employed for this study. The use of mixed methods enabled the collection of varied data types to address the research questions (Tashakkori & Teddlie, 1998). In this topic area, which straddles biomedical and social perspectives, the use of methods eliciting both, quantitative and qualitative data are apt, since this reflects the typical assumptions behind each approach. The overall aim of the design was to gain as full a picture of the issue as the scope of the study would allow. Using multiple methods ensured that the multipronged approach to managing BPSD by both CH staff and medical professionals, which includes pharmacological and non-pharmacological approaches, could be captured by the study.

A sequential two phase design was used (Creswell, 2003):

Phase 1: A short postal survey was sent out to CH managers in three counties in the East of England to gain a broad overview of the management of BPSD in CHs (answering questions 1 and 4) and to assist the sampling for phase 2.

Phase 2: Case studies encompassing: psychotropic medication mapping to gain knowledge of the prescriptions and administrations of psychotropic medication in CHs, observations to illuminate care practices, and interviews to gain a care staff perspective, were conducted in four CHs. These methods allowed an in-depth, contextualised study of the strategies used to manage BPSD in CHs (answering questions 1, 2 and 3).

Terminology

For this thesis I have decided to adopt the term BPSD to refer to the multitude of behaviours PWD experience. Finding a collective term for such disparate behaviours as, aggression, sexual dis-inhibition and repetition was a difficult task. No one option in the literature appeared to adequately refer to the vast collection of predominantly non-cognitive symptoms PWD can experience, including BPSD. In the absence of an ideal term, I have accepted the term put forward by the International Psychogeriatric Association (IPA) for this thesis. A consensus for the term BPSD was first established by the IPA when sixty experts agreed it was the best fit for the behaviours or expressions from PWD that it describes (Reported in Finkel, 2000; Finkel et al., 1997). The association defined BPSD as

“symptoms of disturbed perception, thought content, moods or behaviours that occur frequently in patients with dementia” (Finkel, 2000).

It is apparent that the term BPSD has inherent issues for example; it reflects only a biomedical stance through the use of the word ‘symptoms’. However, other options such as ‘challenging behaviour’ (CB), which was used in the initial stages of this study, also have intrinsic problems making them unsuitable to adequately reflect the issue as a whole.

The term ‘manage’ or ‘management’ in this thesis is used as a way to refer to the approaches, interventions and strategies utilised by CH staff to assist them to cope with or address BPSD. Residents themselves have to manage their BPSD and CH staff have an important role in helping them to achieve this. Additionally, CH staff have a duty to care for many residents and as part of this responsibility they have to ‘handle’ or ‘deal with’ the consequences or impacts of BPSD; the behaviour has to be managed. Therefore, although the term ‘manage’ appears to represent a passive resident and a top down approach, in this thesis the term ‘manage’ reflects something that both residents and staff have no option but to do and is not intended to reflect only the former approach. These terms will be discussed further in Chapter 2.

Personal influence on the study

My professional background is in care work. I have vast experience working within CHs and throughout the duration of this study I continued to work on a part time basis in a care setting offering very sheltered care to older people (not eligible to be included in the potential sample for this study, since it is not a CH). My work over the years has ignited my interest in old age care generally. In my care worker role I have cared for residents with dementia and administered medications. The role has made me acutely aware of the multi-faceted and complex nature of dementia care and some disparity between practice and academic perspectives and priorities. Concern over increasing pressures in the work place, in conjunction with the highly specialised needs of many residents with dementia led me to explore this area. Therefore, I began this study with an awareness of my presupposition that CH staff have a difficult and complex role in the management of BPSD. This directed me towards targeting my focus on care approaches and strategies as a way to explore this issue.

The subject matter of this study has been particularly difficult to situate, it rests between medical and social perspectives. I am a sociologist working in the Faculty of Medicine and Health Sciences and my own inner tension about where I stand between the biomedical model and the social approach appeared to mirror the conflict in the provision of (social) care itself and in the competing academic disciplines tackling this issue. The aforementioned biomedical top-down approach to managing BPSD contrasts greatly with the bottom up PCC approach advocated by more social orientated stances. The literature surrounding this area reflects these tensions and derives from differing academic disciplines. Although in reality the boundaries are blurred, generally medical practice and research approach BPSD as issues stemming from the aetiology of dementia, which are in need of interventions or treatment. This is contrary to practice and research stemming from outside the medical domain where the person is prioritised, not their condition and external sources of behaviours are sought. Even funding for health care is separated from social care funding, although many CH residents have complex health and social care needs.

The two predominant and alternate ways of viewing the management of BPSD have caused a both professional and personal dilemma, since no one position appears to adequately portray the whole picture; making it unsatisfactory for me to adopt any one in its entirety. Therefore, this thesis portrays a sociologist's work in social care with a strong health element. By accepting this position and its inherent tensions I am reflecting the situation of social care for older people itself and moreover, perhaps my experience as a care worker; a role which is also caught between the medical model and the social approach.

The risk in straddling these two main paradigms is the chance of falling between two and diminishing the quality of this study. However, this risk appeared to be worth taking, since the thesis could be greatly enhanced by the competing perspectives. The strength gained from acknowledging and incorporating both the medical prescriptive perspective and the PCC social approach to this issue within this thesis portrays a more accurate assessment of this area. This stance also allowed the exploratory nature of this study to be played out by examining the most salient emergent issues, regardless of their characteristics.

Thesis Outline

This thesis explores the current: pharmacological and non-pharmacological strategies; care practices, and approaches used in CHs to manage BPSD. The theoretical concept of PCC is also considered as part of these strategies. The management of BPSD in CH settings is explored and examined over the remainder of the thesis.

Chapter 2 provides further context for this study through a review and examination of the literature informing this area. The use of antipsychotic medications, PCC and NPIs in relation to the management of BPSD are assessed. Previous CH research is also reviewed. The issues inherent in the available research focusing on the management of BPSD particularly in CHs are explored and the gaps in knowledge are highlighted. The chapter concludes with the research questions and aims for this study to start to address these deficient areas.

Chapter 3 outlines the use of pragmatism as a guiding approach for this study and provides justifications for this choice. The rationale for choosing a mixed method study design, incorporating methods often viewed as being incongruent is set out. The arguments to support the choice to use a two phase study starting with a postal survey and moving on to case studies encompassing observations, interviews and medication mapping is outlined in the study design.

Chapter 4 reports on the aims, method, results and conclusions of the first phase of this study: the postal survey. Some discussion surrounding the use of this method to elicit data from multiple CH managers is included. The methods used within the case studies in phase two of the study are outlined in chapter 5. The process of conducting the research is discussed with descriptions of how the interviews, observations and medication mapping were carried out. Consideration is given to the researcher's role in generating the data and to the ethical issues inherent in CH research and this study in particular.

Chapters 6, 7, 8 and 9 present the case study findings. Together these chapters include: the influence of CH dynamics on the management of BPSD; psychotropic medication use for BPSD; the role of NPIs in the management of BPSD in CHs, strategies used by staff members to assist in the management of BPSD, the tensions and issues intertwined with the management of BPSD in CHs, and a consideration and problematisation of the concept of PCC. Due to the qualitative nature of the majority of these results a discussion element is incorporated throughout these results chapters.

Chapter 10, integrates and discusses the findings from both phases of the study, how they have addressed the research questions and the results (both expected and unexpected). The issues emerging from the findings are discussed, such as the problems delivering PCC in CH settings, and the difficulties offsetting risk and minimising the impact of BPSD. Methodological triangulation, the strengths and limitations of the study, implications for practice, and contributions to knowledge are examined in the final conclusions chapter (Chapter 11). The original contributions to knowledge from this research are:

- The identification and examination of the types of decision-making and strategies that care staff have developed, employed or adopted to manage BPSD within the contextual constraints of their work places
- The problematisation of the consistent delivery of PCC in communal settings where care workers must constantly negotiate competing demands, organisational constraints, and the need to mitigate the risk and impact of behaviours.
- An indication of the use of psychotropic medications for PWD in CHs
- The identification of a gap between rhetoric and practice with formal NPIs used, and viewed, predominantly as activities in CH settings and not employed to specifically reduce or manage BPSD

Chapter 2: The management of BPSD in care homes: A scoping review

Introduction

To explore the management of BPSD in CHs adequately it is first necessary to examine the scope and nature of the existing literature. The management of BPSD is connected to many disciplines such as, nursing, psychiatry, psychology, medicine, pharmacology, and psychosocial approaches. Therefore, for the purpose of this thesis, it was important to approach the literature in a pragmatic way. A scoping review was conducted to gain knowledge of the range and extent of the literature relevant to the strategies used to manage BPSD in CHs. The literature for the review was considered regardless of the discipline it arose from. The review does not inspect the physiology of dementia, dementia cure research, or an in-depth view of pharmacological interventions other than antipsychotic medications, since other medications have limited evidence and are not thought to be as widely used for BPSD. The chapter starts by defining dementia and the terms 'BPSD' and 'management' which are used throughout this thesis. The search strategy is then outlined before a discussion of BPSD and the policy arena. The prevalence of antipsychotic medications, the risks and efficacy associated with their use and other issues related to a reduction in their use are considered. Following this is an examination of NPIs and the evidence for their effectiveness and use; PCC and CH factors are examined before a discussion and the conclusions. The chapter ends with a statement of the research questions for this study.

Definitions and terms

Dementia

Dementia is a broad term used to describe a progressive, but not always linear, decline in cognitive functioning; it can present differently with each person affected. The World Health Organisation currently defines dementia as

‘a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not clouded. The impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation.’ (World Health Organisation, 2010)

This definition encapsulates both the cognitive and non-cognitive symptoms of dementia that can emerge. The cognitive decline in dementia brings with it cognitive symptoms, such as memory loss, language difficulties and a decline in visual spatial skills (Ballard et al., 2001a). BPSD also occur; these symptoms include a mixture of psychological symptoms such as, psychosis, hallucinations and delusions and behavioural symptoms, such as, aggression, anxiety, wandering, agitation, restlessness, repeated questioning and sleep disturbance. Alois Alzheimer described instances of BPSD, such as yelling, hallucinations and delusions, in his first case report in 1906 (Strassnig & Ganguli, 2005).

This study focuses on care approaches and the management of the external presentation of dementia therefore, the underlying type of dementia a person has (such as, Alzheimer’s disease, dementia with Lewy bodies, fronto-temporal dementias or vascular dementia) is not being studied. This thesis describes dementia in general terms and does not differentiate between different dementias.

The term ‘BPSD’

The umbrella term ‘behavioural and psychological symptoms of dementia’ (BPSD) is widely used, particularly by the psychiatric community (Douglas et al., 2004), to describe a multitude of different predominantly, non-cognitive symptoms which can be presented by PWD (Finkel, 2000). A consensus for the term was established by the International Psychogeriatric Association (IPA) and viewed by the sixty experts as the best fit for the behaviours or expressions from PWD that it describes (Reported in Finkel, 2000; Finkel et al., 1997). The association defined BPSD as:

‘symptoms of disturbed perception, thought content, moods or behaviours that occur frequently in patients with dementia’ (Finkel, 2000).

BPSD then, can refer to a multitude of behaviours or symptoms and this, although helpful to collectively refer to these behaviours, can be problematic. Since the definition of BPSD, as defined by the IPA, hinges on “disturbance” the term ignores the lifelong context of these behaviours, depicting them instead as new disturbances and not as exaggerated forms of normal behaviour induced by dementia (MacDonald, 2005). Additionally, the term BPSD does not offer a clear definition of the symptoms, but bands together many disparate symptoms and treats them as one. This means the term can be misleading as symptoms caused by things other than dementia, such as pain or environmental factors, can be located under it and be attributed to dementia (Wood-Mitchell et al., 2008). There is a clinical danger that any symptom a person with dementia exhibits will be assumed to be part of this group of symptoms and not considered as having a separate source. In this way, underlying factors, such as pain, infections, or side effects from medications can be thought of and wrongly categorised as symptoms of dementia. Consequently, they could be ignored. However, other possible terms such as, non-cognitive symptoms or CB also encounter this problem.

Even thinking of the behaviours mentioned above as ‘symptoms of dementia’ can be problematic. The word ‘symptoms’ reflects the biomedical approach and infers that the behaviours and expressions originate from the syndrome dementia itself; a reflection of the medical model of disability (French & Swain, 2012). Some writers have argued that the behaviours expressed by PWD can be caused by a multitude of factors such as, personality, physical health, environmental and psychosocial aspects, such as, from unmet needs and not just neurological impairment (Bird & Moniz-Cook, 2008; Dewing, 2010; Epp, 2003; Stokes, 2000). For example, wandering could result from a person with dementia not knowing the way back to their room because all of the doors look the same (environment). Or aggression could be the result from the frustration of not being understood or being hungry (psychosocial). These are examples of the social model of disability where barriers such as, the environment, underlying norms or other people’s attitudes make things difficult for the person with

an impairment resulting in the expressed behaviour (French & Swain, 2012). Bird and Moniz-Cook argue that the term BPSD does not represent these causes (Bird & Moniz-Cook, 2008).

Consequently, BPSD have been described by some writers, usually from a psychological perspective (Douglas et al., 2004), as 'challenging behaviours' (For example, Bird & Moniz-Cook, 2008). Challenging behaviour is defined by Bird *et al* as:

'Any behaviour associated with the dementing illness which causes distress to carers and/or the patient.' (Bird et al., 1998).

From this definition, the term 'challenging behaviour' includes all non-cognitive behaviours experienced by PWD which cause distress or present a challenge. However, all behaviours do not cause distress; a factor, which could be due to how they are managed. For example, some behaviours may be viewed as challenging or distressing in one setting, but not in another; making the term 'challenging behaviour' inadequate for this study where many views, behaviours and settings were encountered. The term 'distressing behaviour' has the same issue; all behaviour needing management is not distressing. The term 'challenging behaviour' also has inherent negative connotations that the term BPSD does not. By using the term "symptoms of dementia" there is no blame transferred to the person with dementia. Therefore, although using the term CB moves the focus away from viewing these behaviours, like the biomedical model, as symptoms; the use of this term is not altogether satisfactory. Although this study started off using the term CB for the survey in phase 1, the term was challenged by some study participants due to its negative undertone; it was subsequently reconsidered as unsuitable for use in this study.

The terms 'non-cognitive symptoms of dementia' and 'neuropsychiatric symptoms' were also considered and discounted by the author, since they do not indicate the type of symptoms they are describing as clearly as the term BPSD. Additionally, some BPSD (such as repeated questioning) can have cognitive origins which can stem from memory loss. Although the range of implicated triggers is vast and all behaviours may not stem directly from dementia, often they would not occur if the person themselves

did not have the underlying impairment; dementia. Therefore, the term BPSD is used throughout this thesis to encompass all behavioural symptoms of dementia that require management in CHs, whether their cause is environmental, psychosocial, neurological or cognitive. Although the term BPSD is not ideal, the benefit of using it is that it offers a simple way to refer to the multiple behaviours as a collective and does not infer the assumption that they are all challenging or that they do not have cognitive origins. Where it was necessary to identify particular symptoms/behaviours they are mentioned by name.

The term 'management'

This thesis uses the term 'the management of' rather than 'the care for people with' BPSD to refer to the approaches, tools or interventions utilised by CH staff to assist them to cope with or address BPSD. The term 'manage' may be viewed as controversial considering it brings with it the connotation of a top down, or biomedical, approach representing something that is done to the person with dementia, consequently placing them in a passive position. This decision was made because 'management' rather than 'care' has a better fit to the subject matter of the thesis. The study reported within this thesis looks at the strategies CH staff use to cope with BPSD. Additionally, PWD have to manage these symptoms and I have focused on the strategies used by CHs and CH staff to manage, and help PWD manage, these symptoms. The term 'Care for people with BPSD' seems to reflect care practices, such as, bathing or toileting and would not so easily include the use of formal interventions, socially questionable strategies or medication use. The term 'address' was also considered instead of 'manage' as a way to describe what CH staff did with BPSD, however, this term appeared to have a negative undertone reflecting the sentiments such as, 'sort out' 'tackle' and 'take in hand'. Although 'manage' also has some negative connotations such as, 'handle' 'deal with' and 'control' these were perceived as having a better fit with the study focus.

I argue that BPSD are 'managed' on four levels. Firstly, the person with dementia, themselves, has to manage these symptoms as part of everyday living, for example, in the same way they may have to manage or deal with pain. Secondly, the care staff

role is one of support, thus care staff are in a position to assist PWD to manage these symptoms. Care staff also have to manage BPSD in relation to other responsibilities within their work. When considering the duty care staff have to care for all residents, instances of BPSD do have to be controlled or managed. Thirdly, there is an aspect of top down management within care settings, since the CH management, ethos and organisation will guide how BPSD are coped with by the staff team. Furthermore, if formal interventions or strategies are used, decisions for these will have taken place in relation to time, cost and availability at a level higher than the person with dementia, even if they were consulted during the planning process. Looking further at a fourth level, general practitioners (GP's), psychiatrists or other professionals also have to put in place management strategies for BPSD if called upon. Due to the cognitive debilitating nature of dementia, people experiencing BPSD are more likely to have others making decisions for them. Therefore, within CHs, these symptoms have to be managed by the person with dementia, by the care staff, at the CH level and at a medical level. As the focus of this study was to explore how BPSD are coped with in CHs 'management' appeared to be the most apt term.

The focus of this study was on CH and care staff approaches and strategies and not on the person with dementia or their experiences. This is due to the nature of the management of BPSD in CHs, where people with moderate to severe dementia are generally not in a position to initially choose and employ treatments for their care. Therefore, strategies are largely chosen and instigated by people other than those with dementia. Also as the profile of resident needs intensifies in CHs, care staff are under increasing pressure to cope with more instances of BPSD, therefore the knowledge gained by exploring the strategies implemented by care staff is important and has relevance not only to CH staff, but to PWD in their care too.

Aim for the literature review

The starting point for this study was the Government commissioned report 'The use of antipsychotic medication for PWD: Time for action' (Banerjee, 2009). The recommendations from this report to reduce antipsychotic medication for PWD and

use NPIs instead to manage BPSD were blended with my care worker experiences, which created an interest in current CH practices. Consequently, a review of the literature to determine exactly what was known about the use of antipsychotics and NPIs for PWD, and the management of BPSD in CHs was undertaken. This review enabled me to assess the current evidence, approaches, and ideas to gain an appreciation of where the edges of knowledge were located in this area; enabling gaps beyond these points to be identified to inform the development of the research questions and subsequent study design.

Literature search strategy

The literature search was used to inform a scoping, and not systematic, review. A systematic review aims to locate, identify, appraise and synthesise all the evidence relevant to a specific issue, which meets strict inclusion and exclusion criteria in order to answer a question. A scoping review was more relevant for this study due to the multifaceted nature of the management of BPSD in CHs, making it necessary for the scope of the search to be wider than one specific issue, intervention or approach. Conducting a scoping review allowed a broad range of approaches and interventions relevant to the management of BPSD in CHs to be examined (Arksey & O'Malley, 2005). This provided knowledge about the key issues in this topic area and the extent of the existing literature, which facilitated with the planning stage of this study. A systematic review would not have been able to synthesise a wide enough range of literature to frame this study.

Search databases

The electronic databases used to search for the literature were: MEDLINE, CINAHL, ASSIA, AMED, PsycINFO, and Academic Search Elite. These were selected to provide a broad range of medical and social science articles covering all aspects of the management of BPSD in CHs. Further reports, articles and writings relevant to the topic area were gained through searching: unpublished theses; the reference lists of key papers (and the Banerjee (2009) report), and websites. The websites searched

included the Department of Health in England, The Alzheimer's Society and Dementia UK.

Search terms

The search terms used were those appearing to be most salient in the topic area 'the management of BPSD in CHs' and those from relevant mesh terms in the databases. The search terms were under four major categories, the first was 'dementia' and derivatives from it such as, 'Alzheimer's disease' 'Lewy Body disease' 'BPSD' and 'behavio*ral and psych* symptoms of dementia'. The second was 'care homes' and connected terms such as, 'assisted living facilities' 'homes for the aged' 'nursing homes' 'intermediate nursing facilities' and 'residential homes'. The third category was 'antipsychotic agents' and included terms such as, 'psychotropic drugs' 'neuroleptic' and 'medication'. The fourth category was 'interventions' and included terms such as, 'therapy' 'non-pharmacological' 'strateg*' and 'crisis intervention'. If these terms were mesh terms they were exploded to incorporate all categories included within them, if not they were searched individually. Searches were limited to the title and abstract of articles. Further exclusion criteria were used to reduce the large number of articles identified by the searches. All articles focusing on non-humans or children or adults under 65 were excluded, as were those not written in the English language.

The literature was prioritised in relation to the hierarchy of evidence provided by Evans (Evans, 2003) and the Medical Research Council guidance in developing and evaluating complex interventions (Medical Research Council, 2008). By drawing on the directives these sources provided, the quality of the literature identified could be more easily determined, making the critical appraisal of current evidence easier.

The literature review starts with a discussion of BPSD.

What are BPSD?

As mentioned in the introduction, the term BPSD is used to describe a range of issues potentially distressing to the person with dementia and those around them. These

behaviours include, but are not limited to: psychosis, aggression, agitation, apathy, sexual dis-inhibition, wandering, hallucinations, and anxiety. In most cases BPSD may not stem directly from the aetiology of dementia; instead they are likely to arise from a range of clinical, environmental and social factors (Savva et al., 2009). Although BPSD may stem from the confusion or frustration that cognitive symptoms bring, cognitive symptoms are different to BPSD since they generally reflect a decline in functioning and create largely practical difficulties for those with dementia and their caregivers. For example, speech difficulties may be practically overcome with the use of pen and paper or memory problems overcome by the use of a diary and reminder memos. Whereas, BPSD commonly reflect secondary behaviours to the cognitive symptoms, which are generally emotionally challenging and not easily overcome with the use of practical aids. BPSD demand different types of management strategies to cognitive symptoms. Therefore, although cognitive symptoms of dementia can create difficulties, BPSD have been recognised over recent years to be just as, if not more, problematic to PWD and their caregivers (Ballard et al., 2001a; Burns, 2009). The focus of this thesis is restricted to the management of BPSD only.

BPSD are common throughout the course of dementia, particularly in CH populations (Ballard et al., 2001b; Brodaty et al., 2001; Lyketsos et al., 2000; Savva et al., 2009). In a longitudinal, population based UK study, almost all PWD were estimated to be affected by BPSD at some point, with symptoms co-occurring and changing over time (Savva et al., 2009). BPSD can present on a spectrum from mild to severe, many can be disruptive, some can present a risk to the person with dementia or their caregiver and some can be unrelenting; making them emotionally and physically tiring for all concerned. Consequently, people with BPSD often require high levels of supervision and support. Due to these factors BPSD can diminish quality of life (Banerjee et al., 2006), be unsettling and distressing to PWD and their caregivers (Tan et al., 2005) and increase caregiver burden (Chang et al., 2009; Miyamoto et al., 2010; Onishi et al., 2005; Sörensen et al., 2006). As a result, BPSD are associated with earlier placement into institutions (Banerjee et al., 2003; O'Donnell et al., 1992) and can cause considerable cost(s) to society (Beeri et al., 2002; Luengo-Fernandez et al., 2010). Owing to the serious impacts of these symptoms on the lives of PWD (Hurt *et al.*,

2008), on caregivers and on the cost to society, they are legitimate targets for intervention and it is important that they are managed as effectively as possible.

The Policy Arena

In 2007, in the UK, the 'Dementia UK' report, commissioned by the Alzheimer's Society to research the prevalence and cost of dementia, recommended that dementia should be made a national priority (Knapp et al., 2007). Subsequently, in 2008 the All-Party Parliamentary Group on Dementia conducted an inquiry, by consulting stakeholders, into the prescription of antipsychotics for PWD in CHs. They concluded that there are:

'more appropriate ways of dealing with challenging behaviour (than using antipsychotics), which some care homes have employed to good effect, and which should be widely used, such as individually tailored care plans and promoting activities within the care home.' (All-Party Parliamentary Group on Dementia, 2008, page 24)

They recommended that the National Dementia Strategy for England should include an action plan to reduce antipsychotic prescribing for PWD (All-Party Parliamentary Group on Dementia, 2008). Following this the Department of Health in England commissioned the report 'The Use of Antipsychotic medication for PWD: Time for Action' (Banerjee, 2009). This report assessed the available evidence and recommended that, due to the risk/benefit balance, the use of antipsychotic medications for PWD should be greatly reduced. NPIs have instead been recommended as first line treatments for BPSD (NICE and SCIE, 2006, revised 2012). In 2010, the Department of Health in England pledged to reduce the use of antipsychotic medications for all PWD. A Dementia Action Alliance was formed and together the members called for an antipsychotic prescription review (Dementia Action Alliance, 2011). Subsequently, an audit of antipsychotic use for PWD has been conducted to assess the reduction (Health and Social Care Information Centre, 2012).

The next section of this chapter considers the use of antipsychotic agents for BPSD, before discussing the use of NPIs to manage these symptoms.

Antipsychotic Agents

Antipsychotic medications were first used in the 1950s to treat schizophrenia. In the 1990s 'atypicals', newer more sophisticated antipsychotics viewed as being less likely to cause negative extrapyramidal symptoms such as dystonia and parkinsonism were introduced. Their use, alongside the decreasing use of typical antipsychotics, appears to have become widespread. The primary use for antipsychotic medications is for psychosis. As mentioned before, it is reported that antipsychotic agents have been used to manage BPSD. However, the majority of these medications are not licensed by the Medicines and Healthcare products Regulatory Agency (MHRA) in the UK for the treatment of BPSD and their use for this purpose is therefore 'off label'. The only antipsychotic registered for the treatment of BPSD, in the UK, is the atypical risperidone, which is licensed for short term treatment of persistent aggression in Alzheimer's disease (MHRA, 2008). The British National Formulary states that:

'unlicensed use of medicines becomes necessary if the clinical need cannot be met by licensed medicines; such use should be supported by appropriate evidence and experience.' (British National Formulary, 2011)

The use of antipsychotic medications for BPSD appears to stem from the lack of licensed medications to treat these symptoms.

There is an assumption that antipsychotic medications have been routinely and profusely used to manage BPSD. This is particularly so for CHs where it is assumed that antipsychotics have been used, not to treat BPSD, but as a "chemical cosh" to make life easier for care providers (for example, Burstow, 2009). In light of this assumption, the evidence for the prevalence of antipsychotic use in CHs and for people experiencing BPSD will now be examined.

Prevalence of antipsychotic medications for BPSD

In 2010, because of the concerns about the safety of antipsychotic medications highlighted in the Government commissioned report (Banerjee, 2009), the Department of Health in England pledged to reduce the use of these medicines for PWD. In the report 'The use of antipsychotic medication for people with dementia: Time for action' Banerjee estimated (using data from an NHS Information Centre for Health and Social Care analysis using the IMS Disease Analyser) that up to a quarter of PWD in the UK may be prescribed antipsychotics at any point in time. From this Banerjee estimated, conservatively, that around 180,000 PWD were prescribed antipsychotics in the UK. Prevalence is likely to be even higher in CHs due to the increased complexity in resident profiles. There was not enough evidence for Banerjee to estimate the prevalence of antipsychotic use in CHs (Banerjee, 2009).

A limited number of diverse studies regarding the prevalence of antipsychotic use for PWD in CHs have been conducted in the UK. Those available, report a prevalence of antipsychotic use for residents in CHs, regardless of diagnosis, from 15 % up to 58% (Alldred et al., 2007; Connelly et al., 2010; Fossey et al., 2006; Macdonald et al., 2002; Shah et al., 2011; Testad et al., 2010). Studies that give an indication of antipsychotic use, specifically for PWD, in CHs portray prevalence percentages between 33% and 43% (Alldred et al., 2007; Ballard et al., 2002; Margallo-Lana et al., 2001). These findings indicate that there is extreme variation in antipsychotic use across CHs; a finding one study conducted in the United States also suggests (Chen et al., 2010).

In 2011, the Dementia Action Alliance launched a call to action to make sure that all PWD who were prescribed antipsychotics would have their prescriptions reviewed in light of best practice (Dementia Action Alliance, 2011). The National Dementia and Antipsychotic Prescribing Audit, conducted shortly after, obtained data showing antipsychotic prescriptions for all patients diagnosed with dementia from 46% (n=3,850) of GP practices in England. The audit found 7% of people diagnosed with dementia were prescribed an antipsychotic medication, a reduction from 17% in 2006 (Health and Social Care Information Centre, 2012). A study tracking the trend in antipsychotic use for PWD found that there had been a reduction of use from 19.9% in

1995 to 7.5% in 2011, with a mean prevalence of 12.5% over this period (Martinez et al., 2013). These studies, published after phase one of this study was completed, indicate a reduction in antipsychotic use is occurring. One study set in Medway Primary Care Trust in England found that 26% of the people on the dementia register who lived within CHs were prescribed antipsychotic medications (Child et al., 2012). This prevalence is higher than the studies mentioned previously found, this is, perhaps, due to the complex resident profiles and more severe dementia likely to be found in CHs. None of these studies provided an estimate of the prevalence of antipsychotic prescriptions in CHs.

Risks

The use of antipsychotic agents for dementia is associated with multiple side effects and adverse events. Side effects can include incontinence, increased weight (De Deyn *et al.*, 2004), somnolence, abnormal gait (Street *et al.*, 2000) and greater cognitive decline (Ballard *et al.*, 2005). Additionally, extrapyramidal symptoms can occur with antipsychotic use (Schneider et al., 2006a), these include, tremors, slurred speech, dystonia and muscular rigidity. Adverse events are also associated with antipsychotic use. In 2005 the U.S. Food and Drug Administration (Food and Drug Administration (FDA), 2008) issued a warning that the use of atypical antipsychotics for PWD, when compared to placebo, heightened the risk of death between 1.6 to 1.7 times. A meta-analysis by Schneider *et al.* (2005) also observed a similar risk and concluded that short term (less than 8 – 12 weeks) use of atypical antipsychotics for PWD could be associated with a small increased risk of death (Schneider *et al.*, 2005). This effect was observed with meta-analysis and was not seen in individual trials. Subsequently in 2008, based on the findings of two retrospective cohort studies (Gill et al., 2007; Schneeweiss et al., 2007), the FDA warning on heightened mortality risk was extended to include typical antipsychotics. The European Medicines Agency (CHMP, 2008) also reviewed the available evidence in 2008 and came to similar conclusions. A follow up to the DART-AD study (a dementia antipsychotic discontinuation trial by the Dementia and Ageing Research Team (DART)) found that people with Alzheimer's disease, taking antipsychotics, had a long-term increased risk of mortality when compared to those

receiving placebo (Ballard et al., 2009b). A retrospective cohort study supports this evidence with the results suggesting that mortality risk remained over 12 months (Kales *et al.*, 2007). Conversely, a 5 year retrospective study suggests an increased mortality rate in the first 30 days of treatment with haloperidol, olanzapine and risperidone, but not with quetiapine. None of the four antipsychotics were associated with increased mortality after the first 30 days of use (Rossom et al., 2010). Taken as a whole, the evidence suggests a small increased risk of death (around 1-2% compared with no treatment (Food and Drug Administration (FDA), 2005)) associated with the use of antipsychotics for PWD. The evidence as to whether this is a short or long term risk, or whether there is a class effect, is inconclusive.

Antipsychotic use for PWD is also reported to be associated with an increased risk of stroke. Early studies informed the development of a warning from the Committee on Safety of Medicine, which advised a threefold increase of Stroke risk, for PWD, with the use of the atypicals risperidone or olanzapine (CSM, 2004). Meta-analysis has shown a significant risk of cerebrovascular adverse events (CVAE), particularly with the use of risperidone (Ballard & Howard, 2006; Schneider et al., 2006a), although the categorisation of CVAEs was loose, making it difficult to assess the severity of the adverse events. The risk is predominantly associated with risperidone and olanzapine, with a cautionary assumed class effect (Ballard & Howard, 2006). The evidence for this risk is not supported by many recent retrospective cohort studies, which have found no increased risk of CVAEs with the use of either typical or atypical antipsychotics for older PWD (Barnett et al., 2007; Chan et al., 2010; Gill et al., 2005; Kales et al., 2007). The different findings between meta-analysis and retrospective cohort studies makes it difficult to assess the risk of CVAEs with any certainty. Meta-analysis uses more robust data, but randomised controlled trials (RCTs) are likely to use a selective sub sample, whereas retrospective cohort studies are more likely to reflect the real world, but be compromised by confounding variables. The issue is further complicated with the possibility of vascular dementia (Barnett *et al.*, 2007), other side effects of antipsychotics (Ballard & Howard, 2006) or pre-existing conditions (Liperoti *et al.*, 2005) contributing to the incidence of CVAEs. Considering the evidence, the heightened risk of CVAEs, highlighted by meta-analysis, cannot be ignored. It appears

likely that the use of some antipsychotic agents, particularly risperidone and olanzapine, for older PWD can lead to an increased risk of CVAEs. The severity of the risk or whether the risk is the same across all antipsychotics, as it is assumed to be, is difficult to assess from the available evidence.

Efficacy

The evidence for the efficacy of antipsychotic use for BPSD is complex to summarise, with RCTs focusing on different BPSD, measuring different outcomes, using different drugs, different endpoints and assessing different dose levels. For example, in a study of quetiapine Ballard *et al* assessed Alzheimer's disease with agitation, over a 26 week period, measuring outcomes, principally, with the Cohen Mansfield Agitation Inventory (CMAI) (Ballard *et al.*, 2005), whereas a study by Street *et al* focused on olanzapine for Alzheimer's disease with agitation, delusions or hallucinations, over a 6 week period and primarily measured outcomes with the Neuropsychiatric Inventory (NPI) (Street *et al.*, 2000).

Of the trials conducted to establish the efficacy of typical antipsychotics for BPSD, haloperidol has been studied most comprehensively (Ballard *et al.*, 2009c). A systematic review, including five studies (too heterogeneous for a meta-analysis), suggests haloperidol is useful in decreasing aggression, but not for other symptoms of agitation (Lonergan *et al.*, 2002). A meta-analysis of typical antipsychotic use for dementia, conducted by Schneider *et al*, reported that 18 out of 100 PWD were likely to benefit from antipsychotic use (Schneider *et al.*, 1990). After the introduction of atypical antipsychotics in the 1990s, the use of typical antipsychotics for PWD has declined. However, a 2007 study examining prescribing patterns in CHs found that typicals were still used for over a quarter of all patients with dementia who were taking antipsychotics (Alldred *et al.*, 2007).

Many completed trials of atypical antipsychotics have not been published (for example, Astrazeneca, 2005) leading to suspicion of considerable publication bias, favouring studies that show positive results (Ballard & Howard, 2006). A meta-analysis, conducted by Schneider *et al* (2006), included fifteen published and

unpublished trials. They assessed the efficacy of four different atypical antipsychotics for PWD. With small statistical effect sizes found on symptom rating scales, such as the Neuropsychiatric Inventory (NPI), the findings indicate that overall efficacy from treating BPSD with risperidone and aripiprazole is modest. This efficacy was not found with olanzapine and there was a lack of evidence to enable analysis of quetiapine. Another meta-analysis conducted by Ballard and Howard in the same year found results that came to parallel conclusions to the Schneider *et al* findings above. They also separately focused on the symptoms of aggression, agitation and psychosis. The results indicated that the use of risperidone could lead to a significant improvement in aggression, particularly at a dose of 2mg per day. Olanzapine at 5-10mg a day significantly decreased agitation and aggression as a combined category and that risperidone, at 1mg, was associated with a significant improvement in the treatment of psychosis (Ballard & Howard, 2006). The Clinical Antipsychotic Trials of Intervention Effectiveness—Alzheimer’s Disease (CATIE-AD) also found olanzapine and risperidone could be effective for aggression and anger (Sultzer *et al.*, 2008) and were likely to be taken for longer periods than quetiapine (Schneider *et al.*, 2006b). Another meta-analysis indicates that there may be more substantial results with antipsychotics when symptoms of dementia are more severe (Katz *et al.*, 2007). A more recent pooled analysis found similar results to previous studies, with risperidone, olanzapine and aripiprazole showing slightly more effect than quetiapine; concluding that atypical antipsychotics effect, on average, a small improvement in global symptoms (Maher *et al.*, 2011). Overall, the evidence, although limited to a few antipsychotic agents, indicates a fairly small efficacy for the treatment of BPSD, with the atypicals risperidone, olanzapine and aripiprazole having the most effect.

Class effect

The current push for a reduction in the use of all antipsychotic agents for PWD is based on the assumption that antipsychotics are a homogeneous group that have a class effect. Although there is some evidence to support this, for example the similarities found in some RCTs and meta-analyses in the efficacy and risks across different atypical antipsychotics (Rainer *et al.*, 2007; Rosenheck *et al.*, 2007; Schneider

et al., 2005), other evidence has found differences in efficacy and risk profiles between drugs (Ballard & Howard, 2006; Huybrechts et al., 2012; Rossom et al., 2010; Schneider et al., 2006a). It is important to remember that separate antipsychotics, particularly atypicals, have very distinct pharmacological profiles (Jibson & Tandon, 1998). The homogeneous nature of antipsychotics has been questioned in relation to the treatment of schizophrenia, based on different efficacy and side effect findings between agents, conclusions indicate that antipsychotics are a heterogeneous group of drugs (Leucht *et al.*, 2009). Given the current state of the evidence it could be too soon to tell whether withdrawal of all antipsychotic agents is necessary or whether some have a lower risk profile. This raises the question of whether it was right, or too early, to initiate a reduction on all antipsychotic agents without adequate evidence, or indeed, to have started using multiple antipsychotics for BPSD in the first place.

Withdrawal of Antipsychotics

The reduction of antipsychotic use is set in the context of a dilemma about what is best for people with BPSD and their quality of life (for example, whether agitated behaviour or side effects from drugs are best tolerated day-to-day). This means that for any antipsychotic use the balance between risk and benefit has to be considered, therefore, it is a positive step that the Department of Health in England has not totally prohibited antipsychotic use for PWD. There is promising evidence that antipsychotic cessation can be well tolerated by the majority of older PWD (Ballard et al., 2009b). However, people with severe symptoms appeared to benefit from continued antipsychotic use suggesting that cessation may not be the best course of action for every patient (Declercq et al., 2013). Another study found that patients with Alzheimer's disease who had been taking, and positively responding to, risperidone for psychosis and agitation for between 4-8 months relapsed after discontinuation (Devanand et al., 2012). Taking this evidence and considering the likely reasons for antipsychotic use (the high incidence of BPSD in CHs, the negative effects of BPSD on PWD, the difficulty in coping with BPSD and the impact on caregiver burden) along with the small statistical effect sizes for efficacy on symptom rating scales, the continued use of these medications in some cases is justifiable. The Department of

Health's call for a reduction in antipsychotic use, rather than ban can be viewed as a reasonable decision.

Overall, the evidence indicates that withdrawal from antipsychotics could be manageable for those with less severe behavioural symptoms or those not positively responding to them over a long period of time, but that discontinuation could be detrimental for some individuals. One RCT found that use of risperidone for CH residents with dementia was associated with a reduction in burden for nursing staff and this continued over the 12 week trial (Frank et al., 2004). Therefore, even though only a small efficacy is indicated for antipsychotic medications, the reduction in their use may have unintended consequences for care providers; potentially increasing caregiver burden, which could create management problems for care institutions. The decision to reduce antipsychotics is based on the assumption that care providers can cope with the potential consequences of withdrawal. This brings the need for alternative strategies to manage BPSD the fore.

Other psychotropic medications for BPSD

Psychotropic medications such as, antidepressants, antipsychotics, hypnotics and anxiolytics are drugs that affect a person's mental state by altering their perception, emotions or behaviours and could be used for BPSD. Except for some antipsychotic agents there is limited available evidence, but maybe some scope, for the use of these medications for BPSD. Recently a small amount of evidence indicating that antidepressant use for PWD may be helpful for managing BPSD has emerged. A RCT found the antidepressants sertraline and mirtazapine to be no more effective than placebo for depression in Alzheimer's disease, but a secondary analysis showed that mirtazapine may have potential for BPSD; for example, by reducing agitation (Banerjee et al., 2013). Additionally, another double blinded, placebo-controlled study focusing predominantly on the use of the antidepressant citalopram for depression found improvement in some BPSD such as anxiety and restlessness (Nyth & Gottfries, 1990). There may also be a number of adverse events associated with the use of some antidepressants for older people (Coupland et al., 2011). A study tracking trends of psychotropic medication use for PWD found there had been a marked increase in the

prevalence of antidepressant use for dementia between 1995 and 2011 (Martinez et al., 2013). There is some evidence that CH residents with dementia can also have depression (Lyketsos et al., 1999; Theison et al., 2009).

Antiepileptic medications have also been indicated in the management of BPSD. Carbamazepine appears promising since it has been found to have short-term efficacy for agitation in dementia with the presence of few side effects (Tariot et al., 1998). Conversely, a meta-analysis found another antiepileptic, sodium valproate, to be ineffective for the treatment of agitation in dementia and to be associated with considerable adverse events (Lonergan & Luxenberg, 2009). A retrospective cohort study found the mortality rates associated with sodium valproate were higher than those associated with quetiapine and the same as those associated with olanzapine and risperidone when used to treat BPSD (Kales et al., 2012). Currently, there is a lack of suitable and evidenced alternative pharmacological options to antipsychotic agents for the management of BPSD.

Medication use in care homes

A study in Northern Ireland found that the use of psychotropic medication increased after CH admission (Maguire et al., 2013). Therefore, medication use in CHs for BPSD is an important issue to explore, particularly since problems have been associated with this area of practice. In Scotland medication was found to be reviewed infrequently, poorly documented and sometimes covertly administered without appropriate safeguards in place (Care Commission & Mental Welfare Commission, 2009). Poor monitoring and medication administration errors have been found to occur, with dose omissions and administering of wrong doses being most frequent. Distraction of staff when administering medications and poor knowledge about medications or administering procedures account for some errors (CHUMS, 2009).

Medications can be prescribed as regular medications or pro re nata (PRN or 'as required') doses. The use of PRN psychotropic medications in care settings can be problematic. The administration of PRN medications has been found to be highly variable (Baker et al., 2008; Usher et al., 2010), with uncertainty about clinical

responsibility, and documentation surrounding use often inadequate and vague (Baker et al., 2010; Curtis & Capp, 2003). There is also a potential for high doses to be prescribed and go unnoticed (Milton et al., 1998).

Non-pharmacological interventions

The term ‘non-pharmacological intervention’

The phrase ‘non-pharmacological intervention’ is an umbrella term widely used to encompass ‘treatments or therapies that do not involve any medication – specifically for the management of neuropsychiatric symptoms and CBs in all types of patients with dementia’ (Dickson et al., 2012). Please see Appendix A for a list of commonly used non-pharmacological interventions with brief definitions. Other terms used to describe these interventions or therapies include ‘alternative therapies’ or ‘psycho-social interventions’, however, these appear to refer to certain interventions and do not always encompass all interventions other than medication such as, for example, staff training. The phrase ‘non-pharmacological intervention (NPI)’ is not without critique; it stems from the medical model and places psychological or social interventions as ‘non’. However, for the purpose of this thesis the term ‘NPI’ will be used, since it appeared to be the most suitable to encapsulate all interventions, other than medication, under one term.

Types and Classifications of non-pharmacological interventions

As mentioned before, NPIs are recommended as suitable first line treatments for BPSD (NICE and SCIE, 2006, revised 2012). NPIs are likely to have a potential positive effect, not just on dementia care, but also for the general wellbeing of PWD (Cohen-Mansfield & Mintzer, 2005). There are multiple types of NPIs, some are used directly with PWD and some are used indirectly by changing the physical or social environment (Brechtin et al., 2013). NPIs currently being used include: aromatherapy, music therapy, herbal remedies, reminiscence, bright light therapy, doll or pet therapy, multisensory stimulation, staff education, validation therapy (empathy based) and massage. The array of existing NPIs are difficult to categorise: they can often be used in conjunction with each other; some interventions have common

characteristics; they are used for different BPSD; they can be aimed at the person with dementia or at caregivers (such as, staff education or training); they can be targeted towards individuals or groups, and they can constitute short formal or informal sessions or whole care philosophies (Douglas et al., 2004; Gitlin et al., 2012; Turner, 2005). Classification is further hampered by complexities, such as with PCC, which can be viewed as a whole approach to care, a component of other interventions or as a short time spanned intervention in certain contexts. Moreover, staff education is also viewed as an intervention, but can be promoting and teaching PCC. On the whole, these interventions are appealing, since they have capacity to enrich the lives of PWD and have a low risk profile.

As a consequence of the apparent complexities with NPIs, they have been categorised by writers in differing ways. For example, Douglas et al group them under the headings of standard therapies (such as reality orientation and validation therapy), alternative therapies (such as, music therapy and bright light therapy) and brief psychotherapies (such as, cognitive-behavioural therapy) (Douglas et al., 2004). Whereas, Turner categorises them into individual or group interventions (Turner, 2005), Gitlin et al classifies them as general or targeted strategies (Gitlin et al., 2012) and Opie et al have categorised interventions as nursing (such as, timing or approaches) or psychosocial (such as, reminiscence or walks) (Opie et al., 2002). Cohen Mansfield has broken down classifications further and categorises interventions as: social contact (real or simulated), behaviour therapy, staff training, structured activities, sensory, environmental, combination therapies and medical/nursing care interventions (Cohen-Mansfield, 2001). Brechin et al have categorised NPIs as either working to reduce BPSD directly or indirectly. The interventions aimed directly at the reduction of BPSD include functional analysis, PCC, and staff training in communication techniques. Whereas, the NPIs that have a more indirect effect on BPSD for example, by improving people's quality of life or reducing boredom include music therapy, cognitive stimulation therapy and exercise (Brechin et al., 2013). The diverse nature of the many different types of NPIs and the multiple ways in which they are categorised makes it difficult to generate and assess the evidence for their overall efficacy and use.

Person centred care

The dominance of the medical model of dementia was challenged in the late 1990's by Tom Kitwood's paradigmatic theoretical and prescriptive writings. Kitwood asks us to re-think dementia and its negative connotations. He put forward an ethical and moral argument to stop viewing the person with dementia as a reflection of their medical status and instead see the individual (Kitwood, 1997). Kitwood advocates a person centred approach where maintaining the personhood of PWD is prioritised. He argues that social malignancy and the undermining of PWD's personhood, which can occur through seventeen elements such as, ignoring, withholding, banishment, imposition, and treachery should be overcome. Instead improving PWDs experiences should be prioritised. This is achieved by meeting each person's psychological needs of attachment, inclusion, comfort, identity, occupation, and predominantly, love. Kitwood argues that the PCC approach should provide a 'serious and sustained attempt to meet their (the PWDs) psychological needs' (p 85). He does not renounce the physiological and cognitive decline in dementia; however, he does believe that the right social psychology through PCC can change the trajectory of the decline (Kitwood, 1997). Kitwood's ideas challenged the biomedical physiological causation model of dementia based on the pathology and impairment of a PWD and providing a negative view of no hope. His work started to reframe dementia by putting the person first and the dementia second. A positive, holistic care approach focusing on the individual was set out, which created new expectations for care approaches and communication techniques with PWD.

Kitwood's work on PCC has been accepted by many, but has not been exempt from critique (Dewing, 2008). Proponents have argued that limited robust evidence was used to support his claims (Adams, 1996; Flicker, 1999) and the PCC approach needs a high level of resources, and could put strain and a culpability for PWD's behaviours onto carers (Flicker, 1999). The individualised nature of PCC has been rejected by Nolan on the grounds that it is inadequate, since a high level of independence is impossible to provide in healthcare settings. Instead Nolan has put forward relationship centred care as an alternative. This approach is based on

interdependence and is promoted through the 'senses framework' which aims to value and nurture the security, continuity, belonging, purpose, achievement and significance of not only the PWD or older person, but depending on the circumstances, family carers, staff and students too (Nolan et al., 2006; Nolan et al., 2004).

Since Kitwood's work in the late 90s, PCC has become a politically correct concept and 'buzz word' used profusely in the UK's care policies, training, documents and rhetoric. The Mental Capacity Act has reflected a person centred approach by acknowledging individual rights to decision making, even if those decisions are thought to be unwise (Mental Capacity Act, 2005). However, the definition of PCC is often unclear and practice in CH settings can be far from the vision this pervasiveness creates (Brooker, 2003; Brooker, 2007). The work of Kitwood has been developed by Dawn Brooker who has incorporated a relationship centred care component into the PCC approach. Brooker has defined the contemporary PCC approach as a culture having four elements: Valuing people, providing Individualised care, recognising the Personal perspectives of PWD and generating supportive Social environments. These, together, make the VIPS Framework, which has been put forward to be used to improve PCC practice for PWD (Brooker, 2007).

In relation to BPSD, PCC can potentially be a preventative approach to reduce instances of BPSD, or to stop any behaviours that do occur from escalating, by increasing PWD's wellbeing and sense of personhood. In this way a culture of PCC can be an indirect strategy to manage BPSD. PCC is recommended as a guiding principle for dementia care (NICE and SCIE, 2006, revised 2012) and has been found to reduce agitation in PWD in residential care (Chenoweth et al., 2009). However, providing clear clinical outcomes of PCC and measuring its effectiveness can be problematic (Edvardsson et al., 2008). Overall, since the early 1990s the field of dementia care has increased in scope to include approaches other than the medical model. There has been a decided move towards PCC in the literature, guidance publications and policy arena. Alongside it is an interest in the systems surrounding the person with dementia, such as, family members, care staff and organisations. In practice PCC can be variable and the concept can mean different things to different people (Brooker,

2007). Most research attention in this area has focused on policy, hierarchical contexts of care, or service user perspectives; little has explored the role of front line care workers in delivering PCC (Innes et al., 2006). It is not clear how, or if, PCC is consciously being used day-to-day in CHs to manage BPSD.

Effectiveness of non-pharmacological interventions for BPSD

The American Psychological Association (APA) Task Force recommends that to determine sufficient evidence for a NPI, they should first be independently replicated, then undergo efficacy trials, before testing their effectiveness within clinical settings and their cost-effectiveness. Single case experiments and RCTs are the methods the APA recommend to gain good quality research to ascertain the efficacy of these interventions (Chambless & Hollon, 1998). RCTs are viewed by many as the “gold standard” way to gain robust evidence of effectiveness, particularly with pharmacological interventions. Yet, for NPIs RCTs may have to be judged on different criteria to gain appropriate evidence, since placebos and blinding would not be possible in many instances and many NPIs need to be individualised (Cohen-Mansfield & Mintzer, 2005). Traditionally the funding for NPI studies, in comparison to the heavily financed medical and pharmacological studies, has been limited. This needed to be increased if good quality evidence for the efficacy of NPIs was to be gained (Ayalon et al., 2006; Cohen-Mansfield & Mintzer, 2005). Over recent years there has been a slow but steady increase in studies into the efficacy of NPIs for BPSD.

A recent Department of Health commissioned report, conducted by the Policy Innovation Research Unit, reviewed 30 systematic reviews containing the evidence from 220 individual studies. The aim was to provide policy makers and clinicians with an overview of the evidence for the use of NPIs for BPSD (Dickson et al., 2012). The overview of reviews provides a vital summary of the majority of the available evidence in this area at this time, particularly since there are multiple varied NPIs being considered. The review prioritised evidence from Cochrane reviews and high quality RCTs over other evidence types. The overview examined systematic reviews including studies covering eight loose categories of NPIs, these were: sensory enhancement and relaxation; social contact; cognitive and emotional approaches; physical

activities/exercises; environmental modifications; behaviour management techniques; caregiver training and support, and special care units. Caregiver training and support and behaviour management techniques (such as, distraction, an increase in pleasant events, communication skills, and removal of triggers) delivered by staff were found to have the most reliable evidence for managing BPSD. Other NPIs showing a potential effect, but lacking robust evidence, were music therapy, massage or touch therapies, multisensory stimulation and physical exercise or activity. Conflicting evidence was found for cognitive stimulation therapy, reminiscence, reality orientation, light therapy, special care units and simulated interaction. There was not enough good evidence to make conclusions about relaxation, one-to-one stimulation, environmental modifications, pet/animal therapy, white noise therapy or the use of transcutaneous electrical nerve stimulation (TENS). Validation therapy was the only NPI found to have no effect in the management of BPSD. Overall, the authors concluded that the evidence was unconvincing for most NPIs due to poor quality studies, inconsistency across studies, or very little evidence available (Dickson et al., 2012).

Due to the wide range of NPIs implicated for the management of BPSD the Dickson et al review of systematic reviews is an important synthesis of the current evidence. There are some limitations associated with the review of systematic review method. Original RCTs or studies are not inspected first hand and the quality of the evidence has been prior assessed and selected by others. Additionally, the studies included in the systematic reviews used inconsistent terminology, categorisations of interventions and design of studies making results difficult to compare at systematic review and overview stages.

Some recent studies were not included in the Dickson et al overview. One such systematic review specifically concentrated on long term care settings and examined the effectiveness and feasibility of NPIs for BPSD (Seitz et al., 2012). The Cochrane risk of bias tool was used to assess the quality of studies with 40 included in the review. The authors concluded that staff training, sensory stimulation, mental health consultations, exercise and recreational activities may improve BPSD. Many studies were found to be methodologically weak. The authors called for more high quality

studies with adequate sample sizes to address the deficiency in evidence. They also highlighted the reliance a lot of the NPIs had on CH staff or external practitioners' time, which could be costly.

Two other recent studies not included in the Dickson et al review. A systematic review of four RCTs found educational interventions for staff could be effective to reduce antipsychotic use for CH residents, however the studies included used diverse approaches making definitive conclusions difficult (Richter et al., 2012). A meta-analysis for the use of NPIs targeted predominantly at family caregivers (such as, with carer training, support and self care) found them effective in reducing BPSD (overall effect size 0.34) and for improving caregiver responses to behaviours (Brodaty & Arasaratnam, 2012). Although encouraging, many interventions assessed were not targeted at the PWD experiencing the behaviours or care workers therefore, it is not clear how the benefits from these interventions would translate to CH settings. More research into educational interventions in CHs is pending for example, a study protocol for a PCC training intervention has been published recently (Whitaker et al., 2013).

There is some evidence that case specific approaches, using multiple interventions, chosen to fit each individual have been found to be successful (Ayalon et al., 2006; Bird et al., 2009). For example, an individualised treatment plan using multidisciplinary interventions, such as nursing approaches, psychotropic medication, pain management and psychosocial interventions reduced BPSD in nursing home residents in Australia (Opie et al., 2002). A briefing paper published by the British Psychological Society also advocates an individualised approach and introduces a four stage stepped care model. The model has the potential to incorporate multiple NPIs and focuses on thorough assessment with a hierarchical approach to interventions. The first step is recognising and monitoring difficulties, the second involves assessing BPSD and modifying the physical and social care environment, the third step introduces tailored interventions, and the fourth utilises specialist practitioners to provide individualised assessment and interventions. Antipsychotic medications are introduced at step four, if necessary and as part of a specialist intervention (Brechin et al., 2013). Brechin et al are not the only authors to have considered hierarchical models to manage BPSD (see

for example, Barton et al., 2005; Brodaty et al., 2003; Gitlin et al., 2012). These models, although promising in theory, can have significant barriers for their successful implementation. They can be labour intensive, require considerable resources, and be reliant on ongoing access to specialists (Gitlin et al., 2012).

Overall the evidence for the effectiveness of NPIs for BPSD is mixed. At this time, caregiver education, training and support, and behaviour management techniques delivered by staff appear to have the most evidence of effectiveness. There is a growing focus on individualised approaches and hierarchical models, which can each encompass many other NPIs. Many reviews of the evidence are unable to draw any firm conclusions for the efficacy of NPIs for BPSD. For example, a Cochrane review and meta-analysis of 18 trials examining functional analysis for BPSD showed a potential benefit, but due to varied study designs, inability to isolate functional analysis from other intervention components and a lack of CH research there was not enough evidence to draw conclusions at this time (Moniz-Cook et al., 2012). Additionally, a review of 21 systematic reviews found mixed evidence for the efficacy of NPIs for BPSD. Where positive effects were indicated, the evidence was either insufficient, contradictory or lacking in quality. Due to this, the authors made no recommendations for any particular NPIs (O'Neil et al., 2011).

The literature reflects a lack of good quality, rigorous studies into the efficacy of many NPIs. Consequently, numerous researchers are calling for more high quality research in this area (for example, Ayalon et al., 2006; Cohen-Mansfield & Mintzer, 2005; Dickson et al., 2012; Livingston et al., 2005; Seitz et al., 2012; Spira & Edelstein, 2006). Many trials fail to provide sufficient information about NPIs or the practicalities associated with their use to allow replication of the studies (Douglas et al., 2004; Hoffmann et al., 2013). Much research into the use of NPIs has used small samples, differing assessment tools and un-standardised interventions (Leone et al., 2009). Studies also often fail to consider any adverse effects of NPIs (Ayalon *et al.*, 2006); although more recently a limited number of studies are starting to assess for these (for example, Cooke et al., 2010; O'Neil et al., 2011).

Clinical challenges for the use of non-pharmacological interventions

Despite a need for more robust evidence, NPIs are generally assumed to be both safe and effective. However, they can be context specific, costly to implement and often time consuming with restricted availability (Kolanowski *et al.*, 2010). These issues raise particular challenges for their successful incorporation within institutions. A major issue with many NPIs is the lack of standardisation with their implementation (Leone *et al.*, 2009). Since, in many cases, those providing them have to give more of themselves it is impossible to replicate interventions accurately, which has implications for the ability to transfer them to different settings. For example, when delivering music therapy the person running the session may have their own way of doing it, such as, being inclusive and chatty, this may be difficult for another personality to replicate. Providing NPIs is more complex than administering antipsychotics, which are easier to deliver on an as required basis. In this respect they are not equivalent clinical alternatives to medications. The medical model of dementia care leading to the use of pharmacological interventions for BPSD, has also led to an assumption that NPIs can be comparable substitutes to medications. This interchangeability between different philosophically driven interventions could be problematic. Questions arise such as, are NPIs really a viable alternative to antipsychotics, especially for use on an as needed basis or as an emergency resource? Will busy care settings have staff available throughout the twenty four hour day to spend time with specific individuals, when they have a duty to care for all?

Lawrence *et al* conducted a meta-synthesis to explore the implementation of NPIs in CHs. They found that engaging staff and family members in the interventions, redefining staff attitudes about risks and priorities, and maintaining and supporting the provision of tailored interventions all assisted with implementation. Whereas, the extra work NPIs created, the need to reallocate staff time, and for staff to work flexibly could be barriers to implementation (Lawrence *et al.*, 2012). The findings indicated that staff members were gatekeepers to interventions, with residents unable to access them autonomously; in this way, staff are key to the successful implementation of NPIs in CHs (Lawrence *et al.*, 2012; Orrell, 2012). The time to

implement NPIs, and staff with the right education have also been identified as key factors for their successful incorporation into care settings (Kolanowski et al., 2010). However, staff at all levels have been found to be in need of more knowledge about NPIs (Ayalon et al., 2009; Cohen-Mansfield et al., 2012). To enable the flexible use of NPIs in CHs care staff time, awareness education, and staff members' adoption of different approaches, skills and attitudes may be required.

Delivering NPIs can be time consuming, which shifts costs onto the care provider. There is some evidence that NPIs could be cost effective (Matrix Evidence, 2011), however, the majority of savings are made in relation to healthcare costs, which would not directly benefit CHs. There is limited evidence indicating that occupational therapy, cognitive stimulation therapy and tailored activities could be more cost effective than standard care for PWD (Knapp et al., 2013). Nevertheless, using NPIs in care settings may require resources for extra staff, staff training, equipment and/or the use of external practitioners; meaning that care providers would be taking over the cost of interventions for BPSD from the Government. For example, while a 2mg dose of generic risperidone costs 3.2p (British National Formulary, 2011), half an hour's session of aromatherapy by an external practitioner could cost a care provider about £20, or a care assistant's wage for half an hour to deliver an intervention could be around £4, without accounting for equipment or training costs. This cost, if not taken on by care providers, may be either filtered through to residents or result in increased pressure with care providers struggling to cope without formal interventions. At the heart of the issue is whether BPSD are defined and viewed as the responsibility of the medical or the social realm. This is particularly apposite since, in contrast to health care, social care is not free at the point of delivery for those whom need it. The potential cost movement from health to social care exaggerates the contradiction where dementia is defined as a medical issue (as a syndrome or disease) and not a normal part of ageing, yet dementia care is placed within the social realm for financial resources. An issue the Alzheimer's Society is currently campaigning against (Alzheimer's Society, 2008; 2013). Furthermore, without robust evidence for NPIs, the decision for dementia care providers, about which interventions to invest time and money into is a difficult one.

Care home factors

Care home factors were first examined as important influences on resident care in the 1960s by Peter Townsend. At the time, behaviours encountered by staff included loss of memory, periodic loss of mental and physical balance, depression, aggressiveness and exceptional traits of behaviour (Townsend, 1964). As highlighted in the thesis introduction, resident profiles in CHs are now more complex than ever before and include a rising percentage of PWD (Centre for Policy on Ageing, 2012). The prevalence of dementia has been found to be similar in both residential and nursing homes with only small differences between the clinical characteristics of their residents (Shah et al., 2010); indicating that dementia care is necessary in many settings, not just those specialising in dementia (Macdonald et al., 2002). A Canadian study found care assistants in special care units were less distressed by disruptive behaviours such as, aggression, than care assistants working in facilities with no special care units (Morgan et al., 2005). Therefore, it is likely that although PWD can be found in all types of settings, their BPSD will be managed in different ways.

CH staff are on the front line of dementia care; often least trained and having to negotiate divergent needs (Banerjee, 2009; Hussein, 2010). Care work also requires workers to give something of themselves above the physical duties required; it is stressful and emotionally taxing work (Luff, 2008; Schneider et al., 2010). There is inadequate support from specialist services (Alzheimer's Society, 2007) and CHs are well known for having a high staff turnover (Castle & Engberg, 2005). This is due, in part, to the low status of care workers, poor rates of pay, minimal training opportunities and provision, caregiver burden and staff burn out (Duffy et al., 2009; Dunn et al., 1994; Royal College of Nursing, 2012). A survey conducted by the Royal College of Nursing found that many nursing homes: make inappropriate admissions; have a lack of equipment; use inadequate staffing levels, and employ an inappropriate skill mix to meet residents needs (Royal College of Nursing, 2012). There is an underlying opinion in the literature that dementia care in CHs is not the best it can be and is in need of development (MacDonald, 2005). The literature portrays CHs as

complex institutions encumbered by pressures from many sources. It is very likely that these factors have an impact on the management of BPSD in CHs.

Care home management of BPSD

Several approaches and ideas have been developed to guide and improve dementia care in CHs. These include the PCC approach (including the VIPS Framework) (Brooker, 2007; Kitwood, 1997) and the Senses Framework (Nolan et al., 2006; Nolan et al., 2004); both previously mentioned. I will briefly outline a selection of other approaches to provide an idea of the type of ongoing projects in this area. The Dementia Care Matters approach founded by David Sheard advocates the ethos that feelings matter most in dementia care. The organisation 'Dementia care matters' offers: university courses; learning resources such as DVDs; tailored training, and members of the organisation can be contracted to assist with CH development by offering observations, consultancy and guidance over one or two years with a scheme called 'a butterfly project' (Dementia Care Matters, 2013). Another project called 'My Home Life' is a social movement, which promotes quality of life in CHs. It was started in 2006 and provides best practice guidance and a voice for the care sector (MY Home Life, 2014). An education based approach has been implemented by the Barchester group of CHs; in 2009 a business school was started to offer apprenticeships and training opportunities up to Masters level for their staff as a way to improve care (Barchester Healthcare, 2013). An observation tool called 'Dementia Care Mapping' was developed by the Bradford Dementia Group to support the improvement of dementia care. The observation findings are used to understand PWD's experiences and then approaches are developed to help care staff improve the quality of residents' lived experiences (Brooker, 2005; University of Bradford, 2012). These are examples of some of the schemes and approaches available to adopt or emulate at this time. Although they all provide positive steps to improve dementia care, in the main they do not offer explicit strategies to assist in the management of BPSD or with completing care tasks when residents are agitated.

Limited research was found exploring how BPSD were managed day-to-day in CHs by care staff. Most research on NPIs focuses on their effectiveness and the prevalence or

scale of their use for BPSD in CHs is largely unknown. One study examining the prevalence of their use was identified. The study inspected the medical records of nursing home residents and found that safety focused care was the most documented NPI used. The strategies used included electronic monitoring (for residents who wandered) and restrictions in movements by placing in a chair or bed (for residents with aggression, lethargy or inappropriate behaviours). Resident education strategies were the second most frequently used NPIs, with formal therapies targeted at behaviour, comforting, and providing activity being documented as used less frequently (Kverno et al., 2008). It is interesting that safety interventions were documented to be used more than the NPIs commonly thought of in relation to BPSD such as music therapy. The risk of wandering behaviour has been identified as a difficult issue for CH staff to balance with PCC values (Robinson et al., 2007) or resident freedom (Owen & Meyer, 2009) when looking after PWD. Risk enablement for PWD has been discussed and promoted in the guidance 'nothing ventured, nothing gained; risk guidance for PWD' (Department of Health, 2010).

One Japanese study researching the management strategies used in long term care settings for BPSD used 15 interviews with care providers to inform the development of a questionnaire which was then completed by 275 long term care providers (Kutsumi et al., 2009). Four management types were identified. These were: emotional and behavioural concordance techniques such as, listening or going along with the person with dementia; acceptance and supportive techniques such as, reassurance or monitoring; restraining techniques such as, restriction of movements, confining residents to certain areas or psychotropic medications and avoidance techniques such as, ignoring or using other members of the staff team to cope. It was found that psychotropics were used most for delusions, physical aggression and sleep disturbances. The study does not report the use of any more formal NPIs such as, music therapy. The lack of formal NPIs could be due to the rigidity of the questionnaire method or the non-use of these interventions in Japan. This was the only study found, which was focusing on exactly the same subject matter as the study in this thesis; how BPSD are managed in CHs day-to-day. However, the Kutsumi et al study used different methods of data collection to explore this area than the study

reported in this thesis. Additionally, there are likely to be cultural differences between Japan and England. It is interesting that restriction of movements was found in the Kutsumi et al study as well as the Kverno et al study exploring the prevalence of NPI use in CHs (discussed in the previous paragraph).

Discussion

The expected increase in cases of dementia has turned Government, (Department of Health, 2010) academic and media attention on the best way to care for people with BPSD. Social policy and the biomedical perspective conceptualise caring for people with BPSD as a top down management problem, conversely, psychological stances advocate personhood, PCC and a bottom up approach. These factors mean CHs are caught in the middle; trying to negotiate policy, economic difficulties and individualised care approaches. This scoping review of the literature has shown that the management of BPSD has predominantly been assessed from a top down position, with much research examining the effectiveness of interventions (NPIs and/or medications) for BPSD. Although many studies take place in CHs, limited attention has been given to the usual care practices and interventions incorporated day-to-day by these settings to manage BPSD.

The current policy agenda in England, focusing on the reduction of antipsychotic medications for PWD and the use of NPIs instead, appears to be a positive turn for all affected by dementia. A reduction in the risk of adverse events and the potential of medication misuse to sedate PWD is worth pursuing. It appears that it had become routine to use antipsychotics for BPSD, even though the evidence for their use is not compelling and most use is “off label”. The emergence of this practice reflects the desperate need for successful interventions for BPSD and represents the way that the medical model has responded. Together, the possibility of debilitating side effects, increased risks of adverse events, modest efficacy and the likelihood of a manageable withdrawal from antipsychotics make a powerful argument to support the reduction in their use, which may benefit many PWD. The recent literature indicates that a reduction in antipsychotic use for PWD is occurring.

The wider consequences of the antipsychotic reduction are unknown. Reluctant prescribers, inadequate alternative interventions and the day-to-day challenges of dementia care to contend with could leave carers, and PWD, struggling to cope with the impact of this action. Since antipsychotic agents have some efficacy for PWD, the potential reduction in these medications may mean levels of BPSD will increase. This could force CHs to source and use different strategies to manage the situation; only to be confronted with problematic economic decisions and a lack of evidence and obvious choice options for NPIs. The context of antipsychotic use needs to be taken into account. Caring for PWD is physically and emotionally exacting work (Luff, 2008). The romantic notion of munificent care is not always possible when the reality of the essential tasks in care is considered. The move to reduce antipsychotics may work to revolutionise care, with individualised PCC becoming more pervasive, enabling those experiencing BPSD to gain more support. Conversely, it may intensify difficulties in dementia care, leaving those most vulnerable in a worse situation, with added problems created by limited treatment options and availability.

Although NPIs offer a promising alternative to antipsychotics they do not have the ease of use afforded by medication. The limited evidence for their effectiveness and the challenges for their incorporation into care settings raise concerns as to whether the reduction is being initiated before alternatives are readily available. As Banerjee (2009) reports, a dynamic change in the approach to dementia care and in provisions will be needed to successfully incorporate NPIs into care practices. As this could be costly however, questions arise as to whether this will be possible within the current economic climate.

There are other implications from this policy directive. Interventions are morally framed. The current moral discourse situates the use of antipsychotic agents as negative, with their use being viewed as associated with suboptimal care. This could create guilt for those caring for people who genuinely need and are prescribed these medications. Additionally, the reduction in antipsychotic use could create unintended consequences in the form of increased pressure on CHs and GPs or the use of alternative medications.

The literature reveals a tension between the medical and social realms in relation to dementia. Broadly, the management of BPSD is reflected by these contrasting views of dementia. The medical model's treatment has consisted of medications that act within the brain, whereas the social realm has utilised non-pharmacological or psycho-social interventions, which act within the social or physical environment. However, the move to reduce medications and use NPIs for dementia may be an indication that a movement away from the medical model for this condition is starting to gain momentum. Conversely, it may reflect that the medical model is adopting NPIs into their treatment range. Recommending NPIs as substitutes for antipsychotics can reflect the view that NPIs are equivalent to medications, which they are not. The current policy and research status may be indicating a move towards some middle ground, where both approaches consider the benefits of the other. This, in the future, may be the most valuable way forward for PWD.

Conclusions and knowledge gaps

This scoping review has shown that antipsychotic medications have been used for PWD, they are associated with an increased risk of adverse events and have a small efficacy for BPSD. The recent literature indicates that a reduction in antipsychotic use could be occurring however, there is a lack of evidence showing the prevalence of antipsychotic use in CHs. Whether there will be unintended consequences of a reduction in antipsychotic use is currently unknown. There are multiple NPIs (with numerous characterisations) considered for the management of BPSD, some of which are directed at PWD and some at caregivers. The evidence body for NPIs is lacking robust, good quality studies. There is most evidence for Caregiver training and support and behaviour management techniques delivered by staff. Difficulties with the implementation of NPIs into CH settings are apparent and there is limited evidence showing the prevalence or nature of their use in CHs. The support and resources available to CHs and their staff in this changing landscape will be important to assist them to cope.

In summary, there is limited evidence showing how BPSD are managed in CHs on a day-to-day basis. To address this, there is a need to research the strategies used to

manage BPSD in CHs; the levels at which they operate and how they work. With CH residents having higher and more complex needs than ever before, CH staff are under increased pressure to cope with the multiple conditions they encounter. BPSD intensify this pressure and create challenges for CHs at many levels. The current practices and interventions used, staff approaches and the major issues staff face are all of interest. Before tackling the issue of how best to manage BPSD in CHs, it is first necessary to gain foundational knowledge of how the issue manifests itself for care staff within these settings. This information will illuminate the middle ground where care staff grapple with the tensions of both the medical and the social approaches. By examining the strategies used and issues encountered by CH staff, future research will be able to target the areas and issues most in need of development.

As the literature indicates, PWD in CHs are not generally in a position to choose and employ treatments for their care. Instead, care strategies and interventions appear to be decided on, instigated and used as treatments, by people other than those with dementia. Consequently, the main focus of this research is CH wide and on care staff strategies to manage BPSD, since they often are the ones initiating and enacting interventions and/or approaches. The research questions of the study were chosen to illuminate this little explored area and as a means to provide knowledge to underpin future research. The research questions chosen to explore this neglected area and address the gaps in knowledge were:

Research questions:

- 1) What are the formal and informal strategies used to manage BPSD in care homes?
 - a) Why and how are they used?
- 2) How do various strategies work?
 - a) And for whom?
- 3) What resources and sources of support are available to assist care home staff to manage BPSD?
 - a) How are they used?
- 4) What is the prevalence of psychotropic medication use in care homes?

This study aimed to explore the use of the formal and informal interventions and strategies employed within CHs to manage BPSD. In doing so, it will address the current lack of knowledge about how CHs and their staff view and manage BPSD on a daily basis. This is important, since it is only then that an idea of the issues, needs, difficulties and areas for future attention can be identified and acted upon to improve dementia care.

'Formal strategies' refer to any course of action that was explicitly and/or deliberately used to manage BPSD in CHs. 'Informal strategies' refer to any actions that were conducted to manage BPSD, but were not part of an officially acknowledged course, including implicit actions.

Chapter 3: Methodology and Study Design

Introduction

This study sought to explore the management of BPSD in CHs as thoroughly as possible. Recognising that the methodological approach employed for the study would shape the findings I would be able to obtain, a pragmatic approach was adopted to inform the research and allow the best method/s to be chosen to address the research questions. This chapter will define pragmatism and set out the strengths and limitations of this approach for addressing these questions. The literature review highlighted gaps and ambiguities in the understanding of the management of BPSD within CHs. Proponents from the broadly positivist biomedical approach have focused on the efficacy of antipsychotics or NPIs for reducing BPSD. Whereas research stemming from largely constructivist viewpoints centres on PCC and resident behaviours as expressions of need. Little attention has been given to the middle position where aspects from each approach are contended within the day-to-day care for people with BPSD. The prevalence of antipsychotic medications, the nature and use of NPI in CHs, the place of psychotropic medications in relation to other strategies, and the factors that assist staff to manage BPSD were all aspects identified as needing exploration in CHs.

To address this largely neglected area, an exploratory study searching for wide ranging description and an in-depth understanding of strategies commonly used in CHs is fundamental to the research aim. This chapter does not explain how the study was conducted; instead the research processes undertaken are set out in chapters 4 and 5. In this chapter I present a rationale for the choice of pragmatism as a guiding approach for this research and for the use of a mixed methods design in this topic area. The study design is outlined before the methodological challenges accompanying these approaches are examined. A consideration of the effect of my values, standpoint, education and experiences on the choices made about the implementation of the research methodology and design is included. The assumptions inherent in researching the management of BPSD as a topic and those stemming from

the use of a pragmatic approach and mixed methods design are examined at the end of the chapter.

Finding the right approach for this study

To find a suitable approach for this study the research questions were first reconsidered to consider the best way to answer them. To reiterate, the research questions for this study were:

- 1) What are the formal and informal strategies used to manage BPSD in CHs?
 - a) Why and how are they used?
- 2) How do various strategies work?
 - a) And for whom?
- 3) What resources and sources of support are available to assist CH staff to cope with BPSD?
 - a) How are they used?
- 4) What is the prevalence of antipsychotic medication use in CHs?

The diverse nature of the research questions created a dilemma; what would be the best way to design a study capable of answering them all and allow a satisfactory exploration of the management of BPSD in CHs? To fully comprehend the freedom from any philosophical boundaries, even from more blurred and permeable ones, that adopting a pragmatic approach allowed it is necessary to explore the nature of some of the beliefs underpinning some schools of thought.

Philosophical and methodological debates

The traditional approaches to research methods have been viewed, by some, as belonging to two polarised paradigms; broadly known as positivism or constructivism (Tashakkori & Teddlie, 1998). However, although this simplistic viewpoint is used here as a way to illustrate differences, in practice these approaches can be considerably more indistinct and blended. Positivism has, in the past, been the dominant position in Western culture and is, in the main, linked to quantitative methodology (Johnson & Gray, 2010). The traditional philosophy underpinning of positivism accepted the

presence of one true reality, which can be researched without influencing it; thus, when conducting quantitative research the researcher attempted to objectively detach themselves and their values from the entity under study and from their data analysis (Crotty, 1998). The beliefs underlying the use of quantitative methodologies value science, empirical investigation, measurement, objectivity and truths (Sarantakos, 2005). The methods utilised for this approach typically obtain numerical data, which is analysed by the use of statistics. More recently a reworking of positivism; postpositivism has emerged, which acknowledges the goal of an absolute truth is not obtainable when studying human behaviour, yet still uses scientific methods (Creswell, 2003).

The second methodological paradigm can be underpinned by many positions, such as, constructivism or interpretivism (Denzin & Lincoln, 2011). These perspectives portray a wide range of views; however, proponents of them usually use qualitative approaches and acknowledge the subjectivity of their prior assumed ontological position in the research process. Qualitative approaches generally value process, meaning, context and understanding. The data collected is rich, personal and in word form, which is then, in the main, subjectively interpreted by the researcher (Mason, 1996). The philosophical beliefs for the qualitative approach typically include the existence of many truths and numerous socially constructed realities (Sarantakos, 2005). Therefore, in their purist forms, quantitative and qualitative positions have very different approaches to research and divergent, deep-seated, philosophical ideas and beliefs underpinning them.

In the past proponents from these, alleged, binary positions have clashed over their differing assumptions and methods (Tashakkori & Teddlie, 1998). The debates have been divisive and have portrayed the two positions as being incompatible; a premise that has been critiqued in recent years for being unproductive (Onwuegbuzie & Leech, 2005). Assertions have been made that the boundaries between qualitative and quantitative positions are less absolute than the portrayed polarity would lead us to believe (Johnson et al., 2007). In recent times the argument that both types of research have value and can be utilised alongside each other to address complex research problems has gained support (Creswell & Plano Clark, 2011).

Adopting a pragmatic approach

Proponents of the pragmatic approach argue that allegiance to one paradigm (such as, positivism or constructivism) and the associated assumptions about the nature of reality and knowledge connected to it can have negative consequences on research (Morgan, 2007). Loyalty to one way of finding out about the world can limit the potential of a research project by restricting possibilities. This is particularly so when philosophical assumptions constrain the choices of research focus, research questions and the methods to be used. Placing top down boundaries on research decisions in this way has been critiqued by Morgan who argues that adhering to rigid philosophical assumptions to guide the research process can restrict the scope of knowledge that can be gained. Morgan also argues that the assumption that knowledge types are incommensurable can further constrain the potential for knowledge by limiting the researcher to one methodology thereby reinforcing these divisive boundaries (Morgan, 2007). To remedy these issues Morgan campaigns for a pragmatic approach in which commitment to one philosophical paradigm is replaced by allowing the research project itself to be the driving factor. Morgan's proposed approach allows a free and flexible style whereby the most salient issues related to the research topic and questions lead the decisions, and not adherence to prescribed philosophical assumptions. Thus, for this exploratory study into the complex area of the management of BPSD in CHs, which is situated between the biomedical and social spheres, the pragmatic approach was particularly appropriate since it afforded me the freedom to choose what I judged to be the most apposite research method/s to better illuminate this area. Therefore, to explore this area adequately and answer the differing types of research questions, which had emerged from the literature a pragmatic approach was employed (Onwuegbuzie & Leech, 2005).

Pragmatism is a philosophy which arose from the work of Peirce, Mead, James and Dewey (Creswell, 2003); its proponents focus on the practical consequences of an idea, theory or proposal. Generally pragmatists believe an external reality exists independently from the individual and that there are many explanations of that reality and not one absolute truth (Tashakkori & Teddlie, 1998). Since no one method is

prioritised within a pragmatic study, the most suitable methods/s to best answer the research questions can be utilised and thus, allow the most appropriate data to be collected (Tashakkori & Teddlie, 1998). Cherryholmes states that pragmatic research is:

“driven by anticipated consequences. Pragmatic choices about what to research and how to go about it are conditioned by where we want to go in the broadest of senses. Values, aesthetics, politics, and social and normative preferences are integral to pragmatic research, its interpretation and utilization” (Cherryholmes, 1992, p.13).

Thus, rather than a prior allegiance to one philosophical stance or method, research choices are driven by the researcher’s judgement of, for example, the needs of the research question, the constraints and affordances of the setting, and the purposes of the research. The use of mixed methods is included as a viable research design; as long as the methods used are optimal to best answer the research questions. An inherent assumption of this approach is that multiple sources and forms of evidence derived from differing paradigms can be brought together to illuminate an issue. There are proponents who would argue this is not possible or desirable, since the philosophical underpinnings of separate paradigms, methods or data types are not compatible (for example, Blaikie, 2000; Guba & Lincoln, 1994; Kushner, 2002). For example, how can subjective data in the form of words derived from the actors themselves and generated through interactions (such as, from interviews) be valued as a truth as well as (assumed) value free numerical data arising from questionnaires or experiments? Taken back to their philosophical roots these types of data are vastly different and rely on different epistemological and ontological beliefs.

However, pragmatic researchers are more concerned with addressing the research problem or questions in a way that works than whether philosophical beliefs are commensurable. This means respecting, acknowledging and connecting with the associations and assumptions different approaches bring, but using them to enhance the knowledge that can be gained rather than limiting or constraining it (Greene, 2002). Pragmatists generally believe that reality is a process, constantly evolving and

that inquiry into this process can be conducted with multiple tools or methods (Maxcy, 2003). Baert argues that methodological unity within disciplines is a myth and that methodological pluralism can enhance the social sciences by eliciting new viewpoints on any given topic (Baert, 2005).

In this way the use of a pragmatic approach sidesteps the need for researchers to align themselves to any philosophical position with a claim to knowledge. The approach proposes that underlying philosophical beliefs can be constraining and that by circumventing them methodological freedom can be obtained. Thus, the design and methods chosen for this study were those that appeared to be the most suitable to thoroughly answer the research questions and illuminate the management of BPSD in CHs; regardless of inherent ontological and epistemological differences.

Philosophical debates are circumvented in pragmatic research since, they are perceived as superfluous. However, although the underlying philosophies of methods are no longer relevant, the link between the methods used and the type of data that can be obtained cannot be ignored.

Study Design – Mixed Methods

By adopting the position of pragmatism for this study, the design was initially an open field; allowing the research questions, along with influences from my personal experiences, education, standpoint and values, to dictate the methodological and method choices. The research questions emerging from the literature review were dissimilar in nature and this impacted on the choice of study design. Using a qualitative design would gain the in-depth data needed to answer ‘why,’ ‘what’ and ‘how’ questions, but lose any sense of a broader scope of exploration. Whereas, using a quantitative design would allow ‘how many’ (prevalence) and ‘what’ questions to be answered but lose depth in the data. Although the dichotomy between qualitative and quantitative designs (as well as philosophical beliefs) appears clear, in practice the boundaries can be complex, blurred, and blended and are not always rigidly upheld. For example, when what would be thought of as, a qualitative method is used in a quantitative way such as, content analysis on interview transcripts or highly structured observations.

Mixed methods research has been put forward, by some, as an additional third research choice alongside both quantitative and qualitative methodologies (Creswell, 2003; Johnson & Onwuegbuzie, 2004). The methodological positions can also be thought of as residing along a continuum, moving through from qualitative to mixed methods to quantitative (Teddlie & Tashakkori, 2010). Mixed method research typically has pragmatic assumptions at its foundation (Johnson et al., 2007). Mixed methods research can take many forms. Studies can utilise more than one method from the same philosophical paradigm or use methods from divergent ones. Research methods may be used sequentially or concurrently (Creswell & Plano Clark, 2011). Methods can be mixed at different stages of a study. Data from each method can be analysed separately or conflated. They can be given equal status within a study or differ in significance with one type dominating over another (Johnson et al., 2007). Onwuegbuzie and Leech argue that by allowing researchers to be flexible and holistic in their approach, mixed methods research can be seen as the 'gold standard' compared to the purist use of one methodology (Onwuegbuzie & Leech, 2004). Johnson, Onwuegbuzie and Turner define mixed methods research as

'an intellectual and practical synthesis based on qualitative and quantitative research; it is the third methodological or research paradigm (along with qualitative and quantitative research)' (2007, pg 129)

Therefore, taking the premise that there are multiple truths about the social world, a study design that allowed the representation of multiple perspectives was a legitimate prospect. The use of mixed methods to answer the differing sorts of research questions appeared the most appropriate design choice. The design could be tailored to the research questions, which collectively demand descriptive, explanatory and prevalence data to answer them. With this type of design, both qualitative and quantitative methods can be used to address the research questions (Tashakkori & Teddlie, 1998). Since, in its pure form, every method has its own underlying assumptions, strengths and weaknesses, using different methods would be beneficial to illuminate separate aspects of the management of BPSD; contributing to an increased knowledge and enhanced understanding (Creswell, 2003). In this way

intrinsic weaknesses in one method could be overcome by the advantages of a different method (Denzin, 1978).

The use of both, qualitative and quantitative methods were chosen for this study; creating a mixed methods design. Using diverse methods could, in part, reflect the dual approaches to dementia care; the biomedical and the social. It was hoped that by using a mixed methods design, the differing types of data gained would have a wider range and work to complement each other by providing different views of the management of BPSD and supplying a more comprehensive picture overall. Tensions are inherent in the mixed methods approach, yet I believe the benefits of gaining multiple views of the CH management of BPSD outweigh the disadvantages of using different philosophically driven methods. The implications of the ontological and epistemological differences underpinning the methods utilised in this study are examined throughout this thesis when discussing the research findings.

Study design

Before I discuss the rationale for each method chosen to be used in this study I will first set out the nature of the overall study design. Since little is known about the nature of the management of BPSD within CHs this research was exploratory. The study was initially designed to include three sequential phases. However, as with all research, this study has some limitations. The preliminary study design started with a postal survey phase to elicit information from many sources and answer the 'what' and 'how many' questions. This was to be followed up with a second psychotropic medication mapping phase to gain precise prevalence data to address further the 'how many' question and then a third case study phase to generate in-depth data to answer the 'why' and 'how' questions. The central medication mapping phase aimed to gain an accurate prevalence of psychotropic medication administration in up to 10 CHs by accessing every resident's Medication Administration Records (MARs). The numerical data obtained would have answered the prevalence question definitively in a subset of CHs; enabling an interesting discussion comparing the accurate findings to the survey data reflecting manager perceptions of antipsychotic use. It would have also illuminated medication administration details on a CH wide scale. However,

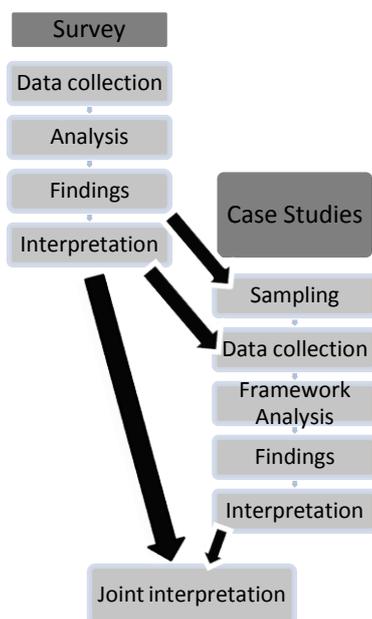
during the process of gaining ethical approval it became apparent that due to the Data Protection Act (The Data Protection Act, 1998, amended 2003) MARs are the property of whom they relate to and not the CHs. If accurate prevalence data was to be obtained, to adhere to ethical principles, individual consent or consultee declarations would have had to be gained for each CH resident. For residents lacking the capacity to consent to the research, guidance would have had to be sought from a potential personal consultee (close family member or friend). The consultee would have had to have been contacted and asked for their opinion of whether the resident in question would have wanted to participate if they had had mental capacity (Mental Capacity Act, 2005). The prospect of gaining a 100% consent or consultee declaration rate from the CH residents to enable a precise CH prevalence of psychotropic use was unlikely and if attempted, the time needed to negotiate it was prohibitive. These factors made the medication mapping phase of the research untenable. Instead, to design a manageable study, the medication mapping phase was incorporated in the case study phase of the research and limited to a sample of residents. Therefore, the final study design had two distinct phases:

Phase 1: A postal survey

Phase 2: 4 case studies: including interviews, participant observation, medication mapping

Each phase contributed information to address differing research questions in different ways. A model of the final study design and how the phases interact is set out in figure 3.1. The study's two phases were conducted sequentially (Creswell, 2003) with the findings from the first survey phase informing the sampling of the second case study phase. The results from each phase were analysed and interpreted separately before a joint interpretation stage to synthesise the findings from the whole study. Equal credence was given to the data gained from each phase of the research. However, the qualitative second phase was a much larger stage of the research and contributed considerably more data than the postal survey employed in phase 1.

Figure 3.1: Model of study design and interactions



Rationale for postal survey: phase 1

To answer the ‘what’ and ‘how many’ questions adequately (questions 1 and 4, see page 61 in this chapter), knowledge deriving from a wide range of CHs with different characteristics would be required, and therefore, a method capable of eliciting data from a large sample of CHs would be needed. A survey appeared to be the most appropriate method. Surveys can ask a multitude of different questions and target a large number of respondents, efficiently, in a short space of time (Robson, 2002; Singleton & Straits, 2005). Thus, using a survey would allow data to be derived directly from a large sample of CH managers, with firsthand knowledge of managing BPSD (Denscombe, 2003) and enable comparisons across the same variables from a large number of CHs (De Vaus, 2002). These features signify that the survey method would be an ideal choice to acquire an idea of the prevalence of antipsychotic use in CHs and to obtain knowledge about the management of BPSD from many CH managers. The information attained would provide a broad overview of the range and types of ways BPSD are managed in CHs and the behaviours that pose difficulties for CH staff. This information was important to provide a picture of the current status quo in CHs, while also providing a sampling frame for phase 2 of the study.

Postal surveys were chosen over electronic surveys (email or online), since postal addresses were available from CH directories in the public domain and email addresses were not. Additionally, postal surveys arrive physically on the manager's desk and are not easily deleted at the click of a button. Their physical presence also makes them portable and allows other staff members to be consulted about the questions. Telephone surveys were considered, however, due to the large sample size needed and the likely difficulty in accessing managers directly at the time of the call, this method was considered unfeasible. Postal surveys to CH managers have, in the past, been successfully used to gain an overview of CH issues and to provide a context for further phases of a study (for example, Froggatt & Payne, 2006) and this study aimed to achieve the same. Due to the logistics of completing the two phases of the overall study in the available timescale there was no survey follow up stage.

The short survey for this study was purposely designed to be quick and simple to fill in (see Appendix B). This design was intended to place a minimum demand on CH managers to complete in order to enhance response rates. The questionnaire questions were primarily standardised. The questionnaire was comprised of 3 dichotomous questions, 3 open ended questions asking for numerical data, 1 listed multiple-response question with an additional free text option and 1 open question asking for free text responses. The survey phase had a cross-sectional design aiming to provide a snapshot of the field at one specific time. The design aimed to identify the similarities and differences between CHs regarding the management of BPSD and to obtain the prevalence of relevant factors across CHs. Global sampling was employed; sending the survey to every CH looking after older people or/and PWD in four counties within the Eastern region. The four counties were purposively chosen to include rural, urban, affluent and poor areas. The data derived from the survey were, as mentioned before, mostly numerical and analysed in SPSS. There were two questions eliciting free text responses, these were categorised (see Appendix C), coded and also analysed in SPSS. Chapter four discusses the survey sampling procedure, along with further information about how this phase was conducted and how the data were analysed.

Although a suitable choice for providing data from a breadth of CHs the survey method does have some drawbacks. The data obtained is of a superficial level, which, although good for providing information from extensive sources, cannot acquire small-scale details and a depth of knowledge (Denscombe, 2003). Response levels from postal surveys to CHs can be low (for example, Gage et al., 2012). Additionally the researcher has no control over the accuracy of the responses gained; socially desirable answers may be portrayed, questions may be misunderstood by respondents or partially filled in questionnaires may be returned (Singleton & Straits, 2005).

By designing a two phase mixed methods study some of the aspects deficient in the postal survey method were able to be addressed by the case study method. Whereas surveys are appropriate methods to gain quantitative data and answer 'what' and 'how many' questions, case studies are a particularly suitable method to answer 'why' and 'how' questions where rich in-depth data is needed to answer them (Eisenhardt & Graebner, 2007; Yin, 2009). I now move on to justify the choice for case studies in phase 2 to address the 'why' and 'how' questions.

Rationale for case studies: phase 2

The aims for phase 2 of the study were to gain in depth knowledge and understanding of how CHs manage BPSD within the settings in which they occur and to identify the factors that help with this. The research questions to be answered in this phase were

- 1) What are the formal and informal strategies address used to manage BPSD in CHs?
 - a) Why and how are they used?
- 2) How do various strategies work?
 - a) And for whom?
- 3) What resources and sources of support are available to assist CH staff to cope with BPSD?
 - a) How are they used?

Several method options were considered to answer the research questions for this phase. Conducting interviews with staff members would allow staff perceptions and

experiences to be gained. However, since factors influencing the management of BPSD in CHs are complex and there were likely to be environmental or medication effects, it was probable that interviews with staff would not illuminate the whole issue. Interviewing residents with BPSD was given careful consideration; yet, since this study focuses on the management of BPSD and this is predominantly played out by CH staff and not residents, it appeared more relevant to explore staff perceptions. Additionally, due to the focus of the study, the residents to be targeted for interviewing would have considerable BPSD with many lacking the mental capacity to fully understand that they were taking part in research. Impairment of verbal communication skills and memory were also likely to create difficulties for both the person with dementia and researcher in an interview situation (Hubbard et al., 2010). Observations on their own were also considered, but there were concerns that without exploring the actors' perceptions within the CHs themselves the understanding gained through my interpretations of the observations may be incorrect or deficient. Furthermore, without looking directly at the MARs, details of the psychotropic medication use for these symptoms would be largely unknown.

Therefore, due to the lack of meaning in separating the management of BPSD from the CH context in which it is played out, using the case study method appeared to be the most appropriate choice to answer the outstanding 'why' and 'how' questions (Yin, 2009). While also adding a different type of data to further illuminate the 'what' questions (question numbers 1 and 3). Since the management of BPSD is a broad and complex topic, to gain understanding of it the research approach needed to be holistic and to take into account many contextual factors (Ritchie & Lewis, 2003). Case studies are particularly suitable to study complex practices in real life settings, in which the researcher has little control, such as within CHs (Yin, 2009). As case studies are unique to the circumstances of the time and place they are situated in the findings cannot be generalised, instead analytical insights and inferences can be made (Thomas, 2011). There are some limitations of the case study method: due to the consideration of the specific contexts of actions the studies cannot be replicated; access to field work sites can be difficult; the presence of the researcher can change the data; the findings can

be subjective, and issues may only relate to the individual circumstances of each case (Sarantakos, 2005).

However, case studies are suitable to use when there is no satisfactory perspective/s providing a full picture of an issue (Eisenhardt & Graebner, 2007; Ritchie & Lewis, 2003); in this case, with the actuality of care practices in CHs largely unknown, neither the biomedical or PCC approaches offer an adequate view of the management of BPSD. By locating this study in between these two approaches and using the case study method it was hoped that understanding could be gained of how BPSD are managed naturally within the settings in which they usually occur. Case studies also enable data to be generated to answer the research questions requiring in-depth data; data that the survey could not provide.

Stake argues that 'the case' should be identified first and then methods should be chosen to study 'the case' (Stake, 2005). In this study the boundary of 'the case' was the management of BPSD in CHs. Multiple exploratory and descriptive case studies were chosen for this study (Yin, 2003), with each case study taking place at a different CH. Using multiple cases enabled stronger evidence to be obtained, since comparisons of the phenomena from different contexts could be gained, enabling a broader exploration of the research questions and contributing to more robust theory building (Thomas, 2011; Yin, 2009).

Phase 2 was the largest phase of this study and was comprised of 4 case studies. To enable the generation of relationships and provide enough time for CH approaches to become familiar, approximately 6 weeks was allotted to conduct each case study. Since little is known about the current situations in CHs in light of the changing policy arena and there was uncertainty about the saliency of the management of BPSD within CHs, this research was exploratory. Consequently a predominantly inductive strategy was chosen to examine this largely unknown entity through first collecting data and then using it to understand how BPSD manifests in CH settings and how CHs respond (Blaikie, 2000). Attention was given to strategies operating at all levels of the CH environments, including the organisational, pharmacological, staff team and individual staff member interventions.

Case studies can encompass many methods and use multiple sources of evidence (Yin, 2003; 2009), which makes them suitable to gain a more in-depth understanding of the management of BPSD and consequently more adequately answer the 'why' and 'how' questions. Using multiple data sources within cases improves the strength of evidence gained from each case study (Eisenhardt, 1989) and increases construct validity (Yin, 2009). Case studies can elicit different types of knowledge by using different methods and data sources. For this study unstructured observations, interviews and psychotropic medication mapping were chosen to illuminate the management of BPSD from different aspects. By choosing to use multiple methods within the case studies comparisons of different evidence types could take place, which worked to strengthen the overall findings. For example, observations worked to interrogate interview and medication mapping data. In the same way, observations may not reveal the meanings that actors give to their behaviours (Knight, 2002), thus, by also employing interviews with CH staff, staff actions could be explored further and observations of behaviour could be explored.

The sampling strategies for the case study phase of the research are set out thoroughly in Chapter 5. Purposive sampling from the survey response pool was chosen to enable the most information rich CHs to be included in the case study phase and to best answer the research questions and optimise the findings. The rationales for the decisions to use observations, interviews and medication mapping will now be discussed in turn.

Unstructured Observations

Since it was likely that the environment would interact with and impact on the complex interrelations of managing BPSD, spending time within CH settings and gaining a close view of daily life through observations seemed to be an essential method to include. Using fieldwork observation in the cases would allow access to the intricacies of events as they unfold (Singleton & Straits, 2005). Therefore, to gain a contextualised view of the formal and informal strategies used to manage BPSD, how they work and to allow interactions within CHs to be studied flexibly in their natural

settings, unstructured observations were chosen as an appropriate method (Sarantakos, 2005).

Observations of the management of BPSD within the CH context generated knowledge stemming from researcher interpretations. The researcher role for the observations was as an observer-as-participant (Gold, 1958; Junker, 1960), with the researcher taking on small tasks in the shared spaces of the home for example, table setting. This approach was chosen to allow the researcher a role, but enable enough freedom to focus on and follow the most relevant actions within CHs as they unfolded (Bailey, 2007). Additionally, the participant observer role would increase opportunities to learn each CH's ethos, to connect with the care approaches used, to feel the atmosphere, experience firsthand particular pressures, and to gather localised knowledge to inform appropriate judgements about my observations (Singleton & Straits, 2005). The unstructured observations focused on the use of psychotropic agents, intervention use and the levels different strategies of care to manage BPSD within each CH operate at (see Appendix D for an indicative observation guide). To allow informed consent the researcher's role was overt; this position also enabled targeted observations.

The risk in adopting a participant observer role included my presence and actions changing the social milieu and order of events, thereby altering the data that could be generated (Singleton & Straits, 2005). Observations can also be: time consuming; subject to observer bias; difficult to regulate, and rely heavily on the perception and memory of the researcher (Sarantakos, 2005). Going native by losing analytical perspective in the study and becoming a pure participant was also a risk (Dewalt & Dewalt, 2011). This was offset in part by not adopting a full care worker role as part of the staff team (thus, being located as separate from the staff) and by being reflexive throughout the fieldwork phase.

In-depth Interviews

Unstructured in-depth interviews were chosen as a suitable method to explore care staff's personal accounts, perspectives and experiences about the complex issue of the management of BPSD (Denscombe, 2003). The flexibility gained from employing

this type of interview was appropriate for an exploratory study seeking to unearth complexities, ambiguities and previously unconsidered issues (Knight, 2002).

However, like observations, interviews can be subject to researcher bias and are time consuming. There is also no guarantee that interviewees will respond honestly to questions and there is a reliance on the interviewer to balance their expectations of the respondents for example, by not expecting too much or too little of the respondents (Sarantakos, 2005).

Nevertheless, the choice of unstructured interviews allowed CH staff the freedom to talk about the topics they felt were important and let the researcher adapt to the information supplied by the participants as the interviews evolved (Bailey, 2007). The interviews were used to gain staff perspectives of the issues important to them associated with caring for people with BPSD, and to obtain more insight into the observations. To ensure relevant aspects would be covered during the interviews a topic guide was created from the literature and survey responses; this was used as a rough guide to the themes to be explored during interviews (see Appendix E for an indicative interview topic guide). Interviews with participants from different roles allowed an exploration of differing staff views and feelings in relation to the management of BPSD and enabled comparisons to be made between different staff level perspectives to offer rich in-depth information, contributing to a better understanding of current practices.

By using unstructured interviews the generation of interview data could be a collaborative process between the researcher and interviewee. A non-judgemental, accepting and friendly approach was adopted to try and validate participants' responses and empower them to be a valued member of the interview process. It was hoped that this technique would make a more comfortable situation for both the participant and researcher, by reducing tensions within the social context of the interview. Consequently, I was hopeful that participants would talk openly and frankly about the management of BPSD allowing the generation of authentic data. Interviews with managers and care staff of all levels were used to allow multiple views to contribute to the data.

Psychotropic Medication Mapping

Psychotropic medication mapping by analysing MARs was chosen as a device to gain a detailed knowledge of antipsychotic and other behaviour, emotion or perception changing medication use in CHs. The examination of medication use has, in the past, been used to gain knowledge of the practices of medication administration (Gray et al., 1996) and to illuminate the prevalence of psychotropic medication in CHs (Macdonald et al., 2002). For each resident participant the MAR sheet from the previous 28 days of medication administration was analysed. This method was chosen to enable a close, accurate examination of psychotropic medication use, allowing a view of whether medications were administered or not, the types of psychotropic drugs prescribed, the frequency of use, 'as required' (pro re nata or PRN) use and of dosage levels (see Appendix F for medication mapping form). This enabled knowledge to be gained about the practice of administration in CHs. The observations or interviews could not provide this accurate and detailed knowledge of medication use. Additionally; these data would not be available from analysing prescription records or medication order forms. The data allowed the extent and nature of psychotropic medication use for some residents with BPSD to be illuminated. The pharmacological management of BPSD in CHs is an important aspect of the overall management of BPSD and knowledge of administration helped to provide a context for the rest of the CH data within each case study.

Data Analysis: The Framework Approach

The Framework Approach outlined by Ritchie and Spencer (Bryman & Burgess, 1994) was chosen to conduct the qualitative data analysis. The framework approach is particularly apposite for a thorough and transparent analysis leaving an audit trail that can easily trace themes back to the data source. The formal analysis started after all of the data had been collected from the four case studies. Analysis was first conducted within cases to allow a comparison between homes and identification of strategies, issues and contextual factors that may influence the utilisation of different strategies in different CHs and then conflated across all cases to illuminate common themes. Grounded Theory was considered for the analysis (Charmaz, 2006), however, due to

my experience of care work, the complex and multifaceted nature of the management of BPSD in CHs and the importance of the wider context from the literature, for example the top down biomedical model and the PCC approach in framing the findings, it was felt that the Framework Approach to analysis would be more suitable. In contrast to a Grounded Theory analysis, using the Framework Approach would not be restrictive in drawing on all aspects of knowledge, such as relevant literature and prior experiences. The analysis process is set out in detail in chapter 5.

Methodological challenges

The challenges of taking a pragmatic approach and using a mixed methods design include maintaining the rigour of each method used. By trying to utilise the strengths from each method there is a risk that none of the methods are mastered and their essence is lost. To try and offset this risk and retain the strengths present in each method, the philosophical assumptions of each method were maintained as far as possible throughout the study duration. The qualitative and quantitative data was analysed separately and the findings derived from separate paradigms were only used to enhance each other at the interpretation phase and not blended (Blaikie, 2000). By preserving the essence of each method used, the strengths of the methods and the data gained from them worked to enhance the findings in separate ways.

Rigour and trustworthiness

Critiques of the case study method are targeted at a perceived lack of rigour involved, the use of non-systematic techniques and researchers portraying biased views (Yin, 2009). To counter these critiques, and ensure that the qualitative aspects of the study had credibility, it was important to conduct the research and write it up in a manner that was both rigorous and trustworthy. This was achieved in several ways.

Throughout this thesis I have attempted to: be explicit and transparent about how the case studies were conducted (see chapter 5); set out the rationales for decisions throughout the research process; portray how data were handled and analysed, and include the discussion of any findings contrary to my analysis interpretations (Denscombe, 2003). Therefore, this thesis includes a lot of information about the

rationales for, and processes of, the study components. For example, explicit information about the sampling decisions and process is provided in Chapter 5. This audit trail approach also assists in helping you, the reader, to assess the credibility of the study.

The time spent at each case study site (between 4-6 weeks) assisted in counteracting instances of reactivity from the participants and respondent bias, since participants had time to get to know the researcher well (Robson, 2002). Sessions with my supervisory team members enabled discussions and reflective examination to take place about the study decisions, justifications, processes and interpretations; this reduced the likelihood of researcher bias (Creswell, 2003). The triangulation of data also contributed to the trustworthiness of the results by corroborating or challenging the findings from one method to another (Sarantakos, 2005). Recording interviews, transcribing them verbatim and making comprehensive observation notes helped to increase the rigour of the study (Robson, 2002). Using the Framework approach meant that a robust and transparent data analysis process was conducted. This approach requires a thorough and lengthy engagement with the data, which involves the researcher immersing themselves in it in a structured way; thereby supporting the development of authentic interpretations that draw on the whole data set. Additionally, the framework allows for the ready identification of patterns and themes emerging from the data and becoming key aspects of the findings across methods, participants and/or case study sites, meaning the interpretations can easily be evidenced and assessed (Bryman & Burgess, 1994). To enable readers to assess the credibility of qualitative research it is also important to discuss the influence the researcher had on the study and the assumptions that underpin it (Denscombe, 2003). These aspects are discussed in the next two sections of this chapter.

Researcher Influence on Study Design

The idea that social researchers can position themselves completely on the periphery of a study is misguided, since research is never free from the presuppositions of those conducting it (Baert, 2005); I hope to enable the reader to assess the impact I had on this study by acknowledging these presuppositions in an upfront way.

The choice of topic, the way the topic has been approached, the development of the research questions, the judgements guiding the study design, how the fieldwork phases have been conducted, and the analysis and interpretation have all been influenced by my experiences, background, knowledge and inherent beliefs and assumptions. It is likely that another researcher would have brought different skills and associated beliefs to the study, would have viewed the topic differently and designed and conducted a different study. Since, my background, my experiences and who I am has influenced every decision throughout this study it is necessary to describe a bit about myself so the reader can see how my past work and education has influenced this study. I have a working class background and have a lot of care worker experience with older people. I have worked in a nursing home, residential home and at the time of the study still worked part time in very sheltered accommodation with older people. My educational background includes a BSc (hons) degree in psychology and sociology and an MA in sociological research. These degrees included modules in both quantitative and qualitative research methods and analysis.

The inclusion of both qualitative and quantitative modules, including their philosophical underpinnings, in my education gave me knowledge and a sense of appreciation for each research paradigm and approach. My lack of allegiance to any one knowledge paradigm has allowed a flexible approach to the research design resulting in the adoption of a pragmatic approach. I believe that multiple truths can be found about the same social reality. This allowed me the freedom to prioritise the research questions above one particular method or school of thought.

My care work experiences have led my choice to focus on the CH and care worker activities, perspectives and issues in relation to managing BPSD rather than resident perspectives or experiences of BPSD. Researching the issue from a CH staff perspective was important to me, since it illuminated the front line of the management of BPSD; a middle road between a biomedical treatment approach and a resident need perspective. This middle road perspective grapples with the pressures from both a top down and a bottom up perspective encompassing the tensions emerging between the two. Insider knowledge gained from my care work experience about how issues such as staff pressures, organisational constraints, role limitations

and the needs of the residents can impact on care made this an interesting research angle for me to prioritise. I was keen to examine the CH and care worker perspectives on this issue. Much of the literature covering antipsychotic and NPI use for BPSD view this issue from a top down treatment perspective (for example, Ballard et al., 2011; Ballard et al., 2008; Deudon et al., 2009). Other literature prioritises different care approaches (Kitwood, 1997; Nolan et al., 2004).

Assumptions

There are inherent assumptions underlying the way this topic of study has been approached. First it is assumed that BPSD are difficult for CH staff to cope with or manage and second that strategies or interventions are used or needed to manage them. These assumptions have stemmed from the Biomedical, psychological and social literature already surrounding the management of BPSD; particularly the literature on antipsychotic use for PWD and the search for effective NPIs for BPSD.

The pragmatic assumption that valid truths can be derived from methods stemming from differing paradigms and work together to illuminate one issue is at the heart of the study design. The design relies on the assumption that many forms of data, from multiple sources can build up knowledge and understanding of a complex issue in a satisfactory way. The design enabled data to be obtained from multiple sources:

- Postal surveys eliciting broad, predominantly standardised quantitative data
- Interviews providing qualitative data from participant accounts generated through interactions
- Medication mapping, deriving data from written numerical and worded documentation
- Researcher interpretations stemming from unstructured participant observations generating qualitative data

To foster this assumption, the study design only synthesised the data at the interpretation stage, thereby preserving and respecting the underlying assumptions in each method. In this way, the essence of each method would be kept intact and by extension, the credibility of the data should have been retained, working to build up a

detailed understanding of the management of BPSD in CHs from many differing sources.

Summary

This study required an approach that would address the diverse nature of the research questions and enable the management of BPSD in CHs to be explored thoroughly. Adopting a pragmatic approach enabled the research focus and questions to be prioritised and the most suitable methods to be chosen to answer them regardless of their underlying philosophical assumptions. The pragmatic premise that there is one external reality, which can be interpreted in multiple ways allowed a mixed methods design to be utilised. Methods generating both qualitative and quantitative data were chosen as the most suitable to answer the research questions demanding different data. The survey phase was designed to gain quantitative data to answer the 'what' and prevalence questions; this data would offer a broad view of the management of BPSD in CHs showing the scale and range of the issue. In contrast, to compliment this data and to answer the 'why' and 'how' questions the case study phase was designed to elicit in-depth qualitative data to provide a deep, complex understanding of this topic from within CHs. The different types of data generated would show the management of BPSD from different standpoints. The two phases were employed to each illuminate the management of BPSD in a different way using the strengths from each method to enhance the overall findings. Utilising a pragmatic approach and employing a mixed methods design would help to facilitate a more comprehensive exploration of the management of BPSD in CHs. By honouring the underlying philosophical position of each method, the findings generated should be both reliable and work to provide transferable analytical insights and inferences about the management of BPSD in CHs.

Chapter 4: Postal Survey

Introduction

Chapter 3 outlined the rationale for a two phase study design. This chapter sets out the first phase of that design: the postal survey. The postal survey method typically stems from a post/positivist approach where numerical data is gathered to obtain data from multiple sources. This type of knowledge can be helpful to provide a view of the field, which can be particularly useful in a changing climate. The push to reduce the use of antipsychotic medications for PWD, along with the recommendation from NICE (NICE and SCIE, 2006, revised 2012) to use NPIs as first line treatments to manage BPSD may mean current practices within CHs are altering at this time. Gaining information from a large proportion of CHs on this issue provided data showing the range of cases and enabled a view of the situations within CHs, at the time of data collection in late 2011, to be obtained. This data was important to determine the behaviours perceived by CH staff as difficult, the NPIs used and antipsychotic prescription levels over a vast number of CHs. As part of the wider study this knowledge also worked to inform the sampling for the case study phase and to add to the interpretations of this issue as part of the whole study findings. When employing the survey method the majority of the work takes place in the questionnaire design, the coding and inputting data to a statistical package. Therefore, along with reasserting the research questions for phase 1, this chapter sets out: the questionnaire sampling frame, the design process, the data collection procedure, the mode of analysis, the results and a discussion of these.

Objectives for Phase 1

The prevailing objective of the postal survey phase was to gain data that would show the range of cases from many CHs in relation to the management of BPSD, thereby establishing the current state of affairs in CHs in the East of England. By doing so an overview of behaviours that are challenging for CH staff to manage, the strategies employed to cope with these and antipsychotic prescription levels across a vast

number of CHs would be obtained. The research questions addressed by this phase are presented below. The underlined sections are not addressed by the survey phase, but are concentrated on within the case study phase (see chapters 5, 6, 7, 8 and 9).

- 1) What are the formal and informal strategies used to manage BPSD in CHs?
- 4) What is the prevalence of antipsychotic medication use in CHs?

The survey was designed to obtain wide-scoped data to be used, both, to gain a breadth of data derived from many CHs to illuminate the management of BPSD and as a starting point for the larger second phase of this study. The specific objectives for this phase of the study were to obtain an estimated prevalence of antipsychotic prescriptions in CHs, and to explore which NPIs are currently used within CHs to help cope with BPSD. The behaviours managers perceived as difficult for staff members to manage in CH settings were also explored. To develop a survey able meet the above objectives and address the research questions many factors were considered; the process of designing and conducting the survey is discussed in the next sections.

Sampling frame development

The population of interest for the survey sample was CHs looking after PWD. CH managers were targeted as the most apposite people to answer the questionnaires; it was perceived that they would have knowledge of the range of issues related to this topic in regard to their CH. However, to take pressure off busy CH managers, to allow consultation between staff members if the answers to questions were not known, and to enhance response rates, the cover letter accompanying the questionnaire also suggested that 'another appropriate person' could fill it in (See appendix G).

After the target population was chosen, the selection of a suitable geographical area for the sample took place. Since the sample for phase 2 of the research would be derived from the survey responses and would be conducted from the University of East Anglia, the Eastern Region was chosen as the most practical focal area for this research. As mentioned in Chapter 3, purposive sampling was employed to choose four counties in the Eastern Region; these included rural, urban, affluent and poor

areas and provided a large geographical scope for the study. The counties were Norfolk, Essex, Suffolk and Peterborough Unitary County.

Once the counties were chosen, a sampling frame of CHs within these areas was sought. The Care Quality Commission (CQC) website (www.cqc.org.uk) was searched; however the website was undergoing many system changes at the time. Additionally, searches by county area were not available; instead only searches by CH name or individual cities, towns or villages could be conducted. As an alternative source of CH information, local authorities were contacted and 3 out of the 4 Councils published CH directories, available in the public domain, for their county. These were obtained from Norfolk, Essex and Peterborough Unitary County. The CH information within the directories included: each CH's name, region, address, telephone number, whether the CH offered nursing care or not, how many residents could be placed there, and what the CH was registered as specialising in (for example, old age, learning disability, terminally ill, mental health, physical disability, dementia). These directories were considered to be suitable sources from which to determine a sampling frame.

Since, PWD, diagnosed and undiagnosed, make up a high proportion of CH residents (Banerjee, 2009), it is likely that most CHs looking after older adults encounter BPSD at some point. Thus, the sample inclusion criteria was not only all CHs registered as specialising in dementia care, but also those looking after older adults. By including all CHs specialising in dementia care and/or the care of older adults it was likely that the questionnaire would be relevant for the targeted sample. CHs specialising in one or both of these categories as well as other categories such as, physical disability or sensory impairment were still included in the sample. CHs not registered as specialising in care of older adults or for PWD were excluded from the sampling frame.

To gain information about CHs in Suffolk (the county without a directory) the CQC website was revisited. Searches were conducted of a 10 mile radius of every medium size or large town in the county, which led to much overlapping of areas and eventually to a full coverage of Suffolk. The search criteria was restricted to those CHs registered as specialising in or offering services for PWD and/or caring for adults over

65 years. The results were downloaded in a spreadsheet format, collated and any duplicates or CHs not within the targeted county deleted. At the time (September 2011) the CQC results only included the CHs' names and addresses (a more recent search in March 2013 obtained results portraying remarkably more comprehensive information about each CH). The website www.carehome.co.uk and Google searches were used to supplement the deficient information about each individual CH in Suffolk. These searches were to determine: how many residents each home was registered for; whether the home provided nursing care or not; and what each home was registered as specialising in. Once the sampling frame was constructed I had a comprehensive list of CHs from the 4 counties. Later the Internet searches were widened in scope and conducted for the whole sample to obtain information about ownership for each of the 747 CHs. Ownership of the CHs was categorised into four types: voluntary, independent, corporate or local authority owned CHs. The complete sampling frame (n=747) was chosen to be targeted for the postal survey. Therefore, global sampling was employed and was comprised of every CH in Norfolk, Essex, Suffolk and Peterborough Unitary County registered as specialising in caring for older adults and/or PWD. The sample included CHs offering nursing care, non-nursing care, and those with dual registration. CHs registered as elderly mentally infirm (EMI) homes, elderly severely mentally infirm (ESMI) homes and as residential homes were also included in the sample.

Survey development and questionnaire design

The questionnaire was designed specifically to make it quick and easy for CH managers to fill in. It was hoped that this would maximise the response rate. The aim was to elicit as much information as possible with minimal effort needed from the respondents to complete the questionnaire. Therefore, a brief, focused questionnaire comprised of only eight questions on one page was developed. To address the research questions the topics prioritised to be covered by the questionnaire were: admission criteria of CHs in relation to CB; the instances and types of CB the CHs experience; the types of treatments or therapies (NPIs) used to manage BPSD; and the

prescription levels of antipsychotic medications. To view the survey questionnaire see Appendix B.

The demographic data already available from the sample information comprised of: CH name, address, telephone number, registration, ownership, specialism and how many residents they could accommodate. This reduced the need for a lot of demographic data to be sought within the questionnaire. To enable accurate knowledge of resident numbers, the first question asked CH managers for the number of residents they were currently looking after. Individual CH names were added to this question on each questionnaire before printing. The question read: How many residents does 'CH name' currently have? The individualisation of surveys was a laborious process, yet it was useful since it enabled the returned questionnaires to be identified and negated the need for an extra question asking for the CH name. The personalisation may also have contributed to CH managers generating a more favourable opinion of the questionnaire.

The questionnaire went through several drafts during its development. Questions were reworded, reordered, and restructured. Consultations with my supervisory team enabled a satisfactory stage to be reached with the questionnaire development. A pre-test, in the form of a stakeholder consultation, was then conducted to inform the development of the questionnaire before the final design was accepted. Personal contacts were used to arrange meetings with the managers of two very sheltered accommodation establishments. These settings provide domiciliary care to many people on one site; each occupant receives the care they need in their own flat within the larger building. To be eligible to live in very sheltered accommodation each occupant has to receive a minimum of 4 hours care a week. The managers of these settings were not eligible to be included in the survey sample; therefore using them to test the questionnaire would not affect the global survey sample in anyway. However, their role within these settings is very similar to the CH manager role and if they found the questions to be acceptable it was likely that CH managers would too.

The stakeholders read through the survey and offered comments on its structure, on the nature of the issues it covered and on the perceived ease that the questions could

be answered. The feedback was mostly positive; stating that the topic was a 'problem that needs looking at' and that the questionnaire was 'easy to fill in'. There was surprise from 1 manager at the amount of therapies and treatments available for BPSD (the options in the multiple-response question). There was some debate between the two about the stigma of antipsychotic use and whether CH managers would report accurately on antipsychotic prescription levels. One stakeholder thought that there 'may be a stigma over antipsychotic use,' whereas, the other thought there 'shouldn't be stigma of antipsychotic use as GPs prescribe, not managers.' These divergent views allude to one limitation of the self completion survey method; it is impossible to verify the information supplied by respondents. Whether respondents would give a socially acceptable answer to the question about antipsychotic prescription levels is unknown and an issue that would be better explored by the case study method. Yet, as explained in chapter 3, a medication mapping phase for this study was unfeasible, leaving the prevalence of antipsychotic prescriptions in CHs an important issue to explore with the survey.

Due to the availability of the CH addresses, but not emails, in the directories from which the sample was derived postal surveys were chosen over email or internet surveys. Telephone surveys were considered, but dismissed due to the time consuming nature of contacting n=747 CHs, the availability of managers at the time of the phone call, and the requirement of immediate responses, which could inhibit the possibility of checking answers with other staff members. As the case studies would be conducted directly after the survey phase no follow ups were sent out to non-responding CHs. Other postal survey studies to CHs, without follow ups, have obtained response rates of between 35 – 38% (Purandare et al., 2004; Rodriguez et al., 2007). It was hoped that the survey in this study would attain similar levels to these, although CHs can be a particularly difficult group to gain high response rates from. For example, one study by Gage et al targeted CHs with a self completion internet questionnaire about integrated working between CHs and other agencies; they only gained a 15.8% response rate (Gage et al., 2012).

The final questionnaire design included open, closed and multiple-response questions. The questionnaire was comprised of 3 dichotomous (yes or no) closed questions

asking whether the CHs were currently looking after PWD, whether they admitted people with CB to the CH and whether they had experienced an episode of CB in the last week. Three further questions were open ended asking for a numerical response; these asked about the number of residents currently in the CH, the number of residents currently prescribed antipsychotic medications and if so how many were prescribed a PRN medication. One question asked about the treatments and therapies used within the CH and offered listed multiple-response choices with an additional free text option if other responses were relevant (a list of the non-pharmacological interventions included with brief definitions can be found in Appendix A). Finally, 1 question was of an open style asking for three free text responses of experienced behaviours that were perceived as difficult to manage. Therefore, in all, information about caring for PWD, antipsychotic use, perceived difficult behaviours and interventions used within the home to manage difficult behaviour was sought. A cross-sectional design was employed to gain a snapshot of the status quo in CHs in autumn 2011.

Data sorting and analysis

The data derived from the survey were coded and then entered into SPSS: V18 (Statistical Package for the Social Sciences). Different types of questions used in the survey required different coding strategies. The dichotomous questions were coded as nominal data, for example yes = 0 and no = 1. The questions eliciting numerical answers were entered as per the responses as scale data. Since one question asking about the use of therapies and treatments for BPSD allowed multiple-response answers the option categories were not mutually exclusive. This question allowed more than one response to be chosen by respondents. There were two coding choices for this type of question: code every possible combination of answers as a separate code or code each tick box as a dichotomous variable (yes = 0 and no = 1). The latter option was chosen as an easier way to enable comparisons of each individual response category with the use of the crosstabs function. The tick box categories provided for this question were not exhaustive, so an option of 'other please specify' was also provided alongside the other options and many other varied responses were

elicited. These free text responses were collated, sorted into categories, member checked with the supervisory team and then coded as dichotomous variables alongside the multiple-response coding variables when put into SPSS (see Appendix C for categories).

Free text responses from one further question eliciting behaviours CH staff found difficult were also collated into categories, member checked and coded as dichotomous variables before being input to SPSS (see Appendix C). The coding categories constructed for the responses to this question were mutually exclusive; except those coding aggression where the variable 'aggression' included answers that were also coded separately as 'physical aggression' and 'verbal aggression.' Collectively 59 variables were created in SPSS.

Before uploading the data to SPSS each returned questionnaire was first coded by hand. This made entering data to the statistical package an easier process. Missing data values were coded as 99 or 999 as appropriate and excluded from the analysis. To enhance the reliability of the data, once data entry was completed, each entry in SPSS was re-checked against the questionnaire to check the input for errors, missing data values or illegal code values. Descriptive statistics and cross-tabulations were used to analyse the data. To statistically test the data the analysis included chi-square tests for independence and t-tests for difference. A probability value of $P < 0.05$ was accepted as the level of statistical significance.

Ethical considerations

As mentioned in Chapter 3, both phases of the research were given a favourable ethical opinion from the Social Care Research Ethics Committee (Reference number: 11-IEC08-0028). For this phase of the research, consent for participation was assumed on return of the questionnaire. All survey responses were allocated a number to anonymise them and any identifying aspects of data were changed to ensure anonymity was maintained.

Results

Survey responses

In November 2011 an information sheet, questionnaire and prepaid return envelope were sent to all managers of CHs registered as specialising in the care of older adults or/and PWD within 4 counties in the East of England (n=747). Survey responses were received from n=299 (40%) CH managers. Two of these responses were from respite only units and were excluded from the analysis and six were from managers declining to take part in the study, this left n=291 (39%) completed questionnaires to be analysed. Two further surveys were returned by Royal Mail due to un-found addresses. The wrong classification of respite units as CHs and the un-found addresses highlight the likelihood of inaccuracies in the CH directory data. Table 4.1 shows categories of the original sample and of the participating CHs.

Table 4.1: Original sample and response sample figures by care home characteristics

	Original Sample <i>n</i> = 747		Response Sample <i>n</i> = 291		% of Responses from Original Sample
	Frequency	%	Frequency	%	
County					
Essex	327	44	109	37	33
Norfolk	224	30	90	31	40
Suffolk	161	21	77	26	48
Peterborough	35	5	15	5	43
Ownership					
Private	661	88	247	85	37
Local Authority	20	3	9	3	45
Voluntary	66	9	35	12	53
Registered as specialising in					
Old age	247	33	99	34	40
Dementia	73	10	29	10	40
Old age and Dementia	427	57	163	56	38
Type of Home					
Home without nursing care	563	75	211	73	37
Home with nursing care ^a	184	25	80	27	43

^aIncludes dual registered homes

Categories reflect those used in the CH directories from which the sample was derived. Responses were proportionate across county, ownership, specialism and type of home. Homes that were registered as specialising in old age and dementia, those

not providing nursing care and those privately owned were the majority in both the original and responding samples.

The sum of all residents from the 291 CHs was 9244 (Mean=32, sd=17.66). As shown in Table 4.2, 80 (27%) of the responding CHs provided qualified nursing care (including dual registered homes). In all, 85% (n=246) of CHs reported caring for PWD even though only 66% (n=192) of them were registered to provide this type of specialist service (see Table 4.1). Just over half of the responding managers (n=149, 52%) reported they would admit people with CB into their home and 124 (43%) managers reported experiencing an episode of CB within the last week.

Out of the homes caring for PWD (n=246) only 58% (n=140) would admit people with CB and just under half (49%, n=118) had experienced an episode of CB in the last week. Homes that provided qualified nursing care had significantly more residents (Mean=42.51 (sd=20.82) versus Mean=27.69 (sd=14.39); $t = -5.86, p < .01$) than residential homes with a medium to large ($r = .49$) effect size.

Table 4.2: Care home factors by home type (Nursing includes dual-registered)

	Home Type		Total n = 291	Missing Data n
	Residential n = 211	Nursing n = 80		
Number of homes				
Caring for people with dementia n(%)	178(84)	68 (85)	246 (85)	
Admitting people with challenging behaviour n(%)	108 (51)	41 (53)	149 (52)	4
Experiencing challenging behaviour in the last week n(%)	86 (41)	38 (49)	124 (43)	4
Using at least one non-pharmacological intervention n(%)	182 (86)	71 (89)	253 (87)	
Identifying 1 or more difficult behaviours n(%)	95 (45)	41 (51)	136 (47)	
Number of residents				
Total number of residents	5843	3401	9244	
Mean(sd) number of residents per home	28(14.4)	43(20.8)	32 (17.7)	
Total number of residents prescribed antipsychotic medication (regular and/or 'as required') n ^a	640	387	1027	17
Mean(sd) number of residents prescribed antipsychotic medication (regular and/or 'as required') per home	3(3.89)	5(7.34)	4(5.13)	17
Total number of residents prescribed 'as required' antipsychotic medication n ^b	190	128	318	14
Mean(sd) number of residents prescribed antipsychotic medications 'as required' per home	1(1.79)	2(3.63)	1(2.45)	14

^aData of prescribed antipsychotics were available for 274 care homes with 8579 residents

^bData of 'as required' (PRN) prescribed antipsychotics were available for 277 care homes with 8684 residents

Missing data were apparent for some of the response variables (see Table 4.2). The prescription level for antipsychotic medications was the most frequent variable with missing data ($n = 17$), with 'as required' use of these drugs nearly as high ($n = 14$).

Antipsychotic use

Seventy three percent of CHs ($n=200$) reported having at least one resident with an antipsychotic prescription within their home. Antipsychotic medications were prescribed to over 5 residents in 23% of homes and to over 10 residents in 8% of homes. One thousand and twenty seven residents were prescribed at least one antipsychotic medication across the 274 CHs (Mean= 4 (sd=5.13), range 0 – 40), amounting to 12% of all residents ($n=8579$). Of the 12% of residents prescribed antipsychotic medications, 8% represent regular prescriptions and 4% represent 'as required' prescriptions. Four percent ($n=318/8684$) of CH residents in the sample and 31% ($n=318/1027$) of those residents prescribed antipsychotic medications are having 'as required' antipsychotics administered based on the judgement of qualified nurses or unqualified CH staff. In all, 38% of CHs ($n=105$) reported having at least one resident prescribed an 'as required' antipsychotic (Mean= 1 (sd=2.45), range 0 – 20); 74 of these homes were not providing nursing care.

An exploration of whether residents in homes providing qualified nursing care were more likely to be prescribed antipsychotics than residents in homes that did not was carried out. A significant difference was observed ($t = -2.264, p <.05, r = .23$) suggesting that homes providing qualified nursing care have on average (Mean=5.23, sd=7.34) more residents prescribed antipsychotic medications than homes that do not (Mean=3.20, sd=3.89). There was no significant difference between the type of home and 'as required' prescriptions. On average the number of antipsychotic prescriptions was higher in those homes which indicated they were caring for PWD than those not caring for PWD. This difference was significant (Mean=4.13 (sd=5.31) *versus* Mean=1.44 (sd=2.89); $t = 4.66, p <.01$), with a medium effect size $r = .44$. This difference was also significant for 'as required' prescriptions (Mean=1.29 (sd=2.57) *versus* Mean=.33 (sd=1.23); $t = 3.76, p <.01, r = .34$) where homes caring for PWD were found to have more residents prescribed antipsychotics than those that did not.

I examined whether CHs using NPIs had a lower number of residents prescribed antipsychotics than those not using them. The difference was found to be counter to what was expected but significant (Mean=4.07 (sd=5.32) *versus* Mean=1.34 (sd=2.16); $t = -5.31, p < .01$) with a large effect size ($r = .47$); suggesting that, in the wider population, CHs using NPIs are likely to have more residents prescribed antipsychotics than homes not using them. This was the same for 'as required' prescriptions (Mean=1.28 (sd=2.57) *versus* Mean=.18 (sd=.53); $t = -5.82, p < .01, r = .35$) where CHs using NPIs were found to have significantly more residents with 'as required' prescriptions for antipsychotics than homes not using them. The number of residents in CHs was significantly correlated with the number of antipsychotic prescriptions in CHs ($r = .43, p < .01$).

Behaviours and related issues care home staff found difficult to manage

Forty seven percent (n=136) of CH managers identified one or more behaviours or related issues that they or their staff found difficult to manage (totalling 330). Ninety five percent (315/330) of these behaviours were reported from homes caring for PWD (n=130). Thirty two percent (104/330) were reported from homes providing nursing care (n=41). CHs providing nursing care were marginally more likely to report behaviours or issues than homes not providing nursing care. The free text answers were grouped into categories and are shown in Table 4.3.

Aggression was reported by 109 (37% of all homes) managers; the vast majority (n = 104) of them from homes caring for PWD. The category aggression included the number of homes stating aggression and/or physical aggression (n=73) and/or verbal aggression (n=33). The impact of difficult behaviours on either other residents or staff was reported by 34 (12%) CHs as being a difficult issue to manage; all of these homes were caring for PWD. Resisting care was reported as difficult to manage by 25 (9%) CH managers. Fifty three percent of homes (n=155) did not report any difficult behaviours or issues; of these 75% (n=116) were homes caring for PWD and 25% were homes providing nursing care (n=39).

Table 4.3: The frequency of reported difficult to manage behaviours and related issues by care home

Behaviours and Issues	Homes that provide care for people with dementia		All homes	
	n^a	%	n^b	%
Aggression	104	42	109	37
Impact on Others	34	14	34	12
Resisting Care	25	10	25	9
Verbal Sounds	22	9	24	8
Agitation	16	7	17	6
Inappropriate Incontinence, Undress or Sexual Behaviour	17	7	17	6
Memory Loss or Confusion	14	6	16	5
Risk to Self (resident with BPSD)	13	5	15	5
Wandering	13	5	13	4
Emotional Behaviours	11	4	12	4
Persistent or Unpredictable Behaviours	8	3	9	3
Absconding	8	3	8	3
Night Time Waking	6	2	7	2
Eating Issues	7	3	7	2
Looking for Attention	5	2	5	2
Communication Difficulties	4	2	4	1
Other Peoples' Attitudes	3	1	3	1
Different Reality	3	1	3	1
Behaviours Requiring One-to-one Care	1	.4	1	.3
Deprivation of liberty	1	.4	1	.3

^a=246 homes ^b=291 homes

The use of non-pharmacological interventions

CH managers were asked which NPIs they used to help care for people with BPSD. In all, 253 (87%) CHs used at least one intervention to help manage behaviour (Mean 4). Ninety four percent (1045/1113) of these interventions were used in homes which were caring for PWD (n=233) and 29% (324/1113) of NPIs were used in homes providing nursing care (n=71).

Table 4.4 shows the interventions reported to be used by homes. The interventions used in the most homes were reminiscence (n=219; 75%), music therapy (n=213; 73%) and animal/pet therapy (n=185; 64%). Free text responses reported as "other" included many categories, such as arranged activities, one-to-one activities, trips out,

occupational therapy and physical exercise. Thirteen percent of homes (n=38) did not use any non-pharmacological therapies; of these 34% (n=13) were homes caring for PWD and 24% (n=9) were homes providing nursing care.

Table 4.4: Non-pharmacological interventions used by care home

Interventions used	Homes that provide care for people with dementia		All homes	
	n ^a	%	n ^b	%
Reminiscence	203	83	219	75
Music Therapy	200	81	213	73
Animal/Pet Therapy	172	70	185	64
Massage	102	41	108	37
Doll Therapy	91	40	92	32
Aromatherapy	53	22	56	19
Multisensory Stimulation	51	21	55	19
Reality Orientation	48	20	52	18
Behavioural Therapy	30	12	32	11
Validation Therapy	30	12	32	11
Other	65	26	69	24
No Therapies Used	13	5	38	13

^a=246 homes ^b=291 homes

Additional free text responses

Several of the returned surveys had extra comments written on them. They comprised of clarifications of the tick answers and added superfluous, but interesting and related information. They are included here, since they work to supplement the survey data by reflecting the complexity of the issues covered in the questionnaire and by illustrating the restrictive nature of standardised questions. Summaries of the comments are reported below under the relevant question from the survey.

Does your home currently care for people with dementia?

There were 12 survey responses with comments for this question. Some were clarifying how many residents in the home had dementia, some were stating that they looked after PWD, but were not registered as a dementia home and others outlined the conditions under which they would have a person with dementia in the home. For

example, this response “We do care for PWD if it develops while in our care” is representative of 4 of the comments from CH managers.

Do you admit people into your care home with challenging behaviour?

The written comments on this question appeared to portray that the issue of admitting or not admitting people with CB to a CH is not always black and white, but could be a grey area. For example, comments such as, “Yes, Occasionally but we need to be able to care for them in our environment” or “Yes, Where we can meet their needs” or “sometimes it depends after assessment” show that whether a home admits people with CB can be dependent on the individual resident and other CH factors.

Two written responses challenged the term “challenging behaviour” used within the question. One crossed it out and wrote instead “unmet needs” the other wrote “I disagree with the term “challenging behaviour” however, we do admit individuals who are struggling to make sense of their surroundings”. These responses infer a person centred attitude from these CH staff and indicate that using the term “challenging behaviour” can be viewed as offensive by some, since it has a negative undertone.

Thinking about the past week have there been any episodes of challenging behaviour in your CH?

- ❖ If yes, thinking about the challenging behaviour that you experience in your CH, which three behaviours do you find most difficult? Please specify

Other than stating behaviours found to be difficult this question elicited written answers referring to the work, ability or training of staff members. For example, the comments “Mainly, however, staff working on the dementia unit have had appropriate training” and “Staff work closely with residents to intervene before issue” show that these CHs feel that staff awareness and training are key factors in the management of CB. Two CH managers commented that residents’ behaviours are not the actual problem. The comments “We don’t see behaviours as negative/difficult. Behaviours are a expression of feeling. We try to understand what the person is feeling in order to minimise what is upsetting our residents” and “Our residents are

not the problem, we have to establish what residents are trying to say. Wandering – residents are usually walking with a purpose” portray a person centred approach and show that when trying to manage BPSD, reasons behind the behaviours cannot be ignored.

Which of the following, if any, therapies or treatments do you use to help you care for people with challenging behaviour? Tick all that apply

Music Therapy	<input type="checkbox"/>	Massage	<input type="checkbox"/>	Doll Therapy	<input type="checkbox"/>
Animal/Pet Therapy	<input type="checkbox"/>	Reality Orientation	<input type="checkbox"/>	Behavioural Therapy	<input type="checkbox"/>
Multisensory Stimulation	<input type="checkbox"/>	Validation Therapy	<input type="checkbox"/>	Aromatherapy	<input type="checkbox"/>
Reminiscence Therapy	<input type="checkbox"/>	None used	<input type="checkbox"/>		

Other, please

specify.....

This question gave rise to comments on differing aspects. Two comments noted negatives of interventions, for example, “Behavioural Therapy – No not here, to control behaviour” and “Reminiscence – upsets many people.” These comments indicate that although these interventions or therapies are usually viewed as good caring practice, it may not necessarily be the case. Another theme from the comments was the cost of therapies and a wish to use more if finances were available. The tailoring of different therapies to different individuals was mentioned by some homes along with the need to rule out pain and other underlying causes of behaviour. One manager stated that some therapies were used in their home but not in a formal way and another stated that some of the therapies mentioned were more living as people chose than therapies. These comments appear to show that the incorporation of NPIs in CHs is not a straightforward issue.

Thinking about the current residents in your CH, approximately how many are prescribed antipsychotic medication?

- ❖ Thinking about those residents on antipsychotic medications, approximately how many are prescribed antipsychotics as PRN (as required) medication?

The comments written for this question focused on the justification of antipsychotic use, such as with these comments “these are constantly reviewed in collaboration with the GP’s to reduce/use for short times. However, we tend to care for individuals who have been put on antipsychotics in hospital and we have to reduce doses down” and “for functional mental health needs” showing that CH managers are aware of the potential connotations between antipsychotic use and the perception that this use is associated with suboptimal care. One CH manager stated that they were “Unable to share confidential info” and another stated that “G.P’s do not prescribe antipsychotics PRN.”

Discussion: Contextualising the findings

The survey phase aimed to elicit information from many CHs and shed light on the management of BPSD in relation to perceived difficult behaviours, antipsychotic use and the use of NPIs. The data obtained from the returned questionnaires has worked to meet these aims. Despite the recent English Government strategy to reduce the use of antipsychotic medicines for PWD, the survey showed that 12% of CH residents in the East of England were reported (in late 2011) to still be prescribed these medications. A judgement over whether a reduction in antipsychotic has taken place in CHs is impossible to determine, since there was not enough evidence to estimate a baseline prevalence within CHs (Banerjee, 2009).

Two CHs in the sample reported having 40 residents prescribed antipsychotic medications, these were large homes, even so, between 40% and 50% of their residents were reported to be prescribed antipsychotics, which is extremely high in comparison to the majority of homes responding to the survey. Seventy four CHs which did not provide nursing care were found to have residents prescribed ‘as required’ antipsychotic medications. In these homes unqualified CH staff are making judgements about whether and when these medications should be administered. This is an important issue to be aware of, since it could lead to poor administration, care

staff stress or to over or under use of these medications. The issue could perhaps be addressed by giving care workers further training or by restricting prescribers to only issuing regular prescriptions alongside an appropriate level of monitoring. The findings show that 27% of CH managers reported having no residents prescribed antipsychotic medication within their home; yet, this could reflect the homes in the sample that did not admit people with CB (48%) and/or those only specialised in only old age (34%) where many residents may not have dementia.

The findings show that although 246 CHs cared for PWD only 66% (n = 192) were registered as specialising in dementia care. This could indicate that there is a need for more CHs to provide specialist dementia care. Out of those homes looking after PWD only 58% (n = 140) would admit people with CB. This suggests a restricted choice for people with BPSD when looking for CHs and could reflect the lack of appropriate provisions for those residents experiencing these challenging symptoms. The apparent mismatch between supply and demand could be problematic for all involved, with people with BPSD finding it difficult to acquire suitable placements and CHs struggling to cope with unsuitable residents for the provisions they offer.

Nearly half of all CH managers identified a behaviour or issue that they perceived as difficult to manage; showing that the care of people with BPSD can be a challenge for staff. Aggression was by far the most reported perceived difficult behaviour to manage by CH staff. Therefore, when developing NPIs, efficacy for aggression should be taken into account. Reminiscence was the most frequently cited NPI used, although its use is not evidence-based for the treatment of BPSD (Ballard et al., 2009c; Woods et al., 2012). It is noteworthy that 87% of homes were using some form of NPI and that those homes using interventions were likely to have more residents prescribed antipsychotic medications than those not. This was a surprising finding and could indicate a high prevalence of BPSD in some homes; for example, in nursing homes where there are more likely to be residents with complex needs, which then require multiple management strategies. Conversely, it could indicate that the use of NPIs does not necessarily offset the need for antipsychotic medications.

There was some missing data on the returned questionnaires. This could be due to an unwillingness to disclose information, a lack of time, or to oversights. Most missing data were in relation to antipsychotic medication use within the home (n = 17). Additionally, the free text comments written on questionnaires highlighted the complexity of this topic. The need to comment to justify antipsychotic prescriptions indicates that the question touched on a sensitive topic and that CH managers are aware of the stigma associated with the use of these medications and its alleged connection with suboptimal care. Equally CHs, particularly large ones, may have found it difficult to surmise about the amount of use within the home due to lack of intimate knowledge of prescriptions and medication types.

Limitations of phase 1: using the postal survey method to care homes

CH research can be problematic. The multitude of different companies, organisations and individuals owning CHs makes them a very disparate group. Negative media representations, the stigma of antipsychotic use and its assumed association with suboptimal care could make CH managers reluctant participants in a survey of this kind. CH managers (the target respondents) are also busy people. It is likely that these factors had an impact on the survey response rate.

Taking this into account, the 40% response rate, which could be viewed as a low level of compliance, is actually a satisfactory response rate for a survey of this type within the CH sector. This is particularly so since CH surveys, typically, have low response rates (for example, Gage et al., 2012). Additionally, CHs are a difficult population to engage in research (Froggatt & Payne, 2006). As mentioned before, other postal surveys sent to CH managers, without follow ups, generated 35 – 38% response rates (Purandare et al., 2004; Rodriguez et al., 2007). The 40% response rate for this survey is at the higher end of this range. The survey has connected with a difficult group and elicited some important and useful observations to start to illuminate this under researched population in this very topical area.

Ignoring the response rate of 40% would be a mistake since non-response bias could be an issue in the data set. For example, it is possible only those CHs with low

antipsychotic use responded to the survey. However, the demographics in Table 4.1 indicate a proportionate response; providing some evidence that non-response bias was random and not systematic. Nevertheless, the results of this survey phase must be interpreted with caution and in retrospect a follow up of the survey may have been beneficial to enhance the response rate.

The unfeasibility of a medication mapping phase (see chapter 3 for an explanation) in this study made validating the level of antipsychotic prescriptions reported in the survey by CH managers untenable. Consequently, the validity of the data relied upon the self-reporting of CH managers, who may have wished to portray their home in a certain way. CH staff cannot prescribe antipsychotic medications themselves; however prescription levels could have been under reported by managers due to the stigma associated with their use. This aspect of the unknown limits the value of these findings. There is also likely to have been subjectivity and some ambiguity over issues, such as the use of NPIs, which are generally difficult to standardise (Leone et al., 2009). Therefore, interpretations of what constitutes an intervention could have been varied, for example, reminiscence could mean an informal chat about the past or a formal session. The additional free text responses on the returned questionnaires show that the complexity of this topic did not easily fit with the rigidity of the survey method. The need for CH managers to explain the standardised answers they had provided could reflect shortcomings within the design of the questionnaire used or within the survey method itself in relation to complex topics.

Conclusions

The survey phase gained data showing the range of cases in relation to the management of BPSD, thereby establishing the state of affairs in CHs in the East of England in 2011. An overview of behaviours that are challenging for CH staff to manage, the NPIs employed to cope with these and antipsychotic prescription levels across a vast number of CHs were obtained. This survey phase was a first attempt to estimate the use of antipsychotics in CHs. Despite measures to reduce antipsychotic use for all PWD in England, the data shows that 12% of CH residents were still prescribed antipsychotic medication. Around half of all CH managers reported they

had experienced behaviours they found difficult. Aggression was reported to be the most difficult behaviour for CH staff to manage. A multitude of interventions, both antipsychotic medications and a variety of NPIs, appear to be used concurrently in many CHs to manage BPSD. The data gained not only addressed the research questions for this phase, but were used to inform the sampling for phase 2 of this study and to contribute to the overall interpretations of the study's findings.

A version of this chapter have been published in the Journal of Aging & Mental Health (**Backhouse et al., 2013**). Full text PDF copy can be found in Appendix H:

Backhouse, T., Killeth, A., Penhale, B., Burns, D. & Gray, R. (2013). Behavioural and psychological symptoms of dementia and their management in care homes within the East of England: a postal survey. *Aging & Mental Health*, 1-7.

Chapter 5: Case Studies: Methods and Processes

Introduction

Chapter 4 set out the procedure for and findings from the postal survey phase of this study. In this chapter we move to the larger second phase of the study: the case studies. This phase was designed to complement the survey findings from phase 1 by obtaining an in-depth understanding of the management of BPSD in CH settings. The way in which qualitative research is conducted can vary considerably. Even using what appears to be the same method can actually be played out quite differently in practice (Mason, 1996). For example, unstructured interviews can take many forms; the researcher's approach can be formal or informal, they can use direct or indirect questions, and the power dynamics within the interview setting can all impact on the data generated and consequently the research findings. This makes the way in which the case studies and their individual method components were carried out important aspects to consider when contextualising this study's findings. The four case studies each incorporated interviews with CH staff, observations and medication mapping. A discussion of how each of these methods were approached and conducted is set out in this chapter. The chapter reasserts the research questions for this phase before setting out the sampling strategy and the negotiation procedure used to gain access to CHs. The researcher's role, limitations of the case study phase and ethical considerations are also outlined within the chapter. Thus, chapter 5 sets out in detail how the research in Phase 2 was conducted, along with the discussion of some issues encountered in the field.

Phase 2: Research questions

As set out in chapter 3, phase 2 of the study was designed to gain in-depth knowledge of the management of BPSD in CHs. The research questions the four case studies addressed are set out below.

Research questions:

- 1) What are the formal and informal strategies used to manage BPSD in care homes?
 - a) Why and how are they used?

- 2) How do various strategies work?
 - a) And for whom?
- 3) What resources and sources of support are available to assist care home staff to cope with BPSD?
 - a) How are they used?

Sampling strategy: Case studies

Since the goal for phase 2 was not to create generalisations, but to gain an in-depth understanding of the management of BPSD in CHs and to learn from cases, purposive sampling was chosen as a suitable method (Stake, 1995). The main aim of the purposive sampling was to gain a sample of CHs most likely to include people with BPSD. In turn, it was hoped this would work to illuminate more of the strategies used to manage these symptoms and therefore, adequately answer the research questions. A second aim of the sampling was to gain a heterogeneous sample (Tashakkori & Teddlie, 1998). Heterogeneous sampling allowed the study to include a variety of CH factors (For example, those CHs with different levels of reported antipsychotic use and CHs providing and not providing qualified nursing care) across the case studies, enabling a variation of cases to be studied (Robson, 2002). Since using heterogeneous cases can make distinct patterns and underlying factors in the data easier to distinguish (Eisenhardt & Graebner, 2007), it was hoped that differing practices or strategies could be illuminated. The sample for the case studies was derived from the survey responses from phase 1. It was potentially more likely that these homes would agree to take part in Phase 2 since they had already taken part in the study to a smaller extent. To select the target CHs the information the postal survey provided was revisited to see what it would represent for the cases. Table 5.1 shows the knowledge categories the survey provided, what these categories were proxy for, and the relevance they would have within the case studies.

Table 5.1: Survey response categories and relevance for case studies

Knowledge Category	Proxy for:	Relevance for Phase 2 of study
Location (County/Address)	Deprivation - Affluence <ul style="list-style-type: none"> • Staff/resources • Paying/ funded residents Rural – Urban <ul style="list-style-type: none"> • Inside/outside space • Visitor access • Available activities 	Impact on BPSD/ strategies Community links
Number of residents	Organisation, Homeliness, Busyness Size of staff team Recognition of residents' individuality	Impact on BPSD/ strategies Environmental effects
Ownership	Values Resources Rules – regulations – policy Staffing levels, Environment Control over admittance	Impact on BPSD/ strategies CH Environmental/contextual effects Ethos
Residential/nursing	Staff training levels Biomedical influence Needs of residents	Types of strategies may differ Approaches may differ Medical influences, or not
Specialising in Dementia/Old Age	More/less equipped for dementia More/less likely to have PWD in CH	BPSD more/less pervasive More/less effective strategies in place
Caring for people with D: Yes/No	Yes -Experiencing dementia	Likely to have strategies in place, Higher likelihood of BPSD
Admit people with CB: Yes/No	Likelihood of CB in home Acceptance of CB – strategies may/may not be in place Attitude towards BPSD/Control	Likely prevalence of BPSD in CH
CB in last week: Yes/No	Frequency of CB	More likely to expose strategies within case study
Difficult behaviours Identified	CB an identified issue CB can be difficult to cope with	More likely to identify issues or difficulties in managing BPSD Prevalence of BPSD - Indicator
Use NPIs	Tackling issue CH open to new approaches Interested in Quality of life/wellbeing	Allow a view of formal strategies
Antipsychotic use: level	CB may have been problematic CH lacks other adequate strategies/has residents with severe BPSD	Allow knowledge of administrations to be gained Illuminate place of medication in strategies
'As required' Antipsychotic use	Flexibility – responsiveness of strategies CB not constant	Allow a view of the antecedents, context, decision making and subjectivity of deciding to use antipsychotics

These categories led to the development of a staged exclusion criteria to narrow down the sample pool of potential case study CHs. The sampling pool started with n = 291 survey responses, the steps of exclusion outlined in Table 5.2 reduced the possible case study candidates to n = 80.

Table 5.2: Sample exclusion process and rationale

Step number	Exclusion steps and rationale	n=Sample size
Start	No exclusions	n=291
1	Exclude homes not caring for PWD (n=45). If homes are caring for PWD there should be a higher likelihood of BPSD and strategies used in the CH.	n=246
2	Exclude homes not experiencing challenging behaviour in the last week (n=128). If challenging behaviour is frequent, it is likely that more strategies will be exposed within case studies.	n=118
3	Exclude homes not identifying difficult behaviours (n=3). An indicator for BPSD. If homes identified difficult behaviours it is likely that issues or difficulties in managing BPSD will be salient. (n=2 did not identify difficult behaviours, but stated they did not see behaviour as challenging- these CHs were kept within the sample pool)	n=115
4	Exclude homes not using NPIs (n=0). If homes are using NPIs it would allow a view of the nature of formal strategies and how they are used.	n=115
5	Exclude homes that do not admit people with challenging behaviour (n=34). If homes admit people with challenging behaviour the likely prevalence of BPSD will be higher.	n=81
6	Exclude homes not supplying antipsychotic use data (n=1). Those homes not supplying antipsychotic data were difficult to classify for next sampling procedure and the lack of data could indicate a reluctance to be transparent or open.	n=80
Finish	Total sample pool left	n=80

The remaining eligible care homes (n=80) were sorted into the categories shown in Table 5.3. Although the aim was to gain a heterogeneous sample the small sample size sought for phase 2 meant that all relevant CH variables could not feasibly be included. Instead the categories of CH providing qualified nursing care and CH not providing qualified nursing care were prioritised along with the reported antipsychotic

prescription levels to further separate out the sample pool. These dynamics were thought to be the most appropriate factors to base the sampling on, since they could impact greatly on the management style of BPSD within the CHs. The survey results showed that 12% of CH residents within all CHs were prescribed antipsychotic medications. Consequently, 12 % was chosen as the centre cut off point of antipsychotic prescription. Responses showing 12% of residents, or more, prescribed antipsychotic medication were categorised as having a high antipsychotic use and those showing below 12% as low antipsychotic use. As shown in Table 5.3 four sample categories were made. By focusing on these four characteristics and including two of each across the sampling subgroups replication could occur, allowing the opportunity to look for similarities and differences between cases during analysis (Yin, 2009). One CH in each section was sought to gain a heterogeneous sample. When choosing potential homes from each of the four sections care was taken to first approach those CHs citing the most instances of difficult behaviours and/or NPI use. This was to increase the likelihood of gaining relevant findings. As the research progressed one case study was indeed secured in each category, making up the four case studies within Phase 2. The pseudonyms for the four case studies conducted are also shown in Table 5.3

Table 5.3: Sampling subgroups for case studies and CHs in the final sample

Care home factors	n=number in sample pool for each sample subgroup	Participating case study CH pseudonym
Care home providing qualified nursing care: High Antipsychotic use – 12% or higher	14	Mirabelle Way
Care home providing qualified nursing care: Low Antipsychotic use - less than 12%	13	Cherry-Plum
Care home not providing qualified nursing care: High Antipsychotic use – 12% or higher	27	Gage Hill
Care home not providing qualified nursing care: Low Antipsychotic use – less than 12%	26	Bullace View

Negotiation Process

Once selected each potential case study CH was sent a covering letter and information sheet about the study. To make any further negotiations manageable letters to only 2

or 3 CHs were sent at any one time. These were followed up a week later with a phone call to gauge the manager's interest in the study and ideally arrange an initial meeting to discuss the research further. The phone calls had mixed success; most often the person who answered the phone would take a message or inform me when the manager would be there, leaving me to ring back another time. Some CH managers would decline outright and others would be interested in the study and arrange a meeting. Please see Appendix I for full details of the initial negotiations.

In all, ten CHs were contacted by letter and telephone. In four instances the initial negotiations resulted in actual meetings with CH managers, each of which followed on to the participation of their CH in a case study. The meetings with CHs allowed the manager to discuss the finer details of the study. These meetings were generally an exchange of information; I gave details about the study and what it would entail, along with information about my background and the manager informed me about the home and its background. I answered any questions put to me. If the manager was still in agreement I asked about practical details for example, what would be acceptable practice when arriving at the home, my role in the home and issues such as food and dress code. As the meetings all led to agreement to take part I gave each manager a photocopy of my Criminal Records Bureau check for their records. One manager had to check with her superiors whether this would be adequate or whether another CRB check needed to be conducted; later it was judged to be acceptable. Since the study design relied on individual consent from all participants some of the responsibility was taken off the gatekeepers (CH managers) and I felt this was a good aspect to point out during the negotiations. Each meeting led to the arrangement of a start date and time for a case study to begin.

Case Studies

The case studies were carried out sequentially and included unstructured observations, in-depth interviews and medication mapping. These methods were conducted alongside each other with observations happening at all times while I was at the homes and interviews occurring as and when they could be negotiated. Medication mapping was conducted towards the end of each case study, once I had

gained resident consents or/and consultee declarations. Table 5.4 shows a breakdown of the data collected. In total, 37 interviews were conducted with 40 interviewees and 384 hours of observations took place over the four case studies. The case study CHs are portrayed in the order they were conducted (from Bullace View through to Cherry-Plum). The time spent at the homes and the data collected during the fieldwork increased at each new case study; this was due to my growing confidence as a researcher as I became more experienced.

Table 5.4: Breakdown of generated care home data

Data categories	Case study data				Total
	Bullace View	Gage Hill	Mirabelle Way	Cherry-Plum	
Weeks at the care home	5	5.5	6	6	22.5
Sessions at the care home	20	23	25	26	94
Interviews	7	8	10	12	37
Interviewees	7	9	11	13	40
Observation hours	78.30	90.45	99.30	115.15	384
Medication Mapping	5	5	6	6	22
Total Participants	14	18	20	20	72

Ethical considerations

As mentioned in chapter 4, the study was reviewed and given a favourable opinion by the Social Care Research Ethics Committee (SCREC reference number: 11-IEC08-0028). There were multiple ethical considerations related to this phase of the research. Many of the residents in the case study CHs were older people with considerable cognitive and/or physical disabilities. Conducting research in settings with vulnerable adults who may not have the mental capacity to give Informed consent was a major concern. The residents with dementia included as participants in the study were often in late stage dementia with severe BPSD as well as cognitive disabilities. The protection of all participants and non-participants, but particularly of the vulnerable adults within the CHs was the main concern going into the fieldwork and great care was taken to ensure they were treated with respect, dignity and that their privacy was protected. Although ethical approval had been given by the SCREC, some of the agreed ethical protocols did not easily translate to practice. For example, sometimes staff consented to

participate in the study, but did not want to read the information sheet or take 24 hours to consider their decision. Micro ethical issues encountered while implementing the ethical protocols and how these issues were addressed will be discussed throughout this chapter.

My priority throughout the fieldwork was the wellbeing of participants and other people in the CH communities (Luff et al., 2011). Participants were informed in advance of the researcher's duty if safeguarding concerns were identified through either observations or from being disclosed to the researcher. Luckily no safeguarding issues in need of reporting to the authorities arose; any such issues would have been dealt with in line with current local authority safeguarding guidelines. At one CH there was a potential environmental health and safety concern noticed and the manager was informed verbally about this.

Participant sampling

During the case studies purposive sampling was employed to select potential staff participants for observations and/or interviews. Purposive sampling allowed the staff members who appeared to be of most interest to the study focus to be targeted as participants (Denscombe, 2003), such as those closely associated with managing BPSD. Multiple perspectives gained from diverse interview participants with different responsibilities can mitigate bias in interview data (Eisenhardt & Graebner, 2007). Therefore, the sampling aim was to gain staff participants from differing roles and hierarchical positions within the CHs. Alongside this, staff who worked closely with the residents with BPSD were prioritised as potential participants, since they would encounter symptoms frequently. Additional to selecting potential participants for the sample, an open approach was adopted and had any staff member expressed a particular interest in participating in the study they would have been accepted.

It would have been easy to prioritise the staff that I had built close relationships with to become participants; however, care was taken to include staff with a variety of perspectives and approaches. One participant had a particularly abrupt manner towards me, yet she was very experienced and had a different care approach from

some of the other staff so I wanted to see if she would consent to participate in an interview. I approached her and asked her if she would like to take part in one, even though I felt a little apprehensive, she said yes straight away. After the interview this participant's manner changed considerably towards me and she became friendlier. By targeting staff members at all levels I was able to gain a varied sample. A mixture of managers, senior staff, care workers and activity staff were recruited in each case study.

Purposive sampling was also employed to select potential resident participants for observations and/or medication mapping. The sampling aim was to gain a sample of residents showing BPSD. In particular, those residents with numerous or persistent BPSD were targeted as potential participants, since their symptoms would hopefully illuminate more staff strategies. In one CH, after informing residents of the study, two residents without dementia were keen to be involved and this was accepted; they provided commentary on some aspects of living in a CH setting with residents with dementia and these insights were valued. Although all residents encountered in the shared spaces of the homes were informed about the study, generally only residents with BPSD were specifically targeted to become participants.

Recruitment: Obtaining informed consent and consultee declarations

Obtaining gatekeeper consent from CH managers prior to the beginning of case studies allowed me access into the CHs; however, once the case studies started I was initially an intruder entering the homes and work places of many people without their explicit consent. This was a matter salient in my mind as I started each case study. During the case study negotiation meetings, all managers had agreed that they would inform their staff and residents about the study and my forthcoming arrival at the home. To this end, I left information sheets with each manager to distribute and/or display. In the event of my arrival only one manager had in fact informed their CH community about the study. This made my initial days at the other homes particularly pertinent, since it was important to fully inform all staff members and residents about the research. Everyone in the shared spaces of the CHs was given an information sheet and informed verbally about the study on the first day of each case study.

However, some staff were not on duty, some residents were in their rooms and some relatives were not visiting at these times, so informing members of the CH community became an ongoing process, conducted as and when needed. This was also the case with residents with dementia with whom I continued to remind of my role throughout the fieldwork and staff whom needed further clarification about the study. To aid the recognition of my researcher role I always dressed in a smart casual way, which stood out as different from the care staff uniform. I also wore my student identification card in a lanyard around my neck at three of the CHs. At the other home I was asked not to wear it since it looked too official; instead I wore an informal homemade name badge, but always made a point of carrying my student card with me as proof of my identity when meeting new members of the CH communities.

Notifying each CH community about the study included informing people who were not potential participants. Since I would spend a lot of time at each home, knowledge of my role and the study was relevant to the whole CH community and not only potential participants. Some individuals did not wish to be given an information sheet or to be informed about the study. In these instances I withdrew in regard to the research, but generally still built up good relationships with the individuals to an extent which felt appropriate for each individual. Residents who stayed confined to their rooms and visitors to the homes not connected to residents, such as work men or women, were not informed about the study by the researcher. Potential participants were encouraged to take time to make an informed decision about consent and I made myself available to people as much as possible to answer any questions. Staff members were asked whether they would be participants in observations and/or interviews, whereas residents were asked whether they would participate in observations and/or whether the researcher could have access to their MARs.

Although all staff were informed about the research and supplied with information sheets and consent forms at the beginning of each case study, it became apparent that this was not enough to recruit staff. Only one staff member from the 4 case studies signed a consent form from this initial stage of negotiation. Instead to obtain participants, suitable staff were approached on a one-to-one basis and specifically

asked if they would like to participate in the study. Several care staff appeared to be quite low in confidence and would respond to my enquiry as to whether they would like to participate in the study with phrases such as, “who me” or “I don’t know anything.” This created a difficult situation since reassuring staff members that they had ample knowledge and that it was their experiences that were of interest had to be balanced against the possibility of coercing them to partake in the study. To work ethically, time was given to potential participants after reassuring them to give them the space to think about their participation. The next time I was at the CH and had contact with these particular staff members I would follow up and enquire how they felt about participating. Occasionally this was enough for a staff member to consent to take part in the study, however, for the majority of times the staff member would not commit themselves to participating. The staff member’s possible participation would be followed up one more time on another occasion and if unsuccessful again, I would refrain from asking that staff member anymore through fear of using coercion.

Participation in the study was voluntary. There were very few outright refusals to participating in the research (n= 4 care staff, n=1 resident, n=2 potential consultees). Instead many potential staff participants or potential consultees would evade the issue, saying they had forgotten the information sheet, or that they were undecided, or they would agree in principle, but never have time for an interview or never get around to signing a consent form. I always had spare information sheets and consent forms with me, which I would offer; however, excuses would be made, so after reminding or asking twice I would withdraw, since any further negotiations would have felt too much like coercion. It appeared that an explicit ‘no’ was difficult for people to say. Participants were informed of the right to withdraw from the study at any time and without consequence, however none did. One resident participant sadly died during the study.

Advice was taken from CH staff about the best ways to approach each resident. In line with the requirements of sections 30-35 from the Mental Capacity Act (Mental Capacity Act, 2005) for those residents whom were assessed either by staff or myself to be lacking in mental capacity a personal consultee (close family member or friend of the resident) was sought. The consultee role was voluntary and potential

consultees had the right to refuse to take up the role. If the role was taken the consultee was asked to provide a declaration about the individual resident as to whether in their opinion the resident in question would have wanted to participate in the study if they had had mental capacity.

Consultees were approached in two ways. Most often they would be in the home visiting their relative and a member of staff would introduce them to me, I would inform them and the resident about my study in a general way, but not ask them to be a consultee in the resident's presence. Due to the nature of my study 'observing the management of that resident's behaviour' I felt disrespectful being too explicit in front of the resident if they were lacking capacity. Instead I would wait until the potential consultee was away from the resident, for example, leaving or going to another part of the home for something before I asked them if they would consider being a consultee and give them an information sheet about the role. This approach appeared to work well, consultees then had the choice whether to talk further with the resident (their family member or friend) about the study, to decline, or to ask questions without fear of offending their relative. I did feel that this approach could exclude the resident in the decision, however, communicating to someone lacking mental capacity and who could be easily confused that I am observing how their behaviour is managed by staff meant bringing attention to that behaviour and this felt like a very sensitive thing. Some potential consultees did discuss the research privately with their relatives. In one case a potential consultee spoke to her mother (a resident with dementia) about the study and the resident denied having dementia and got a little upset. The potential consultee spoke to me the next day and we both agreed that it was best not to include this resident in the study. Other consultees would suggest that we both spoke to the resident about the study together, which worked well on several occasions. Conversely some decided that it would be better to not consult the resident specifically about their participation in the research as they would not understand.

If a resident lacking mental capacity was observed displaying considerable BPSD and I had not already met a relative or friend of theirs, staff were asked to provide me with a contact name and a letter was printed and sent to their relative. The CH staff

addressed and sent the envelopes for me, I paid for postage. In one case a nurse spoke to a resident's daughter over the phone and gained consent for me to send her an information sheet, in this instance I was given the address and posted the letter myself.

It is important to point out that most of the residents participating in this study had advanced dementia and some could not communicate well or coherently. I was always upfront about my role in the home as a researcher to all residents regardless of their mental capacity. I would ask the occupants of a room in the shared space of the home if it was alright for me to enter or be present, they invariably said yes. For those residents lacking in mental capacity I made a conscious effort to read any signs available to indicate if my presence was accepted or not on each occasion I was in proximity to them. Often residents appeared to enjoy my company, but if at any time anyone appeared agitated or upset at my presence I would withdraw from the situation. This only occurred once, however the particular resident was agitated with anyone close to them at that time and was calm again a little while later, nevertheless I respected their space for the rest of that day.

Some staff did not want to read the information sheet and when signing consent forms just ticked 'yes' to everything without reading what they were signing. This left me to verbally check that these participants were in fact happy to consent to everything individually and to make sure they were properly informed about the study by reiterating the information sheet to them. Conversely, one resident consented verbally that I could access his MARs, but would not sign a consent form, saying "I'm not signing anything." These examples illustrate the difficulty that can arise when implementing ethical protocols in fieldwork settings where participants' expectations are divergent from those of the researcher.

Observations and the researcher role

Unstructured observations were chosen to enable flexibility during the case studies and to allow the researcher's attention to focus on the management of BPSD as and when it occurred (Bailey, 2007). The researcher role was as 'observer as participant'

(Gold, 1958); an overt role involving observations in the shared spaces of the homes, while also participating in the setting with simple tasks. This level of involvement was chosen to allow a legitimate role from which to conduct the observations rather than being located on the periphery and as a way to facilitate relationships with members of the CH communities (Gold, 1958). Participating in tasks helped ‘give something back’ to the participating CHs; this reciprocity was important in offsetting any inconvenience the research created for CH residents and staff. Participating in the CH settings meant observations felt less intrusive and more authentic, since the staff and residents did not feel like they were being explicitly watched; instead I became part of the setting. The tasks that I assisted with are set out in Table 5.5. Assisting residents with meals was a particularly good task since it allowed me, not only to build a genuine relationship with residents, but also gave me a valid role and vantage point from which to observe the conduct of others.

Table 5.5: Tasks undertaken as part of the observer as participant role

Observer as participant tasks	
Serving drinks	Collecting plates/cups
Assisting residents with food or drink	Hovering
Laying tables	Making drinks/breakfast
Tidying	Collecting things as asked by staff/residents
Arranged activities (bingo, crafts, cooking, quiz, exercises)	Washing up
Assisting on trips out	Folding laundry
Assisting with the tea/coffee trolley	Walking with residents
	Chatting to residents/staff

In practice, the role of observer as participant was found to be ambiguous and often had to be re-negotiated. As circumstances changed around me my role fluctuated along a continuum; sometimes the observer aspect of the role was more salient and at other times the participant part of the role was more prominent. This could change from moment to moment. Since I was a research tool within the case studies, how I acted, responded and interacted could change the situations in the CHs and alter the data available to me and the knowledge I would be able to gain (Dewalt & Dewalt, 2011). However, this was judged to be a risk worth taking, since by generating close relationships with the CH staff and residents I was better placed to gain a real

understanding of issues important to them. The tasks I conducted did not appear to relieve the staffing pressures to an extent where stress was removed or to remove episodes of BPSD needing intervention. Staff members were predominantly busy with tasks I was unable to assist with, such as those in the private areas of the CHs, manual handling, personal care and medication administration. Therefore, it is improbable that the tasks I undertook impacted on the setting to the extent that they invalidated the data, except in rare circumstances when stepping in was required due to an imminent risk to a resident.

The CH staff in this study were not used to researchers within their homes. Instead, the usual people entering CHs were generally visitors, work experience students, volunteers or new staff needing orientation. Consequently, staff had different expectations of my role. For example, shortly after starting the first case study a staff member asked me if I wanted to observe a bath; obviously I declined and explained the boundaries of my role. Re-negotiating the boundaries of my role was an ongoing process, since some grey areas existed. Personal care (except assistance with feeding), manual handling and going into the private areas of the CHs were clear boundaries I could not cross. However, the boundaries could be blurred for example, what if a resident invited me into their bedroom? In these cases I would go in, since I was invited, if possible I would check with staff before entering.

Taking on an observer as participant role within the CH settings had some negative aspects. Accountability was one issue. By conducting tasks such as those in table 5.5, if something went wrong I would be accountable. What if a resident choked while I was feeding them? What if I gave a resident their mobility frame (a task I was asked to do by residents frequently) and they then got up and fell? The issue of protecting myself as a researcher became salient. Tasks I was familiar and comfortable with from my role as a care worker suddenly appeared fraught with risk from a researcher perspective. I did not stop participating with these tasks, but instead tried to reduce the risks. For example, when feeding residents I would mash the food a great deal if the resident could not swallow well and I would ask staff before I acted to retrieve a frame for a resident if at all possible (sometimes finding staff could be a difficult job). Another negative aspect of conducting tasks as part of the researcher role was

creating expectations. If one day I helped with the tea trolley, I was expected to the next day and consequently this worked to restrict the observations by effectively tying me to one area at one time of day. As my confidence in the research role increased this became less of an issue as I would explain to staff what I would like to observe.

My role in the CHs straddled both the insider and outsider positions. Being aware of the position of my role, the influence it might have on the data I could collect and the knowledge that could be gained was important to contextualise the findings (Merton, 1972). As an experienced care worker I had insider knowledge of the role and the pressures, tensions and expectations connected to it. Yet, within the case study CHs I was an outsider, not part of the staff team, not used to working within each particular home's ethos and not in a position to partake in the main care worker tasks (for example, personal care or manual handling). My care work experience made me an insider of the wider care field, but not within the individual case study CHs. This prior insider experience from different establishments meant that I had knowledge of pertinent questions to ask and issues to explore in ways that a total outsider would not (Knight, 2002). My insider status also contributed to the ease of negotiations when gaining access to the CHs, helped to make stronger connections with potential participants and enabled my role to be reciprocal, since I felt confident enough to help within the CHs. The outsider aspect of my position in the CHs enabled me to maintain some distance between myself and the issue under study. Although I was located within the CH settings and I built relationships with the CH community, I was never an integral part of the care teams within the homes. My location and status within the CH communities is important when considering the study findings (Atkinson & Hammersley, 1994); my perception was that I was viewed as both a researcher and a helpful volunteer simultaneously. By the end of each case study I had an built up a peripheral membership role in the CH communities (Adler & Adler, 1987; Dewalt & Dewalt, 2011). Close relationships meant that I was taken into the confidence of many of the actors within the CH communities. I aimed to utilise the positive aspects of my dual insider and outsider position; for example, by drawing on my knowledge of issues to get close to the data and by using my newcomer status to ask the naive question.

Times and Spaces

Observations were conducted over five or six weeks at each CH on different days of the week and differing times of the day, including evenings and weekends. Observing in the shared spaces of the CHs generally worked well. Yet, at times these public areas could become more private; sometimes there would only be one resident in a lounge, corridor or dining room and no staff, leaving me and the resident together alone. In one instance a toilet door was left open by a resident and another time a resident removed their incontinence pad in the lounge. Some residents also occasionally either came out of their rooms in a state of undress or would start to undress themselves in the shared public spaces of the home. These instances problematised the assumption that the shared, public spaces in CHs were separate to private spaces.

Freedom and Trust

Each case study started off with pre-arranged days and times, for me to arrive. However, by the second week, once the CH staff had got to know me, the arrangements became more flexible. Every manager informed me I could arrive as and when I liked. After this I no longer made a point of pre-arranging specific times with the manager unless I was going to visit the CH over a weekend or had arranged possible interviews during a night shift, in which case I would check first with the manager out of courtesy. I would always be open about when I next planned to arrive at the CH and always told office or senior staff my intentions. Additionally, each time I arrived at the CHs I would report straight away to the senior staff member on duty. The consideration of the CH staff in this way helped me foster relationships with staff members within the homes and to enhance their trust in me. In all, I was afforded great freedom within the CHs. As case studies progressed I was generally able to spend time in any public area of the homes that I chose to. If staff were in need of help or short staffed I would sometimes be allocated a place to be or a task to do. I was always obliging if the task was possible for me to do. The reciprocal nature of the case studies was a very important aspect to uphold; it impacted positively on the trust and rapport between the participants and me. Consequently, by understanding the social milieu and CH circumstances better the data I gained appeared to be more

authentic. Staged withdrawals were implemented by informing all members of the CH community that it was my last week, last couple of days and last day. On the last day I provided chocolates for the residents and staff as a thank you gift for their support.

Note taking

Notes were not taken openly during the case studies; instead I always wore trousers with a back pocket, within which I kept a folded piece of paper and a pen. At opportune moments I jotted down odd things that I didn't want to forget. These moments came at such times when the room I was in emptied, along an empty corridor, when I went to the toilet or I whilst I was having my lunch in my car. Occasionally a staff member would tell me something relevant purposely for my study, in these instances notes were taken publically, since jotting the information down had the dual effect of helping me remember and of showing the participant I took what they were saying seriously. Notes were typed up as soon as possible after each fieldwork session, usually once I had arrived home. If there were important things I wanted to remember I would scribble more notes once in my car before I left the case study site.

Researcher approach

There were odd times when I felt uncomfortable observing situations. For example, a care assistant was speaking to a resident in a harsh tone. Straight after this she looked up and we caught each other's gaze, she looked down again quickly. I could see she was embarrassed and felt she had done something wrong and maybe my face had given away my sense of disapproval. I then looked away and made a point of being busy to relieve her sense of ill ease. An interview had already been arranged for the next day with this staff member; however the next day she withdrew saying she was too busy. After this experience I felt I had to put on a mask to hide any disapproval, I did not want staff to feel I was judging them or to feel intimidated.

My approach to residents and the way I conducted tasks in the home was monitored by staff. For example, a nurse called me over after I had assisted a gentleman with his lunch and complimented me on the way I had spoken to him. Until then I had been

largely unaware of being monitored. This surveillance was positive, since many vulnerable adults lived in the homes. Nevertheless, being watched created an extra pressure to be an exemplary carer; something I was aiming to be regardless of staff judgements.

Data access

The CH environment is full of information. Just being in the environment exposes you to a vast amount of data. Staff communicate with each other about residents or tasks that need doing. Residents, staff or family members talk to each other too; overhearing is inevitable. Residents behave in ways that give away information about themselves. For example, a resident may take their incontinence pad off in public revealing their incontinence or they may be emotional about something revealing their worries. Or the care that residents receive may expose details about them, such as whether they are hoisted or have medications, since manual handling and medication administration can often occur in public spaces. The exposure of information is really helpful for observations, however much of the information you are privy to as a researcher is not yours to have. Many residents, staff and relatives present in the homes did not give consent to be included in the research, such as the residents without dementia, those who had declined or not consented to participate, staff with an auxiliary role (such as hairdressing) and relatives since they were not targeted as part of the study.

Although non-participants were not included in the data, they still hadn't chosen for me to be there. I was present in their home, work place or relative's home without their choice. In comparison to my usual care work role within homes, as a researcher it was not essential for the residents' welfare for me to be there. I dealt with this unasked for intrusion by being upfront about my role in the home and by reassuring any non-participants that they would not be included within my study. Over the weeks I was in each home I built up quite good relationships with staff members, residents and regular visitors to the homes. The relationships I built up with non-participants were just as important as those I developed with participants; these positive interactions were important to overcome any potential uncomfortable feelings on

either side. This was a positive aspect of my fieldwork and enriched my experiences greatly. The relationships were also vital, since the tasks I carried out within the homes were not exclusive to the participants. For example, if I was assisting with an activity like bingo I may sit with a non-participant and help them fill in the score card or I may be asked to assist a non-participant with their meal.

Additional to the vast amount of available data from just being in the CH environment, the staff also offered me access to written data. Each time medication mapping was conducted I took the consent or declaration forms to the relevant staff member to evidence my consent to access the MARs for particular individuals. Yet, after this, in three of the homes I was given unsupervised access to the MARs for the whole home. In two of the homes I had to leaf through other residents' MARs to get to the participants' ones as they were in the same file. In one other home I was directed to a room where the files were stored, the nurse unlocked the cupboard and said she'd be back later. The potential access to MARs of non-participants surprised me and I was careful to only access those I had consent for. The open access perhaps shows that CH staff are not as aware about data protection laws and confidentiality as they should be. This situation highlights the need for researchers to have a strong inner moral guidance and an adherence to their duty as researchers to work ethically. It also provides another example of divergent researcher and CH staff expectations or role protocols. Especially since, in contrast to the researcher role, new or agency care staff would have full access to data after being at the CH for a very short time.

Interviews

All of the interviews conducted were, with the consent of the participants, digitally recorded. Due to the busy nature of the CH environment, gaining interviews proved to be a difficult task even when staff were keen to partake. To try to offset this, I employed a flexible approach, allowing the interviewees to dictate the time and place of interviews (see Appendix J for a list of interview and interviewee characteristics). Finding time for interviews was difficult. Often staff were on duty for long or split shifts and sometimes they were short staffed, so staff breaks were a highly valued time. Consequently, when arranging interviews I did not suggest they take place in

care staffs' breaks or within their own time. Three interviews did take place during staff break times; however in each case the interviewee suggested this time. Two interviewees suggested the interview taking place after their shift and a further two arranged to come to the CH especially on a day off to be interviewed. Five interviews were conducted during night shifts; this was a good time to arrange to interview senior staff (n=3) who were covering nights due to staff shortages, since it was easier to find free time at some stage during a night shift than a day shift. These examples reflect the busyness of CH shifts and the benefit of accommodating each participant's preference. The flexible approach worked to gain interviews in circumstances where it proved difficult to find suitable times.

Several interviews were conducted during shifts when a staff member had a quiet moment, stopped working and 'came off the floor.' Sometimes these interviews had been prior arranged earlier that day or on previous days and sometimes they were ad-hoc interviews conducted in 'snatched time' with little notice during a quiet moment in the routine of the shift. Conducting interviews during working hours was an issue negotiated with management staff at the beginning of the case studies and senior staff as and when interviews occurred. There was an ethical connotation to interviewing staff during their shifts, since while staff were off the floor the researcher was in effect taking the residents' time. This issue was in part counterbalanced by the reciprocal nature of the role 'researcher as participant.'

Further interviews were conducted alongside work tasks. Often staff would arrange interviews at times they would be conducting tasks other than care tasks. Many staff had dual roles as carers and/or activity co-ordinators and as cleaners, laundry staff or kitchen staff. Or as part of the care worker role kitchen work was involved. These tasks away from the residential areas of the CHs allowed a space for interviewing while work was still being completed. Interviewing staff while they were ironing, preparing food, cleaning the kitchen or laying the tables in the dining room were not ideal interview environments, but allowed more interviews to be obtained.

The interviews were conducted in places determined by the participants themselves; these included staff rooms, empty rooms such as, a hairdressing room, vacant

bedrooms, an activity room or in quiet areas of public spaces for example lounges, corridors or dining rooms. The venues for interviews created issues connected to privacy. Interviews were often interrupted either by staff or residents, some multiple times. If the staff member was needed the interview was either terminated or the participant returned shortly afterwards to continue. An empty staff room would become occupied or a resident may join us in the corridor. On these occasions I was led by the individual participant. Intruders to the interviews were always acknowledged and informed of the ongoing process. The participant was asked what they felt should happen and the responses differed. Some participants suggested moving to a more private venue, which we did, others were happy to continue with the interview in situ, in this case the intruder/s were asked if they minded and if they were in agreement we continued (in the case of the intruder being a resident the questions I asked after their arrival were restricted to less sensitive issues). Some staff intruders in this situation would join in answering the interview questions; the issue of consent then became prominent. It became necessary to inform the non-participant verbally about the consent needed and to produce a consent form and information sheet. If the intruder and participant were both in agreement for a joint interview (as occurred twice) we would proceed. These changing circumstances often required quick and instinctive actions to maintain an ethical environment for the interviews to proceed.

Interviewing participants at impromptu moments sometimes with little more than a minute's notice, during night shifts (finishing as late as 2am in one instance) and alongside non-care tasks made the generation of interview data difficult. Distractions, interruptions, tiredness, background noise (such as a radio), short time available for interviews, abrupt termination of interviews and lack of preparation time all created challenges for me as an interviewer. To attempt to overcome these and make the most of the interview opportunities an informal style was employed and the most salient issues to explore were prioritised (see Appendix E for the indicative interview topic guide). The informal style allowed the generation of data to derive from a dialogue between researcher and participant, helping the participants feel more at ease and hopefully able to talk more freely. Conducting interviews in these difficult

circumstances rendered the planned in-depth interviews as, at times, unachievable. Instead flexibility was essential; I adapted to the time, place and person; obtaining the data I could when I could. Interviewees had different styles, some were very confident and open, and others were more reluctant to talk freely and came across as hesitant. To enhance the interview opportunities I adapted to each interviewee, if they were perceived to be lacking confidence I actively tried to provide reassurance that what they were saying was fine. If participants were free speaking I used a more traditional interview technique, since less encouragement and leading was required.

Data management

Once a consent or declaration was gained each CH and each participant were allocated a reference number for identification on documentation to ensure anonymity. Observation notes were typed up and interviews were transcribed verbatim. Digital interview recordings were deleted after analysis. Any identifying aspects within interview transcripts, observation notes or documentation summaries were anonymised.

The consent forms, signed information sheets and hand written observation notes were kept securely in locked filing cabinets within a locked room at the University of East Anglia to be destroyed six months after the study was completed. Typed interview transcripts, observation notes and analysis documents are kept in password protected files on password protected computers at the University of East Anglia and will be deleted two years after the end of the study.

Anonymity and confidentiality

It was important to uphold the anonymity of individual study participants and of the CHs where case studies took place. Identifying data obtained from participants was minimal. However, any identifiable information was anonymised and pseudonyms employed to protect participating CHs and individual participants. This worked to reassure potential participants that the CHs identity, their identity and any identifying details would not be included in this thesis or in any publications stemming from the study. On occasion CH staff asked where else I had carried out a case study or which

CH I was going to next. In these instances I would answer in a similar way to this 'I'm sorry I cannot say, I've promised the other CHs anonymity; just like I wouldn't tell other CH staff that I've been here.' Being explicit about anonymity appeared to reassure the current case study staff further about their own anonymity. This built further trust between myself and the participants. The confidentiality of data was also an important aspect of the research. Information gained from participants was not shared with other CH personnel and care was taken to keep notes and the recording device secure during fieldwork. Although no safeguarding issues occurred, all potential participants were informed that identifiable information may have to be passed on if a safeguarding issue arose, and this would have been passed on only on a need to know basis.

Data analysis: Qualitative data

The vast amount of qualitative data contained in the interview transcripts and observation notes required a structured and logical analytic approach. The 'Framework' approach outlined by Ritchie and Spencer (Ritchie & Spencer, 1994) was chosen as a suitably rigorous process. Due to the nature of the Framework approach (needing to make an index structure that could encompass all themes in the data) the analysis started after all of the data had been collected. This meant that all aspects of the vast dataset could contribute to the development of the framework. Analysis was first conducted case by case to allow a comparison between homes and identification of contextual factors that may have influenced the utilisation of different strategies in different CHs. A cross case analysis then took place; data were conflated and analysed across all cases to gain an over-arching view of the strategies used to care for people with BPSD.

Analysis Process

The 'Framework' approach is a robust, transparent process, which has five main stages of analysis (Ritchie & Spencer, 1994). The first is 'familiarisation' where the researcher immerses themselves in the data by reading observation notes, listening to interview recordings and reading interview transcripts. Not all data were selected to

be consulted at this stage; instead a varied subset was carefully chosen to best represent the data set. Sixteen interview transcripts, 4 from each case study were selected; to provide a varied sample they included staff from different roles within each home. Observation notes from 20 sessions were examined, 5 from each case study; these included notes from the early, middle and late stages of my time at the homes. During the process of familiarisation key ideas and recurrent themes in the data were compiled in a list as they were encountered.

The second stage of analysis is 'identifying a thematic framework.' The framework was created by assembling together ideas from the research questions and topic guides, along with emergent themes and recurring patterns from the list assembled in the familiarisation stage. The framework was then applied to a small amount of data and re-amended (see Appendix K for the final framework). The third stage of analysis is 'indexing.' This involved the framework being methodically applied to the whole dataset. References from the framework were added to relevant parts of the data to create an indexed dataset (an example is shown in Appendix L). The fourth stage is 'charting' where each thematic reference had summaries of the data added to it for each case with page numbers for an audit trail (see Appendix M for an example). Page numbers were also recorded for passages thought to be particularly apt to be used as quotes. The fifth and most complex stage is 'mapping and interpretation' the most creative stage of the analysis. Charts and notes were systematically searched. Associations, structures and patterns were looked for along with comparisons between cases and the dynamics and ranges of key themes or concepts. This process was guided by the research questions, emergent themes, and associations in the data set. The outcomes of this stage are discussed in detail in the findings chapters 6, 7, 8 and 9.

Medication mapping

Medication mapping involved the researcher gaining access to each resident participant's MAR. The last full month completed record was sought to enable the researcher to gain information about the administration of the psychotropic medications the residents were prescribed. A medication mapping form (see Appendix

F) was completed for each resident participant. A mix of qualitative and quantitative data was gained including the medication prescribed, dose, frequency of administration, anomalies in administration and PRN use. These data were analysed alongside observational information relevant to medication administrations to illuminate medication administration practice, prescription information, perceived need and efficacy and 'as required' issues (see Chapter 7 for results).

Limitations of Phase 2

This phase had the potential for researcher bias, as a practicing care worker I have biases and preferred ways of working with people with BPSD that could have influenced my interpretations, interview questions and observation focus. Gaining enough distance from the research subject to see the whole picture whilst still utilising my insider knowledge to assist my researcher role was a difficult balancing act. The literature on 'insiders and outsiders' and on losing analytical interest and 'going native' was used to help me balance these issues (Denscombe, 2003; Dewalt & Dewalt, 2011; Merton, 1972). Ongoing supervision with my academic supervisors was also important to discuss issues and aid my reflexivity during the research process.

Observations may have caused participants to behave in a different way (the Hawthorne effect (Sarantakos, 2005)); the duration of between 5 ½ - 6 weeks for the case studies made it less likely that participants would have been able to conduct themselves differently over a prolonged period.

Summary

The study's mixed methods design incorporated multiple data collection methods and reflected the underlying pragmatic approach adopted for this research. By prioritising the management of BPSD in CHs and the research questions the methods chosen were most apposite to address the research problem. As such, the methods employed as part of the case study phase were apt to provide rich, detailed data and answer the 'why' and 'how' questions posed for this study. The sampling strategy for case study sites was designed to provide access to CHs most likely to accommodate residents experiencing BPSD and include different care approaches. This would help increase

the production of relevant data. Recruitment of care staff was more successful when using direct one-to-one negotiations. Adapting to the situation by slightly amending my approach enabled the recruitment of care staff from a variety of different roles. The diversity of the participant roles meant that multiple differing perspectives and actions could be obtained. These helped enhance the data and made the production of varied insights from the case studies possible. Utilising different and varied data to illuminate one issue reflects the premise of the pragmatic approach and of a mixed methods design. A flexible approach was successfully employed to enable the collection of interview data. This approach allowed data to be collected portraying the participants' perspectives when there was limited opportunity to do so.

The formal ethical protocol did not always translate to the fieldwork setting easily. Difficulties were reduced by employing a flexible approach, endeavouring to make sure the whole CH community were well informed about the research and making sure participants were aware of their right to withdraw from the study at any time. By fostering relationships with the CH community, trust and rapport was built up; this worked to enhance communication between the participants and myself and reduce many potential ethical issues. My role of observer as participant enabled me to take up a legitimate position within the CHs, make connections with the whole CH community and gain a complex view of the management of BPSD from within the settings in which it unfolds.

Chapter 6: Care Home Dynamics

Introduction

Using the postal survey method to explore the management of BPSD in CHs provided an overview of the field. The survey findings ascertained the behaviours and issues causing difficulties for CH staff, the types of NPIs used in CHs, and the approximate level of antipsychotic use from many CH settings. The strength of the survey method lies in illuminating an issue from many different sources, thereby allowing the dataset to portray a general picture of the situations in CHs within a wide sample. These data offered an indication of the management of BPSD on a large scale, reflecting the prominent features of the issue. Yet, the survey method is ill-equipped to deliver an in-depth understanding of contextual factors surrounding the findings obtained. For example, how are antipsychotic medications perceived by CH staff? Are NPIs used formally or informally? Or, are they targeted at residents with BPSD or all residents within the CH? The pragmatic approach taken for this study enables different types of data from dissimilar methods to be utilised to address potential gaps in knowledge. Each method works to illuminate the management of BPSD from a differing aspect. The case studies, to which we now turn, could not provide data from a large number of CHs such as the survey method did; instead the aim was to examine CH contexts in a depth and complexity that the survey method could not achieve. The case study method was chosen to explore factors surrounding the management of BPSD within CHs. Contextual influences are also likely to impact on the care provided for PWD. As such, the influence of CH dynamics such as ownership of the home, staff team factors, and the resources and sources of support CH staff can access are all important areas of exploration in the management of BPSD. The findings in these areas will be outlined, but first the aims for this phase of the study will be revisited.

Aims for Phase 2

The research questions reiterated below will be addressed through the next four chapters. This chapter focuses on CH dynamics. 'CH dynamics' in this context relates

to the interaction between factors; the aspects of the CHs that affect the day-to-day happenings inside them. Specifically, the CH dynamics that impact on the management of BPSD are of interest, including the resources and support available to CHs as organisations and to CH staff. Chapter 7 explores the use of psychotropic medications, and Chapter 8 examines the formal and informal NPIs and strategies, used to manage BPSD in CHs. Chapter 9 explores some of the salient issues and tensions CH staff are grappling with on a daily basis when managing BPSD. Together the findings set out in chapters 6, 7, 8 and 9 begin the process of illuminating this complex area of care; in doing so they answer the relevant research questions for this phase of the study. As stated in chapter 5, pseudonyms are used for each CH and participant (resident and staff member) name used within this thesis.

Research Questions for phase 2

- 1) What are the formal and informal strategies used to manage BPSD in CHs?
 - a) Why and how are they used?
- 2) How do various strategies work?
 - a) And for whom?
- 3) What resources and sources of support are available to assist CH staff to cope with BPSD?
 - a) How are they used?

Introduction to the Cases

The four CHs where the case studies were conducted had varied characteristics. Although some homes shared certain features (for example, two were owned by voluntary organisations); in reality, the homes were all very different. Management style, CH ethos, resident needs and care environments differed greatly between homes and impacted on the management of BPSD. Table 6.1 shows the basic differences and similarities in some CH characteristics. Each CH was situated in a different type of location. Two of the four CHs provided qualified nursing care. All homes were registered to care for residents with dementia, but to different extents. Every CH was of a medium size, caring for between 24 and 38 residents. The staffing

ratios were the highest at Mirabelle Way, perhaps reflecting the complex needs of the residents at a specialist EMI home. Cherry-Plum had by far the most activity staff hours per week.

Table 6.1: Care home characteristics

Care Home Name	Bullace View	Gage Hill	Mirabelle Way	Cherry-Plum
Care Home Type	Residential	Residential	Care Home with Nursing	Care Home with Nursing
Owner Type	Voluntary	Independent	Voluntary	Independent
Registration	4 Dementia places/Old Age	Dementia	Elderly Mentally Infirm	Dementia/Old Age
Location	City	Village	Town	Very Rural
Number of residents	38	25	24	38
Residents prescribed antipsychotics	3	17	4	3
Residents prescribed 'as required' antipsychotics	1	4	0	0
Activity Staff	1	2	2	3
Total activity hours per week	27.5 hours week	10 hours week	16 hours week	39 hours week
Care staff on AM shift*	6	4/5	7	8/9
Care staff on PM shift*	6	4	7	7
Night carers on shift*	2	2	4	4

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

Table 6.1 offers a basic view of the CH characteristics; I now describe each case briefly before moving to a thematic presentation of the findings.

Bullace View

'I think that every individual is different anyway and you'll never get 2 people, you can't just say everybody's got dementia so that's what they're going to do ... I think we try here to sort of, and I try to train down to the carers ... how each person is different, how to manage that person ... like if they want to walk about I try to encourage people to let that person walk about and try not to stop them because that's what they're up and, they want to do, um, wherever they may be going. At the end of the day, that's like not, I don't think it's your place to say no you can't do that because you're not, you're not in charge of

them are you? You know, that's their home' (June, Assistant Manager, Bullace View)

Bullace View is owned by a voluntary organisation. The home is located just outside a city centre in a residential area and is accessed off a side road and down a narrow drive. It is predominantly a home for older adults, but is registered to provide a small number of places for PWD. The home is secure with key-pad locks and door alarms fitted, the garden is less secure with a gate leading to the car park. The majority of residents have full mental capacity; some have mild cognitive impairment and 4 have a clear diagnosis of dementia. The residents all share the same living areas: a lounge, dining room, front hallway, seating areas along corridors, conservatory, and garden. The residents each have access to their own bedrooms with en-suites as private spaces. The home was purpose built in the late 1960s and was thought to be very modern at that time. Now the home is in need of some refurbishment. During my time at the home plans were being made to extend the living room and to widen the corridors. The leadership at the home was supportive, however, the manager was absent much of the time I was at the home and the two assistant managers were in charge of the day-to-day running of it. The CH ethos encompasses a mixed hotel/service side and person centred aspect along with the necessary routine and task driven approach. Meals are served in a large upstairs dining room, although some residents choose to have meals in their rooms. Carers act as waiting staff at mealtimes serving each resident their meal individually, although some assist residents with their meals and some go for their break. BPSD cause tensions between residents with dementia and those without. These tensions, along with the duty to keep all residents at the home safe and happy, are the main issues staff face at Bullace View in relation to managing BPSD. The latest CQC review, conducted in 2012, reported full compliance with the essential standards of quality and safety, although waiting times for residents needing care and constraints from the physical environment were highlighted in the report.

Gage Hill

'it's more assessing people as to whether or not this is going to be an appropriate placement. If they don't have a diagnosis of dementia the likelihood is this isn't going to be a suitable place for them, they are not going to tolerate some of the behaviours that we have here ... I think because the staff here are fairly experienced in what we do, we tend not to use the support so much, that's available because we don't really feel a lot of the time that we need to ... I tend to sort of say we're a free range home (laughs) that's how I determine us ... Just allow, you know, they (residents) can walk around and graze and do what they want' (Susan, Manager, Gage Hill)

Gage Hill is an independent home, owned by a family which possess, but do not run, seven CHs. Gage Hill specialises in dementia care; the home is set off a busy road within a village. The building used to be a house; it was turned into a home over twenty years ago and has recently been extended. The home is now made up of the old house and a new wing. The home is attractive to look at with large windows and flower borders underneath them. There is a secure area inside the home where the residents spend the majority of their waking time. It encompasses a large lounge, although not large enough to accommodate all of the residents, a dining room, a small reminiscence room, a compact quiet lounge, two toilets, one bathroom and two private resident bedrooms. The front door, stairs and further bed rooms are in an unsecured area of the home. The garden is secured by two key-pad locked gates. Most residents living in the home are at a medium to advanced stage of dementia and have highly complex needs. A lot of residents are physically able. The space inside the secure living area is not large, so with twenty five residents at the home, many experiencing BPSD, it can be a chaotic environment. The behaviours most common at Gage Hill include wandering, confusion, emotional behaviours, aggression, verbal aggression, resisting care, and conflict between residents. Behaviours are accepted at the home as part of the range of actions naturally occurring in everyday life, but on a more acute level. For example, becoming frustrated and feeling aggression is not exclusively experienced by PWD, but by everyone along a continuum of emotions,

perhaps just more intensely as part of a person's BPSD. Residents often experience strong emotions, and need support to deal with these as well as their physical disabilities. The leadership at the home was involved and effective. The manager took a practical approach addressing any issues as they arose and often helping with residents if necessary. The care approach is primarily task driven, with an underlying attentiveness to the person. The latest CQC review, conducted in 2011, reported Gage Hill was meeting the essential standards of quality and safety, however, some improvements in medication administration and training were suggested to maintain this compliance.

Mirabelle Way

'I believe that everybody deserves to have a chance of living somewhere that's homely um, and that, you know, that's a strong ethos to follow 'cause it puts a lot on the team, but I hope that my ability to demonstrate will actually if I ask you are you okay, it's because I want to know if you're okay and if I ask you if you need any help and you tell me you need help, then I'll give you that help, I'll be there to offer that, um, so although I'm, I ask a lot of the team, I'm conscious I ask a lot of the team, but I hope on the balance of it they can actually see that the support structure and network is there' (Gill, Manager, Mirabelle Way)

Mirabelle Way is owned by a voluntary organisation and was purpose built nearly twenty years ago; it is situated off a residential area in a dead end cul-de-sac. There is a large car park surrounded by hedging. The home is totally secure; it has an alarmed magnetic key system and locked garden gates. The home is spacious; it has three separate units, each encompassing a lounge, kitchenette, toilet, bathroom, and eight bedrooms. There is also a main lounge, a reminiscence room, conservatory, a large hallway and corridors where residents can sit and a large garden with secluded seating areas. The units provide homely, communal spaces on a smaller scale to the other case study CHs. Mirabelle Way is an EMI home providing qualified nursing care. The home houses residents with very complex mental health needs, some of these being organic (brain impairment, including dementia) and some functional (no brain

impairment). Many residents are also profoundly physically disabled with high levels of nursing care needs. There is strong leadership and management at Mirabelle Way. This provides a problem solving ethos where the staff try to pre-empt, alleviate or accommodate any behaviour that arises. Residents' behaviours are viewed as a challenge for the staff team, rather than as CB from the residents. Behaviours at the home include aggression, repeated questioning, persistent shouting, wandering, conflict between residents, resisting care, and confusion. The care approach is resident and task driven. The latest CQC review, conducted in 2012, reported full compliance with the essential standards of quality and safety, although improvements in staff supervision and in resident feedback methods were suggested.

Cherry-Plum

'as a rural home we have to be versatile, we've always recognised that and in the last 25 years we've had a broad age range and we've seen probably every imaginable challenge that old people face, in fact we've had people in their 50s who've been very dependent and today 90% of people that apply to come here have dementia, what we are learning however is two people are never the same.' (Adam, Owner/Manager, Cherry-Plum)

Cherry-Plum is an independently owned home, which provides qualified nursing care. It is situated in a very rural position. The home is around thirty years old and has undergone multiple extensions over the years by the long standing owner/manager. The home is decorated to a high standard and adorned with many art works, statues and ornaments. The shared spaces offer two lounges, a dining room, seating areas on the landings and entrance hall and a large landscaped garden. The home has no secure areas; the garden is not gated and the front door is unlocked in the day. The admission criteria for the home are very loose to compensate for the rural location, since travelling is necessary to visit the home and could put off potential residents and their families. As long as the home can meet the resident's needs they will be accepted. Consequently, the home has a very mixed community, housing residents with a variety of physical, mental and emotional needs; including residents with dementia. The home has experienced a considerable change in residents' conditions

over recent years and is still very much in the early stages of adapting to residents with dementia and their needs. Behaviours at the home included wandering, aggression, frustration, repeated questioning, anxiety, inappropriate toileting, shouting out, resisting care and aggression. The main issues at the home included: staff team inexperience of coping with behaviours, resident conflict and the mixed variety of resident needs to be met. The leadership at the home was involved and enthusiastic, but slow to adapt to some modern approaches. At the time of the case study, the latest CQC review for Cherry-Plum had been conducted early in 2012 and reported non-compliance in three of the five essential standards of quality and safety. The instances of non-compliance related to out of date documentation, inadequate training provision and infrequent monitoring of the service provided. Since the report the senior staff team had been working hard to address these aspects. Shortly after I left the case study a new CQC inspection report was published stating that Cherry-Plum was now compliant in all five standards, although the ongoing improvements needed further development.

Following these introductions to the cases we turn to a topic led presentation of the findings. With many of the same strategies, issues and tensions appearing from each case study, a thematic led representation of the findings was chosen over a case led account, to reduce repetition.

Care home dynamics and Organisational factors

Ownership and management of the case study care homes

The ownership of the CHs impacted greatly on the managers and how they could support residents with BPSD. All of the case study homes were run in line with a business model. Bullace View and Mirabelle Way were owned by voluntary organisations. Consequently, the CH managers had a whole staff structure above them; they were supplied with policies, procedures, protocols, pay structures, and contacts to approach for support. For instance, Gill, the manager at Mirabelle Way has a great deal of support in the shape of a framework provided by the organisation, as she mentions here:

'(voluntary organisation's name) has a legal team, ... we've got the dementia care specialist team and we've got the clinical care specialist team, ... we've got a policy around DoLS and mental capacity, so their job was to take that legislation, break it down, create a policy that's workable for us as a framework and to say what training do we need to put in place and I think, you know, whilst you've got those specialists doing that ... I think what (voluntary organisation's name) does is it gives you the policies and procedures, it gives you the infrastructure, so you've got, you've got the safety net ... And within, with, under that safety net, as a business manager the rest of it, you know, you are autonomous, you are expected to um, set your budget, manage a budget, look at your staffing' (Gill, Manager; Mirabelle Way)

This passage shows how the expert contributions within the organisation provide Gill with the necessary tools to implement the latest changes in policy effectively. This expert guidance from the organisation assists with the better management of BPSD by providing the home with appropriate training targets, and well constructed policies and procedures. Gill could also obtain advice and support from senior staff in the organisation. In contrast the owner/manager, Adam, at Cherry-Plum had a greater work load and less support because of his set up. The responsibility for preparing and updating policies, procedures, training, budgets, and human resource protocols were all Adam's responsibility and happened onsite. Due to this situation, Cherry-Plum was in a process of development in regard to implementing some of the newer guidelines and up to date training. Adam, the owner/manager talks here:

'We've developed an awful lot in the last few years, we use gold standards quite extensively, we are listening to the inspectors and recognising the high regard we've got to give to safeguarding ... I could never describe my job as boring ... I know my plate is too full ... It is a challenging job ... being a registered manager and a home owner ... a conflict of interests on occasions'
(Adam, Owner/Manager; Cherry-Plum)

It is apparent there was a commitment by Adam to master the new guidelines. The CQC inspectors and negative inspection reports had been beneficial for Adam,

enabling him to identify where improvements were needed and what shape they should take. Progress was being made. It is clear to see that Gill gains more support than Adam who is responsible for doing the same job at Cherry-Plum that specialists do for Mirabelle Way. It is obvious that one individual with multiple other priorities would not have the level of knowledge and efficiency in simplifying and disseminating new guidance as a specialist team would. However, due to the CQC reviews highlighting areas at Cherry-Plum needing attention and the dedication from Adam and his office staff the home is nearly back on target. Even though Adam does not have the support of an organisation behind him, in this case he was able to make use of the CQC inspection report in order to direct improvements at the home.

Gage Hill was owned by a family who possess a small chain of CHs; Susan the manager has autonomy over policies and care decisions, but is restricted with regard to budgets and training provision. She talks about the choice of training providers here:

'the training providers that we've got, I mean one we're using at the moment is one we've been told to use (by Gage Hill owners) and I just think their training material is fairly poor, um, they're not, they're not one of the most expensive, they're not one of the cheapest, but I just think the way that it's delivered isn't a particularly professional way of doing training, um, but I'm told who I have to use and there isn't much else that I can do' (Susan, Manager; Gage Hill)

Here Susan alludes to a restriction on her management role by the CH owners, which influences the type of training her staff team receives. This example shows how owners can impact on actual care practice within the home. During her interview Susan revealed that the owners did not originate from a care background; therefore the training provision decisions are taken by those with a lack of care knowledge and understanding. In this instance, the CH owners' impact on the management of BPSD by dictating the training available, however; within the home Susan has the power and autonomy to make most care decisions. In contrast to the managers in homes owned by the voluntary organisations, due to their lack of knowledge, Susan has no option of obtaining support from the owners in relation to care decisions.

The examples provided here are to highlight the ways in which CH owners can impact on the way a staff team cares for those with BPSD. They are not set examples of the way certain types of owners (such as those from a voluntary organisation or owner managers) impact on care practices and cannot be taken as such. For example, Gill goes on to mention that other CH managers in homes run by organisations are not allowed the same autonomy she is:

'if you're a manager that actually needs to be guided all of the time then, then (voluntary organisation's name's) probably the wrong organisation to work for, you want to work for one of these organisations that doesn't allow you to breathe' (Gill, Manager; Mirabelle Way)

Thus, there can be a marked difference in the kind of support and guidance CH managers receive from, even similar types of, CH owners. Overall the data from the four cases shows that CH managers are not equally supported, with some having more control and autonomy than others, some gaining good quality guidance, and others having to make the best with what they have. Owner/managers, like Adam, are particularly unsupported and have a weighty responsibility to keep up with new legislation and guidance themselves and disseminate it appropriately.

Care home admissions

The admission criteria across the four CHs was remarkably different. The two homes not offering qualified nursing care were unable to admit residents requiring these elements, since they could not meet those residents' needs. Staff from every case reported an increase in residents with dementia at the homes over recent years. Bullace View was in the process of reverting from a home with a minority residents with dementia to a completely non-dementia home. This was because of the difficulties inherent with a mixed dementia and non-dementia clientele, such as, vastly different care needs and resident conflicts. Staff at Bullace View would have liked a separate dementia unit since the mixing of residents with and without dementia was problematic and impractical at the home, with both types of resident missing out in some way (discussed further in Chapter 8). However, this idea had been decided

against by the voluntary organisation. It was felt that targeting care towards the vast majority of residents created difficulties in meeting the physical, mental and emotional needs of the small minority with dementia. At the time of the case study Bullace View was no longer admitting residents with dementia and in the past had moved some residents on to other homes if their BPSD had become too disruptive. There were still some residents with BPSD at the home; it was not clear whether they would be moved on or remain living at Bullace View as long as their behaviour did not become too problematic. The difficulty arising from not catering for residents with dementia is that if residents already living at the home develop dementia and their new needs can not be met they may need to move on to a more specialist environment. Additionally, some residents at the home were suspected to have dementia, but did not have a formal diagnosis. These examples make distinguishing between residents with and without dementia more complex. Therefore, although Bullace View was moving away from dementia care, it is questionable whether any home caring for older adults can be totally dementia free.

Gage Hill had a different admission policy. Residents at the home were all in the medium to late stages of dementia and many were fully mobile. Not all residents had a formal diagnosis of dementia, but all had some elements of BPSD. The high level of residents with BPSD at Gage Hill created an almost constantly chaotic environment. This snippet from my observation notes depicts how it only takes a few residents to create an atmosphere of general disarray:

'After lunch the residents all seemed to get energetic and the home became really hectic. At one point there was 1 resident wandering in another's room, 1 resident stole the cushions from under another sleeping resident, 1 resident was cross and arguing with anyone near her, 1 resident standing and hovering/leaning over other residents in their chairs and 1 resident asking about his wife – this became quite chaotic. Staff were trying to toilet other residents and also trying to appease these residents. The man leaning over others was asked to move on and find a chair as the ladies didn't like it. The staff decided to hover in case something happened as a few of the residents

were annoyed – they decided 1 should continue toileting while 1 hovered' (31st May 2013, Observation notes, Gage Hill)

The multitude of behaviours occurring simultaneously causes a stressful environment for staff and impacts directly on other residents at the home. Residents have to cope with other resident behaviours, either aimed at them or occurring in the same vicinity as them.

In contrast to the relative homogeneity of Gage Hill's residents' conditions, Cherry-Plum had a very loose and versatile admission policy. This was to compensate for the extremely rural position the CH was located in; thereby offsetting the residents and their families who may be put off by the travelling required to arrive at the home. If the home could meet the residents' needs they were admitted regardless of physical, mental or emotional conditions. Janice sums up the situation here:

'I feel we've got such a mish mash of people here ... their needs are so diverse'
(Janice, Night Carer, Cherry-Plum)

Residents at Cherry-Plum either had considerable nursing needs, dementia or profound physical disabilities. The variable conditions of residents admitted to the home required the staff team to have a variety of skills. However, the home was not a specialist home and this could create pressure for the staff team. Like the other case study CHs, Cherry-Plum had experienced increasing numbers of residents with dementia in recent years.

Mirabelle Way cared for residents that few other CHs would be able to accommodate. The home offers qualified nursing care. Residents admitted to the home had very acute organic or functional mental health needs and had arrived at the home through many routes; some had been compulsorily admitted under the Mental Health Act (1983/2007). The routes of admission included: legal guardianship (CH has legal powers over resident, including telling them where they must live for the resident's own welfare and to protect other people), Community Treatment Orders (resident under compulsory supervision after discharge from an involuntary hospital stay), Section 117s (as an aftercare service to particular patients who have been detained

under the Mental Health Act), and through straightforward admissions. Gill, the manager was the gatekeeper; like Susan at Gage Hill, she prioritised making appropriate admissions. Gill believed everyone deserved *'a chance of living somewhere that's homely'*. However, at the pre-admission assessment she checked whether Mirabelle Way could meet the needs of the potential resident in light of the guidance from the CQC and the voluntary organisation, as well as whether she felt the potential resident would fit in to the unit where the vacancy had arisen. Overall the four case study CHs had vastly different criteria for admission. Interestingly, the nature of the resident populations within each home reflected these varied criteria, making admission policies and decisions an important factor in determining the incidence or forms of BPSD staff would encounter.

Moving residents on

Moving residents from a home to other care providers appeared to be connected to admission criteria, the registration of the CHs and the type of residents living in the homes. Of the case study CH sites, Bullace View used the strategy of moving residents on most frequently. This was due to the registration of the home as predominantly catering for residents without dementia and the home not being set up to provide care for residents with BPSD. Anne discusses the process leading up to moving residents on:

'as soon as they start to deteriorate you've got to try and, well we personally here, we try to see if we can do things about it before we can move them on, we, um, try different things like a gentleman that we had, he used to just come out of his room and go into all the upstairs rooms, so we thought well maybe if we could move him downstairs, you know, we try out lots of different things before that, but obviously if they're really bad and we cannot meet their needs anymore and they're disruptive, if they're a danger to themselves or other residents, um, then the manager will then have a discussion with the family ... and just basically the family have to find them somewhere else more suitable.'
(Anne, Assistant Manager, Bullace View)

The excerpt from Anne states that being unable to meet a resident's needs, disruptive behaviour and being a risk to themselves and/or others were viewed as reasons to move a resident on from the home. It appeared that the communal living nature of CHs meant that the welfare of the majority of residents was often prioritised over that of specific individuals. Later in the interview Anne mentions that the manager, and not the voluntary organisation, made the decision to start the process of moving residents on. Several staff members at the home expressed their perceptions that a separate unit for those with dementia would be preferable to mixing residents with and without dementia. As the excerpt suggests, the resident's family is involved in the process too.

Mirabelle Way did not generally move residents on, but Gill, the manager, could not guarantee keeping all residents indefinitely, since the impact of individual's behaviour on other residents and staff had to be considered. Gage Hill sometimes moved residents on who deteriorated to require nursing care, which they could not provide. Residents were rarely moved on from Cherry-Plum. All three of these homes (not Bullace View) actually admitted some residents, who had been moved on from other homes which were either not able to manage their BPSD or meet their care needs. The implications of moving residents on could be both positive and negative. One benefit of moving on to a more suitable care provision was that residents could benefit from a more specialised service for their needs. This excerpt from Gill's interview shows how a more suitable setting can make a difference to a resident's life:

'one of the new residents um, his wife said to me the other day because he's had two bad experiences in other homes, she said 'what I'm absolutely amazed at is that everybody talks to my husband, they let him know they're approaching because of his partial sightedness, they tell him what he's going to be eating' she said 'and we haven't seen that in any of the other homes that he's been in' (Gill, Manager, Mirabelle Way)

The highly trained staff at Mirabelle Way were obviously more aware of, and attentive to, the resident's needs than staff in his previous homes had been, making the move beneficial to the resident. Conversely, moving a resident on could potentially cause

uncertainty and disorientation for residents and their relatives as this excerpt from Karen, an Activity Co-ordinator at Bullace View alludes to:

'I have had a resident that has been moved on recently that I have kept in contact with, I go and visit her in my car on my days off sometimes. So I still see her and she, you know, she don't remember me when I go, but then she slowly remembers me when I get there, so yeah, and that, and then thinks that I'm taking her back home, which she thinks sometimes is still here at Bullace View which obviously it in't (sic)' (Karen, Activity Co-ordinator/Carer, Bullace View)

In this instance, since the move, the resident could occasionally be confused as to where she now lives, making it an unsettling experience, even if only for short periods. In this way, the uncertainty experienced after moving to a different care home has the potential to increase a person's BPSD.

Environmental effects

The physical environment of the CHs could influence the way behaviours were viewed and managed at the case study sites. For example, the corridors at Bullace View were very narrow. This made it difficult for staff members with a trolley or hoist to pass beside residents. Those who wandered were most frequently found in the corridor and as a result, congestion was common. This situation made some staff perceive wandering as negative, since residents in the corridor hindered staff in continuing their work. Sometimes other residents would also find it frustrating when they were held up by wandering residents in the corridor and their wheelchair could not pass through. In this case the physical dimensions of the building caused the behaviour to be problematic rather than the behaviour itself being so. The corridors were planned to be widened in the upcoming refurbishment to alleviate this issue.

Space was viewed by many staff members from each case study as a helpful factor when managing BPSD. Laura, a carer who had been working at Mirabelle Way for four months, talks about the difference the space makes there compared to the CH she used to work in.

'my old home was literally all of them (residents) in one massive, like an old fash, what I call an old fashioned home, you know, you've got one big lounge with all the hard chairs, big upright chairs isn't it? All the way round the edge, you know and um, yeah you couldn't, you couldn't defuse some of the situations there because everyone was together all of the time, whereas here you can take them to all the different parts, um, to, to try and change their mood really.' (Laura, Carer, Mirabelle Way)

The CH environment at Mirabelle Way has many separate areas. Residents do not have to live 'on top of each other' where tempers can fray. Residents who were mobile or can ask to be moved had a choice of where to be, those who were unable had decisions of placement made for them by staff. Due to the separate spaces in the environment staff had the option of moving residents (including those who are mobile and those with mental capacity) away from triggers, other residents, or sources of frustration. As Laura alludes to, a change of scene can be enough to change a resident's mood. In this way, separate spaces are important to reduce BPSD (such as, aggression or anxiety) or the consequences of them (such as, other residents becoming aggressive too or being scared). The use of separate spaces to manage BPSD or reduce the likelihood of it happening was documented often in my observation notes, as these two examples show:

'Jim was calmer now in an armchair (taken in especially for him) in the empty dining room so he could sit in the sun and in a room where no other residents were. Marie sat with him until he calmed down, she rubbed his hand. Jim – reduce impact on others = lead away' (Observation Notes, 14th June, Gage Hill)

And:

'There was music therapy to be held this afternoon at 2.30pm– the lady sings with her guitar and brings a few instruments with her – the residents sing along and, if they can and would like to, they dance with Teresa – Bert was there until it started, but as the room became more full he started moving about in his chair and becoming agitated - Teresa took him out 'he's not going to settle' this was before the music began to reduce the escalation of his behaviour.

After the music had finished Bert was nowhere to be seen in the other downstairs areas ... he had been taken upstairs' (Observation Notes, 22nd October 2012, Cherry Plum)

The removal of residents experiencing BPSD from busy communal areas of the homes to separate spaces appeared to be an important strategy that staff used. By moving agitated residents to quiet spaces they could reduce the triggers for the ongoing behaviour and limit the impact of any behaviour on to other residents. All of the case study CHs had separate spaces for residents to go to. Out of the four, Gage Hill had the most compact environment and had the highest number of observed instances of BPSD too. However, the behaviours could have reflected the complex nature of the residents admitted there and not the space restrictions.

Environmental factors at the CHs, other than separate spaces, which helped with the management of BPSD included: numbers or photos on bedroom doors to reduce the number of times that residents went in others' rooms; dimmer light switches to reduce the impact of personal care on a resident's mood during the night, and secure areas allowing residents a relative freedom within them (discussed further in Chapter 9). However, freedom could be difficult to provide even within secure areas; as these examples illustrate. At Gage Hill doors from the main lounge led directly to the garden. When these doors were left open on warm days to provide residents with the freedom to go in and out as they pleased, other residents found the draft too cold. This prompted a closing of the doors where residents' movements were restricted once more. Then access to and from the garden was impeded by a closed door, which some residents with dementia could not negotiate without staff help. Additionally, at Cherry-Plum the lift broke down occasionally (twice during the six week period I was at the home) so residents with bedrooms on the first floor were stranded upstairs for the day. This caused residents to be restricted and bored, so frustration built up, which caused difficulties for staff.

The environment was occasionally altered by the staff team as a way to reduce instances of BPSD. For example, at Mirabelle Way a new resident, David, had a fear of enclosed spaces, so the staff had taken his bedroom door off before he moved into the home. This worked to reduce his anxiety, helping his behaviour once he moved in.

Removing the door could be viewed as depriving the resident of his privacy or creating a fire risk, but as long as it was in the resident's best interest the manager, Gill, was confident enough to defend the decision. Overall, the environment could impact positively or negatively on residents with BPSD and on the strategies used to manage them. Sometimes staff were in a position to alleviate situations and issues and other times they had to accommodate them.

Staff team characteristics

Caring for residents with BPSD

As expected CH staff had an assortment of experience and training levels. Many staff members had started in the homes never having worked in care before. Gage Hill, the case study with the most instances of BPSD, found it hard to retain new staff; with many leaving within the first week of starting. One new carer there was reported to have left due to being too frightened to stay in the same room as the residents with dementia. Carla, a carer there, professed that she did not know dementia had '*so many faces*' until she started working at Gage Hill. It became apparent that many staff found working with residents with dementia a new challenge, as Bernadette from Gage Hill states

'I'd never worked with dementia and it is very, very scary, but once you get used to it, it sort of is the norm now for me' (Bernadette, Carer; Gage Hill)

Here Bernadette reflects a desensitisation that occurs over time when working with residents with BPSD. New, inexperienced carers were perceived to be fearful of residents with dementia and not as good at managing BPSD as the longstanding carers were. The majority of carers who had been in the job a long time professed that the management of BPSD was just one part of the job and not anything out of the ordinary. Generally, staff members at each CH were aware that not every carer was capable of providing dementia care. Dawn, a part time carer at Cherry-Plum, doubted whether she, herself, could cope with residents experiencing BPSD when she started caring at the home.

'some people (sighs) are much better at dealing with people than I am, I'm okay with doing the run of the mill general stuff, but the challenging stuff I find more difficult ... I'm just afraid of making a mistake ... I'm frightened of firing someone else up, although I don't think I would ... I just try to be placid and all the rest of it with them, but it doesn't always work, does it?' (Dawn, Part-time Carer; Cherry Plum)

This excerpt illustrates that the challenges posed by residents with BPSD are different to the general care needs faced when delivering non-dementia care. As such, carers for PWD have to cope with a mix of general care needs as well as the challenges from BPSD; making their approach to every resident important. As Dawn states, this can be a daunting task since situations could escalate easier when working with residents with BPSD. The interview data showed that dementia care was not viewed as easy and it was perceived that it took a certain kind of person to be able to undertake it. Staff were also reflective about their work and concerned about the best way to do a good job.

Knowledge, Experience and Training

CH staff appeared to draw on many aspects to inform their approaches to residents with BPSD. Experience in the job, rather than training, was viewed as the main feature in guiding staff how to manage BPSD. Experience was gained through working with residents with BPSD, from watching and listening to other staff members, and from getting to know the residents. Past experience of looking after family members with dementia and life experiences (such as being a parent) were also viewed as helping factors for staff to be able to cope with BPSD. There was a general sense that there was no definitive right or wrong way to manage behaviour; instead you had to find your own way within the confines of the policies and procedures provided. For example Elaine states:

'we are learning all the time, everyday you come in here and you cannot say to someone 'I know it all, I know how to do it' ... every resident can be so different each day.' (Elaine, Carer, Mirabelle Way)

Here Elaine suggests that even for experienced care workers, learning in the job and about the residents is a continual process. The changing nature of residents' behaviours mentioned in Elaine's interview reflects a need for a flexible and adaptive care approach.

Staff training had mixed reviews; although most staff said it was helpful for everyday practice, reducing fear of dementia and providing staff with new ideas. Other staff believed that training did not make you a good carer. For example, Carla states in this excerpt:

'I've had the training for dementia and, and, but just the dementia awareness, it's a lot more that you learn actually being here (laughs) ... the way you treat people is in you (taps chest) no form of training can make you feel what you feel inside or the respect ... yes I've had training in dementia awareness, I've had training in safeguarding and vulnerable adults, but that doesn't make you a carer ... It doesn't make you the carer you are, there is something inside us that's the certain type of person that can' (Carla, Senior Carer; Gage Hill)

The person you are, your background, your personality, your own common sense judgements and experiences were seen by many staff as more important to make you a proficient carer. These individual characteristics of staff members impacted on the management of BPSD. Different staff perceived behaviours in different ways; with some seeing them as problematic and some not. For example, one carer, Jen, at Cherry-Plum was a Christian and found swearing very offensive, whereas other staff did not. Each staff member also had their own approaches, level of confidence, standards and ideas of what was acceptable. Some staff stated that they really enjoyed the challenging nature of caring for residents with dementia and were confident in managing any behaviour. For instance, Elaine, a carer from the EMI home Mirabelle Way states:

I prefer the challenging side of it, yeah I love the challenge ... I know that sounds more ... Um bizarre I suppose, but no I prefer that side of it ... Yeah I do like the physical and the mental side of it, I do ... I couldn't do residential, I

couldn't do residential, I could not make them cups of tea all day and take them shopping, no, that's not me (laughs) (Elaine, Carer, Mirabelle Way)

This type of statement was not uncommon from carers in the specialist homes (Mirabelle Way and Gage Hill); staff acquired high levels of job satisfaction and stated that they would not want to work in non-dementia homes. Overall staff who preferred dementia care appeared to like the feeling that they were doing something 'specialist' rather than just carrying out a service role. This was reflected by many carers stating that dementia care had more 'kudos' than old age care alone. If you mentioned you worked in a dementia home or an EMI home the general public viewed you with a higher regard. For example, Elaine talks about public perception of the care role here:

'they might think it's a little residential home and it's not, it's a very acute home you know. ... It's hard, it is hard, yeah and if the truth be known, in actual fact I was talking to a woman outside the other week, she was a carer in 'town name' she was waiting at the bus stop and she was talking to another woman ... and she looked at me and she said 'oh where do you work?' I said 'Mirabelle Way' and she said 'you deserve £100 an hour' she's a carer out there in the community and they know about this home ... Because um, in actual fact ... another member of staff used to say 'oh I'm just a carer' I said "carer's name" you're not just a carer, you work in an EMI and tell them you work in an EMI"
(Elaine, Carer, Mirabelle Way)

This excerpt from Elaine illustrates the importance she connects to distinguishing between dementia care and old age care, especially in light of a more positive public perception of the role. This, in part, reflects the nature of dementia care as being far more mentally and emotionally demanding than old age care. Anne, the assistant manager at Bullace View moved from a specialist home to the predominantly residential home; here she talks of the change:

'I used to work in an EMI home where they were really, our home took what no-one else could have ... I loved it, I absolutely loved it and coming here was so boring ... it was so boring because I was like 'well I've got nothing to do' they were all, well, you know, and I was actually really worried about, I know it

probably sounds wrong, but I was worried coming to talk to normal people because I was so used to having the most randomist conversations about the most randomist people that I didn't quite know ... obviously I've got used to it, but I find the difficult, the better, I love it, it really, they, I'd go straight back into a dementia home now if I could I really would' (Anne, Assistant Manager, Bullace View)

Anne appears to find the challenge of looking after residents with dementia more stimulating than looking after those residents without it. The status of working in a home with residents no other home could take may have also been an appealing factor. The higher standing, deferential public perception, stimulation and personal challenge of dementia care all appear to be factors that staff valued about the role. Other staff were more wary of residents with dementia and felt uncomfortable, scared or nervous when difficult behaviours occurred. Overall, the confidence of the staff team appeared to be important for managing BPSD.

Although experience and the person inside were thought of as helpful aspects in the care for residents with dementia, training was thought to have a place too. However, much of the dementia specific training focused on informing staff about what happens to the brain and about the different types of the syndrome. Some staff implied that learning about the aetiology of dementia did not help you look after PWD better. For example, Janice states:

'To be quite honest, to me, yeah that's nice to er know what sort of dementia somebody's got, but really, that doesn't alter how you should treat them does it?' (Janice, Night Carer; Cherry-Plum)

Staff approaches to residents with BPSD were less frequently covered by training. Mirabelle Way provided the most comprehensive training; this included arming staff with strategies and techniques to manage behaviour safely. As well as dementia awareness training, break-away, self defence, de-escalation, personal safety, and safe restraint techniques were all covered in the training programme for staff at the home. Gill, the manager, at Mirabelle Way believed very strongly that if the knowledge base of staff is sound, proper care can be provided, confidently.

'if you've got a good sound knowledge base and you actually know that your knowledge base is sound and it's good and it's current, up to date thinking or it's really good research based then ... you know you're on good firm ground'
(Gill, Manager; Mirabelle Way)

The high level of training at the home reflects Gill's ethos as well as the acute mental health needs of the residents at Mirabelle Way. Occasionally there were limitations in implementing training. For example, June, the assistant manager at Bullace View, had been trained in Dementia Care Mapping, but had no time within her role to put it into practice, so although she felt it was a good approach, it was not used in the home.

The two homes providing nursing care, Mirabelle Way and Cherry-Plum, both employed general and psychiatric trained nurses. General nurses were viewed as experts in details, task completion and biomedical aspects of nursing. As Janice states here: in

'general nursing you're taught to be efficient, on the ball, always get ahead because you never know what's going to come' (Janice, Night Carer; Cherry-Plum)

In contrast, psychiatric nurses were perceived in two contradictory ways. One was as taking a slower approach with residents, listening, giving residents time and not placing as much emphasis on efficient task completion as general nurses. Another perception was that as nurses with mental health training, they were used to controlled and secure psychiatric units where a strong approach to behaviours was sometimes necessary. Typically, the mix of both, general and psychiatric nursing skill sets within the homes was a great advantage, since a lot of knowledge could be exchanged; allowing each type of nurse to learn from the other. With many CH residents currently having highly complex physical and mental nursing needs, aspects from each discipline are required in CHs. With the current and projected increase in dementia, perhaps future nurse training should develop the incorporation of both, psychiatric and general skills to provide nurses with the mixed skill sets needed to meet the complex needs of today's residents.

Staff teams

The staff team dynamics at each CH impacted on the management of BPSD. Within staff teams support appeared to be strong at each case study. Generally teams were cohesive; staff would liaise between roles, share ideas, cover shifts for each other and work as a team. By pulling together staff could support each other at times of need. Generally night staff at the CHs appeared to work more strongly as a team than day staff. Janice portrays the night staff cohesiveness here:

'I think on the nights we're a terrific team ... We all know each other, we all know each other's strengths and weaknesses. Um, we trust each other incredibly um, at night because there's only four of us and when there's 40 residents we're in charge of the whole building, you know, if the phone rings somebody's got to answer it, nobody from the office is going to pick it up'
(Janice, Night Carer, Cherry-Plum)

Here Janice alludes to, the need to pull together at night due to the limited number of staff on duty. By working together closely the extra responsibilities staff have at night could be shared by the whole team and not one individual.

The hierarchical nature of the staff teams allowed for a support structure for staff members where peers were typically relied on in the first instance and then staff with higher levels of responsibility were approached if needed. The distribution of responsibility was also hierarchical with senior staff taking responsibility for most care decisions and the majority of formal strategy choices to manage BPSD. Senior staff members also arranged reviews or referrals, liaised with other professionals and families, were on call at night, and managed medication orders and administrations. Managers made decisions about resident admissions and if residents were to be moved on.

Staff role blurring

Formal staff roles in the CHs were not always strictly adhered to. Frequently, staff shortages required staff to cover a different role to their own. For example, it was not

uncommon, especially in Bullace View or Gage Hill (the two homes not providing nursing care), for the manager, assistant manager or a senior carer to cover absence by kitchen staff and to prepare the meals for the day as the main cook. In each of the four case study homes the manager or assistant manager covered at least one night shift during the six weeks I was at the home. At Mirabelle Way the manager covered three night shifts consecutively. Often staff redistribution would be at the expense of the care team. For example, if staff members were utilised in the kitchen they were no longer available to the floor or if they were covering a night shift their day shift may not be covered. If care staff were swapped they were usually no longer available to help on their regular shift (for instance, they may do a night shift instead of an evening shift) and shifts ran one staff member short. This could result in a frantic shift for the remaining carers, adding to stress and pressure, and ultimately affecting the residents and the care they received. Kitchen duties and night shifts appeared to be prioritised over day care shifts, where it was perceived that staff could manage with one less staff member.

Activity staff were often redeployed in times of staff shortages. For example, at Gage Hill, Holly, an activity coordinator was also hired as a laundry worker. When another laundry worker was off sick she was asked to cover the laundry rather than continue with her previously arranged shift in the activity coordinator role. This also occurred at Bullace View where, Karen, the activity coordinator also worked as a carer and was at one point required to show a prospective resident around the home instead of continue with her activity duties. Karen was also required to cover care or kitchen shifts if the home was short staffed instead of providing the activities arranged. This reflects the status of activity work at the homes: viewed as an extra, but not essential. If an activity coordinator was off sick their shift was not covered, although, on one occasion, Bullace View did have a volunteer who worked on a day that the activity coordinator was away at a training event. The secondary position of activity staff, and the limited hours they worked, makes utilising them to target NPIs at BPSD a poor option. Instead care staff, viewed as essential and on duty 24 hours a day, would be better placed in the current system to deliver these interventions.

At Mirabelle Way the whole staff team managed behaviours. Laundry workers, domestic staff, administration staff and gardeners all fostered relationships with residents at the home. The contact between these staff members and the residents was encouraged and as such, at times, they were in positions where they managed behaviours too. The administration staff were often accompanied by residents in the office even though some things would regularly go missing. Sometimes a resident would be aggressive or shouting; at other times they could be sorting through the office folders and paperwork or just sitting quietly. One day Lucy an administration worker had to go around the corner to make a telephone call in another room as a resident was shouting so much. I made notes of an informal chat I had with her later that day:

Lucy (office worker) said they were supposed to write incident sheets, but that there was no time as she had had (resident name) in the office a lot of the morning so had not got much work done and was now behind with things ... she cannot possibly fill out all the incident forms she would need as the behaviour was pretty constant. Lucy said it was difficult. When she took the job she thought she would be in an office working, she didn't realise that residents would be in and out all the time. She said she wouldn't change it, but that it was hard to cope with the behaviour sometimes. (16th July 2012, Observation notes; Mirabelle Way)

This open access policy meant that residents' behaviours could make non-care staff's working lives more difficult, yet the residents, and often the non-care staff, gained a lot from it. The close relationships between all staff members and residents came across as a positive aspect of the home. It was not uncommon to find a resident helping the domestic staff or for the laundry staff to be affectionate with residents. This open set up presented Mirabelle Way as prioritising the home as belonging to the residents, not the staff team. This was not found in the other case studies to the same extent.

Confidence/adherence to social norms

The homes where the most perceptible ethos was apparent were Gage Hill and Mirabelle Way. This could be due to their specialisms; Gage Hills being dementia and Mirabelle Ways as a specialist EMI home. The strongest ethos was provided by Gill, the manager at Mirabelle Way; it was based on two main aspects. These were a sound, up to date knowledge base to inform decisions and a resolve to always work towards the best interests of the resident. She states

'if we're doing it (any care action) for the right reason then I'm quite happy to justify anything' (Gill, Manager, Mirabelle Way)

Therefore, if these factors were in place, with documented evidence, Gill had the confidence to defend the care staff's actions to relatives or even a court of law. The confidence Gill had in the staff's actions perhaps stemmed from the vast amounts of training on offer at the home. This confidence allowed her to be proactive in many instances. For example she felt able to ask external professionals for things, able to say no if she felt their advice was not right for the resident, able to pre-empt prescriptions by contacting pharmacy staff or surgeries to forewarn them of impending changes or to chase things up. In all, informing herself of current best practice and knowing what was available to the home enabled Gill to be confident in her practice and assert herself to get the best support for the residents in her care. In this way behaviours were managed at an organisational and management level by providing the necessary staff training, obtaining support from external sources and by promoting a person centred ethos to allow staff to do a good job.

CH staff at all case studies appeared to be aware that residents' relatives, and visitors to the homes, would form opinions about the care they provided. Consequently, behaviours deviating from a social norm were difficult for staff members to accept, since to the external eye they might be viewed as evidence of suboptimal care. Examples of this could be if a resident was wearing multiple layers of mismatched clothes or eating a meal with their fingers. Hazel talks about the difficulty meeting relative's expectations when a resident resists care:

'you've then got relatives input, you know, 'why isn't my Dad in his nice ironed shirt every day?' Well your Dad, we couldn't even get him out of bed this morning, he wouldn't let us (laughs). And then you have to explain that to them, um, and some families don't necessarily always understand' (Hazel, General Nurse, Mirabelle Way)

This example shows the difficulties inherent in meeting, both residents' needs and relatives' expectations. Resisting care is a common event from residents with dementia; it is not always easy for staff to make sure people in their care are presented well. In the first instance staff members were likely to try to assist residents to do things in the usual way for the resident's dignity, but accept the behaviour, or situation, if the resident found it easier or resisted help.

The adherence to social norms appeared to be connected with confidence. If a social norm was deviated from it could create an issue in some homes. In the case of the confident manager, Gill, from Mirabelle Way many things that were issues in other homes were not given the strong ethos created there. For example, if a resident had a dressing gown on during the day it was not viewed as a problem as long as the resident was safe and happy. The philosophy professed by Gill was *'does it matter? If not, what is the problem?'* This ethos came through in Hazel's interview. Here she talks about a resident who:

'quite often sits there in the afternoon with a dressing gown, but if she's dry it's fine ... Yeah, I think the only time I'd have concerns about that is if she's sitting there in her nightie and it hasn't been done up and you've got male clients there, then it might be a bit different' (Hazel, General Nurse, Mirabelle Way)

Hazel clearly identifies the times when sitting in a dressing gown would *'matter'*, for example, if a resident was wet or had a public loss of dignity. If not, the act of being in a dressing gown was not viewed as an issue. In Cherry-Plum a resident with a dressing gown on during the day would be viewed slightly differently; the pressure to protect residents' dignity in light of them not being dressed in the day was a concern, as Jen explains:

'If they were wandering we'd try and encourage them to, to get dressed um, obviously 'cause it's respect to them really 'cause it's, if they're wandering around during the day and we've got visitors coming ... you've got people coming in and there's residents walking round in their pyjamas, it's not very respectful to them, um, for that to happen ... I mean early evening you'll find they'll be wandering around in their pyjamas and that but, I mean they have their dressing gowns and stuff but you just don't get the sort of people coming in that time of night that you do during the day' (Jen, Carer, Cherry-Plum)

The outward appearance of residents and the CH environment, although important to all homes, appeared most important at Cherry-Plum. Protecting residents' dignity could have been connected to the pressure of visitors entering the home and forming opinions of bad care, especially since Jen implies that residents in the same attire would not be viewed in the same way when visitors would not be at the home. The difference between Cherry-Plum and Mirabelle Way could be due to the differing expectations of visitors at each home or to the different ethos in each home (Mirabelle Way's as more accepting if the resident is happy and Cherry-Plum's as more concerned by external appearances). Visitors' expectations at specialist homes, such as Mirabelle Way are perhaps more likely to take into account the nature of the residents' conditions, thus accepting deviations from social norms more readily.

Bullace View and Cherry-Plum appeared, from the period of observation, to be less confident in caring for people with BPSD. For these non-specialist homes, residents with BPSD created great challenges and uncertainty for staff. Having a minority of residents with dementia appeared to make staff view BPSD with more fear and consequently, as more of a problem. This could be because BPSD was the exception rather than the rule so had not become a usual feature for staff to cope with. At Bullace View, where many residents had full mental capacity there was more concern over those residents who deviated from social norms.

Support and Resources

External agencies

A variety of external sources of support were available for CH staff at all case study homes. Each external agency had a separate role. Table 6.2 sets out the sources of support the case study sites used during my observations or mentioned in interviews. A brief description of the support they provided for CH staff is included. The main sources of support used by CH staff to help them manage BPSD were GPs, the mental health (MH) team, the crisis team, and consultant psychiatrists. These resources principally supplied biomedical help, which was predominantly based on medication reviews. Access to GPs was straightforward and occurred regularly. Two of the homes had regular GP visits, the other two called them in as necessary.

Table 6.2: External sources of support for care homes

Source of Support	What Offer
General Practitioner	Medical care – medication prescriptions
Community Mental Health Team	Resident review - Medication review – help residents with complex mental health conditions
Crisis Resolution Team	Emergency help within 24 hours for acute and severe psychiatric crisis
District Nurses	Nursing duties in non-nursing homes
Consultant Psychiatrist	Medical management of mental health conditions – medication reviews
Community Psychiatric Nurse	Care co-ordinator – places residents at CHs, can be contacted for support in the first 6 months of a placement
Staffing Agencies	Staff cover
Pharmacy	Medication preparation and dispensary
Hospice	End of life care advice
Care Quality Commission	Standards – reports highlighting areas of improvement
NICE	Guidelines
Police	Help in emergencies-such as, a resident absconding
Hospital	Medical care for residents
Social Services/Local Authority	Resident funding and placements
Social Worker	Resident placements and reviews
Dementia Helpline	Advice
Emergency Services	Urgent help if an emergency situation arises
Full Nursing Care	Funding
Dietician	Diet review
Speech and language Therapist	Help residents with disorders of speech, language, communication and swallowing
Physiotherapist	Help residents with physical difficulties
Church	Pastoral care, volunteers
Alzheimer’s Society	Online forum, 24 hour help and support

The crisis team was viewed as a helpful resource in times of need, with the main function perceived as keeping residents out of hospital. The crisis team could be called by CH staff in times of urgent need with a response within 24 hours. The MH team was inaccessible to CH staff directly; instead, in all the case study homes, a GP was the gatekeeper and had to refer a resident to them. The only exception was for those residents admitted under the Mental Health Act where access to a consultant psychiatrist was made available to the CHs for those particular residents if required. There was usually a considerable wait of up to 6 weeks before MH team staff arrived, often leaving CH staff and residents in an indeterminate state. In normal circumstances access to a consultant psychiatrist was gained by going through the referral system run by the GP.

Funding

Each home was run as a business, meaning that financial resources were important. Care funding was an issue for most homes and the amount received was depended on the nature of the CHs admissions. For example, residents could be funded: by the Local Authority (Adult Social Care) if they were not financially affluent, privately if they had savings, through social care if they were admitted to a CH through a Section 117, or through NHS Continuing Healthcare if they had a complex medical condition and substantial, ongoing nursing care needs. The amounts achieved from each source are remarkably different. Adam, the manager at Cherry-Plum raises an important point about the funding obtained through the Local Authority:

'it's extraordinary what's expected for so little, the um, the amount that they, um, social services pay, a standard contract is £54 a day, I mean you can't get the Travel lodge in under that' (Adam, Owner/Manager; Cherry-Plum)

This basic fee level would not go far if extra resources, such as another staff member or NPIs were needed to cope with a resident's BPSD. However, Adam goes on to say:

'at the moment we've only got a few at that level, fortunately because of challenging needs and dementia we've been able to secure better funding (through Continuing Healthcare).' (Adam, Owner/Manager; Cherry-Plum)

Obtaining more funding, although a complicated process for CH staff, does reflect the recognition by external agencies that residents with BPSD need more input from staff than those without.

People as resources

Visitors to the CHs could be great resources. Many family members visited daily at regular times and helped staff by feeding their loved one, occupying them or helping to manage their behaviour. Some of the relatives appeared to be incredibly helpful in managing behaviour. Jim, a resident at Gage Hill is unsteady on his feet, but wanders a lot. He becomes agitated and grabs on to people very hard, sometimes injuring staff or residents this way. Jim's wife arrives at Gage Hill most afternoons, the time of day Jim's behaviour becomes worse; she spends time with him, feeding him, walking about with him, often with him grabbing her. The one-to-one attention she gives him supports the staff by freeing them to be able to look after the other residents and by assisting them to cope with Jim's behaviour if he becomes very agitated. This daily help is almost like having another member of staff on hand, it provides Jim with better care and his wife stated that she was *'pleased to have a role'*.

Volunteers could also be invaluable to CH staff. In the different case study sites they helped by: driving the minibus on trips, sewing, manning a pop up shop, creating displays, helping with activities, flower arranging, or by generally helping out.

Mirabelle Way offers opportunities to work experience students annually and has also had Duke of Edinburgh award students volunteering in the home. Some staff helped with activities and trips in their own time. Volunteers did not generally help with the management of BPSD, but did help take the pressure off staff by enriching residents' lives through socialisation and by physically helping with tasks and activities, thereby enabling staff to have more involvement with those residents with BPSD or catch up with outstanding duties.

Conclusions

This chapter has allowed an exploration of the CH dynamics of the four case studies and how these relate to the management of BPSD. The CH features, staff team

characteristics, and the resources and support the CH staff have access to were all found to be important factors. Indirectly, the ownership, type of admissions, environment and resources all impact on staff practices. The differing forms of ownership of the homes dictated the support, resources and guidance the manager received. Individual owners allowed their managers differing levels of autonomy and control. The hybrid role of owner/manager brought the most work and responsibility without support and as such, appeared to be a disadvantage. The four case studies showed that CH owners can vary greatly in the role they play to support managers, provide direction and supply resources. The CH environment can impact on residents and on staff perceptions of behaviour. Multiple spaces were viewed as helpful in the management of BPSD. Admission criteria were important in reflecting the type of resident cohort that staff would encounter in the homes. Each of the four cases had a different clientele, and therefore different care and behavioural challenges for the staff team to cope with were apparent. Funding availability for residents also depended on the type of admission each resident had experienced or their condition.

A substantial proportion of the management of BPSD appeared to rely on the staff team and the individuals within it. Training, experience and personality all merge to contribute to the response residents receive when they are experiencing BPSD. Care experience was viewed as the most important factor to help staff manage BPSD. The need to be flexible and adapt to residents behaviours emerged as important factors, as well as the need for a mixed skilled staff team. Training was perceived to be helpful, although the benefit of dementia awareness training just covering the aetiology of dementia was questioned by some staff members. Practice based training was found to be more helpful and perhaps should be prioritised over learning about how dementia manifests itself within the brain. Staff members often took on other roles to their own so that the CH could muddle through; an example of the team pulling together so that the CH could function. The nature of caring for vulnerable adults is that it is a job that needs to happen; therefore staff would be redistributed to different roles if necessary to enable the work to be carried out. This was the same with kitchen duties, where staff would be pulled from care roles to cook for the day. The basic need for meals meant that this role was prioritised over care; in the same

way care or laundry was prioritised over activity duties. Staff shortages were a frequent occurrence. There were very good levels of support within the staff team, with the hierarchical staff structure being utilised if necessary.

External sources of support for the differing CHs were similar. Access to external resources in relation to the management of BPSD was generally to organisations offering biomedical assistance and medication prescriptions or reviews. Therefore, the majority of help on offer to CHs for BPSD would seem to lead them towards medication gatekeepers. Volunteers were a great source of help at each case study and worked to take pressure off staff members. Generally, the data showed that many CH factors can indirectly or directly impact on the management of BPSD, whether this is at the level of the wider organisation, CH, staff team, or individual staff member.

Chapter 7: Medication Use

Introduction

The multiple CH dynamics explored in chapter 6 proved to be important influences on the management of BPSD. The staff team, environment, residents' conditions, CH ownership, and the resources on offer all impacted on the way BPSD were perceived and could be managed. This chapter moves on from indirect influences to an exploration of the actual strategies used by CH staff to manage BPSD. Medication use is one such strategy and this will be explored in the current chapter. As established from the literature (see page 33) antipsychotic medication has been used to manage dementia behaviours. Attention from the media on antipsychotic use for PWD, guidance from NICE to use these medications as a last resort, and the recommendation by the Department of Health in England to reduce their use indicate the relevance of examining the practice of using antipsychotic medication in this way. To investigate this area the case studies were designed with a medication mapping component to obtain data to illuminate the use of psychotropic medication in CHs for residents experiencing BPSD. Staff knowledge of medications, administration practices, monitoring procedures and PRN use were also explored, but through interview and observation methods within the case studies. The findings are portrayed below.

Medication use in care homes

As a starting point for the exploration into the use medication for BPSD within CHs the survey responses from phase 1 were re-inspected for the four case study sites. Table 7.1 depicts the reported approximate level of antipsychotic prescriptions for all residents in each CH, regardless of diagnosis.

The data show the survey response from Gage Hill, undoubtedly, reported the highest antipsychotic prescription level (68%) for residents. This high prescription level can be explained in a number of ways. Gage Hill also had the highest observed frequency of BPSD out of the four cases. The home's registration is as a specialist dementia home, which admits residents with moderate to severe dementia. Gage Hill does not offer

nursing care; the only nurse on site is the manager, so there are fewer medically trained staff members to monitor medications. Additionally as residents at the home do not require nursing care, they are more likely to be physically able and/or medically fit than those at nursing homes, meaning their feelings and needs can be expressed through physical behaviour. The highly complex mental health needs of the residents and the small and densely populated living areas at Gage Hill may also contribute to BPSD being more pronounced there than at the other homes. The other 3 CHs reported far less antipsychotic use (between 8-17% of residents).

Table 7.1: Antipsychotic prescription levels from participating case study care home survey responses

	Care Home Name			
	Bullace View	Gage Hill	Mirabelle Way	Cherry-Plum
	n (%)	n (%)	n (%)	n (%)
Number of residents	38	25	24	38
Number prescribed antipsychotic medications	3(8)	17(68)	4(17)	3 (8)
Number prescribed PRN antipsychotic medications	1(3)	4(16)	0 (0)	0 (0)

Medication mapping findings

Medication mapping was conducted for 22 residents over the four case study sites. The aim was to map psychotropic medications only. Fourteen of the 22 residents were prescribed at least one psychotropic medication. Table 7.2 shows the psychotropic medications that residents were prescribed, as well as the antiepileptic medication sodium valproate, which will be discussed shortly. In total 31 psychotropic medications were prescribed to the 14 residents, of these 6 were prescribed as PRN medications. The highest number of psychotropic medications prescribed to an individual resident was 5 (n=2). Five of the 14 residents prescribed psychotropic medications were prescribed antipsychotic medication, 11 were prescribed antidepressant medication, 6 were prescribed hypnotic medication and 6 were prescribed anxiolytic medication (categories derived from the British National Formulary (BNF)). Antipsychotic agents were the least prescribed psychotropic medication found. This could be a reflection of the outcome of the Department of

Health's recommended reduction of antipsychotics. Conversely, unintended consequences of this proposed action could be occurring and due to the pressure not to prescribe antipsychotics, other psychotropic medication may have been introduced in their place. Alternatively, it could be an indication that antipsychotic medications are usually used less than other psychotropic medications, such as antidepressants, which may be being prescribed appropriately for depression. Or that the prescriptions for this very limited sample are atypical and antipsychotic medications are prescribed more freely to other CH residents.

Of the 5 residents prescribed antipsychotic medication, only 1 was prescribed an older style typical antipsychotic (haloperidol). The remaining 4 were prescribed the atypical antipsychotics, quetiapine or risperidone. Only risperidone is licensed to manage BPSD in the UK (MHRA, 2008). Prescribing other antipsychotic medications for BPSD would mean their use was off label. The high instance of antidepressant medications for residents (11/14) is remarkable and could be, in part, due to the association between depression and dementia (Diniz et al., 2013; Saczynski et al., 2010). Conversely it could be connected to the sedative effect that many antidepressant medications have (British National Formulary, 2013), therefore potentially impacting on the instances of BPSD.

All 6 residents at Mirabelle Way (shown in Table 7.2) who had their MARs inspected were prescribed at least one psychotropic medication. This could reflect the nature of the CH, which is a specialist EMI home where residents have very complex needs. Surprisingly, out of the 5 residents at Gage Hill whose medications were mapped only 1 was prescribed an antipsychotic medication, whereas Table 7.1 shows the survey response from this CH reported that 17 of their 25 residents were prescribed an antipsychotic medication. This finding could be due to many factors: a reduction in antipsychotic use for residents between the survey (November 2011) and the case study (May 2012); the residents on antipsychotics experiencing little or no further BPSD, since the residents targeted for medication mapping were generally showing BPSD, or due to a change in residents at the home, with those previously on

Table 7.2: Medication mapping across participating case study care homes; residents' psychotropic prescriptions

Care Home Pseudonym/Age	Medication	Class*	Dose per administration	Number of doses daily	Total daily dose	Frequency of behavioural and psychological symptoms of dementia (BPSD)**	Observed BPSD
Bullace View							
Ena/89	Mirtazapine	Antidepressant	15mg	1 alternate days	7.5mg	Medium	Wanders, absconds, shouts
Joan/92	Amitriptyline	Antidepressant	10mg	1	10mg	Low	None observed
Violet/83	Mirtazapine	Antidepressant	45mg	1	45mg	Low	Depression, low mood
	Risperidone	Antipsychotic	0.5mg	1	0.5mg		
	Venlafaxine	Antidepressant	75mg	2	150mg		
	Zopiclone	Hypnotic	7.5mg	1	11.25mg		
	Zopiclone	Hypnotic	3.75mg	1			
Gage Hill							
Jim/78	Citalopram	Antidepressant	20mg	1	20mg	High	Grabs, wanders, aggression, agitation
	Sodium valproate	Antiepileptic/manic	100mg	3	300mg		
Thelma/89	Mirtazapine	Antidepressant	30mg	1	30mg	High	Calls out, aggression
	Sodium valproate	Antiepileptic/manic	200mg	1	200mg		
Iris/77	Risperidone	Antipsychotic	500mcg	2	1mg	Medium	Anxiety, agitation
	Mirtazapine	Antidepressant	15mg	1	15mg		
Mirabelle Way							
Micheal/68	Zopiclone	Hypnotic	7.5mg	1	7.5mg	Medium	Wanders, takes things, constantly on move, grinds teeth
	Sertraline	Antidepressant	100mg	1	100mg		
	Sodium valproate	Antiepileptic/manic	300mg	2	600mg		

Table 7.2 Continued...

Care Home Pseudonym/Age	Medication	Class*	Dose per administration	Number of doses daily	Total daily dose	Frequency of BPSD**	Observed BPSD
Mirabelle Way Continued...							
Ron/81	Mirtazapine	Antidepressant	15mg	1	15mg	Medium	Shouts, resistant to care, aggression
	Quetiapine	Antipsychotic	25mg	4	100mg		
	Diazepam	Anxiolytic	2mg	1 PRN	2mg		
	Sodium valproate	Antiepileptic/manic	200mg	4	800mg		
Patricia/71	Diazepam rectal	Anxiolytic	10mg	1 PRN	10mg	Low	Later stages of dementia, profoundly disabled
	Sodium valproate	Antiepileptic/manic	200mg	2	400mg		
Nigel/73	Amitriptyline	Antidepressant	10mg	6	60mg	Medium	Shouts out, agitated
	Lorazepam	Anxiolytic	1mg	3	3mg		
	Sodium valproate	Antiepileptic/manic	100mg	1	100mg		
David/68	Zopiclone	Hypnotic	3.75mg	2 PRN	7.5mg	Medium	Confused, wanders, grabs, aggression
	Diazepam	Anxiolytic	2mg	2 PRN	4mg		
	Haloperidol	Antipsychotic	5mg	2 PRN	10mg		
	Haloperidol	Antipsychotic	5-10mg	3	30mg		
	Mirtazepine	Antidepressant	15mg	1	15mg		
Mary/83	Zopiclone	Hypnotic	3.75mg	1	3.75mg	Medium	Verbal aggression, controls others
	Mirtazapine	Antidepressant	15mg	2	30mg		
	Quetiapine	Antipsychotic	25mg	2	50mg		
	Sodium valproate	Antiepileptic/manic	200mg	3	600mg		
Cherry-Plum							
John/87	Lorazepam	Anxiolytic	1mg	1	1mg	Low	Says rude things
	Zopiclone	Hypnotic	3.75mg	1 PRN	3.75mg		
Bert/80	Lorazepam	Anxiolytic	1mg	2	2mg	High	Agitation, aggression, frustration,
	Zopiclone	Hypnotic	3.75mg	1	3.75mg		

*Categories from BNF **Researcher rating, Low, Medium or High frequency of BPSD from case study observations

antipsychotics no longer at the home or at a different stage of dementia and no longer requiring assistance to manage their BPSD at the time of the case study.

Table 7.2 also shows the types of BPSD I observed from individual residents whilst undertaking each case study. A loose indication of the frequency of behaviours is also provided, with classifications as follows: 'low' – seldom experiences BPSD 'medium' – frequently experiences BPSD and 'high' – almost persistently experiences BPSD. There does not appear to be any particular connection between BPSD and the psychotropic medications prescribed. Some of the residents not prescribed any psychotropic medications experienced medium or high frequency levels of BPSD. Behavioural and psychological symptoms of dementia observed from these residents included resisting care, wandering, confusion, repeating questions, inappropriate toileting, different reality, verbal aggression, anxiety, shouting out and physical aggression towards others. There was no clear reason why some residents had been prescribed psychotropic medications and not others. Perhaps those taking psychotropic medication had experienced more intense symptoms before their prescription. Or perhaps those residents not prescribed psychotropic medication were easier for staff members to manage than those taking it had been before their prescription.

Whilst I was at the second case study, Gage Hill, Susan the manager mentioned that one of my participating residents (Jim) had been prescribed an antiepileptic drug, sodium valproate (Epilim), a medication for the treatment of epilepsy or mania (British National Formulary, 2013) off label for his BPSD. From this time I also checked for sodium valproate when conducting the medication mapping. Somewhat unexpectedly, 7 out of the 17 further residents whose medication was mapped were prescribed sodium valproate. When compared to the finding showing 5 residents with antipsychotic prescriptions out of the total 22 residents who had their MARs inspected, this is surprising. It is impossible to clearly know if sodium valproate was prescribed as an anticonvulsant or as a psychotropic (antimanic), therefore it is included in Tables 7.2 and 7.3 with the rest of the psychotropic medications. The residents prescribed sodium valproate are, with the exception of one, those with an observed medium or high frequency of BPSD. These data are obtained from a limited sample making it difficult to make and definitive conclusions. However, the apparent

common prescription of sodium valproate could indicate that the pressure to reduce the use of antipsychotic medications for PWD has enacted a shift towards off label use of this medication for BPSD. This may be an attempt to find alternative ways to continue to manage BPSD through use of medication without use of antipsychotics. An updated Cochrane review published in 2009 undertook a meta-analysis of 5 RCTs and found, that when compared to controls, valproic acid derivatives made no improvement in the agitation of PWD, but there was an increase in adverse events (Lonergan & Luxenberg, 2009). The lack of evidence for the efficacy of sodium valproate for BPSD, along with the increased risk of adverse events is a concern. If sodium valproate is being used off label for BPSD, it could be that the unintended consequences of reducing antipsychotic medications for PWD has led to a similar situation occurring, just with a different medication, which is currently less prominent in the public discourse and not (yet) subject to policy imperatives.

Table 7.3 shows details of the medications and regular doses residents were prescribed along with the recommended daily doses as stated by the British National Formulary (BNF) (British National Formulary, 2013) and Table 7.4 shows the same, but for PRN prescriptions. Mirtazapine was the antidepressant medication prescribed most frequently (7/12). This could be due to the sedative effect associated with it (Luckhaus. C et al., 2003). All antidepressant medications were prescribed as regular doses and none were omitted over the 28 days studied. Only 2/11 residents were on the maximum recommended dose for an antidepressant that they were prescribed.

All 6 residents prescribed a hypnotic were on zopiclone. As Table 7.4 shows two residents were prescribed zopiclone as a PRN medication; however, over the 28 days all potential doses had been administered, although 11 administrations had been for 1 tablet instead of the specified maximum of 2. Tables 7.2 and 7.3 show that one resident was prescribed 2 different regular doses of zopiclone (7.5mg and 3.75mg) which took her over the daily recommended maximum dose of 7.5mg to 11.25mg to an unlicensed dose; these medications had both been administered on all of the 28 days studied. This may well indicate the absence of (and need for) a medication review to assess the appropriateness of continuing with 2 doses of the same medication on a routine basis.

Two types of anxiolytics were prescribed; 3 residents were prescribed lorazepam and 3 were taking diazepam. The prescriptions for diazepam were all PRN (one of which was for emergency use) and only 1 had been administered to 1 resident over the full 28 days. Of the 3 antipsychotics prescribed, both haloperidol and quetiapine were each prescribed to 1 resident at daily doses over the recommended maximum. The daily dose of haloperidol exceeding the maximum was made up of a regular dose of between 5 and 10mgs, 3 times a day and a PRN dose of 5mgs, 2 times a day. Generally the regular dose of 5mg was given at breakfast and bedtime and 10mg at tea time (20mg daily). The PRN dose was not administered at all over the 28 days studied. Therefore, although the maximum daily prescription was up to 40mgs, the maximum administered over the 28 days was 20mg daily (5 regular doses were omitted due to the resident being sleepy). However, a quetiapine dose of 100mg, 50mgs over the maximum daily recommended dose (50mg), was administered regularly over the 28 days (25mg x4 daily); although 5 doses were omitted due to the resident being sleepy. Risperidone was prescribed to 2 residents at a level that fell within the usual recommended dose.

Sodium valproate was prescribed in doses lower than the usual recommended range for epilepsy (1-2g), with 5 of the 7 residents on daily doses of 300mg or below and the highest dose being 800mg. These low doses could indicate that the sodium valproate prescriptions were being used off label to control BPSD, since if these medications had been prescribed for epilepsy one would expect that the doses would have been considerably higher in order to effectively manage epilepsy. This is particularly apparent since the recommended starting dose of sodium valproate for epilepsy is 600mg, increasing by 150-300mg every 3 days and these doses were static across the 28 days. Therefore, the information in Table 7.3 adds to the argument put forward on page 171 by further indicating that the use of sodium valproate could have been off label for BPSD.

Table 7.3: Medication mapping across participating case study care homes: psychotropic regular doses

Medication	BNF Recommended daily dose range*	Number of residents prescribed n = 14 n (%)	Mean daily dose over 28 days	Range of daily doses	Potential doses over 28 days	Dose omissions over 28 days
Antidepressant						
Mirtazapine	15 -30mg usual 45mg maximum	7 (50)	22.5mg	7.5 (15mg alternate days) - 45mg	210	2
Amitriptyline	30-75mg usual 200mg maximum	2(14)	35mg	10-60mg	196	0
Citalopram	20mg usual 20mg maximum	1(7)	20mg	20mg	28	0
Sertraline	50mg usual 200mg maximum	1(7)	100mg	100mg	28	0
Velafaxine	75mg usual 375mg maximum	1(7)	75mg	75mg	28	0
Hypnotic						
Zopiclone	3.75mg usual 7.5mg maximum	4(29)	6.6mg	3.75-11.25mg	112	0
Anxiolytic						
Lorazepam	0.5-2mg usual 4mg maximum	3(21)	2mg	1-3mg	168	0
Antipsychotic						
Haloperidol	0.5-3mg usual 3mg maximum**	1 [1 regular dose and one PRN] (7)	18.75mg	15-40mg	140	5
Risperidone	500mcg-1mg usual 2mg maximum	2(14)	1mg	1mg	112	0
Quetiapine	25-50mg usual 50mg maximum***	2(14)	75mg	50-100mg	168	5
Antiepileptic/Antimanic						
Sodium valproate	1-2g usual 2.5g maximum	7(50)	357mg	100mg-800mg	448	5

*Recommended daily doses for older people if specified **30mg for schizophrenia ***800mg for mania and depression in bipolar

Table 7.4: Medication mapping across participating case study care homes: psychotropic PRN doses

Medication	BNF Recommended daily dose range	Number of residents prescribed n = 14 n (%)	Mean daily dose over 28 days	Range of daily doses	Potential doses over 28 days	Doses administered over 28 days
Hypnotic						
Zopiclone	3.75mg usual 7.5mg maximum	2(14)	4.89mg	3.75-7.5mg	56	56
Anxiolytic						
Diazepam	7.5-15mg usual 30mg maximum	3 (21)	0.07mg	2-10mg	112	1
Antipsychotic						
Haloperidol	0.5-3mg usual 3mg maximum (30mg for schizophrenia)	1 (7)	0mg	2.5-5mg	56	0

Omissions of regular doses were not found in all CHs; only at Mirabelle Way. Reasons for these omissions were documented on the MARs as the residents being sleepy or in the case of sodium valproate 'other treatment given'. The omissions of regular doses at Mirabelle Way could be due to the specialist nature of the home and highly trained staff there; those administering medications at the home were all nurses with mental health knowledge meaning they may have had the confidence and medication knowledge to make omission decisions where administering staff members at other homes would not.

Pro-re-nata (PRN) medication use appeared to vary between medications, with diazepam rarely being administered and zopiclone always given. Approximately 1 in 5 (6/31) psychotropic medications were prescribed to residents for PRN use. Out of the 6 PRN prescriptions diazepam (n-3) was administered once out of a possible 112 doses, zopiclone (n-2) was administered each of the potential 56 doses over the 28 days (at 11 of these times, only 1 (3.75mg) out of the possible 2 tablets (totalling 7.5mg) prescribed were given) and haloperidol (n-1) was not administered at all out of 56 possible doses. It is clear that zopiclone, even though prescribed as a PRN, was administered very regularly to the 2 residents on it. This could indicate that a medication review should take place to re-prescribe this dose as a regular dose for particular residents.

Due to the nature of the case studies and the methods utilised in them, whether each resident had a diagnosis of dementia was not determined, nor was the reason the psychotropic medications had been prescribed (this information is not documented on MAR sheets). Therefore, it is possible (but unlikely) that the medications set out in Tables 7.2, 7.3 and 7.4 had been prescribed for other reasons than for BPSD, such as functional mental health needs. Nonetheless, overall the medication mapping data provides a good indication of the psychotropic medications for 14 residents. However, the use of psychotropic medications in CHs is not completely illuminated by information on resident prescriptions, doses and administrations. In order to obtain a clearer picture of this matter the findings that were obtained and generated through observations and interviews in the case studies to facilitate further understanding about medication use for residents with BPSD will be explored.

Observation and interview findings: Medication use

Knowledge of psychotropic medications

Across the four case study sites staff had varying levels of medication knowledge. Senior staff typically had more knowledge than carers, since they were the ones who administered the medications. Several carers had no, or very little, knowledge about residents' medications, for example how many they were taking, at what times, or what they were for. A characteristic response from numerous carers when asked about medications was similar to this one from Naomi:

'to be fair I never know if, I don't often know if somebody's taking any medication because we don't really deal with anything, yeah, unless ... someone's said that they are, but...' (Naomi, Carer, Gage Hill)

Staff members who administered medications had much more medication knowledge. However, the level of their knowledge was also variable, with senior staff, staff who ordered the medications, and staff who regularly administered medications generally having the most knowledge. Staff members who only administered medications occasionally, due to: being part time, members of night staff, or carers who infrequently 'acted up' as a senior member of staff had less medication knowledge. Staff knowledge usually included how to administer medications, what they were for and their main side effects. This knowledge was vital to inform PRN administration decisions and for improving the monitoring of residents on medications. Some administering staff worked hard to keep their medication knowledge up to date. They either looked up medications in the current BNF or sought information from other professionals. For instance, when new medications were prescribed for a resident at Cherry-Plum by the Crisis Team, Audrey and her colleague asked for advice about the ongoing monitoring of the new medications:

'we sort of said 'right, okay if she's on this medication do we have to review it?' because I'm not psych trained 'do we have to review it in X amount of months or?' he said 'no, that's safe, that you'll need to review' and he was really good' (Audrey, General Nurse, Cherry-Plum)

The knowledge that Audrey obtained from the Crisis Team psychiatrist enabled her and her colleague to be confident about how to monitor and review the new medication. This example illustrates how staff members' medication knowledge can work to improve the care provided.

Instating and reviewing medications for BPSD

In general, staff from each case study were aware of the stigma surrounding the use of antipsychotic medications in CHs and were defensive about their role in this, as illustrated here by Susan.

'medication in care homes is always something that, it's kind of viewed that care homes put people on medication and I can't prescribe anything unless the doctor gives it to me, so it's nothing to do with the care home at all.' (Susan, Manager, Gage Hill)

Susan was keen to distance herself from the prescription of medication and to stress that although CHs take the impact of negative media portrayals, it is the GPs and psychiatrists who prescribe these medications. Prescriptions for residents can also be made before the resident moves into a CH or during a stay in hospital. This leaves CH staff to contend with the issue of reducing or stopping these medications. This process often has to be initiated from CHs, since routine medication reviews by prescribing medical professionals appeared to be rare.

Medication effects appeared to be monitored continuously by staff in each CH. If a drug was perceived to be ineffectual or to have negative side effects the GP would be called in to review the prescription. In the same way, a GP would be called if staff noticed a marked change in a resident's behaviour (although one nurse stated that she would always check for a urinary tract infection in the first instance, (Heather, General Nurse, Cherry-Plum)). Overall, the CH staff appeared to be quite well supported by health professionals in relation to medication issues. The majority of residents at Bullace View and Mirabelle Way were registered with one surgery; enabling the same GP to make regular visits to each CH. This continuity was beneficial for all concerned, since relationships could be built up between CH staff, residents and the GP. The GP could then utilise their past knowledge of the resident and the CH to help make

medication decisions. CH staff reported that for difficulties relating to residents with BPSD the GP either made changes to a prescription themselves or referred the resident to the MH Team, so that specialist psychiatric staff with particular mental health training could make the decisions over medications. However, CH staff can feel frustrated by this referral process, as Susan states here

'so you can have people who have behaviour, challenging problems all sorts of things and you have to wait 6 weeks to get a referral through, which can be a bit of a nuisance when you think all I want is just a little bit of, just something, just to calm things down a bit, but they (GPs) can be reluctant to prescribe and the referral process does, can take quite a long time.' (Susan, Manager, Gage Hill)

This excerpt shows how CH staff and residents are sometimes left for weeks to cope with their current difficult situation before pharmacological support is given. It also illustrates how in some situations Susan was clearly keen for some medication to be prescribed. CH staff cannot prescribe psychotropic medications themselves, yet prescribers may feel pressure from them to give some form of medication to a resident. This is particularly so since medical professionals have been especially called in by CH staff to address the difficulties experienced from BPSD. Sometimes their visit may be after a stressful 6 week wait, and the medicalised treatment regime GPs and psychiatrists offer is dominated by drugs. If something needs to happen to ease the situation, medications may be the only intervention that GPs and psychiatrists are able to prescribe, especially if alternatives such as psychotherapists are expensive, in short supply or could be ineffectual for the present symptoms. However, if the situation has reached a crisis point CH staff can contact the crisis team who should arrive at the home within twenty four hours.

Staff reported that when the MH or Crisis Team arrives they predominantly review the resident's medication. Brenda, a team leader at Gage Hill explains what they want from the MH Team:

'normally it's the medication, um because the behaviour it will then, you know, because we tend to deal with it, you know, we're quite, quite good at dealing

with all the different issues, we put up with quite a bit (laughs) um so gradually, I mean it does take time, you know it isn't just a quick fix, you can't just have another tablet and it works, you know. Sometimes it takes months to, you know, we don't necessarily want them (residents) to have to go anywhere, if we can do it here and they can get the medication.' (Brenda, Team Leader, Gage Hill)

Brenda's excerpt implies that pharmaceutical help is the main function required from the MH Team, who along with the GP and Crisis Team are the gatekeepers to medications. Brenda reflects the confidence CH staff feel at Gage Hill; that they can manage everything else themselves other than medication, for which they have to access a gatekeeper. She also alludes to the time it takes, and the trial and error process needed, to find a suitable medication for each resident. This highlights the issue that psychotropic drugs cannot be used as a 'one type suits all' intervention. The determination to keep residents at the home and prevent a hospital admission was shared across the case study CHs. Keeping resident out of hospital could also be a factor in the gatekeepers' decisions to prescribe medications; better another medication prescribed than a hospital admission. A medication prescription in this situation could be viewed as the better choice for both the resident and for the use of NHS resources.

CH staff typically stated that when GPs and psychiatrists were at the homes they liaised with them about residents' conditions and medications. In two of the case study CHs (Mirabelle Way and Gage Hill) staff would anticipate a visit from the MH team by gathering documented evidence of the behaviour in the weeks before their arrival, often with the use of behaviour charts (a form filled in frequently documenting behaviour such as, what behaviour and when, where and why it occurred). Susan talks about the benefit of using a behaviour chart before a visit from the MH Team:

'we tend to want to pre-empt what they (the MH Team) want to do, that we have behaviour charts flagged up so that you can know throughout the course of a 24 hour period, we sort of highlight all the hours in different colours, you know are they asleep, are they settled, are they restless, are they agitated so that you can sometimes see patterns, that it's round about this time is when

they're bad and things like that do sort of help them (the MH Team) when they come because they then can look at it and see when are their bad times? When's the best time to give this type of medication if you're going to be giving it? If you know, I mean with Jim (resident waiting for the MH Team) he's been put on medication and it's not really doing anything so it's a question of do we take him off it? Possibly try him with something else? But it is just getting that balance between being able, I mean you saw what he was like today (very agitated). So it's trying to get him so that he's manageable without overly sedating him and still enabling to have some quality of life and that's, can be a bit tricky (laughs).' (Susan, Manager, Gage Hill)

The use of a behavioural chart works to thoroughly inform the visiting psychiatrist of the situation; speeding up the process of prescribing, since a monitoring period, which may be suggested to gain more knowledge about the behaviour has already occurred. As Susan mentions, the documentation gathered can provide an indication of the times when behaviour occurs; allowing the prescriber to identify the best time of day for medications to be given. The process Susan mentions reflects the monitoring and reporting role CH staff have with regard to resident behaviours and medication efficacy. Here the medication is not working, so the review process has been activated to try and create a better outcome for the resident and the CH staff. As mentioned earlier this process can take up to six weeks to even meet with the MH Team, before the possible experimental process of altering Jim's prescription to find suitable medication can commence. Meanwhile Jim and the CH staff are left in an undesirable and powerless situation.

Staff reported that changing a resident's medication for BPSD is often a trial and error procedure. Alterations to prescriptions could be implemented for many reasons: to address changes in behaviour, to try a reduction or an increase in dosage, to stop prescriptions no longer needed, or to negate unwanted side effects. Medication could also be moved to a different time of day to manage behaviour better. Medication adjustments were reported to occur repeatedly until the right fit was found for the resident. This could mean that a resident is taken off psychotropic medications altogether since none were found to suit them or that it is perceived to be better to

keep the resident on them. Here Gill, the manager at Mirabelle Way talks through an example of this process:

'There's a gentleman ... who has amisulpride and the (NICE) guidance would be he shouldn't be having it. However, we reduced it a little bit and his behaviour came back, so then you can actually justify, well actually we've looked at the guidelines, we've tried to work with the guidelines, but it's meant this gentleman's quality of life has been affected so therefore we needed to put that back on' (Gill, Manager, Mirabelle Way)

The rationale for antipsychotic use in this excerpt is that reduction brought the unwanted behaviour back. Another justification used by the CH staff for antipsychotic use is when behaviour settled after introducing or increasing a psychotropic medication. The data from the four case studies showed that senior CH staff are acutely aware of the need to reduce antipsychotic medications; they appeared to monitor residents closely and consult a GP if they had any concerns.

Staff monitoring of medications

During my time at Cherry-Plum, the process of staff monitoring had picked up that a resident taking risperidone was leaning to the side while she walked (this can be a side effect of risperidone). The staff initiated a review with the GP and the risperidone was stopped. A further monitoring period occurred, in which the resident became more agitated, frustrated and confused. Staff tested her urine and found she had an infection; antibiotics were prescribed. Once the antibiotics had finished and the infection gone, the resident was still in an unsettled agitated state. The GP was contacted again by staff and the risperidone reinstated. In this instance the GP and CH staff had the responsibility to choose between the resident leaning or being in a constant state of agitation; the lean was viewed as a the better option for the resident to cope with. This trial and error process was common to try and reach a balance for residents. Andy, a psychiatric nurse, who worked nights at Cherry-Plum suggested to other staff that the prescription of further medications could be used to offset some of the negative side effects of antipsychotics:

'the side effects, you know, things we used to use, sort of the psychiatric um antidote, things like Kemadrin and Disprol ... you know like they're (the resident) on Largactil you know, or even Amitriptyline you know some of those, you used to use the antidotes like Kemadrin or Disprol to reduce some of the bad effects you know... So she said she might look into that ... if there's bad reactions ... You know if it means that you get the benefits and counter some of the, you know, reactions, just might modify it and enable them to continue' (Andy, Psychiatric Nurse, Cherry-Plum)

It was unclear if this practice still occurs, it was not happening at Cherry-Plum during the time I was there and since it was my final case study I could not explore the issues at the other cases. It is an interesting idea. The reduction of some of the antipsychotic side effects possibly could have saved the resident mentioned above a stressful few weeks.

The balance discussed above was evident with all antipsychotic use. The benefits had to be judged to outweigh the risks. For instance, if a resident is in an agitated state most of the time is it better to be on a medication to improve their quality of life, but one which could bring increased risk of adverse events? Or better to cope with the agitated state everyday and not have the increased risk of adverse events? The decision is usually dependent on the severity of the resident's condition, their day-to-day quality of life and the ease of managing them safely in the CH environment. Relatives had input into some medication decisions and had to grapple with this dilemma as Anne discusses here:

'he (the doctor) always says you need to ring the family before we can start this, um, yeah he always says, um, or he says get them to ring me if he wants a chat about, like if he wants a proper doctors chat, you know, but um, and I mean, the resident who was mischievous, her family hummed and hawed about it for a while and had several chats with doctor ... because they didn't want her to have a stroke. They used to come in crying because they didn't want to see her like the way she is' (Anne, Assistant Manager, Bullace View)

The excerpt shows clearly the difficulty family members can have making the choice between an increased risk of adverse events or a continued suboptimal daily life for their relatives. This segment also illustrates willingness, by this particular doctor at least, to include family members in the decision making process for antipsychotic medications. The role of CH staff as a liaison point between the doctor and relatives is highlighted too.

Perception of Psychotropic Medications

Psychotropic medications were perceived by most staff administering them as having both positive and negative aspects. Particular residents were perceived to be in a more settled state and easier to manage when a suitable medication had been found for them. Marie, a carer from Gage Hill provides an example:

'Katherine was a nightmare to like try and get her washed, you know, she wasn't eating, nothing and um, the crisis team have come out for her and her appetite has changed, she's eating more, she's sleeping better at night, you know, so I think it does work, you just have to give it time to kick in with her so.'
(Marie, Carer, Gage Hill)

Here a real difference was noticed in the resident's BPSD due to the initiation of new medication. Staff typically thought medications for BPSD could work when the correct fit was found for each individual resident. Many administering staff members were aware that antipsychotic medications could also cause negative side effects, such as drowsiness and further confusion. There was less awareness of parkinsonian side effects and cardiovascular risks. Adam, the owner/manager at Cherry-Plum, explains how he feels about antipsychotic medications:

'I don't like them very much, anything with 'pine' on the end, it knocks people out it makes them eat sleep and drink worse, it makes them unsteady on their feet, there's an awful lot of bad publicity and quite rightly too around the antipsychotic drugs and they are used very cautiously now ... Um, it is difficult um, Greta, she's on medication now, which seems to suit her, it's getting that balance' (Adam, Owner/Manager, Cherry-Plum)

Adam's negative perception of antipsychotics is tempered by the positive effect their use is having on one resident. This portrays a difficult dichotomy, with the risks of these medications keenly felt, yet the benefits required for some residents. The balance which Adam talks of was mentioned by many staff members. It refers to the need for a resident to be in an appropriate mental condition; not with a really poor quality of life from either distress through BPSD or detrimental side effects from medication. Reaching equilibrium for the resident between the two extremes was the main aim.

There was a general perception some residents would need antipsychotic medications and others would not. Hazel, a general nurse at Mirabelle Way, talks about the need for individualised care approaches:

'I would say again it depends on the individual, 'cause what might relax somebody and helps them, you know, maintain everyday living might not be for the next person and as much as I would say that you know antipsychotics are horrible drugs I, I'd be lying. They're there for a reason and I think if they're used appropriately, then fine, some people with never need them and can rely on um, counselling sessions, can, diversionary activities all those things, other people, still great if they had those activities, but will still need that drug'
(Hazel, General Nurse, Mirabelle Way)

Hazel portrays an opinion, which was shown by many administering staff; that all residents have different needs and sometimes a resident might require an antipsychotic medication. Although Hazel alludes to a negative perception of antipsychotic medications, she can see some residents have a genuine need for them *'if they are used appropriately'*. Hazel perceives that antipsychotic medications still need to be used, for some residents, alongside NPIs.

Administering Medications

Medications in the two nursing homes were administered by nurses and in the two non-nursing homes by senior care staff. However at Mirabelle Way nurses would occasionally use carers to physically administer medications to residents, especially to

those residents with BPSD. This sub-administration was controversial, with the care specialist at the head office of the voluntary organisation and some staff against the practice. Administering staff members have to remove the correct medications and doses from, for example, a medicine bottle or dosette box in readiness to give to the resident. At this point they would sometimes pass the medications on to carers to administer and consequently, could lose the ability to be sure that the resident has taken them. Nurses (or within non-nursing homes, seniors or carers) have to sign for medication administrations and are accountable for the medication/s being taken, which in the case of sub-administration, they might not have personally witnessed; thereby making the practice problematic. The standards of medications management do allow the practice in principle:

'A registrant (registered nurse) is responsible for the delegation of any aspects of the administration of medicinal products and they are accountable to ensure that the patient, carer or care assistant is competent to carry out the task'
(Nursing & Midwifery Council, 2007, 2010)

Thus, nurses have the responsibility for the medication administration even when carers are physically giving the medication to the resident. The argument for using sub-administration at Mirabelle Way centred on utilising the close relationships carers had with residents. Since carers generally spent more time working directly with residents than the nurses did, they had a better rapport with residents who would, consequently, be more compliant taking their medications with them. Fay, a carer at Mirabelle Way, who often sub-administers for nurses, explains her technique:

'No I'm quite direct with it really, I'm just like 'here you go' and then not make too much of an ordeal out of it basically ... Sometimes it doesn't work but, but then on other occasions, it doesn't work initially and then I'll say 'well you know this is for such and such' and then that will work sometimes, but then sometimes it just doesn't help (laughs) you know so ... Yeah just try and if you feel like you're pushing them just walk away again like, obviously never force anyone, I think that's the problem, sometimes they feel a bit forced and that probably puts them off taking them' (Fay, Carer, Mirabelle Way)

Fay touches on an interesting point here; the reluctance of residents to take their medications if they feel pressured or 'forced'. Since nurses are busy, often with many medications to administer over a meal time, it is not difficult to see how residents may feel rushed. Carers often stay in the same room as residents at meal times; perhaps making their role more suitable to physically administer medications to residents without making them feel pressured. Sub-administration relied on the nurses being able to admit that others could be more successful than them, personally, at some tasks. Thus, they needed to be able to acknowledge limitations in their own practice. Sub-administration was not particular to Mirabelle Way, but occurred, to a lesser extent, in all the case study CHs. However, Mirabelle Way was the only home, which spoke of it in the context of a strategy to raise medication compliance with residents who experienced BPSD. In the other case study CHs the practice appeared to be in place to use time and staff more effectively. For example, if a resident was being assisted to eat their meal, the administering staff member would ask the carer feeding the resident to also assist them with their medication. This would usually, but not always take place under the watchful eye of the administering staff member.

Sometimes medications were administered covertly or overtly within foods. Overt administration of medications in food happened when the staff member administering the medications told and/or showed the resident they were putting them in the food before the resident ate it. Covert administration of medication in food was viewed as more contentious and this practice appears to occur less now than in the past. Janice, a night carer at Cherry-Plum for nearly twenty years, has noticed a change over the years:

'They're not drugged ... whereas I feel that we did use to do that ... You know to keep them quiet so they didn't offer any challenging behaviour and things like that and there wasn't so much concentration on medicine being, you know covertly, oh well, you just slipped it into a sweet and they eat it you know ... And nobody thought anything about it, so yeah I think dementia, how we manage people with dementia has changed a lot' (Janice, Night Carer, Cherry-Plum)

The excerpt shows that perceptions and practice of covertly administering medication (and heavily drugging residents with dementia) have changed over the years, along with the tightening of rules and regulations. Here Gill, the manager at Mirabelle Way, talks about what needs to happen for this the covert administration of medications to occur presently:

'if you're going to be thinking about a covert medication and you discuss it with the consultant and the GP and the family, you also still need to do a best interests, why are you doing it, and if you cannot clearly say you're doing it for the resident's best interests, um then actually you're doing it for the wrong reason' (Gill, Manager, Mirabelle Way)

Currently, to allow this practice, a collaborative risk assessment with a resident's GP and relatives has to be put into place to protect the resident and staff as Gill alludes to. Covert medication administration was important if a resident was assessed as not having the mental capacity to decide about taking their medication (or not) and could be paranoid, anxious or determined not to take medications. The use of this practice enabled residents to have their medical conditions controlled. A lot of medications were crushed up or put in food, especially at Gage Hill and Mirabelle Way where residents were generally very confused. The concept of swallowing medications was foreign to some residents with marked BPSD who did not understand what to do, whereas eating food was a familiar action and they were aware of how to do it. Written evidence, such as collaborative risk assessments were not viewed during the study.

Pro-re-nata (as required) Medications

As the medication mapping data shows, PRN psychotropic medications were not habitually prescribed in the case study CHs; regular prescriptions were more commonplace. When PRN psychotropic medications were prescribed their administration could be problematic. The premise of PRN administrations in CHs relies on the administering staff asking residents if they need the medication at that time or on them reacting to a perceived need and then administering the drug. When caring for residents with dementia this can be difficult, especially if the PRN medication is a

psychotropic. If the medication is an analgesic (pain relief) staff can ask a resident with dementia if they are in pain or hurt anywhere and they may understand and be able to confirm if they are or not, or use a recognised pain assessment scale (for example, Warden et al., 2003). Yet, in the case of a PRN psychotropic medication, asking a resident if they need a tablet to calm them down or help with their behaviour can be problematic. As with covert medication, PRN psychotropic medication administration also needs to be in the resident's best interests. Here Heather talks through an issue inherent in using PRN medications for residents with BPSD in care settings:

'Well PRN (as required) means exactly what it is, you know and that's a nurse's discretion, I always find that's a difficult one, whether it's analgesia, drugs for psychosis or any drug that's PRN it's going to be down to the nurse's interpretation as to whether that person needs it at the time um, and so you often do find a what I call a yo-yoing effect, whereas I, you know, I might come on and like Pauline, the lady you were feeding at lunch time ... four times a day she can have diazepam and um, you know, I can sort of think in any one given day, nah she doesn't need any, my colleague can think well she needs it those four times a day ... so it is very subjective um, but of course they are what they are, they're meant to be to just take the edge off when somebody's a little agitated ... I prefer to see things in black and white and just have it as in place (regular prescription) ... which is, nine times out of ten we do do that so um, but that's how it works, it's subjective ... it's at the nurse's discretion' (Heather, General Nurse, Cherry-Plum)

Heather clearly draws attention to the subjective nature of PRN medication administrations. When caring for residents with BPSD, with respect to psychotropic medications this subjectivity is increased, since often the administering staff member cannot confer with the resident to determine the need. Residents with BPSD rarely have sufficient mental capacity to make a decision at the time they may need the PRN medication. Additionally, conferring with a resident to determine the need for a medication to help calm them could work to increase their behaviour; a counter effect to the staff aims. The decision about psychotropic PRN administrations is often left solely to the discretion of the administering staff member. In non-nursing homes this

can be a carer with minimal medication knowledge other than basic administration training.

In the excerpt above Heather mentions her preference of regular prescriptions to remove the subjectivity of PRN decisions. She states that most prescriptions are regular at Cherry-Plum. Yet, regular psychotropic prescriptions were also found to be used subjectively by a minority of staff; particularly those with mental health training. During the process of medication mapping it became apparent that some staff would omit regular psychotropic medications if a resident was asleep or very calm. Hazel, a general nurse at Mirabelle Way talks about the practice

'I think Ron, he's not on PRN, but he's on quetiapine, quite often his doses are missed out because he's asleep, why would I wake this man up to give him something that's going to get a (laughs), maintain his mood, you know, it's stupid ... It is a case of, today he's fine, he doesn't need any of that ... And we, we would document it obviously on the medicine chart' (Hazel, General Nurse, Mirabelle Way)

Hazel's excerpt appears to portray a flexible approach, reacting to the resident's condition at the time of administration; if an antipsychotic is perceived to not be needed, it is omitted. The negative media coverage of antipsychotic use may also be influencing this staff practice. However, this action was viewed as wrong by some staff who would not purposely omit a regular prescription medication (except, for example, if a resident refused it repeatedly or was incapable of taking it through illness), since it was prescribed to be given regularly.

The flexible practice of omitting an antipsychotic medication with a regular prescription when it was perceived as not needed was viewed differently by staff members; as either good or bad practice. The Standards for Medicines Management encourage administering staff members to use their judgement:

'The administration of medicines is an important aspect of the professional practice of persons whose names are on the Council's register. It is not solely a mechanistic task to be performed in strict compliance with the written

prescription of a medical practitioner ... It requires thought and the exercise of professional judgement.' (Nursing & Midwifery Council, 2007, 2010)

In principle, omitting psychotropic medication, prescribed as a regular dose, is an acceptable practice, although this guidance is set out in a general sense, making it ambiguous in relation to this specific example. It also just relates to registered nurses and does not cover senior care staff or carers administering medications in non-nursing settings. The staff members in these roles are generally likely to have less medication knowledge or training.

Pro-re-nata antipsychotic medications were not administered routinely in any of the case study CHs. When they were given, the timing of the administration was important. If administration was too early, the resident's behaviour may not have been going to escalate to a level where the medication was required, causing a needless administration. If it was too late, the resident's behaviour or mood could be past the point where any intervention would be successful. Gill, the manager at Mirabelle Way, talks about the issue here:

'I think the key is knowing your residents because um, if someone's at fever pitch you can't give PRN anyway ... You know, without getting hurt, so, so, so the key to it is around knowing your residents ... And knowing if somebody's started to um, and in fact in the personal safety training ... I teach them (the staff) the cycle and the cycle says that actually if somebody's here and they start to escalate um, if we don't intervene then, if they get to there we know that it's going to take an hour to an hour and a half to come down ... If we then try and do something else they're going to go straight up and it's going to make it worse for two or three hours. So the key is that actually we know people, so if they're starting to go up this route what have, what have we got, whether it, it may not be meds, it may be distraction, you know a whole host of things that you would try and do before somebody got to that point that you would then actually know that any intervention now is just going to be, you know a disaster for that person and a disaster for the team. Um, and I think it's realising that

antipsychotics do have a part to play ... It's about how you use them and what you're using them for.' (Gill, Manager, Mirabelle Way)

Gill alludes to multiple factors here. First, knowing individual residents is vital to enable staff to judge situations and time administrations of PRN psychotropic medications well. Second, psychotropic PRN medications cannot be administered if the resident's behaviour or mood has escalated too far. Third, trying to intervene once behaviour has escalated is viewed by Gill as being detrimental to the person with dementia and to the whole staff team; for this reason the option of waiting to see how behaviour progresses is a risky strategy. Fourth, other interventions may be tried instead, or alongside, antipsychotic medications to try to halt the escalation of, or de-escalate, a resident's mood. And fifth, Gill perceives antipsychotic medications, used in the right way, as an important resource within the strategies available to her.

Knowing the resident and timing the PRN administration were themes that also came through when I asked Brenda, a team leader from Gage Hill, about her decision to administer a PRN psychotropic medication earlier in the shift:

'because the lady um, was agitated and she started saying that she wanted to go home, and it's just the way she says it and you think oh she's becoming unsettled, she's shouting, um, and if you can't even reassure her that, you know, that she could perhaps go out another day or something, and it won't work, so then that's when we make the decision, so that we have to use a PRN tablet ... otherwise it makes all the others unsettled, so, and it's upsetting for her as well ... if we left her to carry on, she ends up getting tearful and then it's not very nice, so ... Yeah and also we noticed that it was getting more often, so she is now on another tablet as well so, but we've still got the PRN when we need them, but, um, so it's something, just looking out for little things' (Brenda, Team Leader, Gage Hill)

Here, knowing the usual course a particular resident's behaviour takes influenced the administration decision. Past experiences with the resident becoming unsettled, shouting and subsequently being tearful help Brenda to suitably time the medication administration. As Brenda states, little things, such as the way a resident says

something alerts staff to the need to intervene. Initially reassurance is tried as a way to halt the escalation of the behaviour or mood, however, as Bernadette, a carer at the same home states about the same resident:

'you can't even reassure her once she's got past that stage of non-reassurance there's nothing else you can do but give a tablet' (Bernadette, Carer, Gage Hill)

There appears to be a time when reassurance will not work and staff feel their only alternative resort before the resident gets to an unreachable stage is to administer a PRN psychotropic medication. Overall, the data suggests that staff use their knowledge of residents to judge situations, they initially try to calm residents down with reassurance or distraction; if this approach is unsuccessful PRN medications are turned to before the resident gets to a stage where they are unapproachable. If knowing the resident helps administration decisions, night staff and agency staff who may well not know residents as well as regular day staff have less information when making these decisions.

In addition to the administration decision, PRN medications require more documentation than regular medications. Mirabelle Way used the most explicit guidance and documentation method for these administrations; a PRN protocol. As Gill explains:

'So the protocol that sits by the MAR sheet clearly says this is the meds, this is when you would give it, so in fact um, so if someone is written up for PRN lorazepam it would identify when you might give it so it might be 'cause someone is really, really agitated, it may well be because someone is lashing out. So there'll be clear guidelines as to why you would give PRN medication ... So and that applies to any PRN medication um, even down to pain relief because you need to ask yourself the question why am I giving this? ... so we use a ... detailed PRN protocol sheet' (Gill, Manager, Mirabelle Way)

The staff member administering the medication was required to write down on the protocol the justification for each administration in relation to the guidance. As Gill mentions, this has an effect on staff who then question the reason for the

administration to make sure it is in the resident's best interests and justly required at that time. The PRN protocol also helped with monitoring as Hazel explains:

'then we can see a pattern arising, they'll think well if we've given this man PRN once or twice a day, then we need these medicines reviewed' (Hazel, General Nurse, Mirabelle Way)

The record of administrations and a rationale for each one, work to inform staff of the overall picture for the resident. Staff members can then react to this and initiate a medication review. The team leader at Gage Hill, Brenda, (see excerpt on page 192) also alludes to the ongoing monitoring that occurs, for instance, when it was noticed the frequency of PRN administrations had increased, another medication had been prescribed.

General administration practices

When caring for residents with BPSD administering staff members had to contend with competing demands while conducting their medication duties. For example, residents coming to the medication trolley, multiple interruptions, residents with difficulties knowing what to do with the medications, residents with difficulties swallowing, people not wanting to take medication, confused residents and residents who were asleep. Staff had to adapt to each resident, for example one resident at Cherry-Plum would only take her tablets while standing up or walking along.

Medication refusals appeared to be infrequent, but did occur. If medication was refused by a resident, staff were observed trying to encourage them to take it, if they declined staff would generally leave them and go back to try again a few minutes later. To get reluctant residents to take medicines administering staff were observed using jam, mousse or sweets to help take the taste of the medications away or distracting the resident with comical conversation while the medications were given. The observations showed that if these strategies were not successful in getting the person to take the medication other staff member were occasionally asked to sub-administer the medication or the administering staff would continue to try at intervals. If the medication was not taken after many attempts or if it was spat out repeatedly staff

appeared to give up and either destroy the tablet or sent it back to the pharmacy for safe disposal.

Some medication administration bad practices were noted at the case study CHs. These included not locking the medication trolley up or in place when it was unattended and not waiting with residents who may not have sufficient mental capacity to know what they should do until they had totally finished taking their medications. Over the period of case study observation I found several medications either spat out on tables, plates or the floor, or still in a pot ready to take. On occasion I would alert staff to these tablets, since I was concerned an unintended resident might take them by mistake. Bullace View had a picture of each resident between each MAR sheet to aid correct administration.

Conclusions

These data on medication use in CHs for BPSD show that most administering staff have a good knowledge of the information they need to know to give out medications. These CH staff had to administer medications in frequently busy, hectic environments with multiple interruptions hindering their actions. Many carers had very limited knowledge of residents' medications, but more rapport with, and intimate knowledge of, CH residents than most senior staff. Sub-administrations were used in one home (Mirabelle Way) to increase residents' compliance in taking medications. While these occurred in all of the case study CHs to various degrees, in other homes this was apparently for ease or to save time rather than to improve compliance. Covert medication administration was used; however staff professed that the correct risk assessments and procedures had been followed to allow this. Regular doses of some psychotropic medications were omitted on rare occasions if residents were sleepy. Individual staff members disagreed about the appropriateness of such actions and whether it was good practice adapting to the resident's condition or poor practice by going against the prescription.

The CH staff had an important role in monitoring residents' BPSD and organising resident reviews. Reviews were usually at the request of CH staff. When they occurred, reviews predominantly focused on re-assessing the resident's prescriptions. GPs were

gatekeepers to medications and to specialist help. Access to GPs was a relatively quick process, however unless there was a crisis situation specialist help could take up to six weeks to arrive. This left CH staff and residents experiencing BPSD in an undesirable state with no or limited assistance to help them cope during this time.

Psychotropic medications were perceived to be a required part of care for residents with BPSD at particular stages. Administering staff members were aware of the negative effects of the medications, but also recognised their value in difficult situations. The right fit between individual medications and residents was viewed as an important factor in the efficacy of psychotropic medications. Trial and error was required to find a suitable outcome. In all case study sites it appeared that PRN administration decisions were based on previous knowledge of the resident's usual patterns of behaviour and the right timing. It is likely that CH administering staff who work part time or nights would have less resident specific knowledge to base their PRN decisions on.

The psychotropic medication mapping findings (albeit from a limited sample) indicated that antipsychotic medications were used considerably less than antidepressant medications. Indeed, antipsychotic medications were the least prescribed psychotropic medication found across the sample. Additionally, the unexpected finding that sodium valproate was prescribed more than antipsychotic medication suggests that alternative 'off label' medications are being administered to residents with BPSD in CHs.

The majority of all prescription doses were in the usual recommended range, yet 3 prescriptions exceeded the maximum dose for the particular medication (haloperidol although high dose only through PRN and never given, quetiapine and zopiclone). This finding is concerning; however, due to the limitations of this study in terms of not determining resident diagnoses or reasons for prescriptions the exact need for these high doses cannot be determined and may have been justified. Overall CH staff across all sites had a considered approach to psychotropic medication use for residents with BPSD and felt that there was, and would remain, a need for these medications in certain situations.

Chapter 8: The Use of Non-pharmacological Interventions and Strategies

Introduction

Chapter 7 showed that CH staff consider medication to be a useful strategy, if the situation requires it. However, pharmacological interventions are just one part of a range of varied strategies used in CHs to manage BPSD. This chapter examines the non-pharmacological strategies found to be used in the case study CHs. These included formal strategies like NPIs and activities, but also other more subtle strategies, which could be viewed as being part of everyday care practices such as, PCC, the use of routines and flexibility, the placement of residents, staff approaches, monitoring, communication techniques, and distraction. Since the primary focus of this study is the strategies used to manage BPSD, resident behaviours are discussed only in the context of examining the strategies used by CH staff. Before exploring the case study findings, the survey responses from phase one will be revisited for background information.

Survey Responses

Table 8.1 shows the NPIs reported to be used at the four case study sites along with the behaviours their staff had found difficult to manage. Managers from the two independent homes, Gage Hill and Cherry-Plum reported using more NPIs (n-6 and n-7 respectively) than the two voluntary organisation owned homes (n-3 and n-2).

Animal/pet therapy was used by staff at all four case study CHs and reminiscence therapy was reported by three. Managers at Bullace View and Gage Hill both reported aggression as a behaviour their staff found difficult to manage. The manager at Mirabelle Way stated that staff felt they could manage most behaviour due to the specialist orientation of the home as an EMI home.

Table 8.1 has asterisks by some NPIs to indicate that they were observed in use during my time at at each case study CH. However, the categorisation as an observed 'NPI' is a loose one. Across the case study sites, CH staff would sometimes use the names of NPIs to describe widely varied activities and under these headings ticked on the survey

responses from these CHs I also saw wide variations. For instance, I observed a type of animal/pet therapy at each case study site. At Bullace View visitors would bring in their dogs and allow residents to pet them; there were also tropical fish in tanks at the home. At Gage Hill an activity staff member would bring her dog into the home to spend time with the residents. At Mirabelle Way a specialist therapy dog, a Pat Dog, would come into the home with their owner to spend time with the residents and at Cherry-Plum a cat and some chickens lived on site and visitors were also permitted to bring their dogs whilst they were at the home. Therefore, although I witnessed a form of Animal/pet therapy at all of the case study CHs, this was in the loosest possible sense since all instances were very different from each other and, with the exception of the Pat Dog at Mirabelle Way, probably could not really be formally classed as a NPI. At no time was any animal/pet therapy targeted at BPSD specifically. The subjective nature of Animal/pet therapy, as portrayed here, was typical of all the stated NPIs used at the homes.

Table 8.1: Survey responses from case study CHs: NPIs and behaviours

Survey Responses	Care Home Name			
	Bullace View	Gage Hill	Mirabelle Way	Cherry-Plum
Number of NPIs reported to be used at the home	3	7	2	6
List of non-pharmacological interventions reported to be used	Animal/pet therapy* Reminiscence therapy* Doll therapy	Music therapy* Animal/pet therapy* Multisensory stimulation Reminiscence therapy Massage Doll therapy* Aromatherapy	Animal/pet therapy* Behavioural therapy*	Music therapy* Animal/pet therapy* Multisensory stimulation* Reminiscence therapy* Massage* Aromatherapy*
Response when asked which behaviours are difficult for staff at the home	Aggression Repetition Absconding	Physical aggression Verbal aggression Resisting care	(we manage most behaviours)	Shouting out Lack of mental capacity

*NPIs I observed during my time at the case study CHs

Another example was music therapy, where at Gage Hill it consisted of staff putting a CD on and occasionally spontaneously dancing with residents to the music for a short time. At Cherry-Plum this consisted of a lady visiting the home once a month for an hour with instruments and her guitar taking requests and singing along with residents and activity staff. The subjectivity and disparity between the actions that different CH staff classed as NPIs makes the use of these interventions difficult to assess and discuss in general terms. Nearly every activity or NPI encountered could refer to a wide range of actions just like those shown in the examples mentioned. Even the term 'massage' was found to refer to diverse practices, such as a practitioner coming in with aromatherapy oils or observation of a carer rubbing a resident's hand during an informal chat. With the subjectivity in staff perceptions noted the next section moves forward to explore the activities and NPIs found to be used in the four CHs.

Activities and non-pharmacological interventions

When activities were considered, the subjective nature of NPIs was further confused. This was particularly evident since in many instances the difference between NPIs and activities was indistinct. NPIs such as music therapy, aromatherapy and reminiscence were not used directly to manage BPSD; instead they were classed as activities and targeted towards all residents at the case study CHs in order to improve quality of life. Generally staff did not perceive activities to be interventions (ways to intervene with, offset or mediate behaviour); they were viewed as ways of occupying the residents. This was a surprising finding since the NICE (NICE and SCIE, 2006, revised 2012) guidelines recommend NPIs as first line treatments for BPSD. Due to this guidance, my expectation going into the case studies was that activities, such as aromatherapy, music therapy or massage would be thought of by CH staff as interventions that could have an effect on BPSD, and so made use of, possibly on an 'as required basis' to be used in a similar way to PRN medication. This was not happening within any of the case study CHs. Instead when the types of activities that could be classed as NPIs were occurring they were often prearranged rather than spontaneous in reaction to, or as a counter measure to de-escalate a resident's BPSD. The only targeting of NPIs or activities towards BPSD that I observed at the CHs were music played on a CD, playing

football with a resident or taking a resident out for a walk. In these instances the activities were used to distract a resident from their agitated state. For instance, at Mirabelle Way I observed the approach that Hazel talks about here:

'I think it depends on the individual too, that if you know them well, what would work um, first off, it would be you've got to act very passive, very you know, slow and calm and try to distract them from what is actually aggravating them ... okay lets go for a walk or lets go in the garden and play football or trying to distract' (Hazel, General Nurse, Mirabelle Way)

These types of distraction techniques that Hazel speaks of were a common strategy used by staff members at each of the four CHs if a resident was starting to become agitated. Music was occasionally used in this way too; a CD was sometimes put on (especially at Gage Hill and Cherry-Plum) as a distraction from triggers and to take a resident's mind off their agitation. However, generally at all four case study sites, NPIs if used, were used as activities aimed at all residents at the home, regardless of condition, to improve wellbeing and quality of life and not for behaviour management. In this way they could potentially work indirectly to prevent instances of BPSD occurring.

Table 8.2 shows the activities that were observed during my time at the four case study sites. Each home provided a variety of activities and NPIs. Although not specifically targeted at residents experiencing BPSD, activities were perceived by CH staff as being worthwhile. Naomi talks of the general benefits of activities in CHs:

'it's stimulation isn't it? It's having something to do through the day um and I think it's like a bit of a circle isn't it, if you've got, if you've burnt some energy off then you're going to sleep better through the night and just, it just always helps' (Naomi, Carer, Gage Hill)

Naomi reinforces the idea that activities were targeted at improving quality of life and mentions the indirect benefits they can have on all residents, including those who can experience BPSD. Her excerpt mentions a cycle where stimulation provided by activities in the CHs helps residents to have an interesting and occupied day; this

reduces boredom, provides purpose and enjoyment, and increases the chances of sleeping well at night. Therefore, residents have a more fulfilled life, maintain a natural daily cycle and are potentially less likely to experience BPSD through tiredness or boredom. In this way activities were seen as likely to impact positively on residents experiencing BPSD (indirectly) by improving their mood. Overall the data indicated that activities not targeted directly at managing BPSD were perceived to have a valuable role in CHs to help care for PWD.

Table 8.2: Activities/NPIs observed at the case study care homes

Case Study Care Homes			
Bullace View	Gage Hill	Mirabelle Way	Cherry-Plum
Television	Television	Television	Television
Arts and Crafts	Arts and Crafts	Arts and Crafts	Arts and Crafts
Walks outside	Walks outside	Walks outside	Walks outside
Newspapers	Gardening	Newspapers	Newspapers
Trips out	Bingo	Trips out	Trips out
Jigsaws	Jigsaws	Outside Entertainment	Music Therapy
Flower arranging	Music – CD	Music - CD	Music - CD
Reflexology	Dominoes	Pat Dog	Games-quoits/skittles
Church service	Floor dominoes	Dominoes	Dominoes/Cards
Quiz	Church service	Gardening	Aromatherapy massage
Staff leaving party	Jubilee celebration	Football/catch	Helping staff with jobs
Hand massage	Reading with residents	Helping staff with jobs	Read to residents
Exercises	Dancing	Aromatherapy massage	Church service
Nail varnish applied	Nail varnish applied	Olympic celebration	Halloween party
Cooking	Doll Therapy	Nail varnish applied	Bingo
Outside Entertainment	Exercises	Cooking	Quiz/giant crossword
Reminiscence	Games-skittles/catch	Holiday	Reminiscence
		Behavioural therapy*	Multisensory bath
			Catch

*Not used with a resident experiencing BPSD

Activities at all four case study sites were orchestrated predominantly by activity staff although to a lesser extent outside practitioners and carers also coordinated them. When carers arranged activities with residents there was the difficulty of the interrupted nature of their work. This included such instances as alarms going off, residents needing assistance, visitors arriving and tasks needing to be completed, which all took carers away from ongoing activities. In contrast activity staff called on carers if situations arose, such as a resident needing personal care or assistance, and

therefore their role, which did not include this type of care enabled them to remain with the activity. Holly, an activity worker from Gage Hill illustrates this point:

‘I just sort of basically go and get a carer as quickly as possible (laughs) ... well I think that’s the only thing I can do ... because they’re always asking to go to the loo and, you know and I always think ‘oh God’ so I have to go and get a carer again, I say ‘oh so and so wants the loo’” (Holly, Activity Worker, Gage Hill)

The boundaries of the activity worker role allow tasks that arise to be passed on to care workers and enable the activity to keep going. Conversely, as the care worker role encompasses a broad spectrum of tasks with multiple aspects it appeared to be more difficult for carers to complete an activity with residents without being sought, or expected to also be available, for other tasks.

External practitioners facilitated more specialised activities at the CHs. Those I observed in the CHs were those delivering music therapy, aromatherapy massage, entertainment and Pet therapy (the Pat Dog at Mirabelle Way). Table 8.3 shows that there were eight activity staff employed over the four case study CHs. Activity time varied greatly across the case study sites, with a range from 10-39 (Gage Hill and Cherry-Plum respectively) hours per week. Three activity staff, one at each CH, except Bullace View, reported that they felt very uncertain of what they should be doing and were finding their way each day on the job, feeling a little out of their depth. Guidance and training was minimal for activity staff at both of the independently owned homes (Gage Hill and Cherry-Plum). Some training opportunities in delivering activities were offered to those working at the voluntary organisation owned homes. In general, the individual activity staff were given the responsibility to decide which activities to do with the residents.

Table 8.3: Activity staff and hours by care home

Case study findings	Care Home Names			
	Bullace View	Gage Hill	Mirabelle Way	Cherry-Plum
Number of activity staff	1	2	2	3
Total activity hours per week	27.5	10	16	39

The set up at Cherry-Plum for activities was slightly different from the other CHs. At Cherry-Plum the activity staff were called social care staff. The social care role was targeted at enriching daily living through social interaction rather than always organising activities. This was a relatively new approach for the home that at the time of the fieldwork had started just over a year ago. The owner/manager, Adam, outlines the change to the new approach:

'we used to do a lot more ambitious social care, I've explained to you how I've changed from the typical activities and outings ... And now it's much more about a seamless interaction going on, it, we don't even recognise it as social care we're just simply undergoing normal living, but that has to be facilitated because they're so dependent ... But in the old days of taking them to the theatre and taking them shopping and then, honestly it was exhausting, it took a lot of resources and sometimes the residents were in a spin the next day, they really couldn't cope 'cause it was so disorientating ... And they don't remember it the next day, what, what really you need to do is just try and build into a normal day interests ... little trips, stay within the grounds um, are very important too and on a nice day a little picnic somewhere, these things work beautifully ... families like to think that their loved ones are being whisked around all over the place, it's not necessarily what the resident wants ... Or benefits from' (Adam, Owner/Manager, Cherry-Plum)

The shift in emphasis from doing noteworthy activities to enriching daily living is clear from Adam's excerpt. The enhancement of everyday life for residents has been prioritised over perceived lavish activities. Other issues are also noticeable from Adam's explanation; he portrays the perceptions that: relative expectations are mismatched with the goals of the CH staff and the residents' needs, that the benefits from extensive trips out were perhaps not worth the resources needed to facilitate them, and that as residents do not remember trips they are less worthwhile to run. In Adam's opinion enriching daily living was more important than trips that happened once in a while.

The social care approach at Cherry-Plum appeared successful with residents gaining more one-to-one attention and with some activities and trips also still occurring.

Teresa, one of the social care workers talks through a typical day:

'I normally go to everyone's room, try to go to absolutely everybody, just to make sure they're all alive and well and sometimes you, you might get someone crying, you know, they've had a bad night, so if there's any issues, there normally isn't ... I usually calm them down, there's one lady in particular, I calm her down, put a bit of music on, get her singing and then she forgets all about it and then she stops crying like and Ray's a bit like that ... he starts the shaking and the heavy breathing and if I can distract him and get him watching a little DVD or just walking around the building with me, coming to see and when I get those ladies to the table he usually escorts me and he forgets and he stops shaking, it's, it's strange a lot of it is loneliness I think... I go round to every room, um, and basically start bringing people down for a cup of tea and that in the dining room ... I offer juice and sherries and that sort of thing so ... I usually help feed those that can't feed themselves ... It's usually 2 o'clock by the time we've finished that and then I go for the 15 minute break and then I usually go and do bingo or a giant crossword, down in that lounge ... some like to join in, some don't, but rather than sitting watching TV, I turn that off ... they usually all enjoy a game of bingo and that's it, then I go home' (Teresa, Activity Worker (Social care), Cherry-Plum)

This excerpt reflects very closely the observations I made of this approach at Cherry-Plum. A loose schedule, in which the social care staff could spend time with whoever they wished doing whatever they thought best; often targeting those who were vulnerable or most in need of emotional support. Social care actions included chatting, having a cup of tea, going for a walk, doing small tasks with residents such as, putting fresh water in a vase of flowers, reading to residents, generally socialising with residents, and often an arranged activity in the afternoon.

Social care staff at Cherry-Plum also assisted residents to eat at mealtimes; taking some workload off the care staff. Simon, a social care worker there explains that the role is about:

'Minimising what they (the residents) can't do, it's obviously a little more tricky with the dementia side of things 'cause yeah, you try and second guess them I suppose, but without taking away what they want to do ... Certainly if somebody has been very upset, stressed, frustrated, whatever, spending time with them, when you come away they're a totally different person, so I, I personally believe it proves that if they have that one on one care, that calming influence um, I'm in the fortunate position, I don't have to get involved with personal care so a lot of the residents see me as that lovely chap that goes round and will get us a drink and will talk to us and will do something with us. Rather than you're being task driven ...Um, it's then about improving their stay here' (Simon, Activity Worker (Social care), Cherry-Plum)

Simon (and Teresa in the previous excerpt) had a very flexible role which allowed the time to spend with those residents who most needed individual attention. Simon's perception that residents can become a 'totally different person' after spending time with them on a one-to-one basis illustrates the importance of having staff available to residents with BPSD. The social care role was facilitated by the lack of fixed tasks that are inherent in a care worker role such as, serving meals, toileting and assisting residents with dressing/undressing. The social care role worked well. Care staff appeared to view the social care staff positively since their role eased the care work by occupying residents with BPSD, with the addition of assisting with mealtimes.

Activity staff in all homes, except Bullace View (the CH with the least residents with dementia), stated that pre-organised activities were often not easy to adhere to. This was contrary to the majority of the case study observations, where it appeared that many of the larger activities occurring (such as, bingo, trips out and music therapy) were pre-arranged. Jess talks about the issue here:

'I think I did learn early on ... I had my whole afternoon planned out and it wasn't going to plan at all, no one was interested or I don't know, not in good

moods, had a bad morning whatever and um, I sort of tried a few times and one of the residents said 'it's not always going to work that you' you know 'going to be able to do what you want to do' so we changed it, we did something else completely different, but, actually it was great it turned into a good afternoon and I realised that yes I, flexibility is the key to this job, it has to be' (Jess, Activity Worker, Mirabelle Way)

The changeable nature of residents' moods and the different needs of multiple individuals make the undertaking of a planned activity a difficult task. Jess found that the best approach to delivering activities was to be flexible. During her interview she also reiterated this point by mentioning that spontaneity was better than planned and rigid activities. In this way the residents' conditions, moods and wishes could be best matched with a suitable activity each time.

When activities, planned or spontaneous, were conducted many residents were reluctant to take part or attend them and would decline or leave the vicinity as soon as one was being organised. This occurred at all case study sites except Mirabelle Way where limited group activities occurred. This created a difficult issue for activity staff who appeared to believe that some residents may gain some emotional benefit from the activity if they were to take part. The balance between encouragement and coercion to get residents to partake in activities was a difficult judgement for staff to make. Holly, an activity worker at Gage Hill touches on the issue:

'I have to try and get them, you know, say 'oh come on, do you want to do it' 'no, no, no' 'come on' but once they're doing it they're absolutely fine, it's like when we done all the sunflowers, I brought the pictures of sunflowers in and got all the crayons and paintings or whatever out and put some paper in front of them and said 'draw your own sunflowers from this picture.' Mable was going 'oh I can't do that, I can't draw' but she got on really well, she absolutely loved it in the end ... you know they all say they can't do it, but then when it comes to it they enjoy it' (Holly, Activity Worker, Gage Hill)

Holly suggests, encouragement was viewed as worthwhile since it would sometimes get residents to take part and subsequently they would enjoy the activity. However,

due to the reluctance of some residents to join in activities, even after encouragement, there were a number who refused to take part in anything going on at the CHs. The excerpt alludes to Mable being reluctant to do the activity since she felt that she would not be able to do it and perhaps her self esteem was threatened. This was different to residents who did not want to take part due to not liking the activity.

In addition to these residents, the inclusion of a number of other residents was avoided by some staff members. Jess provides an example here:

'I feel awful saying this but they've, I don't know, it's just very hard to actually get them to do, that they can physically do anything and um, I, once they did suggest maybe go and put a tambourine in their hand and I don't know, maybe but I just found that must be patronising to be honest, I don't know if that's just me but ... I suppose I didn't feel comfortable doing that um, so yes I suppose I've kind of veered away from those residents um, because it's, I don't know, it's very hard to know activity wise what to do.' (Jess, Activity Worker, Mirabelle Way)

Jess' acknowledgment that she '*veered away*' from residents with severe disabilities due to not knowing what activities to do with them was not an isolated situation. Other activity staff also mentioned the difficulty in involving some residents. Not knowing what to do to engage particular residents, avoiding those with BPSD due to feeling '*uneasy*' around them and through fear of upsetting them, and a perception that for the activity to be relevant to the resident it appeared '*babyish*' or condescending to staff members were all reasons given as to why residents were left out by activity staff. It appeared that residents least able to engage in activities independently, perhaps most in need of support, were as a result less likely to get that support. Although Jess shows an awareness of the potential threat to a resident's self esteem that a patronising activity may have, this practice highlights an inequality in the delivery of activities. Therefore, the residents experiencing BPSD, for which NPIs are recommended as first line treatments (NICE and SCIE, 2006, revised 2012), could perhaps have less access to these activities than residents without BPSD.

Sometimes residents with dementia were also assumed to either want to or not want to attend activities. This appeared to be a habitual screening, with those usually taking part assumed to want to and those not usually participating assumed as not wanting to and no longer asked. At all four case study sites there appeared to be the same core of residents joining in with activities or attending events. Staff appeared to be aware of this. Teresa, an activity (social care) worker at Cherry-Plum, talked about the *'favoured few'* residents who were always targeted to be included in activities. She made a conscious effort to spend time with the residents who she perceived as being more isolated, either through severe disability or BPSD. Similarly, Barbara, a nurse at Mirabelle Way pointed out difference between those residents:

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

Therefore, those residents more obvious in their demands appeared to gain more input from activity staff (and in some situations care staff). Residents with dementia all experience the syndrome in different ways; the activities or interventions they may be exposed to appeared to depend on how they were perceived by staff. In all, the data portrayed some inequality in the allocation of activity provision; with specific residents (particularly those willing, able, demanding and easily manageable) benefitting more than others (often those with difficult to manage BPSD or severe disabilities).

Activities and trips out were photographed by CH staff in all of the case study CHs. The photographic evidence was displayed on walls, in newsletters or in photograph albums in each CH for visitors to see. Mirabelle Way occasionally used the local media to portray activities that had occurred at the home. The public relations side of activities appeared to be important to CH senior staff. As well as being a reminder for residents and staff of fun times, staff appeared to be aware that evidence of activities looked good to the outside world and could be used as a marketing device. The documentation of the activities was perceived by staff members as a way to promote the quality of the care at the homes to outsiders. Staff appeared to feel that the public

perception of the home could be enhanced by showing clearly the positive events that had occurred in the homes.

Each home, except Gage Hill, had access to a minibus and organised trips out for some residents. I accompanied two trips out during my fieldwork. One was from Mirabelle Way to a local garden centre where we looked around and enjoyed tea and cake and the other was from Cherry-Plum involving travel and a boat trip for the day, including a picnic lunch. Bullace View took some residents on a trip to a pub while I was at the CH, but I was unable to accompany them, when invited, due to prior commitments.

Mirabelle Way had even taken four residents away on a holiday earlier in the year. This had been a successful event. However, as with all the trips out during my time at the CHs, the residents who took part appeared to be those perceived as manageable and not those with considerable BPSD.

The selection of certain residents may have been due to the real and perceived difficulties in occupying some residents with BPSD. For example, one resident, Bert, at Cherry-Plum often appeared bored, agitated or restless. Care and activity (social care) staff tried to occupy him to distract him from his BPSD and from damaging property or frightening other residents. Their efforts often seemed to be unsuccessful. Bert had a very short attention span and regularly got frustrated with whatever staff were trying to get him to become involved in. I observed this directly when staff tried: cards, dominoes, quiz questions, objects to fiddle with, ball game, bingo and music therapy. For example, one particular instance occurred when Teresa, a social care worker, put on a music CD for the residents after their evening meal and handed around instruments, as the observation notes below illustrate:

'Teresa put on some music in the dining room after the training – we used instruments and four residents really enjoyed a sing-a-long and a dance. Bert was really put out and cross about the music and Teresa asked him if she should take him out of the room, but he wouldn't go, instead he stayed and got a bit angry with the frivolity going on. He said 'that's enough' and other similar things, at one point banging the table with his fist. He would not join in or leave, but he was cross with the music – the four ladies were loving it. Teresa had

earlier tried to get Bert involved in a game of catch which he did not like. He seems to need some occupation but gets annoyed with any. This creates a dilemma for Teresa who initially put the music on for him, but he would not be involved' (Observation notes, 24th October 2012, Cherry-Plum)

The difficulty in engaging Bert, and a few other residents with BPSD across the case study sites, in any activities was a real problem for activity staff. Those who took part and made a connection with activities were often those with less severe BPSD. The example above left Teresa with a dilemma about whether to continue or not as the four residents were having a really nice time joining in with the music, but Bert was agitated by it. In this instance it was impossible to deliver PCC to all residents since they had divergent wishes and needs. The music carried on for a short while before it was stopped; this happened slightly early in order to appease Bert. The findings highlight the individual nature of the needs of residents with BPSD, where diversionary activities may not suit everyone.

Activity staff (with the exception of Karen at Bullace View who was also employed there as a carer), did not have access to care plans or handover sessions where they would have been informed about residents' histories, conditions or recent episodes of BPSD. This could be a disadvantage, since not knowing about residents' ongoing conditions or current issues meant that they could not tailor their approach to individual needs in a way that they could have done had they had this knowledge. Jess, an activity worker at Mirabelle Way talks about the issue:

'when I first started because I knew obviously they all have care plans, the residents and I sort of said 'oh' you know 'should I read them?' and someone said 'well no it's quite nice if you just sort of because you work, you're not the carer as such, you're the activities, keep it fresh and just don't read too much into why they're there etcetera' and then and I quite, I really quite liked that because I'm just then taking the resident at face value, you know and I'm not judging them on anything, I'm just going in, seeing them for them and there are times when I think oh maybe I should have known that. I remember one experience in a lift that was ob, I shouldn't have been alone with a man in the

lift, but that's, that was a real exception, generally I really ... I don't know if I should, but I don't see that as my role, I just like the fact that I come in and um just work with them' (Jess, Activity Worker, Mirabelle Way)

The excerpt from Jess illustrates both positive and negative aspects of the lack of knowledge about residents. To be unaware of residents' conditions and recent behaviours could be a disadvantage for activity staff to adapt their approach to the individual appropriately. The ignorance could also put them in potential danger, as alluded to by Jess in the excerpt. Conversely, no knowledge about residents' conditions can allow activity staff to make up their own mind about residents and not be tainted by information which could promote negative opinions. Additionally, viewing residents as people and not objects of care could potentially elicit a more normalising approach from activity staff. Whether positive or negative, the lack of knowledge activity staff or volunteers had about residents' conditions was a feature in all three CHs other than Bullace View. This difference in knowledge CH staff can access could be due to the activity role being viewed differently to the care work role in CHs, since care tasks more closely represent the medical model, which traditionally have access to medical records and activity tasks are more aligned with the social model which do not.

Overall, the case study data showed that activities were used for enrichment and not to manage BPSD. The findings also highlighted some inequalities in the delivery of activities, along with some question over whether activities are suitable to be used for all residents. If CH staff are not using formal NPIs or activities to manage BPSD, what strategies are they using alongside medications? The rest of this chapter outlines some of the other factors which assisted CH staff to care for residents with BPSD and the main strategies which emerged from the data.

Person centred care (PCC)

Aspects of PCC were often observed during my time at all four case study sites. Person centred care became apparent through indicators such as, individualised care, resident choice, valuing PWD, inclusion, respect, communication and resident autonomy, strong and supportive personal relationships between staff and residents, and viewing situations from the residents' perspectives. However, PCC did not appear to be

delivered consistently in any of the CHs. Allowing residents the choice of which food to eat or when they would like to get up or go to bed (as long as they were able to indicate choice) was generally common in all of the homes. Residents' rooms were also personalised with their own belongings. At Mirabelle Way some of the communal spaces also had residents' personal belongings in them, for example, in one unit a resident had completed a jigsaw puzzle, which had been framed and hung on the lounge wall.

Knowing the resident, as discussed in Chapter 7 in relation to medication use, also emerged as an important factor in the delivery of PCC. Heidi mentions why here:

'it takes a while to get to know them (the residents) but once you know them you know which (approach) is appropriate for which patient' (Heidi, Carer, Bullace View)

Adapting their approach to suit individual residents was something that staff appeared to do constantly and knowledge of the resident guided this. For instance staff members appeared to know whether individual residents would react well to a hug, or whether this type of contact would have been a trigger for their BPSD to emerge since they needed space.

Residents with dementia often could not communicate their needs or preferences and staff had to pick up on non-verbal cues. In addition to prior knowledge from care plans and handovers, trial and error appeared to play a part in this process, especially with those residents who could often be perceived as lacking mental capacity globally or at a particular time. However, some staff did attempt to include the resident in care decisions, as Audrey describes here:

'it is a case of trial and error so, and if something doesn't work you try something different so, but I'd also include them (the resident) in the conversation and the reason why because they might be, have that little lucid window that they could completely take on board what you're doing' (Audrey, General Nurse, Cherry-Plum)

As this excerpt from Audrey alludes to, strategies were predominantly instigated by staff, with occasional resident input if possible. The guess work approach by staff ultimately let staff gain more knowledge of residents by assessing the reactions to each approach or strategy they tried. The accumulated knowledge of the resident through this trial and error process allowed staff actions to be guided by past successes with each resident.

Successes and failures were communicated throughout the staff team to create a combined staff knowledge. Karen talks about it here:

'some (staff) say well that don't work, but this has worked for them, I mean we'll try that out it's just ... one thing might work for another and then not for another, but then if they didn't know about that thing, they have then got the choice to try it and see if it works for them as well, it's just word of mouth, it's communication, finding out different things and, it's trial and error, basically everyday is different and everyday is trial and error' (Karen, Activity Worker/Carer, Bullace View)

Communication throughout the staff team was perceived as important to spread knowledge of strategies already tried by staff and of their outcome. In this way over time staff could acquire knowledge of residents' likes or dislikes, and this worked to inform the modification of their approach. For instance Marie, a carer at Gage Hill found out from others that a resident enjoyed her hair being brushed, she offered to brush her hair at quiet times or if the resident was becoming agitated and the lady (Rita) appeared to love it.

The trial and error approach coupled with more general knowledge of the resident allowed staff approaches to be tailored for each individual resident, which in turn decreased their unmet needs, lessened the likelihood of frustration building up and provided more suitable and PCC. These factors appeared to be important in reducing the likelihood of BPSD occurring. Therefore, PCC had an important role in the management of BPSD.

Lack of person centred care

As well as finding the presence of PCC in all of the case study homes, the observation data showed that this approach was not used in a consistent way. The instances where it did not happen occasionally led to some form of BPSD, but not always.

Organisational factors and individual staff member approaches could both result in the lack of PCC. One extreme example including both organisational and individual staff member failures to provide PCC occurred at Gage Hill. The routine for staff, provided by management was to clean the toilets and wash the floors in the lavatories near the end of the morning shift after everyone had eaten lunch and those who needed had been to the toilet. Once the floors had been washed the doors to the toilets were locked until they had dried for health and safety reasons. This practice effectively made the two downstairs toilets unusable for half an hour. My observation notes show how this practice could impact not only on PCC, but also on the delivery of fundamental care practices:

'After lunch a carer washed the toilet floors. George stated that he needed the toilet, he was told by Marie that he would have to wait as the floors were wet and it was not safe ... George kept shouting repeatedly that he needed the toilet, he asked another resident to tell the staff he needed the toilet desperately. The staff at this point were writing their notes and having a handover and did not take him. He had to wait over half an hour (in total) when an afternoon staff member who had just came on shift took him to the toilet'
(Observation notes, 30th May 2012, Gage Hill)

Here the organisational routine was prioritised over the residents' needs and wellbeing. The lack of PCC was not only poor care practice, but impacted on George's behaviour. As he became increasingly desperate and frustrated he shouted more and more. The individual staff members could have chosen to dry the floor with paper towels and taken George to the toilet or reported the incident so that the management could have had an opportunity to review the routine, but neither occurred. In this instance the rigidity of the routine and the staff members meant that tasks were prioritised over a resident's needs. The situation led to frustration and

shouting; resident behaviour and stress or distress for both George and other residents which could have easily been prevented. These observation notes show an example of the social model of disability where, in this case, the impairment was dementia and the organisational environment imposed a limitation, which resulted in disability including both, lack of independence in going to the toilet and frustration (BPSD) (French & Swain, 2012). Here, organisational constraint and not the aetiology of dementia were instrumental in causing the behaviour; making the term BPSD a misnomer. However, had George not had dementia it would have been unlikely that he would have been in this situation. The unjust circumstance George experienced reflects the way impairment in care settings can lead to dependency and consequently limit personal power.

Other instances showing a lack of PCC at the homes also appeared to be due to routines or tasks prioritised over residents' needs or wishes. For example, a resident at Bullace View asked if they could go back to their room, they were told it was nearly lunch time and so they were not taken back to their room. The reasons for this appeared to be that the staff were busy toileting other residents at the time and that if they took the resident back to their room they would then have to move them again to the dining room in a short space of time; this appeared to be perceived as a waste of time and effort. PCC appeared to be difficult to deliver when there were other necessary tasks needing to be completed (such as toileting other residents), when staff were busy (for example, because of staff shortages or unexpected events impacting on efficiency) or when there was a schedule to maintain when the routine was perceived as more important than the individual's need for PCC. Andy talks about the issue here:

'Being in a care home situation ... It's all sort of like you know, um, so practically oriented, you know, it's just getting tasks done, you know, whereas the person can go, literally go out of the window really' (Andy, Psychiatric Nurse, Cherry-Plum)

Andy highlights the negative side of task driven care; how the person and PCC can be second place to 'getting tasks done' in a CH setting. The data from the case studies

portrayed the lack of PCC as sometimes having an impact on the occurrence of BPSD, but not always.

Routines and flexibility

The individualised resident care choices elicited through PCC paradoxically appeared to merge into routines in the CH settings. Resident choices offered through PCC gave staff knowledge of residents' likes and dislikes. This knowledge, so helpful with tailoring staff interactions with and strategies for residents, also provided staff with knowledge of when and how residents usually liked things to be completed, which over time appeared to become routines. The benefit of routines for residents with dementia appeared to be providing familiarity and certainty. Christine and Natalie endorse this observation in this excerpt from their joint interview:

Christine: Yeah, you change their routines they're

Natalie: *Don't like it*

Christine: Oh no

...

Natalie: *'cause once they've got a routine I think that helps, doesn't it?*

Christine: Yeah

Natalie: *I think it*

Christine: Yeah, it is routine isn't it, a lot of it

Natalie: *They, perhaps they can't remember, but because they've got in such a routine it just, just comes naturally, that's what they do'*

(Christine and Natalie, Carers, Cherry-Plum)

It appeared that routines could be positive for residents with dementia, which could help to manage their BPSD by providing reassuring familiar situations. The disadvantage of routines, as the excerpt alludes to is that residents become institutionalised and can find it difficult when there is an upset in their usual schedule, which could lead to BPSD. Additionally, by doing things one way staff appeared to assume that residents wanted to do the same things and in the same ways each day and appeared less likely to give residents choices. Staff too appeared to be

institutionalised and it appeared that in many cases they felt the need to adhere to the routine and provide a task driven approach.

It emerged from all four CHs that staff flexibility was very important when caring for residents with BPSD. Due to the individuality of residents and the changeable behaviours encountered from moment to moment, flexibility was essential to a successful staff approach. Having a flexible approach afforded staff the opportunity to adapt to individual residents' needs at each contact. If a resident was refusing care or agitated this flexibility allowed staff to withdraw and return to the resident at a later time to try to deliver care again. If this was not successful other staff members would often be utilised to see if they could be successful. Flexibility within each staff team allowed for adaptation to residents preferred modes of interaction, changeovers of staff, trial and error delivery of care, and the use of care staff strengths. Overall both routine and flexibility appeared to be helpful in caring for residents with BPSD, although the utilisation of routines could also create occasional difficulties.

The placement of residents

Another strategy used by CH staff at each case study site was the placement and segregation of certain residents. Removing residents from or placing them in certain areas of the home was a common strategy employed for particular residents for multiple reasons. These included: to reduce the impact of a resident's BPSD on other residents or staff, to reduce their interaction with triggers, to remove them from problem areas in the home (such as, areas of danger or busy areas), or to make provision of their care easier.

For example, some residents at Mirabelle Way and Cherry-Plum would shout or call out almost constantly. If reassurance, distraction or trial and error attempts to meet the resident's needs did not work (particularly in situations where the resident was unable to communicate needs in other ways), these residents were often removed from communal areas to minimise the impact of their behaviour on other residents and staff. The placement of residents for this reason occurred during my time at

Mirabelle Way and Cherry-Plum. There were no residents at Bullace View or Gage Hill who persistently shouted so I was unable to determine whether this strategy would have occurred within these homes as well. Frequently residents who called out constantly, often immobile, were left in their bedrooms to minimise disturbance in the communal areas of the homes. Audrey talks through her experience with a resident who calls out:

'constant calling out, oh constant ... you'll say 'you're calling?' 'no I'm not' okay 'any particular reason why you're calling?' 'no dear' you can even be standing there holding her hand and she'll go 'stay with me' so I'll go 'are you alright?' hold her hand 'help' 'I'm here' you know (laughs) you're looking at me, but they've no recollection of why they're calling ... and sometimes we do have to shut the bedroom door, especially um, the lady that's in 16 and the lady that's in 19 um, 'cause if not she would like to go and murder her basically, so you do have to think well I'm going to have to shut that fire door and her bedroom door ... because if, if I can't get through why you're calling and she doesn't know she's calling, so you check the obvious, are they wet, are they hungry, are they thirsty, you know and if everything is okay 'I'm not calling, I'm not shouting, somebody else is shouting' 'no you're shouting' 'no I'm not' and you think well there's no point' (Audrey, General Nurse, Cherry-Plum)

As Audrey states, on occasion bedroom doors would be closed to prevent the noise from residents calling out impacting on others in the rest of the home. Audrey's excerpt also shows that staff members would not initially ignore the shouts, but sometimes the resident calling out would not realise they were calling or be persistent in calling despite staff attempts to help them. In this case the data suggests that staff feel there is not a lot that can be done to assist the resident with their behaviour except limiting the impact of that behaviour on themselves and on other residents or visitors to the homes. The positioning of residents behind closed doors is a strategy which excludes individual residents for the good of the many. Therefore, the communal nature of CHs and the duty to care for all residents was likely to have had an effect on the implementation of this strategy, but to the detriment and 'othering' of individuals.

The placement of particular residents was a frequently used strategy in all four CHs, but to differing degrees. At Bullace View and Cherry-Plum residents needing assistance to eat their meals, residents with severe cognitive or physical disabilities and particular residents with BPSD were positioned at separate tables or in different rooms to the more able residents, particularly at meal times. Jen explains the situation at Cherry-Plum here:

'We tend to have two dining rooms, er, not two dining rooms, two lounges sorry and um, one lounge is for people that have got severe dementia, so if they are upsetting the other residents in the norm, in the if you like 'normal' lounge, whatever you like to call it, we then sort of move them either to their rooms or to a safe place or to the lounge where we've got the less, sort of vulnerable, sort of people and we keep an extra eye on them and 'cause that is a sort of, sort of, I don't like to call it dementia lounge, but that really is sort of what it is for really, so er so we tend to sort of move them round there' (Jen, Carer, Cherry-Plum)

The clear separation of residents Jen talks of appeared to take place for several reasons. As Jen alludes to, this was a strategy employed to assist staff to deliver care more easily. For example, the rationale for positioning the residents with substantial needs together was that staff members found it easier to monitor these residents. Additionally, my observations showed that one carer could simultaneously assist two residents to eat their meal if those needing help were seated together. However, the observed practice appeared to show a limited monitoring of residents, since the lounge was to one end of the home and it appeared to only have a staff presence at meal times. The categorisation of residents with dementia as 'other' or in some way non-normal is clear in this segment, although Jen does hint that she knows that the terms, and perhaps the practice of separating residents, are not politically correct. For Jen and a few other participants, there seemed to be a tension between the actions that seem to best meet most people's needs, and what she feels she ought to be doing. This tension could put an additional burden on the care staff, since the decisions are their responsibility and they would perhaps be vulnerable if they were found not to be using person centred principles. Nevertheless, the placement of residents due to

their diminished cognitive abilities or BPSD reflected inequality in the care delivery at the two homes.

The excerpt from Jen's interview also reflects that the situating of residents separate from others was used to minimise the impact of their behaviours on other residents. Similarly, Dawn, another carer at the same home explains why some particular residents are segregated at meal times:

'it's because she(Dorothy) can aggravate people sometimes because she likes to take (food) off their plate ... Mm and that's not very nice ... Not to those that know what's what ... So that's the reason why ... So that's why she's put in there ... In the same regard Ray because he aggravates people because he's tap, tap, tap, tap, tap, tap, (with his cutlery) on the table constantly and they sit there and they're going 'hhuuhuuuhuu' (laughs) and it's jangling their nerves a bit ... But see if he does it in this lounge we can go 'Ray' (in a singing voice) and he stops and he looks at us and we talk to him for a little bit, you know and then that sort of stops him for a little while ... 'Cause obviously you don't want him aggravating anyone in there either ... just the same, but because he's there we can watch him a lot easier' (Dawn, Carer, Cherry-Plum)

Behaviour that impacts on those residents with good cognitive ability was viewed as the catalyst for moving a resident to the other lounge at mealtimes. Residents with milder levels of cognitive disability were more able to voice their dislikes and annoyances to staff members than those with considerable cognitive difficulties. This appeared to result in separation and disparities in levels of choice for residents with moderate cognitive decline. The segregation or placement of residents with BPSD or cognitive decline in this way may have been helpful for those residents without dementia or with less cognitive decline. This excerpt from my observation notes describes part of an informal chat I had with Kitty, a resident participant without dementia, at Bullace View. She talks about living with PWD, she told me:

'how PWD would wander into her room, or keep undressing and how difficult it was to be relaxed about it when these things kept happening. She spoke of her worry when in the dining room and lounge, how she felt she had to keep watch

over those with dementia as they sometimes tried to get up and may fall. She said it wasn't her responsibility, but that she couldn't help it. The impact of living with PWD was clearly salient in Kitty's mind.' (Observation notes, 27th March 2012, Bullace View)

These notes show how living with residents with dementia can impact on other residents. Kitty appeared to feel worry and concern for residents with dementia. She felt a responsibility to watch over them, which hindered her own relaxation and enjoyment of social or meal times. Therefore, the segregation of residents with dementia could work to reduce anxiety and improve the emotional welfare of those residents without it. The dissimilar nature of residents' conditions could explain why both Bullace View and Cherry-Plum employed this strategy, since the residents at these homes included those with and without dementia. Residents at the other two CHs generally all had dementia or serious MH conditions and were, perhaps, less likely to complain about the behaviour of other residents.

Through observations I noticed that a small number of residents were not separated and positioned in this way even though their cognitive disabilities, BPSD or requirement for assistance with food would have made them likely to be placed away from the main body of residents just as others had been. I asked Tracey, a carer at Cherry-Plum why one resident with similar disabilities was not also positioned separately to most other residents. She explains here:

"cause her daughter doesn't want her in the other room ... Certain families say they don't want them in there ... Because they generalise that as, ah, how can you put it, um, people who are more, they don't want to accept the fact that their parent is more dependable (sic) or there's a resident in there who keeps shouting and they don't like that ... And they want their mother away, or their father away from that, so yeah, that is to do with the family' (Tracey, Carer, Cherry-Plum)

Therefore, family input prevented some residents being positioned separately to the main body of residents. Family reluctance for their relatives to be positioned separately indicates that placing some residents away from the others was viewed as a

negative action. It also portrays the stigma against residents with certain disabilities, the implications of having or not having a family advocate, and reflects the inequity inherent in this care practice.

The placement of residents who were more physically able, a risk to others and perhaps exhibited behaviours which could be more destructive (for example, those who occasionally damaged property) occurred differently to those who were immobile or safe to be left unsupervised. As Heather mentions here:

'it's a stupid nurse who puts Betty in the ... sitting room, the other end of the house and I, it's like putting a 2 year old in the middle of your room and then going off and doing your hovering, you just wouldn't do it ... so those sort of strategies, what I call common sense strategies to be honest ... But they safe guard them, I still think the best strategy when you, when you are short of someone to care for someone closely is to keep them near you ... I've always believed in that, just keep them as near to you as possible and then you can always hear ... when things are not right' (Heather, General Nurse, Cherry-Plum)

Therefore, instead of aiming to position residents away from other residents the emphasis here was to position residents who were difficult to manage in this way near to a staff presence. Bert, a resident that staff found difficult to manage due to his levels of frustration, mobility and destructive behaviour was not placed in the other lounge at Cherry-Plum. Instead he was positioned near to the nurses' office to enable easier supervision of his behaviour.

I have used examples from Cherry-Plum to illustrate these points: as this theme was emerging from the analysis it was explored further at this last case study, yet positioning was a strategy employed equally at Bullace View and to a slightly lesser extent at Gage Hill and Mirabelle Way too. The findings show that positioning was a major strategy used to assist staff in the management of BPSD.

Staff approaches

There were several aspects to the approaches used by staff which appeared to assist in the management of BPSD at the homes. Perseverance was one. If a resident was agitated, staff often repeatedly tried to distract or reassure them. If a resident was refusing or was resistive to care, staff would keep trying every so often to give that care. This strategy often resulted in eventual success. Giving residents time (if possible) also appeared to be a helpful strategy, since residents were distracted for longer, had company and attention and were provided with a chance to calm down. Accepting residents' behaviours and using a calm problem solving trial and error approach also appeared from observations, and was perceived by staff, to be helpful.

Staff-resident relationships emerged as important. Trust between individual staff members and residents could be used to reduce the likelihood of BPSD emerging. Barbara explains here:

'I always think well it doesn't matter who it is, they work here and they know the confidentiality bit and they know, they've built up a relationship with the resident and why not use it if it's going to, sort of reduce their anxiety about having clothes changed or eating.' (Barbara, General Nurse, Mirabelle Way)

The excerpt illustrates how staff who had good relationships with residents could be used to make interactions and care tasks less stressful for residents. Staff-resident relationships were important in each home, but they were utilised most at Mirabelle Way where this was employed as a common strategy. The main priority was keeping the resident happy and calm so staff would swap units to attend to particular residents if this could be helpful for a particular resident.

Ignoring residents' behaviours was a strategy occasionally used by some staff at all four CHs, not to manage BPSD, but for individual staff members to cope with them personally. This avoidance approach appeared to be due to staff being scared of a resident's behaviour, not knowing what to do, or just not taking responsibility for that resident and holding back to let other staff notice it and intervene. At other times, particularly at Gage Hill where there were lots of instances of BPSD staff ignoring

residents behaviour was used an active monitoring strategy, which will be explored in the next section.

Monitoring

Monitoring appeared to be an important aspect of the management of BPSD. It occurred in two ways: one was for staff to informally monitor residents' behaviours at all times while they were going about their work (discussed here), the other was a more formal type of monitoring which included documentation, team discussions and the use of surveillance technology (discussed in Chapter 9 pages 234 - 240).

At all four CHs staff would often monitor situations and only intervene if they felt it was necessary. This approach was employed most at Gage Hill, perhaps due to the high occurrence of BPSD at the home and the reality that if staff members attended to every instance of behaviour they would have had no time for routine care tasks. Sometimes this strategy would work and the resident would discontinue disturbing or risky behaviour with no intervention, but sometimes staff would have to intervene if behaviour escalated. Monitoring was an important strategy used by staff to determine how and when they needed to act. An example occurred while I was interviewing Carla in the empty dining room at Gage Hill and mid interview she went to investigate a potential conflict between residents in the next room; she had been monitoring this during the course of the interview. When asked about the point that she would intervene she said:

'Well, it's usually the change of tones and you can hear another resident getting agitated, then I always go and have a look to make sure, normally it's just verbal, but sometimes your lady can get a little bit...' (Carla, Carer, Gage Hill)

Constant monitoring, even through an interview situation reflected a routine staff approach at Gage Hill. This informal monitoring was difficult to notice at first, since it occurred while other tasks were being carried out. Listening or watching residents to determine if behaviours or situations were escalating was a skill many of the staff employed seamlessly at the home. Monitoring in this way occurred at the other homes too but only if a situation had been noticed first, not constantly and in the subtle way

of the staff at Gage Hill. Monitoring also occurred in a more formal way at the homes; this aspect of monitoring will be explored in Chapter 9.

Communication: techniques used by staff when talking to residents

Knowledge of individual residents also guided staff in which communication techniques to use. Reality orientation and validation therapy were both used at all four homes, but not as formal strategies, or systematically. Instead they appeared to be used sporadically and casually as a natural part of communication with residents. Their use was not termed by staff members as 'reality orientation' or 'validation therapy' or often, even as a strategy. Reality orientation was observed when staff members explained the real circumstance or the truth to confused residents during communication with them. June discusses an example of this:

'Someone will come up to me and say 'have you seen my mother?' and I'll say 'no' (confused voice) and they'll go 'do you know where they are?' And then all of a sudden they'll think about it and go 'oh they're dead aren't they?' And I'll go 'yeah' you know so. I don't want to say they're dead ... because that's like taking someone through the whole grieving process again and that's not fair, but on the odd occasion they'll recognise and they'll know and there'll be days where they're good and you can tell them the truth, but days where they're bad and you can't.' (June, Assistant Manager, Bullace View)

June describes a subtle way of re-orientating residents; by using a confused tone of voice in the hope of jogging their memory. She alludes to a flexible approach where the way to cope with confused residents is adapted to each residents condition at the time. June also describes the negative impact that reality orientation can have in certain situations. For example, when residents believe a loved one of theirs is still alive as this excerpt from Phoebe portrays:

'Someone went up to this resident and said 'oh your husband's dead' and for days on from that we couldn't do nothing with her, she was mortified; it was like it happened yesterday. She was gutted, we couldn't calm her, we couldn't reassure her and that went on for days' (Phoebe, Carer, Gage Hill)

In this instance telling a confused resident in a different reality the truth and trying to re-orientate them to the real situation caused great hurt and distress.

Therefore, sometimes staff members chose to validate a resident's different reality as a kinder way to manage the confused behaviour. Janice provides an example of this approach here:

'she (Hilda) came to me the other night, she gets up in the night, she lost a child when she was, she lost a baby ... And she does get up and say 'who's looking after my baby tonight?' and we just say to her that 'it's in the nursery and if the baby wakes up we'll come and get you, we promise' and I know that's not the truth, but ... Sometimes you have to, you do have to enter their world, don't you?' (Janice, Night Carer, Cherry-Plum)

Going along with a resident's different reality and validating their experience, as Janice portrays in this excerpt, was in some situations, perceived to be a less stressful direction to take the resident in. However, this approach could be construed as deceiving or lying to the resident. Some staff members would also play along with a resident's reality stating that they had spoken to a (deceased) family member and that they were alright, as a way of reassuring residents. Both approaches had negative and positive aspects. If staff went along with a resident's different reality they were lying and in effect could have been deluding them further, but the resident was perhaps rather less likely to become upset. If staff reoriented a resident to the present or told them an accurate version of the situation, which was truthful, this could have very negative consequences.

Distraction

Distraction appeared to be a core first line strategy, which care staff used in the moment if residents were agitated or frustrated. Whether it was through communication, leading residents away from the area, putting the television or some music on or offering a cup of tea, distraction worked a lot of the time if residents' anxiety and agitation were not too heightened. Rob talks about the use of a cup of tea for residents experiencing BPSD:

'I'd say the best method ... is making them a cup of tea, I know it's something simple and it might sound a bit silly but the majority of the time that usually works ... and maybe after 10 minutes of sitting there their outlook on what's going on is different, so I mean that's how quickly it can change isn't it? I mean it can change so, they can change from being very angry with you, to you walking out of the room and coming back with a cup of tea and they're fine'
(Rob, Carer, Bullace View)

Indeed, at all four case study sites a cup of tea appeared to be a standard distraction technique in use. As mentioned at the beginning of this chapter football, a walk and music, along with conversational chatting were also all used as distraction techniques. Distraction seemed to be a basic and successful strategy for a lot of residents who were experiencing slight BPSD. For those residents who were agitated or aggressive, distraction appeared to be less useful, since it seemed as though residents could not forget about their emotional state as easily.

Moving residents on

Of course, as discussed in Chapter 6 page 144, moving residents on from the home to other care providers was also a CH strategy used to manage BPSD.

Conclusions

This chapter has explored the role of NPIs and activities in CHs to aid the management of BPSD. These interventions/strategies were not found to be specifically targeted at reducing BPSD. Instead they were used to increase wellbeing and enhance the daily lives for all residents at the CHs. Activities or NPIs did appear to be indirectly beneficial for the management of BPSD by occupying residents and reducing the likelihood of boredom or frustration, but did not seem to be selected for this. Definitions of NPIs were found to be subjective to individual staff members, with a variety of actions being classed as the same intervention or activity. Generally CH staff did not class NPIs as such; instead they were described and understood as activities. Activities were predominantly facilitated by activity workers, but some carers and external practitioners did deliver occasional sessions. Activity staff generally had limited

knowledge of residents' conditions and restricted training. Activity workers usually had to decide which activities to conduct and some felt out of their depth and not sure what to do with the residents. Pre-planned activities and trips occurred, however sometimes flexibility was required and activities had to be adapted to residents' needs at the time of delivery. Additionally, some residents were not interested in activities, were reluctant to join in and occasionally residents' BPSD would become worse at such times. Overall, activities, although not targeted at BPSD were perceived to indirectly help in their management.

Other strategies and approaches were found to be utilised by, or assist, staff in the management of BPSD in CHs. Person centred care was frequently observed and viewed by staff as an important aspect in reducing BPSD. Staff members using their knowledge of residents to adapt their approach to the individual appeared to be successful. However, activity staff generally did not have access to care plans or attend handover sessions and therefore, could have limited information about changes in resident needs and behaviour making it difficult for them to adapt to each resident's changing needs. A trial and error process seemed to assist both care and activity staff in gaining knowledge of suitable approaches to use with residents. Flexibility appeared to be a very important feature in delivering care to residents with BPSD. Residents' moods and behaviours could be adapted to by staff, which enabled the most suitable care approach to be used at the time. Routines could also be useful with their rigidity reassuring residents, yet problems could occur if these were subsequently deviated from or if the routinisation of practices in relation to the organisation appeared to supersede the need for flexibility concerning individual needs.

Distraction appeared to be the main and core strategy used by staff to assist them to manage BPSD. Taking residents minds off their agitation appeared to reduce the escalation of situations. A 'cup of tea' appeared to be used most frequently as a distraction. Monitoring was important to assist staff to intervene with residents at the most suitable moment. Communication techniques for residents experiencing a different reality included re-orientating them to the current circumstances, which could be upsetting to them. Alternatively staff appeared to go along with their reality, sometimes deceiving residents so that they would not become upset. These two

strategies were employed interchangeably by care staff and appeared to often depend on the individual staff member's perception of which approach would be best for each individual resident at the time of delivery. Residents were moved from homes to more suitable care settings if staff could no longer cope with their behaviours or meet their needs. Three of the case study CHs were on the other side of this process and regularly accepted residents that other CHs could not cope with.

The findings portrayed some inequality within the case study CHs, with those residents who were severely disabled, with lower levels of cognitive ability or with marked BPSD not receiving the same choices as more able residents. The positioning of residents was an important strategy, particularly in those homes caring for a mix of residents both with and without dementia. Segregation of residents appeared to be implemented for multiple reasons. The easier care of residents for staff and the reduction of impact on others were the main reasons cited for this strategy. Other instances of inequality for these residents rested on the fear of, or lack of responsibility towards, these residents by staff members.

Overall the findings show that many strategies are being employed by CH staff to manage BPSD. It was surprising to find that NPIs were not (routinely) used to manage BPSD in CH settings. Instead more subtle and indirect strategies and factors appeared to assist staff to manage these behaviours. Generally strategies or approaches were not employed as planned and conscious actions to reduce BPSD, but occurred naturally as part of everyday care practices. Additionally, however, some undesirable and potentially problematic findings emerged from the data, which portrayed a lack of PCC, segregation and inequity in the delivery of care; these were found in all of the case study CHs, but to differing extents.

Chapter 9: Issues and Tensions in the Management of BPSD

Introduction

The last three chapters have portrayed an examination of the influence of CH dynamics on practice, how medication is used within CHs for residents experiencing BPSD and the strategies used by CH staff to manage BPSD. The findings, together, highlight the complexity of caring for residents with BPSD in CHs; for instance: environmental effects, staff knowledge, resources, the actions of medication prescribers and administering staff members, the provision of activities and care staff approaches all come together and interact to influence practices. However, a number of issues and tensions emerged from the data, which have been underexplored in the past chapters. Caring for residents with BPSD in CHs can cause staff to encounter some difficult situations and dilemmas. Providing adequate care for residents with dementia who are resistant, keeping all residents safe, and the satisfactory monitoring of residents with BPSD are all actions, which CH staff members are expected to fulfil. Many everyday care practices such as these have inherent ethical dimensions when residents lacking mental capacity or experiencing BPSD are involved. Managing BPSD in CH settings touches on difficult areas such as human rights, freedom and restrictions and risk. Although an examination of these issues does not directly answer the research questions, the tensions staff have to grapple with on a daily basis, as found within the case studies were considered vital to adequately explain some of the strategies used in CHs in relation to the management of BPSD. Additionally, as part of an exploratory study, these emergent findings were considered important to gain a more comprehensive understanding of this complex area of practice. Therefore, this chapter will explore some difficult issues found in the data; intertwined with these issues are further strategies employed by CH staff to cope with BPSD. By examining these issues and tensions it is hoped that areas of contention in the management of BPSD will gain more attention and the rationales for some of the strategies used by CH staff will be highlighted.

An illustrative example (Example 1)

An example from my observation notes is included below as a starting point to exploring the multiple issues emerging from the data. This particular example touches on many of the difficult areas staff members have to cope with as part of their work. Therefore, it will be referred to as 'Example 1' during the discussion of a few separate concerns throughout this chapter. The observation notes were generated from one afternoon at Gage Hill, however the issues portrayed were found, in some form, at each of the four case study CHs:

'Jim was very agitated – he was wandering around the home (secure area) – he had moved a couple of ladies frames away from them. One told me he had banged her knee with it – she said she was okay – once he had moved on I gave them the frames back. Jim still walked around grabbing things – he went to grab a resident's arm she moved it. Staff became concerned for other residents and tried to lead him away, as they did he grabbed them tightly – Marie (carer) was grabbed – she asked him to let go or hold her gently in a firm tone – he was really gripping hard – once she wriggled her arm free her wrist was very red. Vera (carer) also tried to assist him away from other residents – he grabbed her too she was pulled along behind him for a little way – she asked him to let go 'let go please' – he didn't (staff generally walk around with him and then try to get free from his grip as it hurts) – twice he pulled Vera's work blouse open as it had popper fastenings. Brenda (team leader) said to me 'he is best left alone, but cannot be when he is likely to hurt other residents, at times he needs 1 to 1 attention'. Vera offered to take him around the garden but he was too agitated to go with her (he didn't comprehend). Brenda came to help and calmed him with an upbeat voice and soothing rub to the back – he sat down on a table beside her (Brenda accepted this as better than not sitting) and Marie joined them and rubbed his back – he seemed to be calmer – Jim put his arm around Brenda in an affectionate way – he soon got up (after about 5 minutes) again though and Brenda went with him, he had hold of her arm (he likes to hold on – security?) he soon after grabbed another resident's frame off her (Thelma) as

she was walking along – I ran to hold her hands to support her – she was okay and looking on at Jim and her frame in wonder – Brenda who was still with Jim tried to get the frame off him, she had to wrestle it off him as another resident was sitting beside where they were and it may have hit her if she had not, as it was being swung around – she got it off him and got it back to Thelma. Jim then tried to grab the resident sitting beside where he was – he grabbed her clothes – his hand was loosened with assistance so he then walked with Brenda around the home. Jim did eventually settle (for 5 minutes) and the tea trolley came around – Rachael (activity worker) was there and I was helping her with a game of bingo – Jim got up again and went close to Marie who was wearing a cloth apron, he grabbed it – she called Vera for help as it was getting tight around her neck – Vera assisted Jim to walk to the quiet lounge and sat with him there for a while (10 minutes).

Other residents get out of his way, get cross, shy away, go a different way or laugh as he comes near. Marie later took Jim out in the garden and walked up and down. The MH team has been contacted for Jim and the home is now waiting to be contacted by them. Susan (manager) said that ‘he has been put on an off label med (sodium valproate, Epilim) but it does not seem to touch him at the moment, the trouble is that to touch his behaviour it would probably knock him out and make him drowsy’. Jim was difficult for about an hour and a half in total.

During the time above Vera wanted to clean up a spillage in the dining room where someone could have slipped but she was needed to stay with Jim. Jim also tried to get on a stool near the window – Vera panicked and ran to assist, Jim grabbed her again – Marie took the stool away.’ (Observation notes, 14th June 2012, Gage Hill)

Example 1 shows that caring for residents with BPSD could be incredibly difficult for staff members. Both, the resident experiencing BPSD and other residents nearby could also find situations stressful. In this example, and throughout the four case studies, it appeared the behaviour that residents were displaying or experiencing was not the

main problem for CH staff; instead the consequences of behaviour seemed to be the catalyst, which forced staff members to act. In Example 1 staff were trying to reduce the impact of and risks for other residents posed by Jim's behaviour. However this meant that the impact was turned onto staff members who were grabbed tightly or pulled along. The hour and a half where Jim was experiencing very agitated behaviour on and off was difficult for staff to contend with. Protecting residents and staff became a main concern. Staff prioritised addressing Jim's behaviour over their other responsibilities and consequently, they got behind with their routine tasks and a slip risk was left unattended in a separate room. Distraction did not work since Jim was already in a heightened state; staff tried to soothe him, but also, at times, felt the need to physically prise his hands off things (the frame, a resident's clothes, an apron, staff member's arms). The difficulty in coping with Jim's behaviour in a communal setting was very apparent. If Gage Hill had also had a separate, non-occupied secure area to take Jim to, the impact of his behaviour could probably have been diminished and consequently, less intervention needed. The situation portrayed highlights a negative aspect of the open plan and heavily occupied secure area in the home, although the secure area did work to limit Jim's behaviour to within the CH only. Example 1 also provides an indication of the circumstances CH staff have to cope with in the time (usually 6 weeks) between asking for help (the MH team referral) and receiving help.

The observation notes in Example 1 touch on two key situations when staff members from all of the case study CHs appeared to feel the need to step in and manage BPSD. These were: when there was a risk of some sort, or when the behaviour impacted on other staff or residents. A third situation, not included in example 1, where staff members appeared to feel the need to step in also emerged from the findings; if a resident experiencing BPSD had a public loss of dignity. Staff actions to offset the risk, impact or loss of dignity could sometimes be restrictive or contrary to residents' wishes; sometimes leading to staff enacting a type of forced care, restraint, or depriving residents of their autonomy. However, the alternative was to encounter risks, let others feel the negative effects of BPSD or let a resident with BPSD have an undignified or humiliating experience. Balancing the safety of the resident with BPSD against restricting them in some way appeared to be a major tension for staff to

negotiate; with staff appearing to sometimes get it right and sometimes not. Example 1 also shows how BPSD can impact on the resident experiencing them in the form of malignant social psychology from other residents. The safeguarding/autonomy balance and other difficult issues stemming from the data will all be discussed throughout this chapter. To begin, the surveillance and monitoring of residents will be explored.

Monitoring and surveillance of residents

The monitoring and surveillance of residents was an important aspect in the management of BPSD. Monitoring was important in Example 1, since staff had communicated to each other that Jim was agitated and were observing him as closely as their other routine duties allowed throughout the shift to enable them to intervene if needed. In contrast to the casual and ongoing monitoring all staff members did as part of their day-to-day role (discussed in Chapter 8, page 223), this section examines the formal monitoring of residents with BPSD that occurred in the CHs.

Communication between staff team members about residents

Surveillance appeared to contribute to the management of BPSD in each of the four CHs. Residents were constantly monitored. Staff communication and documentation about residents' behaviours was a major part of the monitoring; it was ongoing and updated every shift. Handover reports at the beginning of most shifts, informal chats during shifts and the informing of senior staff about important issues occurred throughout the 24 hour care provided. Using these mediums, residents' behaviours and conditions were discussed throughout the staff team. During the fieldwork I only sat in on two handovers, these were both at Cherry-Plum and in response to the manager's request that I should do so. Small excerpts of the observation notes from each handover are below; they are suitably generic due to a lack of informed consent from all residents at the home:

'On arrival (8am) I joined the handover report, it lasted 30 minutes and went through every resident in turn. The staff talked of a new resident who had been found out by the gate yesterday. Staff were worried that he would abscond ... at report there was the night nurse, a day nurse, 6 carers and me – 2 carers were

doing breakfasts and answering bells, although other carers had to answer bells mid report making them miss some of it – there was talk of another new resident’s suggestive behaviour and which dementia it may come from. It became apparent that staff had little knowledge of the new residents before they arrived at the home and some didn’t even know if they were male or female ... Staff talked of bowel movements and times since residents last went – suppositories were to be given to those who may need them (constipation may impact behaviour if a resident is uncomfortable) – also of ideas of what to do for a lady’s sore ear’ (Observation notes, 3rd November 2012, Cherry-Plum)

And

‘Today I sat in on the early afternoon handover – the nurse, Heather, led it and she talked about medication changes, what needed chasing up, monitoring and doing ... The staff talked about behaviour ... They laughed, joked, discussed and updated’ (Observation notes, 11th October 2012, Cherry-Plum)

These excerpts show that multiple aspects of residents’ lives are discussed between staff at handovers. This scrutiny appeared to enable the staff team to orchestrate a management approach to issues as they arose. Verbal communication appeared to be vital to keep staff members updated with relevant information; allowing them to adapt their approach and be aware of any new issues that might affect the way they should act. However, this practice left residents, especially those with severe BPSD, with very limited privacy. Their every move was scrutinised, discussed and sometimes acted on. Surveillance of residents, in some situations, appeared to be a necessary, but intrusive strategy to enable staff to be updated and to both anticipate and manage some BPSD situations. Families and external agencies were also informed of changes in residents’ conditions when it was perceived necessary by staff members.

The first excerpt from the handover meeting also shows how failures can occur in the communication of knowledge. For example, the lack of information passed on to staff about new residents, which made it impossible for the staff team to adequately prepare or adapt to the individual needs of new residents from their arrival. Additionally, during the handover the alarm call system sounded, which meant that

two staff members left to attend to residents' needs; consequently they missed out on potentially vital information to allow them to work optimally.

Documentation

Documentation, although secondary to verbal communication, was another important medium, which assisted in keeping staff members up to date. Documentation was used as a monitoring tool to provide evidence of changes in residents' conditions. This evidence was used to inform staff members or external professionals accurately about residents' conditions and the situations in the CHs, thus enabling them to put in place sufficient targeted support (pharmacological or other). However, the predominant role of documentation in the management of BPSD appeared to be to provide evidence. The documentation recording instances of BPSD and subsequent staff members' actions appeared to be viewed as a tool to: validate care practices, provide evidence to support staff accountability, and to safeguard staff members from accusations. This passage from the interview with Gill, the manager at Mirabelle Way, provides an example of this:

'after taking the handover tonight um, and a couple of people have refused to have, to eat this evening and as long as that's been handed over to me, it's been documented in their care plan, so if a relative were to come and say, I'd say well actually this is what they were offered and they chose not to have it, but it's been documented and actually we're following that through, so should at 3 o'clock in the morning that person suddenly be hungry' (Gill, Manager, Mirabelle Way)

By documenting the difficulty in providing care for PWD, the justifications for care practices, or the strategies in use, staff could insure themselves against potential allegations of neglect or even mistreatment. Elaine also portrayed the importance of documentation for staff accountability in her interview:

'it was then documented um, in the care plans and also on documentation that we have to do if there's an incident ... Mm, to cover ourselves legally and everything else' (Elaine, Carer, Mirabelle Way)

Staff at each CH, but especially Mirabelle Way, appeared to be aware that they had to use documentation to insure themselves against potential contestation in relation to their practice, especially socially questionable practice, such as use of forceful restraints or forced care (examined later in this chapter). Overall, the data showed that the role of documentation was viewed as necessary, not only to provide evidence of residents' conditions and the care practices used, but essentially, as a way to protect staff.

Technology for surveillance

Technology was employed at all four CHs in the management of BPSD to assist with the monitoring, surveillance, safeguarding of residents and the reduction of the impact of residents' behaviour. All homes had an alarm system for residents or staff to use when help was required or there was an emergency. This feature is standard in most CHs, even those not caring for residents with dementia; however, to assist in the care of residents with dementia extra alarm options had been added to the systems at the four case study sites. At Bullace View, Gage Hill and Cherry-Plum alarm mats were in use (also termed wander mats, pressure mats, bell mats). These were mats which were connected to the alarm system and would set the alarm off if someone stood on them. They were used predominantly, although not exclusively at night time, placed on the floor near a resident's bed or at their bedroom doorway to alert staff when specific residents were awake and potentially at risk of falling or of wandering. Alarm mats were not used in the communal areas at Gage Hill as there was always a staff member close by. However, Bullace View and Cherry-Plum used the mats during the day in communal areas or bedrooms to assist with the surveillance of particular residents. Karen, from Bullace View, explains the rationale for their use:

'for people like who are prone to fall, or wander out of their room at night time ... for instance you're in a chair and you're prone to falls or wandering, then, that, you stand on it and that will ring the alarm bell so staff can see that it's a priority to get to that room first. Either, so they don't walk into others' rooms or they're prone to having a fall and that and they could injure themselves.'

(Karen, Carer/Activity Worker, Bullace View)

Karen's excerpt highlights the reasons for the use of alarm mats at Bullace View. My observations endorsed her explanation and showed that if a resident stood on the mat the alarm would sound and a staff member would go and investigate. Often residents were offered assistance to the toilet or asked to sit down again. This appeared to be to reduce the risk of falling or to prevent wandering, which could lead to injury, absconding or an invasion into other residents' private spaces. It could also have been to reduce staff work load; if residents were seated they were not in the way or causing any issues for staff to resolve. The rationale for the use of alarm mats also supports the main finding, discussed throughout this chapter that risk and potential impact on others were the foremost reasons for staff to intervene in situations.

The use of alarm mats, designed for surveillance to alert staff to resident movements, sometimes had unintended consequences. Janice provides an example of how helpful alarm mats can be for monitoring residents' movements, but also how their use can then be taken advantage of by the residents themselves:

'he (Ray) does, an awful lot ... he'll go and get, go in ladies bedrooms, he seems to ... Identify ladies bedrooms ... he does tend to always find his way into Phyllis' strangely enough ... He does tend to aim for her room, but sometimes he will come up the corridor as well and we can usually intercept him before he does too much damage (laughs) ... 'cause of the wander mat, I like to have it beside the bed, because I think then leastwise as soon as he puts a foot on the mat we know he's up, but um, it has made us wonder a little bit lately because a few times, I think he's working out that, that he knows that we react when the mat is there because a few times we've been down and he has just been putting his leg back in bed, do you see what I mean? ... So I think he's making the connection, you know if I put my foot on here somebody will come and speak to me' (Janice, Night Carer, Cherry-Plum)

Here Janice clearly illustrates the benefit of the alarm mats, especially at night, since staff can intercept residents before they disturb anybody else. The connection Ray has made between getting out of bed and staff arriving is an interesting point, since it shows how the method of surveillance was turned to the resident's advantage to gain

staff attention. Alarm mats were also a potential trip hazard, although to my knowledge none occurred during my time at the CHs. However, on two occasions at Bullace View I observed a resident picking an alarm mat up and flipping it over. This triggered the alarm and staff came in and replaced the mat on the floor in front of the resident. The use of the alarm mat in the public lounge had the added difficulty that other residents might stand on it and trigger the alarm. Also since the rooms were large, the resident it had been placed in front of could circumvent the mat and leave the room without staff knowledge; leaving staff with a false impression that they were aware of the resident's whereabouts. This occurred on one occasion at Bullace View and staff searched for the resident in question, finding them along the corridor in another part of the home. Another underlying issue with alarm mats was that by assisting staff surveillance of residents' movements, they could be seen as detrimental to residents' privacy.

Cherry-Plum did not use alarm mats, instead, in each resident's bedroom there was a magic eye sensor. Once a resident was in bed the magic eye was turned on and staff were alerted if they got out of bed. James explains here:

'We have magic eyes, magic eyes down over there ... It's just a sensor yeah and it's obviously invisible, it's infer-red ... that will just go off, um, say Ron is in bed and then he decides to get up or his leg falls out of bed and that will just, that will ring outside and that will let us know that he's up or he's moving ... So, he might need help, so... Yeah, most people's rooms and obviously like Percy who's up and down quite regular, he's not really at risk of falling or being in trouble and he locks his door at night anyway so if it went off we wouldn't be able to get in to turn it off, so we leave his off and, he'll come out when he's ready anyway and Mabel has hers off 'cause she doesn't, she sometimes, she only gets up to go to the toilet and she's not really a great fall risk, at risk of falling so er, and Sarah doesn't have hers on, but we go in and check her regularly, yeah ... It's just people like Ron and Nigel ... who are, they are at risk so if they get up then we need to be in here.' (James, Carer, Mirabelle Way)

This excerpt explains why the magic eye sensor was not used for every resident, only those who may need assistance, be at risk of falling, or could disturb others. These modes of surveillance were useful for staff to pre-empt residents' actions, especially during the night when there was not a large staff presence to monitor residents and when wandering residents could disturb other residents' sleep.

Risk assessments and documentation were completed when alarm mats were introduced for individual residents, yet there appeared to be limited or no attempts to gain resident or relative consent for their use. Magic eye sensors were installed at the time Mirabelle Way was built therefore, they were already in place and used at the discretion on the staff. These modes of surveillance may have been reassuring for relatives. The surveillance and monitoring of residents appeared to be important in the management of BPSD by keeping staff members up to date about residents; evidencing staff actions and ensuring residents' whereabouts were known. However, at what point does this high level of surveillance (used by staff to reduce risk and the impact of BPSD on others) become an unethical intrusion into resident privacy?

Security and safety: restriction versus resident autonomy of movement

Staff accountability for residents' welfare and their duty of care meant that resident safety was an important priority in all the CHs. Therefore, instances of potential risk were taken seriously. This led in some circumstances to residents with dementia being restricted in their movements or self-determination.

Additional to the surveillance techniques used to monitor residents, their autonomy and freedom was restricted at the four case study sites. All of the case study CHs, except Cherry-Plum, had secure areas and alarmed or locked external doors. The secure areas of the homes allowed residents to have relative freedom of movement, albeit in the restricted space within. The freedom afforded to residents within the secure areas generally allowed them the autonomy (or self-determination) of what to do and where to be as long as they were inside these areas or spaces and not at risk, in need of urgent personal care or having a negative impact on others. Brenda touches on the benefit of a secure area here by talking of the difficulties experienced before

Gage Hill had an extension and the change after a more secure area for residents was introduced:

'we'd have to unlock the door to let people in and course then you're trying to stop people to go (sic) out and they'd get upset or they'd stand and hold the door, um, whereas now the actual front door is behind the keypads so at least you can let people in, you haven't got, you haven't got to upset the residents and you can let people in easily so it is better ... Yeah, I mean they've got more room with having the extension, but because it's like open plan they can just wander round how they want to, but they're safe because they can't get to the, the main stair-case and to the front door' (Brenda, Team Leader, Gage Hill)

This excerpt from Brenda shows how the behaviour, wandering, could be perceived as, and actually be, less problematic due a secure area. The relative freedom within the confines of the secure areas allowed staff to know residents' whereabouts and be reassured that they were in a safe area; for example, that residents were not absconding or in off limit places of risk such as, the home's kitchen or stairs. Without secure areas staff would probably have felt the need to actively monitor residents more frequently to ensure their safety and therefore, paradoxically, residents may have been afforded less freedom and self-determination.

Sometimes the security systems could fail. During the case studies I observed: a visitor not closing the external door properly and therefore leaving it slightly open; a resident getting through a door behind a staff member before it closed, and a resident going out through an alarmed, but not locked door. Often in these cases a staff member would encourage the resident back in through the door to the secure area. Staff appeared to feel pressure to return residents to the place where they were supposed to be and some were very anxious if residents managed to leave the secure areas. Occasionally a resident would be resistant to return back inside the secure area. The following example, which occurred in a separate room from me during a pause in an interview, illustrates the pressure staff can feel to keep residents safe; sometimes to the detriment of the care they provide and the resident's wellbeing (my questions in bold):

(Emergency bell) INTERVIEW PAUSED WHILE VERA GOES TO ANSWER IT –
RESUMED WHEN VERA RETURNED

'Ella is there near the front door and she wouldn't go back in (to the secure area), so she's just kicked me and hit me.

Oh no, are you alright?

(Laughs) Yeah

So how did she get through the door then?

Well because someone, they must of rushed through and didn't realise that she was behind them and she got in ... she trod on me foot and kicked me and, I thought she was going to go over the table actually because the table's right by the door and I had to push her in and she grabbed the table. I thought she was going to go over the top and there's Thelma (another resident) having a go at her ... The thing is we can't leave them out there because if they go up stairs and fall down we don't know, that's why we try not to let them go up the stairs here because you don't know if they're on the floor.' (Vera, Carer, Gage Hill)

Vera portrays a hectic situation due to a resident overcoming the restriction in the space allowed to them. Vera appeared to panic and when the resident refused to go back in and became aggressive towards her; she used a forceful action, to make the resident return to the secure area. This situation not only reflects the way secure systems can fail, but also the fear staff can have about residents being outside of the safe area and the sense of obligation to return them at all costs; to the extent that they create a risk to the resident themselves. The justification for this action was to reduce potential risk; however it was replaced with a real risk. The excerpt reflects an emotional and physical impact of the situation on Vera where she experienced anxiety and pressure to return the resident to the secure area and was physically hurt by the resident. Conforming to the institutional protocol led Vera to act in a physical, uncaring and socially questionable way towards a resident.

It must be noted that although there appeared to be an overriding pressure to return residents to the secure area for all staff at Gage Hill, I observed other instances of residents getting outside the secure area at the home with staff members being less anxious about it. They would usually take a less direct and urgent approach and would take time to verbally persuade or encourage the resident back in to the secure area. Perhaps Vera's individual approach or her reaction to the physical aggression she received influenced her actions. In any case, Vera had already handed her notice in to leave Gage Hill at the time of the case study due to finding physical aggression from residents too difficult to manage especially at an emotional level.

Forceful restraint

The use of forceful action or restraint against a resident, as in the previous excerpt from Vera's interview, was not viewed as a formal strategy by the staff at Gage Hill. The need to occasionally (my observations showed six times in total over the 90.45 hours I was at the CH) physically assist residents to do things against their will appeared to be an implicit strategy. Viewed by the staff as an unfortunate, but inherent aspect of the job, necessary to cope with the situation they were faced with at the time. At Mirabelle Way these actions were explicitly termed as forceful restraints and were also used occasionally (observed twice with non-participant residents in the 99.30 hours while I was at the home, however I was assured by numerous staff that the use of a forceful restraint was rare), but viewed as a formal strategy. Training was provided in the correct techniques to use and documentation around instances of their use was stringent. James explains about the use of forceful restraint here:

'a lot of us have had the training, I think if you are confident enough to do that and if, if you really needed to do that, but obviously if it was going to, um, if he was going to make, if it was going to be unsafe for one of us or for him (a resident who had been forcefully restrained at the home recently) or for us, then and an action needed to be taken then we would ... we would do it I think, yeah.' (James, Carer, Mirabelle Way)

James depicts risk as the rationale for using forceful restraint as a strategy. Additionally, he states that many staff have been trained ready to use a forceful restraint and alludes to a reliance on staff member's individual approaches and their confidence to enact one. Barbara endorses James' statement:

'some of them (the staff) even though they would have training in it, they wouldn't feel comfortable using it and it's something that you don't want to use, you really don't want to, you have to do' (Barbara, General Nurse, Mirabelle Way)

Barbara alludes to some individual staff member's opinions of forceful restraint and the discomfort that this caused them. She feels that using a forceful restraint is not a choice and in some circumstances she perceives it as a necessary strategy. Hazel explains further about the use of a forceful restraint:

'we can't make any restraints and if we do use it, which we have done in the past and probably will do in the future even the fact that um, you're holding Trevor's hands to stop him from hitting somebody or the wall, or from breaking the wall, or kicking the door that is restraint, we then have to fill out an incident form er, to say why Trevor might come up with bruises on his wrist tomorrow because we had to restrain him because he was blah, blah ... because of the culture we live in now, the sort of culture of being sued I think as staff, qualified staff we are so super, you know, don't touch anybody (laughs) which is fine ... legally you're just so wary that somebody could sue you for anything' (Hazel, General Nurse, Mirabelle Way)

In this excerpt Hazel alludes to a forceful restraint being used to protect a resident when they were perceived as going to do themselves or someone else some harm; therefore to safeguard a resident. Hazel states that they cannot make restraints, but that they do in certain circumstances where the risk or impact of behaviour is great. The need for staff members to document their actions to cover themselves was also viewed as vital. This generally appeared to reflect an element of defensive practice for staff to cover themselves and the CH, but also to inform future care planning for the individual resident. During my observations, forceful restraints only occurred at Gage

Hill and Mirabelle Way. However, they were viewed differently at the two homes: as a calculated and accountable strategy at Mirabelle Way and more informally, as actions in the moment at Gage Hill. Both homes used them to achieve a desired goal, usually to reduce or offset a clear risk or the impact of BPSD. For example, at Mirabelle Way a gentleman who had absconded and was running and walking in the middle of a busy road was forcefully restrained and at Gage Hill Jim was forcefully restrained by his wife and staff when he was particularly agitated. The use of forceful restraints at these homes and not the other two case study homes could have been due to resident profiles; both Mirabelle Way and Gage Hill were looking after residents with far more severe cognitive decline and BPSD.

No forceful restraints were observed while I was at Bullace View or Cherry-Plum. This did not mean these homes were not also faced with difficult situations balancing restrictions and resident autonomy. Eileen talks here about what staff members at the home do if a resident is wandering:

'Try and encourage them to sit down, er, a couple of our ladies ... they do tend to wander a lot and because they're not so steady on their feet we try and encourage them to sit down with a cup of tea or a sandwich and, or things like that. Sometimes it works, sometimes it doesn't. Sometimes, one of our ladies, she's adamant she wants to go home and no matter how many cups of tea you give her or how many times you sit down and talk with her there's no changing her mind ... you have to, um, judge how she's going to respond to you. Sometimes she'll come and sit down and other times she'll be adamant that she wants to go, there's nothing you can say or do to stop her ... just let her go (not home, but from the seated position to wander and try to get through the locked external door), yep, because we're stuck between a rock and a hard place, in our home we're not allowed to restrain by any stretch of the imagination, not even for safety, so we can't do that, so if they're adamant that they want to go somewhere and do something we have to let them.' (Eileen, Carer/Part Time Senior Carer, Bullace View)

This excerpt shows again that the goal of staff is to reduce risk and that this often occurs to the detriment of residents' autonomy. Distraction and encouragement are used, but not always successful. Eileen alludes to the difficult tension between restricting residents and allowing them to act in a way they want to, even if it would increase their BPSD or have a risk attached. She states that staff at the home are not allowed to restrain, even for reasons of safety. Therefore, it is difficult to say what would happen if a situation where imminent risk to a resident or staff member occurred, such as some of those observed at Gage Hill or Mirabelle Way.

Other restrictions in residents' autonomy of movement also occurred at the CHs. At Cherry-Plum there were no secure areas, yet, restrictions of a different type were used. As mentioned in chapter 8, Bert was placed in the landing area so staff could better monitor his movements. However, in the landing area he was also restricted in his movement due to the closed door at the top of the stairs and the lack of places he could physically get to. Other than a table and access to newspapers there was not a lot for Bert to do in this area. Therefore, although there were no secure or locked areas, Bert was still confined due to his inability to cope with the stair door and a lack of other places to go.

Stair gates were used at Bullace View and Gage Hill to prevent residents falling down the stairs. The gates were put in place to prevent this risk, but similar to other means of security, they also worked to restrict residents' freedom of movement. A resident at Mirabelle Way had a stair gate in her bedroom doorway, not to restrict her movements, but to protect her from other residents wandering in. James explains here:

'Caroline upstairs has got one (a stair gate) on her door because ... he went into her room one day and took her crisps and her chocolate off her from out of her hands and she can't get up and defend herself in any way. So that really frightened her ... so that was better for her, she wanted that little bit of security there' (James, Carer, Mirabelle Way)

In this instance the use of the stair gate was to reduce the impact and associated risk of other residents wandering into a room of a vulnerable resident. Therefore, the gate

was used as a strategy to make the communal living of the residents in question easier. Similarly, to the stair gate, some residents with less cognitive impairment at all case study homes chose to lock their bedroom doors to prevent other residents wandering into their rooms, particularly at night. Overall, these measures were to reduce the impact of BPSD on other residents; they were sometimes to keep residents in and sometimes to keep them out. Restrictions in movement were put in place by the organisation, staff and sometimes by other residents. There was perhaps the need for the CHs to consider the need for deprivation of liberty safeguarding authorisations (Care Quality Commission, 2011; Mental Capacity Act, 2005). To my knowledge Mirabelle Way was the only CH to have one in place; this was for a resident who repeatedly tried to abscond from the home.

A balance between neglect and forced care

Often residents with dementia would be reluctant to receive personal care. Refusals of care or resistive behaviour could lead to BPSD, particularly aggression and created a difficult situation for CH staff. The decision whether to leave a resident who was resistant in a soiled state or to provide personal care against their will was a difficult balance to achieve. Occasionally there were situations where staff felt they had to act, as Hazel mentions here:

'it's fine if somebody doesn't want to have a wash or change their clothes every day, fine, but if somebody's wet and they're going to get urine burns, then it's a case of they've got to be changed, because then it's neglect because they're going to end up with sores because of it' (Hazel, General Nurse, Mirabelle Way)

Hazel differentiates between the non-essential need to deliver daily care to promote hygiene and a clean appearance and the more urgent need to provide necessary personal care. In the case of a clearly wet or soiled resident, staff at all four CHs felt the need to act rather than leave the situation. The question of how and when they acted was a difficult issue. Often, trial and error was used until care was provided, as Jen shows here:

'if they are really resistant and really don't want you to do it, then we leave them and we go, we go back about ten minutes later because then their moods can change and if they're really resistant, I have on a couple of occasions where one person has, one resident has been really resistant against particular carers ... That's not a problem, then we just send somebody else in there ... a different face or whatever, er, it tends to work well, we, we do get round those sort of things, it's not very often that people go without care because they won't have it, we tend to wait and then go back or even if they don't, they want to stay in bed 'til lunch time and don't want care 'til after lunch they have care after lunch, there's no set rule ... you know, there's no really, real reason unless obviously they've got a soiled pad and you have to do something, you know we tend to try and work round them as well' (Jen, Carer, Cherry-Plum)

This excerpt from Jen's interview depicts her perception of working around the residents rather than working with them. A flexible trial and error approach was used; this appeared to be adopted in all four case study CHs. When a resident refused necessary care they would try to encourage them to receive it and if that did not work they would try again later. If they still had no luck they would send in another care worker to see if they were able to assist the resident. A difficult situation arose when residents still refused care and were perhaps wet or soiled and needed to be changed. To provide personal care to the resident would involve forcing care onto them against their wishes (an abusive act) and to leave them would be neglectful and perhaps lead to urine burns or sores. Staff were accountable for providing care to residents and to leave someone soiled for a period of time was generally viewed as bad practice. It appeared as though most staff would try to conduct the care as soon as possible, particularly if the resident was in a public area (as this represented the potential for a public loss of dignity). Gill sets out Mirabelle Way's approach here:

'if we've got to do something and we know that somebody's perhaps unsettled or agitated then we do the minimum that we need to do and we walk away and then we go back 10 minutes later and see how that person is' (Gill, Manager, Mirabelle Way)

As Gill states, the approach at Mirabelle Way was to do the minimum care possible, leave the resident to calm down and then return to see if they were alright. Elaine, also from Mirabelle Way, talks more about enacting forced care at these times:

'we didn't hurt her and we had to each have a towel and you wrap it round, so you can't get hurt, she can't get hurt, but we're not hurting her, but if we left her so that we just grabbed her wrists we'd hurt her and she would probably hurt us ... you use pillows against their bodies, so that they're buffered, we're buffered and that's only training that Gill has shown us ... Yeah, because that is when, that is mostly when dementia people are at their worst, it's they feel embarrassed and we know that, so we don't sort of say 'have you pooped yourself?' or whatever, you know, we just get on with the task but we know as soon as they're cleaned up and their pants are pulled up, like you or I, I suppose um, they're fine.' (Elaine, Carer, Mirabelle Way)

Elaine alludes to the use of towels or pillows to protect both the staff members and resident during the act of forced care. Through this she highlights the physical nature of forced care, but also shows consideration for the personhood of the person with dementia receiving the care. Elaine's description of just getting on with the task appears to reflect Gill's ethos of doing the bare minimum and getting out of the situation. Elaine also indicates that generally after the event the resident quickly recovers. This was an opinion also stated by Carla, a senior carer at Gage Hill:

'a lot of the aggressive behaviour or the, it's usually because of personal care, that seems to trigger most people that are prone to, you know be verbally or mildly or viciously, you know, aggressive, but it always seems to be on contact, when you're trying to do something they don't want to do, but it's got to be done because they're wet or they're soiled, you know, and, and, but then after it they're back to give you a cuddle and a kiss and it's forgotten, you know, soon as you've finished 'off you go then' and it's gone, it's like, yeah, they've forgotten it and I've forgotten it, you know, and it's just that moment, but yeah, it's, it can be, you know, it's sort of, sometimes there's two or three of you have to, sort of assist, you know, and I feel, feel for them, you know because if, if you

could just, and I wish I could just get through to them and say 'well if you could just sit quietly it would take two seconds' you know (laughs) yeah and you're like 'just sit' you know and you're trying, and you're talking to them, trying to reassure them 'we're just going to change you, you are alright, make you comfortable if you just sit quietly, it will be done in a minute' but course they don't understand, yeah, but that, that's, I find it heart-rending really' (Carla, Senior Carer, Gage Hill)

Carla provides the essence of the situation; it is an unpleasant, but necessary aspect of caring for residents with dementia. She states that forced care can incite instances of aggression from residents and that sometimes there are two or three staff members assisting in carrying out the care task. Similarly to Elaine, Carla states that the violation the resident feels appears to be gone shortly after the incident. Carla also feels empathy for the resident and their predicament. The cognitive decline appears to impair the ability for staff to reason with or explain what needs to be done to residents and understandably residents become aggressive. At each of the case study CHs, but particularly Gage Hill and Mirabelle Way with their resident profiles including many individuals with severe dementia, staff found this issue difficult to balance. The brutal act of forced care in these circumstances appears to be bad practice, however the alternative is to leave residents wet or soiled, which is also bad practice. It appeared to be a no-win situation, which posed difficult decisions for staff members. The lesser of the two bad practices, in terms of impact on the resident, appeared to be difficult for staff to determine. Resident physical and social harm (to become sore or/and smelly) had to be weighed against a violation of the person (forced care). Forced care could be defensive practice from staff who do not want to be accused of neglect, so carry it out to the detriment of residents' PCC. However, the lack of forced care for residents who persistently resist, at some point in time, would become neglect. There appeared to be no definitive answer, but this circumstance created difficult issues for staff to negotiate. Forced care was viewed as essential in some situations, however, apart from being socially questionable; it also caused more instances of BPSD, the very behaviours CH staff wanted to reduce.

Impact of behaviour on self (person with BPSD)

Many of the findings in this chapter have been interconnected with the impact of BPSD on other residents or staff. However, residents experiencing BPSD could also feel the impact of their own behaviour; from the effects of staff interventions or from other residents who often appeared to shun residents with BPSD. Janice outlines a situation where she is concerned that the strategies employed by staff to reduce instances of Ray spreading faeces over furnishings may impact back on him:

'And the thing is you can, every time he gets up you can take him through and put him on the toilet, but he gets quite angry and then I'm not sure that it doesn't give off mixed messages because does he then think, is he pooing to get attention ... or is he sort of fulfilling, sort of thinking 'oh well they're going to take me to the toilet' is it almost a if I do this, this happens or if you do this, this happens, you see what I mean? ... I find it quite hard. And apart from that the mess ... You know and he does smear it on the walls, he'll smear it on the curtains, he does, he's got a door stop, there's a sausage thing to stop the draft and that's one of his favourite places to poo. We have tried putting a commode there at night ... Where his favourite place to poo is, but he just doesn't seem to (laughs) he poos somewhere else instead (laughs) ... And the thing is, we've tried lifting him, if you know what I mean, when he first came in we religiously toileted him every four hours through the night, but then really that's not good because you're interrupting sleep patterns um, and he's not getting the quality of sleep, so does that add to his confusion? The fact that he's tired, does that add to his behavioural problems because he's confused, it's really, really difficult isn't it? ... You know and the fact that you just keep rocking up every four hours and saying 'come on Ray we're going to get you out of bed and take you to the toilet' I mean if somebody did that to me I'd be absolutely bloody pissed off really ... He can get a bit argy-bargee, I mean an odd time he will sort of, how can I say? Rear up, you know, sort of said 'oh I'm not having any of this' he told me one day 'I'm going to chuck you in the sea' ... if room 20 goes off you know you're going to run like hell because it's going to be Ray and that mat, by the

time that mat has gone off he's got time to get his trousers down (laughs) ... So if you can intercept him, guide him through (to the toilet)' (Janice, Night Carer, Cherry-Plum)

Janice clearly sets out how the strategies used to reduce the instances of inappropriate toileting appeared to have a negative impact on Ray himself. Paradoxically, the strategies used to prevent one BPSD (inappropriate toileting) have resulted in another (frustration/aggression). She alludes to him maybe using the staff strategy for his own benefit, also to it annoying him and to the strategy having a knock-on effect on his condition or behaviour the next day. Janice is obviously concerned about this, but the alternative is to leave Ray to continue toileting inappropriately, which for dignity and hygiene reasons in a communal setting is not ideal. Surveillance was used so that Ray's actions could be intercepted and staff could prevent any public loss of dignity for him, or any impact on, or risk to, others. Overall the observations showed that the person with BPSD experienced an impact from their behaviour, including malignant social psychology, as mentioned in example 1.

The problems delivering person centred care in care home settings

Competing demands

Divergent wishes of residents

At times the delivery of PCC appeared to be problematic in each of the four CH environments. The communal living nature of homes and the divergent needs and wishes of different residents made it impossible for staff to facilitate individualised care for every resident all of the time. This was shown in the example in Chapter 8 (page 209), where Bert disliked the music when other residents were enjoying it.

Competing demands were also observed when:

'Ray was banging his cutlery on the dining table in tune to the music, he was also humming – a carer, Natalie, came through and said 'Ray' sharply – he stopped momentarily and then started again. Dorothy complained about the noise he was making' (Observation notes, 6th November, Cherry-Plum)

In this instance it was impossible to keep both residents happy, Ray wanted to continue to bang his cutlery, but Dorothy (and maybe Natalie) found the noise too much. This situation depicts the impact behaviours can have on other residents and even, at times, staff in communal settings. Ray was placed in the other lounge away from Dorothy. The divergent wishes (or competing demands) of these residents meant that both sets of needs could not be satisfied at the same time and someone had to experience something they did not choose or wish to do. In this instance, Ray was removed from the situation to keep the peace and maintain the stability of the home.

Person centred care was difficult to deliver when residents in the same area had divergent needs or wishes.

Resident conflict

Resident conflict has recently been gaining recognition in the abuse literature (Castle et al., 2013; Pillemer et al., 2012). Conflict between residents was also a common source of competing demands at the case study CHs. Staff could not attend to each resident's needs in these circumstances, but had to intervene in the way they thought was most suitable; usually by targeting one resident for intervention or trying to pacify more than one resident at a time. These two interview excerpts from staff at Gage Hill (the CH that appeared to experience the most resident to resident conflict) depict the difficulty staff find in acting in a person centred way to both residents:

'you're trying then, it's hard because you don't want to move one on and let them think they're doing wrong. Um, just try and like, try and keep each other from, apart from the situation as well. It's hard when someone's, I don't know, trying to, to hurt the other person, it's hard for their wellbeing, you're trying to look after both of them but when one's more aggressive to the other' (Naomi, Carer, Gage Hill)

And

'it's when they start lashing out, then you'll step in 'please don't do that' and you'll move them away, you'll just move them apart, say 'right you come with me and you go that way', sometimes it works and sometimes it, it don't, it just

depends on what frame of mind they're in as well.' (Bernadette, Carer, Gage Hill)

These excerpts, again, point to the presence of risk as a catalyst to for staff to act. The difficulty Naomi feels in intervening in a way that both residents would feel acceptable is present in her excerpt. Additionally, Bernadette's excerpt depicts her approach as moving off with one resident and sending another away; the resident sent away is likely to feel less valued than the resident with the staff member. Resident conflict often resulted in competing demands for staff members.

Person centred care was difficult to deliver when there was conflict between residents.

Organisational responsibilities

Staff were also faced with competing demands because of organisational factors. Rob discusses one issue here:

'the bell mats yeah, yeah they're handy, so that sort of notifies us, but I mean, sometimes that doesn't even make a difference to whether you can get there quick enough or not, so I mean sometimes like in the evenings when we're busy and we're getting people ready for bed, the bell mat goes that can, that can ring for a good 5 or 10 minutes without us going and answering it because we're busy with other residents and you can't, especially if we're like hoisting someone you can't just leave them, we're not allowed, we have to keep two of us with the hoist' (Rob, Carer, Bullace View)

The excerpt shows how routine tasks can create competing demands and how a PCC approach can be abandoned when other tasks need to be completed. For instance, if a bell sounded and a resident received no assistance for 10 minutes they could easily feel that their needs were not being met. The competing organisational factors may also have led to suboptimal care.

Person centred care was difficult to deliver when there were competing demands from residents or from organisational responsibilities.

Constant attention required

Additionally, in situations where residents were demanding constant attention it often appeared to be impossible to offer PCC all of the time. Either those needing attention would get it and others would miss out or other residents' needs would be attended to and those with constant demands would miss out. My observation notes showed how this occurred with repeated questioning:

'A lady repeatedly questions staff 'where am I?' 'Why am I here?' ... 'I don't want to be here'. She does not appear to be anxious; instead the questions seem to be habitual. Staff generally answer her questions (observed with Elaine, Barbara and Fay) they bop down to her level and are very affectionate with her – she is momentarily reassured but it does not last for a minute as she asks the same question straight after they've answered it – staff then ignore what she is saying so they can get on – they haven't the time to constantly answer questions' (Observation notes, 20th June, Mirabelle Way)

In an ideal world the lady in question would have someone to answer her questions each time she asked them. On some occasions staff did attempt to get her to recite a poem she liked, but she was not always able or willing to be drawn out from the repeated questioning. Staff could not physically listen to and answer these all of the time; this type of PCC would require a one-to-one staff/resident ratio, which was unfeasible at the case study CHs with the staff numbers they had. Chapter 8, page 217, showed that the same issue occurs with residents who would continually call out, since they would eventually be left, as staff felt they could not be of further use and had other residents or tasks to attend to. Competing demands of this kind were common in the four CHs and often made the delivery of PCC problematic. The duty to care for all residents in the CH setting meant that staff members were pulled in different directions and had to make judgements throughout the course of their shift about which resident to attend to at which point.

Person centred care was difficult to deliver when one or more residents required constant attention.

Interrupted Work

The interrupted nature of care work also problematised the delivery of PCC at the homes. For example, one resident (participant) without dementia highlighted the issue during an informal chat about my study, as my observation notes show:

'We chatted and she (Kitty) told me her views of living with people with dementia. She spoke about going for a bath, which had been run for her and the carer wheeling her along when a person with dementia started asking questions of the carer who stopped and saw to the person with dementia, as she thought they should, but how she thought that those without dementia seemed to lose out as a result.' (Observation notes, 27th March, Bullace View)

The concern Kitty expressed and the example she gave about other residents taking priority, even momentarily, over her care show how much PCC is valued by residents. Also how difficult it is for staff members to deliver it exclusively when they are faced with competing demands. The alternative in this example was for the staff member to ignore or fob off the resident with dementia and prioritise Kitty. Yet, this action would have meant that the resident with dementia would have lost out on any sense of PCC. The communal nature of care settings may mean that total PCC could never be achieved and some compromise would always have to be reached.

Person centred care was difficult to deliver when interruptions in the delivery of care occurred.

Mitigating risk or impact as the priority at the time

When a behaviour caused an impending risk, or had a considerable negative impact on others, staff members appeared to prioritise strategies that would diminish or offset these issues. In these situations (such as, in Example 1 where Brenda wrestled a frame off Jim to prevent another resident being hurt by it) PCC appeared to become a second order priority for staff; overcome by the main concern at the time. This hierarchy of care priorities reflects Maslow's hierarchy of needs where basic needs like safety need to be fulfilled before higher level psychological needs such as, love or self-esteem can be met (Maslow, 1943).

Person centred care was difficult to deliver when managing the risk or impact of behaviours had to be prioritised over usual care.

Not knowing a resident

Providing PCC could also be problematic when staff did not know residents with dementia well. Without knowledge of residents' ways, likes and dislikes staff members were less able to adapt their approach or address resident needs in the most suitable manner. Residents with dementia often find it difficult to communicate their preferences; this makes PCC more difficult to provide to this clientele without prior knowledge of the person. There were some situations in which a lack of resident knowledge occurred at some, or all, of the case study CHs. The use of agency staff, new staff and part time staff led to some care workers looking after individual residents with limited knowledge of their past histories, preferences or personalities. Isabelle spoke of a strategy she uses to assist new staff in getting to know residents quickly:

'Yeah there's sort of the new ones when they come in, that's nice to put them on the tea trolley with somebody, that way they can get to know that resident, whether they need a feeder cup or whether they can feed themselves, as in a cup of tea and that, that's nice as then they get to know that resident as well on their first sort of few weeks of being here' (Isabelle, Carer, Cherry-Plum)

The tea trolley was viewed by Isabelle as a good way for new staff to find out about residents. The arrival of new residents at the CHs also meant that staff had inadequate knowledge of residents until they had built up a relationship with them and got to know them better, as Hazel states:

'I think probably the only times that is difficult is when we actually get a new resident and we don't know how to handle them or what their behaviour is going to be like and what's going to make it better for them and for us, ultimately as well' (Hazel, General Nurse, Mirabelle Way)

Getting to know new residents was made easier by the documentation about them being freely available to staff members before they arrived at the homes. However,

this did not always occur, as my observation notes from 3rd November 2012 at Cherry-Plum on page 235 showed previously, and as these notes depict as well:

'Information given to staff about new residents is poor, Audrey told me that she had asked the manager and all she (Audrey) knew about a man arriving today was that he's male and a bit like another resident. The staff are not told much before new people arrive – hard to prepare – deliver the right care – so early days in home are turbulent' (Observation notes, 9th November, Cherry-Plum)

This excerpt shows that the staff at Cherry-Plum often have very little information to go on to adapt their approaches to new residents. When residents have dementia or experience BPSD they cannot easily communicate their preferences. This situation meant that PCC was difficult to deliver until staff built up more knowledge of the new residents, often through a trial and error approach. The other CHs, particularly Mirabelle Way, provided more information about new residents to staff. The information known could have been a direct reflection of each home's admission process.

Person centred care was difficult to deliver when staff did not know the preferences of residents with dementia.

The concept of person centred care

Person centred care is an ideal. There is great social pressure for care institutions to promote and deliver this (currently viewed as politically correct) ideal. An examination of PCC in CH settings and the difficulties inherent in providing it to all residents, particularly those with dementia, has led me to critically appraise the concept itself and the feasibility of adopting (or providing) the approach exclusively in CHs. Meeting residents' fundamental needs is not the same as bending to every notion a resident has. In the extreme, if PCC were able to be facilitated at all times the effects of the approach may not reflect any other aspect of society and 'normal' daily living. No-one in life gets things their own way at all times. The difficulties highlighted by the data have led me to question if, at the extreme, it could be damaging to facilitate an

individual's wishes at all times? Perhaps each resident's right to personhood and right to experience a natural life is not fulfilled by having their own wishes enabled at all times. It seems likely there is a continuum, where meeting residents' needs in a person centred way is an important aspect of care that we should strive towards, but it is impractical to expect this to extend to making sure every wish is always fulfilled. Not only would the delivery of PCC in CHs to this level be impossible to provide at all times, but taken to the extreme, it could deny a rounded sense of personhood.

The findings set out in this chapter and Chapter 8 show that when the 'ideal' is translated to practice within a CH environment the limiting dynamics of: the organisational setting; particular circumstances, and the care workers' roles can constrain its delivery. In response to these pressures care staff have developed, implemented and adopted strategies to manage practice demands on a day-to-day level. The use of socially questionable strategies, as part of this, works to further lessen the PCC doctrine in the CH settings. Due to the difficulties translating PCC into day-to-day working practice the concept perhaps needs to be undistilled. The tension between the ideal and what is materially possible for care staff to achieve, within the scope of their roles and the resources available to them, can then be reduced and expectations can be made more realistic. Tensions between community centred care and PCC, and the requirements of the care worker role to fulfil residents' basic needs and complete routine tasks must be taken into account, especially in difficult situations. The theoretical contribution this thesis makes in relation to PCC is discussed further in Chapter 10 page 273.

Conclusions

This chapter has examined the main issues and tensions emerging from the data connected to the management of BPSD in CHs. It was important to include these issues, since they provide the rationale for many strategies used in CHs to manage BPSD. Additionally, they are important aspects of care work, which are negotiated on a daily basis by staff who occasionally end up on the wrong side of the difficult balance between providing care or allowing the presence of risks. Although risk assessments were used, risk enablement decisions, having to be made 'in the moment' through

balancing the benefits for the resident against potential harm from their actions (Department of Health, 2010) appeared to be difficult for staff members, since they had to take on the responsibility for any danger that residents encountered.

Surveillance of residents, particularly those with dementia, was an important staff strategy in the management of BPSD. Communication was important to assist in the monitoring of residents, particularly verbally, through handovers or informal discussions. Documentation appeared to be used to enhance communication, to cover staff legally and to provide an accurate record of residents' care. Documenting the management of BPSD was viewed as a way to insure staff against allegations. Technology was used to assist in the surveillance of residents by alerting staff to residents' movements. Together, communication, documentation and the use of technology enhanced the surveillance of residents. However, surveillance of this level occurred to the detriment of resident privacy. This surveillance could be viewed as reflecting the 'medical gaze'; a concentration on the body over the mind of the individual and also a way to socially control residents (Foucault, 1973; 1977).

There appeared to be two main reasons why BPSD became problematic: risk and impact. Risk (the need to keep all residents and staff members safe) and the impact of BPSD appeared frequently to be the prerequisites for staff action; some of these actions had moral and ethical dimensions. A public loss of dignity was also a catalyst for action by staff, but this occurred less frequently than the presence of risk or an impact of BPSD. The need to offset or reduce risk or the impact of behaviour (on self and others) meant restrictions on residents' autonomy occurred. The human right to liberty and security is particularly relevant to these issues. The findings showed the need for a fine balance between resident autonomy, which could create risk or impact on others, versus dilemmas arising from restrictions on residents' behaviour and/or actions. The balance between keeping residents safe from harm and reducing their freedom of movement or autonomy was a major tension in the four case study CHs, shown for example, through the presence and use of secure areas. However, the point where restrictions in autonomy and self-determination become a violation of liberty is not clear in all circumstances. Staff appeared to feel a pressure to keep residents safe and this occasionally meant that they acted in a socially questionable way.

Forceful restraint was used by staff in the two CHs I visited that were caring for residents with severe BPSD and cognitive decline; it was used differently by the CHs, as a formal and informal strategy. Reasoning with some residents, or for the staff members to communicate what they wanted the resident to do, appeared to, occasionally, be impossible. In these cases if there was a substantial risk or considerable negative impact of behaviour staff felt they would have to intervene. Forced care was also given to residents who needed, but resisted care. There was often no ideal solution: forced care or restraint on one side versus potential neglect, risk or impact on the other. Staff found balancing these issues difficult and often felt forced, themselves, to act against a resident's wishes.

These findings problematised PCC, by portraying several instances where its delivery became difficult. These were when there were: competing demands, resident conflict, organisational responsibilities, divergent resident wishes or conflicts of interest, interrupted work, constant attention sought or a lack of staff knowledge about residents. Due to this, a question was posed about the extent to which PCC can practicably be provided in CHs. This chapter has examined the issues and tensions emerging from the data; this has enabled some socially and ethically questionable practices to be explored. These show a side of caring for PWD which is far from ideal and would, perhaps, not be mandated in official guidance. From these findings two questions have arisen: if these strategies are not the best methods to use, what else can staff do to mitigate the risk and impact of BPSD in CH settings? And if practices that are socially questionable and would not officially be mandated are being used and accepted, how far is the step to abusive practices?

Chapter 10: Discussion

Introduction

The principal aims of this study were to explore the current formal and informal strategies used to manage BPSD in CHs and to understand how and why they are used. The pragmatic approach adopted for this study enabled data to be elicited from multiple sources to answer the diverse research questions. Choices for the research design and implementation were influenced by the literature and my past experiences and assumptions. Therefore, the methods employed pragmatically to 'best' answer the research questions were chosen subjectively. The postal survey phase provided data from a range of care settings and gained an overview of the management of BPSD in CHs. In contrast the case study phase supplied an in-depth view, which illuminated the care practices used to manage BPSD within the four case study CHs in some detail. Together these distinct methods have contributed in different ways to answer the research questions. Having examined the findings from the survey phase and the case study phase individually, a discussion of the overall findings is now necessary to definitively answer each of the research questions and to draw some general conclusions. The sample sizes, particularly from the case study phase, mean that generalisations cannot be made from the research findings, however by prioritising and drawing on aspects of the findings that are transferable they can be useful for the field of knowledge (Morgan, 2007). The chapter starts by outlining the central findings and then addressing each research question in turn. The findings are then related to the previous literature, highlighting how this research has contributed to the understanding of the management of BPSD in CHs.

Central findings

This exploratory study found that multiple, diverse strategies were used in CHs to manage BPSD. The central finding was that the rhetoric surrounding the management of BPSD (to use NPIs as first line treatments) did not appear to match a large amount of the day-to-day practice in CHs. In the main, formal NPIs such as, music therapy or

reminiscence were not found to be thought of, or be employed, specifically as part of the management of BPSD in CHs. Instead they were predominantly targeted at all residents and viewed as activities to improve daily living. Used in this way formal NPIs could only have an unintended effect on the management of BPSD by potentially preventing or reducing some instances of behaviour occurring.

The study has also identified the types of decision-making and actions that care staff have developed, employed and adopted to manage BPSD within the contextual constraints of their place of work. Many of these strategies were non-pharmacological, and not employed consciously as interventions to reduce behaviours or antipsychotic use. The majority were informal, implicit and/or much more likely to be perceived by staff as part of usual care practices rather than ways to manage BPSD; for example with distraction, the placement of residents, communication techniques and PCC. When BPSD did occur, it was often found to be the risk and impact that they posed, rather than the behaviours themselves, that were major issues for CH staff. The findings showed that to manage these issues strategies that were, in some cases, uncomfortable to consider and socially questionable such as, surveillance, segregation, forced restraint or forced care were used. Although these could be viewed as bad practice, my interpretation is that they were not used maliciously by staff members, but as a means to get through the day and cope with the risk and impact created by BPSD within the constraints of the job. Particularly since the previously identified CH dynamics such as staffing levels, the CH environment, management styles, and the confidence of the staff team were sometimes factors in the use of these strategies. The delivery of PCC was problematic due to the risks and impact of BPSD too. Communal settings, which were comprised of multiple individuals with complex needs along with competing demands on staff members also made PCC difficult to provide consistently.

A lower than expected level of antipsychotic use was found in CHs, which indicates that some reduction has taken place. Yet, other psychotropic medications (antidepressants and the antiepileptic; sodium valproate) were found to be used more than antipsychotics to manage BPSD. The findings showing the use of these

medications and socially questionable strategies could indicate some unintended consequences from a reduction of antipsychotic use for PWD.

Key findings

- There is a gap between rhetoric and practice for the management of BPSD in CHs
- Multiple diverse formal and informal strategies were used in CHs to manage BPSD
- Antidepressant medications and sodium valproate were found to be prescribed for CH residents more than antipsychotic agents
- Many formal NPIs were used and viewed as activities and targeted at all CH residents to improve wellbeing and not consciously used as part of the management of BPSD
- When BPSD occurred, the risk and impact associated with them appeared to cause more difficulties for CH staff than the behaviours themselves
- Several socially questionable strategies were found to be used to offset the risk and impact accompanying instances of BPSD or to provide essential care
- PCC was found to be problematic to deliver consistently to residents with dementia in communal CH settings
- Care home staff struggle with balancing safeguarding and resident autonomy
- Unintended consequences of a reduction in antipsychotic use could include the use of other psychotropic medications and the need for staff to more frequently resort to socially questionable strategies to manage BPSD and their consequences

Addressing the research questions

The findings will now be set out and related to each of the research questions. To reduce repetition questions 1 and 2 will be addressed together.

- 1) What are the formal and informal strategies used to manage BPSD in CHs?
 - a) Why and how are they used?

2) How do various strategies work?

a) And for whom?

The findings from both phases showed that many BPSD caused difficulties for CH staff and that multiple and diverse strategies were used to manage these. Strategies were generally used to prevent BPSD occurring, stop their escalation, or to offset the risk or impact arising from them. Some strategies such as, medication use or formal NPIs were predominantly planned and used routinely. Some strategies such as, PCC or communication techniques were used as general day-to-day care approaches and some strategies were used in the moment as and when they were needed such as, distraction, PRN medications or forced restraint. The major strategies found to be used will now be addressed briefly in turn.

Psychotropic Medications

Medication use was an explicit and formal strategy used in CHs. The survey data showed that antipsychotic medications were reported, in 2011, to be prescribed to 12% of all CH residents regardless of diagnosis; indicating a reduction in their use may have occurred. These findings can be viewed as being in line with the National Dementia and Antipsychotic Prescribing audit, which found 7% of people diagnosed with dementia to be prescribed these medications (Health and Social Care Information Centre, 2012), since CH residents are more likely to have dementia than the general population. The case study findings showed that usually CH staff were aware of the stigma associated with antipsychotic medications. However, CH staff were prepared to, and, at times, thought it was necessary to seek pharmacological assistance from prescribers for residents experiencing distressing BPSD. Only gatekeepers in the form of medical professionals such as, GPs and psychiatrists had the power and authority to prescribe and review medications. The findings showed medication use was generally monitored well by CH staff. Staff member's decisions to administer PRN medications or to omit regular doses were subjective and the practice of sub-administration was common.

Psychotropic medications were being used in CHs for residents with BPSD.

Antidepressant and antiepileptic medications appeared, from the small medication

mapping sample, to be used more than other psychotropic medications. Although this study could not determine the reasons for medication use, the higher use of these medications over antipsychotic agents raises concerns that antidepressants could be being used for their sedating effect and that sodium valproate is being used 'off label' for BPSD. If this is the case, it could be that the unintended consequences of reducing antipsychotic medications for PWD has led to a similar situation occurring, just with different medications, which are currently less prominent in the public discourse and not (yet) subject to policy imperatives. The perhaps 'off label' use of sodium valproate for BPSD was an important finding, which would benefit from further exploration. The probable reduction in antipsychotic use, along with the higher use of antidepressants for PWD found in this study is congruent with the findings in the trend tracking study conducted by Martinez et al (Martinez et al., 2013).

Non-pharmacological interventions/Activities

A different picture of the use of NPIs in CHs was obtained from each of the study's phases. The survey findings showed that CHs were employing multiple strategies to manage BPSD. Eighty seven percent of CHs reported using at least one intervention to manage behaviour, with reminiscence, music therapy and animal/pet therapy reported to be used by the most CHs. The case study findings portrayed a different situation. Although formal NPIs were used in CHs, these interventions were predominantly viewed, and used, as activities for all residents to enhance their daily lives and not as strategies to reduce or manage behaviour. Activities were often planned and used routinely with residents and not used in the moment to manage instances of BPSD. NPIs, or activities, were generally viewed as a way to improving resident wellbeing and therefore, predominantly found to help residents and staff to manage BPSD only in an unplanned and indirect way. Non-pharmacological strategies were used, but as components of usual care such as PCC and communication techniques, but not as perceived interventions. Due to the general lack of intent to target BPSD with the use of NPIs/activities, this finding is at odds with the rhetoric and clinical guidance suggesting the use NPIs for the management of these behaviours (Banerjee, 2009; NICE and SCIE, 2006, revised 2012).

Staff approaches

The findings showed that staff approaches were important strategies, sometimes used as a component of the care ethos, but predominantly used informally as individual choices made by each staff member at each point of delivery. Staff approaches such as, communication techniques, PCC, distraction, trial and error, and getting to know individual resident's preferences and adapting to them accordingly all assisted staff members to manage BPSD more effectively by calming individual situations or residents. Generally, these strategies were used daily as part of good care provision, but also sometimes as specific attempts to try and prevent BPSD from occurring or escalating. CH staff appeared, in the most part, to work in a flexible manner responding to each person with BPSD slightly differently depending on their individual needs and personality. In this way informal NPIs were targeted at BPSD, but were viewed by staff as usual care and not interventions. These 'usual care' strategies are similar to the behaviour management techniques (such as distraction, communication skills and the removal of triggers) found to be amongst the interventions having the most reliable evidence for managing BPSD in the overview of systematic reviews study by Dickson et al (Dickson et al., 2012).

Some staff approaches appeared to depend greatly on the ethos and management style in the CHs. Strong, confident and supportive leadership and guidance (as shown in the findings from Mirabelle Way) appeared to empower staff with the knowledge and self-assuredness they required to be able to put residents' best interests first and, if needed, defend their actions, which could sometimes be viewed as going against social norms. Management styles reflecting a need to complete tasks and work in specific ways appeared to leave staff feeling less empowered and unable to deviate from organisational routines. Therefore, they were not confident enough to be totally adaptable to residents' needs, a strategy which could reduce BPSD and enhance the delivery of PCC. The findings show the value in strong leadership and staff empowerment.

Resident placement and segregation

The placement or segregation of residents emerged as important strategies used by staff to prevent BPSD occurring, diminish or offset the risks that BPSD could create and to reduce the impact of these behaviours on other residents and sometimes staff.

Residents were seated at separate tables, placed in different rooms or removed from communal areas to their own private spaces. Consequently, their behaviours were less likely to impact on other residents or staff.

These strategies often seemed to benefit staff members and sometimes other residents rather than the resident with BPSD themselves, who could sometimes appear to be sidelined or excluded. The findings showed that the placement of residents was not carried out maliciously, but as a way to manage BPSD in communal settings. The pressures on staff to care for multiple people with diverse needs within the constraints of their roles and the CH dynamics, while simultaneously maintaining the social equilibrium of the CH, appeared to require them to develop and use strategies that could be viewed as questionable.

The finding that resident placement and segregation were components of everyday care at two of the case study CHs indicates an inequity in some care provision based on cognitive ability or BPSD. These strategies were only identified infrequently in the literature. Restriction of movements or confining residents to certain areas, to reduce falls and make up for low staff numbers, were strategies also found in the Kutsumi et al Japanese study; the only research found to focus on the exact same subject matter as this thesis (Kutsumi et al., 2009). The findings from this thesis are similar, but extend this literature by examining the reasons these strategies were enacted in England; namely, to assist staff to reconcile their accountability for residents by reducing the impact and/or risk of BPSD in communal settings.

Surveillance

Surveillance appeared to be used as a preventative measure by staff to mitigate the likelihood of risks and impact from BPSD occurring, and as a way to monitor residents' behaviours to inform care planning. Technology in the form of alarm mats, sensors and

alarmed doors worked to alert staff of residents' movements, which enabled quicker intervention. Surveillance predominantly worked for the staff teams' benefit, to assist them to keep all residents safe and carry out their work more easily. Other residents also benefitted, since surveillance allowed staff to intervene with the resident experiencing BPSD before they could have an impact on them. The residents with BPSD experienced a loss in privacy due to care staff surveillance measures, but could have benefitted through a reduction in potential risk to themselves. The finding that close surveillance took place for some residents shows the way that safeguarding was prioritised by staff and one way in which staff members' accountability for residents was enacted.

Forced care or restraint

Forced care and forced restraint were found to be used occasionally as strategies to manage BPSD posing an immediate risk or to provide necessary assistance to residents who were resisting care. If used, it appeared that the minimum force was usually taken to quickly manage the situation. Forced care worked to complete perceived outstanding and essential care tasks. Forced restraint was employed to prevent or stop an imminent risk to the resident or others, albeit by perhaps creating another. The safeguarding/autonomy balance was a difficult aspect of the care workers' jobs, with judgements of whether to intervene with forced restraint often being made by individual care staff in the moment. Decisions over the forced care/neglect balance were usually less instant and determined in pairs, or within the staff team, before any action was taken. Since staff members were accountable for residents' welfare, forced care or restraint worked to help them keep the individuals they were responsible for in a safe or properly cared for state. These strategies were unpleasant for residents at the time of use, but also worked to safeguard them. The findings that forced care and restraint were used in CHs emphasises the difficult nature of the care worker role; balancing safeguarding against allowing residents autonomy or providing proper care against a fear of being neglectful were very complex issues.

Moving residents on from the care home

Moving residents on to other care providers due to difficulties managing BPSD was a formal strategy found to be used only in the non-specialist, residential, mixed dementia and non-dementia home; Bullace View. Moving residents on happened if the home felt they could not meet the individual's needs or if the BPSD were perceived as being too disruptive by causing risks or impacting on others. Moving residents on occurred only after a period of trial and error with different strategies such as, changing bedrooms, reviewing and trying different medications, and resident placement. The moving of residents to a new home was usually instigated by the CH and became the responsibility of the resident's relatives. The strategy worked to help the CH staff by removing residents who were perceived as difficult from the home, but also helped the resident in the long term, since hopefully after the disruption of the move they would become settled in a more appropriate place for their needs.

The other three case study CHs were regularly recipients of residents from other homes who had moved them on. Occasionally these case study CHs had to move residents on, but this appeared to be due to other factors than BPSD such as, not being able to meet nursing care needs or a section taking place.

3) What resources and sources of support are available to assist CH staff to cope with BPSD?

a) How are they used?

Resources and support

The findings showed that multiple resources and sources of support were available to assist CH staff to manage BPSD. People appeared to be a major resource. High, or adequate, staffing levels, particularly of care staff and activity workers helped in the management of BPSD by providing residents with stimulation and good care, which therefore, reduced instances of BPSD occurring or worked to stop them escalating. Shifts which were short staffed appeared to be more hectic and stressful for the care workers, making it harder for them to manage BPSD effectively. Family members and visitors to the homes were also valuable resources, particularly those who were at the

CHs regularly, since they often took on tasks such as assisting their relative with a meal.

Some of the resources and support CHs received seemed to depend on the ownership of individual homes. In this study the independently owned homes appeared to be less supported than those owned by larger voluntary organisations. Large organisations had frameworks, guidelines and structures for CH managers to implement, which were lacking in the smaller scale businesses. They also had a staff structure above the CH managers which could be called on for support. The owner/manager in the sample appeared to have the least support; with additional responsibilities to contend with such as, for the production and upkeep of policies and procedures. Funding for residents could be variable depending on the source of the money, often with privately funded residents or those receiving NHS Continuing Healthcare funding paying more than those funded by Social Services. The fees residents' paid were an obvious key resource, since, particularly in the independent homes, they directly affected the budget available to the CHs.

Other sources of support and resources came from external practitioners who acted as gatekeepers for medications and biomedical treatments. General practitioners, the MH team and crisis team all had a role in supporting CHs to manage BPSD. Generally, when CH staff sought help from these professionals they were seeking pharmacological help. Often, unless the GP could help or there was an urgent crisis warranting the crisis team, CH staff had a long period of waiting before they received specialised assistance from the MH team.

Multiple other CH dynamics assisted in supporting the CH staff to manage BPSD or had capacity to positively impact on the overall situations in CHs. These included the CH environment, CHs admission criteria, staff team characteristics, knowledge, experience and training of the staff team, ownership and management styles, and the role blurring of staff.

4) What is the prevalence antipsychotic medication use in CHs?

The survey findings showed that approximately 12% of all residents, regardless of diagnosis, were reported by CH managers to be prescribed at least one antipsychotic medication. The data showed that 4% of these represented PRN prescriptions. The findings obtained from medication mapping indicated that antipsychotic medications were not used for residents with BPSD to the extent that antidepressant and the antiepileptic medication sodium valproate were.

Unexpected findings

The findings surrounding risk, impact and difficulties delivering PCC have a vital role in explaining several of the motivations for the less socially acceptable strategies used in CHs to manage BPSD. For example, the examination of the use of forceful restraints was greatly illuminated by discussing the rationales for this action; risk and impact on others. Risk and impact will now be discussed. The problematisation of the delivery of PCC is considered under the heading 'Theoretical contribution'.

Risk and Impact on others

The foremost issues CH staff encountered in the management of BPSD appeared to be the risk that they posed and the impact they could have on other residents or staff rather than the behaviours themselves. Currently, strategies such as, distraction, PCC, segregation, resident placement, surveillance, PRN medications, non-PCC and forced care are sometimes being used as responses to these situations.

A lot of the strategies used to manage the risks and impacts stemming from BPSD in CHs are would not be endorsed by best practice guidance. The concern is that if socially questionable strategies become accepted in practice the next step may be a more unacceptable abusive strategy. For example, if segregation becomes an accepted practice in CHs, at what point may it lead to neglect? However, what else can staff do to keep the social equilibrium in CH settings if a resident is persistently calling out? Additionally, care staff receive mandatory safeguarding training and are aware that they are using, what could be construed as, negative practice. This could create uncomfortable inner conflicts for staff who have limited alternative options to draw on in the management of these kinds of behaviour. The reduction in antipsychotic

medications for BPSD could have unintended consequences; less efficacious or sedative effects on residents may mean that socially questionable strategies are used more frequently.

Although strategies to prevent BPSD occurring and reduce them escalating are important, strategies, guidance, or training assisting staff to better mitigate risks and more easily reduce the impact of behaviours in communal settings, when they do occur, may be another valid area for attention. The rhetoric to reduce antipsychotic use and use NPIs instead as first line treatments for BPSD does not address these issues. The difficulties arising from the communal nature of CH settings have been ignored by most policy and guidance. However, one report has highlighted the difficulties CH staff can face balancing risks and the rights and freedom of all residents (Owen & Meyer, 2009). The findings from the current study extend these findings by examining further how these issues are resolved day-to-day in CHs in relation to BPSD.

Theoretical contribution: The delivery of person centred care problematised

The findings from the case study phase identified challenges that hinder the implementation of PCC in certain circumstances within CH settings. Recognising the difficult situations that front line care staff have to negotiate is important to enable consideration of how PCC should translate into practice settings. Over recent years PCC has dominated the best practice discourse and has become synonymous with good quality care and being 'politically correct' (Brooker, 2007); if it is not always possible to provide it CH staff may be under undue pressure to provide it.

The findings have examined the problems inherent in delivering PCC in CHs from a care worker perspective. The complex communal nature of CHs makes it impossible for staff to value, empathise with, and tailor care and interactions to each individual resident at all times for example, when there are competing needs such as conflicts between residents, or if there are imminent risks to other residents. Priorities for staff members change and in the moment can often be to mitigate situations of risk or reduce the impact of behaviours in order to protect residents or staff. Connecting with

the person as an individual and valuing their rights may not always be possible to promote at that time when upholding more basic needs may need to be the priority (see Maslow's hierarchy of needs (Maslow, 1943)). Consequently, there is a tension between PCC and community centred care. Without one-to-one care and spacious environments this tension is hard to overcome. These fundamental difficulties make providing many elements of the VIPS Framework (Valuing people, providing Individualised care, recognising the Personal perspectives of PWD and generating supportive Social environments (Brooker, 2007)) at these times problematic. Perhaps Nolan's concept of relationship centred care is a better fit for the findings in this study, since the Senses Framework values the security of the whole CH community (Nolan et al., 2004). Those conceptualising PCC and promoting its endorsement in practice need to acknowledge these limitations and make expectations of the approach more relevant and feasible for practice, thereby reducing pressure on care staff.

The argument here is not against the delivery of PCC as a notion, which can be very beneficial to residents, particularly to those experiencing BPSD, but to highlight the problematic nature of delivering the 'ideal' in CHs and the impossibility of it occurring at all times. By challenging the misleading prospect of delivering a wholly PCC approach in communal settings and identifying problem areas it is hoped that expectations on care staff to delivery of this approach can become more realistic. Currently staff could feel inadequate for failing to consistently achieve the 'ideal'. A search for suitable ways to alleviate detrimental organisational dynamics and to implement this approach more easily in difficult practice situations would be useful.

The staff team's duties to care for and be accountable for all residents meant that, at times, some residents had to make concessions to others' wishes or staff had to intervene into a situation in a way a resident would not want. These findings have led to a questioning of whether a wholly PCC approach would be a reflection of any other aspect of society or, indeed, the best way to maintain a residents personhood. That residents should suddenly be able to orchestrate things exactly as they would like them endorses the misleading notion that people get to determine their own wishes and enact all their choices throughout their lives, outside of care settings, and when they are living independently. This notion, taken to its extreme, shows PCC to be at

odds with the usual ups and downs of everyday life where give and take is needed and doing things your own way not always possible. Therefore, the finding that PCC was delivered by staff, but continuously, perhaps, reflects a usual existence.

Due to the limited size and diverse sample the case study results cannot be generalised however, some tentative theories can be generated, which will have relevance for the wider field of study (Yin, 2003). In this way, this thesis has contributed to the debates surrounding PCC by challenging the plausibility of delivering this individualised approach consistently when caring for PWD in communal settings. This critique of PCC from the data found when exploring front line care worker' experiences is an important contribution to the current literature. This is particularly so, since the findings challenge the assumption that PCC is the priority of care staff at all times. The identification of the circumstances that challenge the delivery of PCC, and perhaps make care staff use socially questionable practices, is important to add to debates about translating the PCC 'ideal' into practice and how potentially problematic practices come into use.

Methodological findings

The findings from the postal survey and case study phases did not match completely. Whereas, both methods found a lower than expected use of antipsychotic medications in CHs, they had divergent findings in relation to the use of NPIs. The survey questionnaire design was able to obtain results that portrayed the NPIs used across a wide range of CHs. However, the standardised design of the questionnaire meant that the findings could not determine the nature of or underlying reasons for using NPIs. The conclusion from this phase was that CHs were using a wide range of NPIs to manage BPSD. In contrast to the survey phase, the limited sample for the case studies could not gain information from a wide range of sources, but managed to elicit nuanced, in-depth data about NPI use in a small number of CHs. The conclusion from this phase was that formal NPIs were predominantly used as activities for all residents and not targeted at managing BPSD. The difference between the findings from each method in regard to the use of NPIs is an interesting finding in itself and reflects the way that methods used can influence the results of a study. The divergent findings

illustrate the benefit of a pragmatic approach and a mixed methods design, where a more comprehensive overall picture can be built up as the different types of findings converge. Therefore, the overall conclusion that CHs may use multiple NPIs (as the survey data found), but they are likely to be predominantly used and viewed as activities instead of intended interventions for behaviour (as the case study data found) has benefitted from both approaches. In this way the pragmatic position, situated outside of philosophical stances, allows differential data to be assessed and the value of each method to be recognised.

Using the Framework approach for data analysis

The use of the Framework approach (outlined in Chapter 5, page 127) to analyse the large amount of qualitative data generated by this study generally worked well. The process during the initial indexing and charting stages was laborious because the whole dataset had to be read through and categorised twice; consequently, at the time, the analysis appeared to be slow to get going. In retrospect this was a necessary aspect of building a transparent audit trail for the analysis and a deep and prolonged engagement with the data was essential to fully understand the findings the study had generated. At the end of the process I was left with a useful resource where: source documents or sections of text could be found easily; I could assess, compare and contrast the evidence within or across sites, methods or participants; the analysis procedure was transparent; an audit trail was apparent, and the construction of the charts enabled an easier writing up of the results. Overall, for this particular study the Framework approach worked well. It allowed data sourced from different cases, methods and participants to be grouped in the same way alongside each other, which worked to provide main findings from across the whole study; while also allowing these different data to be isolated enabling comparisons between them. However, when compared to analysing qualitative data by coding them thematically with the use of NVivo the Framework approach required, in the beginning, a lengthier process to get started.

Triangulation

By charting the data sourced from different methods alongside each other under the same index categories the Framework approach aided triangulation. Although data derived from different methods were analysed in the same way, the different sources could still be identified separately. Analysing interview and observation data in the same index meant that each method contributed to a more rounded and comprehensive examination of the issues or themes under study. This enabled the corroboration of findings within and between methods and comparisons to be made between what participants were saying and what they were seen to be doing. The triangulation of different sources in this study was invaluable, since it enabled the accuracy of the data to be checked; enhanced the understanding of the index themes, and brought credibility to the findings (Creswell, 2003). In the main, convergence was found across the methods on many issues. Although, the triangulation of methods greatly enhanced this study's findings, using different data collection methods made the study more labour intensive and time consuming.

Contribution to the wider field of knowledge

The scoping review of the literature in relation to the management of BPSD in CHs (see chapter 2) found that there was a policy drive to reduce the use of antipsychotic medications to manage BPSD and that NPIs were recommended as first line treatments instead. There was a lack of evidence about the prevalence of antipsychotic use in CHs. There was also unconvincing or mixed evidence for many NPIs due to poor quality studies, inconsistency across studies or lack of available evidence. There was most evidence for the effectiveness of caregiver education, training and support, and behaviour management techniques (such as, distraction, an increase in pleasant events, communication skills, and removal of triggers) delivered by staff (Dickson et al., 2012). Although a lot of research is being conducted looking into the effectiveness of NPIs for BPSD, there were very few studies exploring the usual day-to-day management of BPSD, particularly in CH settings. The literature generally took a top down view by looking at the efficacy of interventions for BPSD, but often did

not fully considering the complexity of how these behaviours manifest in CH settings and where the main issues lie for CH staff.

Therefore, this study has added to current knowledge about the management of BPSD by exploring and examining day-to-day front line practices in CHs. The findings from this research have started to fill the some of the gaps identified in the scoping review. The postal survey provided the approximate use of antipsychotics in CHs in the East of England and the case studies examined which strategies were being used by CH staff and how they were used. Therefore, this thesis adds to the existing literature by providing a bottom up view of what is happening on the front line in CHs to manage BPSD. The findings confirm Banerjee's (2009) assertion that a dynamic change in the approach to dementia care and in provisions will be needed to successfully incorporate NPIs into care practices. The findings extend knowledge by providing a detailed analysis of current practices of managing BPSD, and how and why they emerge. This knowledge can work to inform the development of best practice to incorporate NPIs effectively into day-to-day care practices.

The literature review found that the current knowledge around the implementation of NPIs in CHs includes the identification of multiple challenges for their use (see page 50). For example, NPIs can be: costly to implement; context specific; time consuming; they can have restricted availability, and there is a lack of standardisation making them hard to replicate (Kolanowski et al., 2010; Leone et al., 2009). This study adds to this knowledge by identifying and examining other issues affecting the implementation of NPIs in CHs. For example, the findings that NPIs are predominantly not viewed, or used, as interventions to assist in the management of BPSD in CHs; activity staff can be untrained and inexperienced, and other factors such as mitigating risk sometimes take priority over delivering NPIs. In addition, the use of NPIs may be used at a global level to improve behaviour and the quality of life of all residents rather than at an individual level to assist a particular resident to manage their BPSD. These are important findings, since they illuminate the difficulties in practically implementing NPIs in CHs and show a disparity between the policy rhetoric and practice.

The dichotomy between rhetoric and practice

The findings from this study in regard to the use of NPIs in CHs are in sharp contrast to the rhetoric surrounding this issue. The policy and guidance rhetoric is that NPIs should be used as first resorts in the management of BPSD. However, this study has found that in practice this is generally not happening. There are multiple issues which prevent NPIs being used as first line interventions. Staff members were found not to view NPIs as interventions to manage or reduce BPSD, but as activities to improve the daily life of residents. Untrained or/and inexperienced staff or volunteers are often the people left with the responsibility of delivering or providing activities. When used, activities are often aimed at the whole CH community and are not individualised. There can also be a lack of resources in CHs. For example, sometimes there are staff shortages, which mean staff members can be redistributed away from activities to care or kitchen work. The dichotomy between policy and practice in this area is concerning, since the use of antipsychotic medications appears to be reducing, but the infrastructures to allow NPIs to become integral aspects of practice are not yet in place. This could be leaving CH staff and residents experiencing BPSD in difficult situations. Policy makers may need to look into: mandatory training for activity workers; issuing more specific guidance on how to decide which NPIs to use in CHs and how to implement them successfully, and the funding of NPIs so CHs can afford to implement them (since antipsychotic medications are funded through health and NPIs by the CHs themselves). Questions arise about whether policy directives have been doing enough to support CHs to cope with the recommended reduction in antipsychotic use and consequences of this action.

Hindsight: if I conducted the study now

Looking back on the research approach, design and processes, there are a few aspects I would change if I were to explore this area again. During the survey phase I would have employed a second follow up stage to increase the response rate. Additionally, I would have explored the option of looking at pharmacy or GP records to gain prevalence rates of antipsychotic use in CHs. In an ideal situation, during the case study phase I would have included resident and family member interviews to gain

other perspectives of the management of BPSD. However, the boundary of the study had to be drawn to make the study feasible to complete in the time available.

Additionally, in retrospect, the scope for the case study phase was slightly too large. Encompassing CH dynamics, medication use, the use of NPIs, the use of other care strategies and emerging themes during the fieldwork gave rise to a large dataset. Although depth in the data was gained, the findings chapters could have examined some aspects in more detail than the space allowed. The range of features under study also translated into a long thesis length. Therefore, this study could have benefitted from a smaller scope going into the case study phase. Nevertheless, the data obtained and generated provided evidence about multiple aspects of the management of BPSD; this was important for an exploratory study and allowed the complexities in this area to emerge.

Areas of interest for future research

This study has many findings, some of which are of interest for future research. The finding that sodium valproate was prescribed for residents with dementia needs further exploration. More data on residents' prescriptions, along with an examination of prescribers' views of the use sodium valproate for BPSD; the pressures from policy, CH staff or family members; decision making processes, and influencing factors could work to explore this finding further. If the uses of sodium valproate, and/or a greater reliance on antidepressant medications, are unintended consequences of the reduction in antipsychotic medications for BPSD, it poses a concern for policy makers, residents, relatives and prescribers and needs further investigation.

At present there is insufficient evidence for many NPIs. More research on the effectiveness of NPIs is needed to enable an evidence base solid enough for CH staff to be confident in their choices to invest in them and consequently, implement them in their homes to assist in the management of BPSD. Finding cost effective ways of incorporating these interventions in CHs is also a priority.

Many issues that caused difficulties for staff in the case study CHs stemmed from the risk and impact posed by BPSD. These issues were major causes of staff stress, which

also often forced staff to intervene or act in a non-PCC way; developing and implementing socially questionable strategies. Therefore, there is a need to examine this area further. Identifying and trialling more acceptable strategies or orchestrating and evaluating positive organisational dynamics that assist staff to cope with the issues emerging through risk and impact in CHs could be one idea. The stark findings that there are: inequalities in care delivery within CHs between residents with dementia or BPSD and those without, difficulties with implementing a PCC approach, and issues that infringe on residents human rights are also important areas in need of future development.

Summary

This chapter has brought together the two phases of this study and set out how the research questions have been answered. A discussion of the main aspects of the study has taken place. The concluding chapter focuses on the most important findings from this study. Methodological triangulation, a critical evaluation of the study and the implications for practice are also examined.

Chapter 11: Conclusions

Introduction

This research aimed to explore the management of BPSD in CHs. The findings have provided insight into the strategies and daily practices used to manage these behaviours. By doing so, the issues and tensions that play out on the front line when caring for people experiencing BPSD in these settings have also been examined. A pragmatic approach was used, which incorporated a mixed methods design involving a postal survey followed by four case studies. The case studies incorporated interviews with care home staff, observations, and the medication mapping of a number of residents' MARs. The data from the two sequential phases were analysed and discussed separately before the findings were brought together and examined in relation to the research questions (see Chapter 10). The implications of those findings, an evaluation of this study, and what this study adds to knowledge about the management of BPSD in CHs will now be set out.

Methodological triangulation

The strength in using a pragmatic approach to this study was that different sources of data converged to illuminate the management of BPSD in CHs. Knowledge was gained from: a vast number of CH managers in the survey phase, CQC inspection reports, and in the case study phase from interviews with a variety of CH staff, researcher observations, and directly from MARs. The data obtained and generated have provided multiple findings, which have been useful to explore different aspects of the management of BPSD in CHs. These data have, together, provided a more comprehensive picture of this issue than would have been possible using only qualitative or quantitative research methods or a single method study. The pragmatic, mixed methods approach was particularly apt to explore this area of study, since the management of BPSD in CHs encompasses multiple aspects. Therefore, a main strength of this study was the variety of knowledge produced to shed light on this under-explored area.

The potential limitation of a pragmatic, mixed methods approach was that the multipronged exploration of the management of BPSD would provide many findings, but that they would be lacking in thoroughness or depth. Although it is clear that some of this study's results could benefit from further data to augment the findings (such as, a larger sample for the medication mapping), the aim of the case study phase was to explore the management of BPSD in a small, but focused sample of CHs. As an exploratory study, the data gained was adequate to illuminate this area, address the research questions, examine issues and tensions, raise further questions, and identify areas for future research. Using one method could have led to a larger dataset for that particular mode of data collection, yet not uncover the large number of issues or aspects that using mixed methods allowed. Consequently, the research questions guiding this study would not have been answered sufficiently. However, due to the design, this study has multiple diverse findings making the prospect of an overarching conclusion encompassing every aspect difficult.

In general, the triangulation of data from different sources added value to this study. The findings from different methods complimented each other and enabled a more comprehensive examination of the management of BPSD in CHs to take place. This worked to enhance the findings by drawing on more perspectives to add to the understanding of the different aspects under study. This, in turn, increased the credibility of the findings. Very few issues in relation to triangulation emerged. This was, in part, due to keeping the integrity of each method used by adhering to each underlying philosophy. The only difficulty with triangulation encountered in this study was reaching overall conclusions from contradictory findings. For example, when the survey and case study findings were compared and found to portray slightly different pictures of practice, drawing on the most likely scenario from these findings was a complex process. This was overcome by considering the strengths and limitations of each method used to gain the differing findings, thereby viewing each dataset through the lens of the method generating it to determine the meaning of those data.

Critical evaluation

My experience as a care worker appeared to be of great assistance during the case study fieldwork stage of the research. Although it is inevitable that I have influenced this study from the topic to the design, data collection, analysis and interpretations, there is also a chance that the findings are biased by my care work experience and underlying assumptions. The risk of bias has in some way been alleviated by the continued intellectual counsel and discussions with my academic supervisors, but the subjectivity from my assumptions, perceptions and beliefs is still likely to be present. The limitations of the postal survey phase (such as the reliance on the self-reporting of CH managers, subjectivity in the interpretations of the questions, and the response rate) are set out in Chapter 4. However, the strength of this method was gaining information from a wide range of CHs on the management of BPSD.

During the case study phase the relationships and trust that were built up appeared to enable the generation of in-depth and candid data. My insider status, in relation to care work, appeared to counteract my outsider status from each CH after the initial days at the case study sites. Participants would take comfort from my insider knowledge of the profession and appeared to feel able to trust me and open up to me. I feel certain that some of the data I obtained would not have been available to me if I had not have had experience of care work. Simultaneously, my relatively new role as a researcher allowed me to assess and consider familiar aspects of care in completely new ways. The mix of care worker and researcher appeared to be beneficial during both, the data collection and analysis stages of the research, since I had a general underlying understanding of issues, but used an altered lens to examine them. It is possible that my observer as participant role reduced staff pressure, affected the social milieu, and made situations unnatural, consequently invalidating the observation data. This risk was offset, in part, by my role not including tasks which make up a large part of the care worker role such as, personal care and manual handling so not registering on staff stress levels. The fieldwork stage at each CH also took place over an extended period of time with a noticeable relaxation from staff about my presence occurring.

The two phase design of the study with the survey responses creating the sampling pool for the potential case study CHs meant that only those CHs who had responded were potential homes for the fieldwork. Additionally, CH negotiations could not be commenced until the survey responses had arrived. This impacted on the timescale of the study, since it took more time than had been anticipated to send, receive and analyse the survey returns and create the sampling pool before case study negotiations could begin. These negotiations also took longer than expected and therefore reduced the time available to conduct the case studies.

The study was conducted in the East of England. Although there were a small number of people in the sample from differing cultural groups, generally the findings only reflect an English, white population, which could limit their transferability. Additionally, due to the exploratory nature of the study and wide scope of investigation, the literature relevant to many findings was not explored in the scoping review. This makes it impossible to assess the uniqueness of some aspects of the data.

Conflict between policy and practice

The main finding from this research was that there is some conflict between policy and practice in regard to the management of BPSD in CHs. Namely, NPIs are predominantly not viewed, or being used, as interventions to manage BPSD in CHs, but as activities aimed at all residents to improve daily living and quality of life. This is an important finding, since if policy and guidance is not fully applied to practice on the front line of dementia care it needs to be known and the reasons for this understood. Only then can measures be put into place to assist with the implementation of the guidance. The findings from this study add a much needed practice perspective to the debates around the best way to manage BPSD in care settings. The issues identified need to be overcome to allow the successful incorporation of NPIs into practice on a day-to-day level; enabling them to be used on the front line as and when needed. The lack of policy support for CHs has meant care staff have had to think on their feet in regard to the strategies they use to manage BPSD and this has led to some questionable strategies being implemented. Policy makers need to consider issues such as: how NPIs are financed; staff training in the utility and delivery of NPIs, and which particular NPIs

have solid evidence for their use. Perhaps then CHs can better implement the guidance and NPIs will become the first line resorts for the management of BPSD that they are recommended to be in these and other settings.

Implications for practice

Perhaps the most fitting end point for pragmatic research is to elicit some implications for practice from the findings, thus making the research useful to the field of study in a practical way. Although the sample size of the case studies was limited, some emergent themes can be transferable and have value in the form of practice implementations. There are three key messages from this exploratory study for practice:

- Due to the disparity between rhetoric and practice, to assist in a preventative approach there is a need for some amelioration to the way NPIs are used in CHs to bridge the gap. Perhaps a new role for someone with the necessary skills to take on the responsibility for providing and targeting evidenced based NPIs at residents experiencing BPSD in CHs would be beneficial, since the findings showed that this was not happening. Alternatively, activity staff could be better informed about NPIs and trained to use them, so they are aware of how they could benefit residents experiencing BPSD.
- Routine medication reviews a few weeks after residents' admissions to CHs could assist CH staff and prescribers in finding the correct balance for each individual. In this way, medications prescribed before admission could be reviewed and any BPSD still present a short while after new residents' had settled in could be assessed and addressed. Education for medication administering staff, especially in relation to PRN administration or omissions of regular doses to help them achieve a unified approach, may also be beneficial.
- Thought should be given to whether communal settings housing residents both, with and without dementia is a beneficial option for all concerned. Initially this recommendation could be viewed as supporting the segregation of residents with BPSD from others. However, the findings showed that the inequity of care at the point of delivery and exclusion or segregation through

the placement of residents was often due to staff prioritising residents with good cognitive abilities over those with less. Additionally, in contrast to the CHs looking after residents with mixed profiles, the specialist case study CHs had staff members who were less afraid of residents with BPSD and more accepting of behaviours. At the very least there should be a spacious environment with separate areas: to enable residents with different needs to have them met more easily; to reduce the need for staff to have to intervene and appease situations or remove individuals from their locations to maintain the peace, and to allow space for those residents who do become very agitated and/or aggressive.

Contribution to knowledge

This study explored the strategies and practices used to manage BPSD in CHs. The main finding was that the practice in CHs does not match the rhetoric of profuse antipsychotic use in need of reduction and the use of NPIs as first line treatments for BPSD. Instead, multiple diverse strategies are used in CHs to manage BPSD. Antipsychotic medications appear not to be used profusely (12% of CH residents reported to be prescribed at least one), with antidepressants and the antiepileptic, sodium valproate, appearing to be used in CHs more than antipsychotic agents. NPIs are predominantly viewed as, and targeted at, improving the wellbeing of all residents and therefore, only indirectly and unintentionally helping in the management of BPSD. Many strategies used by CH staff were implicit and much more likely to be perceived by them as part of usual care practices rather than ways to manage BPSD. This is an important finding and shows there is a need for further work to implement NPIs and practices into CH settings to target the prevention or management of BPSD. Person centred care was found to help in the management of BPSD by reducing instances of behaviours occurring or by offsetting their escalation. However, difficulties which hampered the delivery of PCC and made this approach impossible to provide consistently emerged from the data. Therefore, a key theoretical contribution from

this study is the problematisation of PCC and its delivery in communal settings from a front line care worker perspective.

The thesis has shown how CH staff are grappling with difficult issues on a daily basis within the constraints of their roles and organisations, for example, trying to keep all residents safe and provide adequate care in complex communal settings. The needs for CH staff managing BPSD to protect all residents under their care; placate situations, and keep the peace were salient issues in the data, but are under researched and explored in relation to the management of BPSD. Care staff accountability for residents appeared to cause tensions when the impacts of behaviour or risks were encountered; socially questionable strategies (surveillance, placement, segregation, secure areas and forced restraint) were sometimes used to manage these issues. The rhetoric reflects a general unawareness of these strategies used in CHs to cope with the risk and impact of BPSD therefore, appearing disconnected to the reality of the situations in CHs.

These strategies require careful consideration, since they are not used maliciously, but as a way to cope with the complex actuality in CHs. However, if difficult situations can lead to the development, implementation and acceptance of socially questionable strategies this raises concerns about the point where abuse may become accepted too. The use of formal NPIs in CHs could, as a preventative measure, have scope to reduce instances of BPSD occurring. However, in their current forms they are not workable to assist staff in managing many of the difficult practicalities posed by risk and impact when BPSD do occur such as, when a resident is absconding or aggressive to another resident. Identifying and starting to inspect issues of risk, impact, and staff accountability as rationales for using socially questionable strategies to manage BPSD in CHs is important to develop understanding of how problematic practices can creep into practice.

The findings about the state of affairs that currently exist in CHs are important, since they challenge the dominant positive view of managing BPSD without the use of antipsychotic medications. If the unintended consequences of a reduction in these medications include, for example: an increase in staff members feeling the need to employ resident segregation, placement or forced care as a strategy; or to introduce other alternative off label medications (such as, sodium valproate), which have similar

inherent risks to those with antipsychotic medications, it is worth questioning whether this recent action is having the beneficial effect it was planned to.

By utilising a pragmatic, mixed method approach incorporating two phases a range of findings in this complex area have been identified and examined. These findings are important in the sense that they start to unpick the complexities faced when managing BPSD in CH settings. The study has demonstrated that CH staff are using multiple methods to assist them to manage BPSD. The emergence of unexpected findings reflects the design of this exploratory study, employing methods which allowed the researcher to follow interesting aspects of the data that arose. This cross-disciplinary view, coupled with diverse forms of evidence derived from different methods has generated dissimilar data, which when considered collectively provides a comprehensive overview of the management of BPSD in CHs.

The original contributions to knowledge from this study are:

- The identification and examination of the types of decision-making and strategies that care staff have developed, employed or adopted to manage BPSD within the contextual constraints of their work places
- The problematisation of the consistent delivery of PCC in communal settings where care workers must constantly negotiate competing demands, organisational constraints, and the need to mitigate the risk and impact of behaviours.
- An indication of the use of psychotropic medications for PWD in CHs
- The identification of a gap between rhetoric and practice with formal NPIs used, and viewed, predominantly as activities in CH settings and not employed to specifically reduce or manage BPSD

References

- Adams, T. (1996). Kitwood's approach to dementia and dementia care: a critical but appreciative review. *Journal of Advanced Nursing*, 23(5), 948-53.
- Adler, P. A. & Adler, P. (1987). *Membership Roles in Field Research*, London: SAGE Publications Ltd.
- All-Party Parliamentary Group on Dementia. (2008). *Always a last resort: inquiry into the prescription of antipsychotic drugs to people with dementia in care homes*. Alzheimer's Society, London.
- Allred, D. P., Petty, D. R., Bowie, P., Zermansky, A. G. & Raynor, D. K. (2007). Antipsychotic prescribing patterns in care homes and relationship with dementia. *Psychiatric Bulletin*, 31(9), 329-332.
- Alzheimer's Disease International. (2009). *World Alzheimer Report*. Alzheimer's Disease International, London.
- Alzheimer's Society. (2007). *Home from Home: A report highlighting opportunities for improving standards of dementia care in care homes*. Alzheimer's Society, London.
- Alzheimer's Society. (2008). *The Dementia Tax: Charging people with dementia for inadequate care: The evidence for change*. Alzheimer's Society, London.
- Alzheimer's Society. (2013). *Charging for care* [Online]. London: Alzheimer's Society. Available: http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=1069 [Accessed October 2013].
- Arksey, H. & O'Malley, L. (2005). Scoping studies: towards a methodological framework. *International Journal of Social Research Methodology*, 8(1), 19-32.
- Astrazeneca. (2005). *Study Finds Seroquel Effective and Well Tolerated* [Online]. Astrazeneca. Available: <http://www.astrazeneca.com/Media/Press-releases/Article/20050304--STUDY-FINDS-SEROQUEL-EFFECTIVE-AND-WELL-TOLERATED> [Accessed May 2011].
- Atkinson, P. & Hammersley, M. (1994). Ethnography and participant observation. In: Denzin, N. K. & Lincoln, Y. S. (eds.) *Handbook of qualitative research*. Thousand Oaks: SAGE Publications Ltd.
- Ayalon, L., Arean, P., Bornfeld, H. & Beard, R. (2009). Long term care staff beliefs about evidence based practices for the management of dementia and agitation. *International Journal of Geriatric Psychiatry*, 24(2), 118-24.
- Ayalon, L., Gum, A. M., Feliciano, L. & Arean, P. A. (2006). Effectiveness of nonpharmacological interventions for the management of neuropsychiatric symptoms in patients with dementia: a systematic review. *Archives of Internal Medicine*, 166(20), 2182-2188.
- Backhouse, T., Killeth, A., Penhale, B., Burns, D. & Gray, R. (2013). Behavioural and psychological symptoms of dementia and their management in care homes within the East of England: a postal survey. *Aging & Mental Health*, 1-7.
- Baert, P. (2005). *Philosophy of the Social Sciences: Towards Pragmatism*, Cambridge: Polity Press.
- Bailey, C. A. (2007). *A Guide to Qualitative Field Research*, London: SAGE Publications Ltd.
- Baker, J. A., Keady, J., Hardman, P., Kay, J., Jones, L. & Jolley, D. (2010). Psychotropic PRN use among older people's inpatient mental health services. *Journal of Psychiatric & Mental Health Nursing*, 17(5), 463-8.
- Baker, J. A., Lovell, K. & Harris, N. (2008). A best-evidence synthesis review of the administration of psychotropic pro re nata (PRN) medication in in-patient mental health settings. *Journal of Clinical Nursing*, 17(9), 1122-1131.
- Ballard, C., Corbett, A., Chitramohan, R. & Aarsland, D. (2009a). Management of agitation and aggression associated with Alzheimer's disease: controversies and possible solutions. *Current Opinion in Psychiatry*, 22(6), 532-540.

- Ballard, C., Creese, B., Corbett, A. & Aarsland, D. (2011). Atypical antipsychotics for the treatment of behavioral and psychological symptoms in dementia, with a particular focus on longer term outcomes and mortality. *Expert Opinion on Drug Safety*, 10(1), 35-43.
- Ballard, C., Hanney, M. L., Theodoulou, M., Douglas, S., McShane, R., Kossakowski, K., Gill, R., Juszczak, E., Yu, L.-M. & Jacoby, R. (2009b). The dementia antipsychotic withdrawal trial (DART-AD): long-term follow-up of a randomised placebo-controlled trial. *Lancet Neurology*, 8(2), 151-157.
- Ballard, C. & Howard, R. (2006). Neuroleptic drugs in dementia: benefits and harm. *Nature Reviews Neuroscience*, 7(6), 492-500.
- Ballard, C., Lana, M. M., Theodoulou, M., Douglas, S., McShane, R., Jacoby, R., Kossakowski, K., Yu, L.-M. & Juszczak, E. (2008). A randomised, blinded, placebo-controlled trial in dementia patients continuing or stopping neuroleptics (the DART-AD trial). *PLoS Medicine / Public Library of Science*, 5(4), e76.
- Ballard, C., Margallo-Lana, M., Juszczak, E., Douglas, S., Swann, A., Thomas, A., O'Brien, J., Everratt, A., Sadler, S., Maddison, C., Lee, L., Bannister, C., Elvish, R. & Jacoby, R. (2005). Quetiapine and rivastigmine and cognitive decline in Alzheimer's disease: randomised double blind placebo controlled trial. *British Medical Journal*, 330(7496), 874-879.
- Ballard, C., O'Brien, J., James, I. & Swann, A. (2001a). *Dementia: management of behavioural and psychological symptoms*, Oxford: Oxford University press.
- Ballard, C., Powell, I., James, I., Reichelt, K., Myint, P., Potkins, D., Bannister, C., Lana, M., Howard, R., O'Brien, J., Swann, A., Robinson, D., Shrimanker, J. & Barber, R. (2002). Can psychiatric liaison reduce neuroleptic use and reduce health service utilization for dementia patients residing in care facilities. *International Journal of Geriatric Psychiatry*, 17(2), 140-145.
- Ballard, C. G., Gauthier, S., Cummings, J. L., Brodaty, H., Grossberg, G. T., Robert, P. & Lyketsos, C. G. (2009c). Management of agitation and aggression associated with Alzheimer disease. *Nature Reviews Neurology*, 5(5), 245-255.
- Ballard, C. G., Margallo-Lana, M., Fossey, J., Reichelt, K., Myint, P., Potkins, D. & O'Brien, J. (2001b). A 1-year follow-up study of behavioral and psychological symptoms in dementia among people in care environments. *The Journal of clinical psychiatry*, 62(8), 631-636.
- Banerjee, S. (2009). *The use of antipsychotic medication for people with dementia: Time for action*. Department of Health, London.
- Banerjee, S., Hellier, J., Romer, R., Dewey, M., Knapp, M., Ballard, C., Baldwin, R., Bentham, P., Fox, C., Holmes, C., Katona, C., Livingston, G., Lawton, C., McCrae, N., Moniz-Cook, E., Murray, J., Nurock, J., Orrell, M., O'Brien, J., Poppe, M., Thomas, A., Walwyn, R., Wilson, K., Burns, A. & Lindesay, J. (2013). Study of the use of antidepressants for depression in dementia: the HTA-SADD trial – a multicentre, randomised, double-blind, placebo-controlled trial of the clinical effectiveness and cost-effectiveness of sertraline and mirtazapine. *Health Technology Assessment*, 17(7).
- Banerjee, S., Murray, J., Foley, B., Atkins, L., Schneider, J. & Mann, A. (2003). Predictors of institutionalisation in people with dementia. *Journal of Neurology, Neurosurgery & Psychiatry*, 74(9), 1315-1316.
- Banerjee, S., Smith, S. C., Lamping, D. L., Harwood, R. H., Foley, B., Smith, P., Murray, J., Prince, M., Levin, E., Mann, A. & Knapp, M. (2006). Quality of life in dementia: more than just cognition. An analysis of associations with quality of life in dementia. *Journal of Neurology, Neurosurgery & Psychiatry*, 77(2), 146-148.
- Barchester Healthcare. (2013). Available: <http://www.barchester.com> [Accessed 12.01. 2014].

- Barnett, M. J., Wehring, H. & Perry, P. J. (2007). Comparison of risk of cerebrovascular events in an elderly VA population with dementia between antipsychotic and nonantipsychotic users. *Journal of Clinical Psychopharmacology*, 27(6), 595-601.
- Barton, S., Findlay, D. & Blake, R. A. (2005). The management of inappropriate vocalisation in dementia: a hierarchical approach. *International Journal of Geriatric Psychiatry*, 20(12), 1180-1186.
- Beeri, M. S., Werner, P., Davidson, M. & Noy, S. (2002). The cost of behavioral and psychological symptoms of dementia (BPSD) in community dwelling Alzheimer's disease patients. *International Journal of Geriatric Psychiatry*, 17(5), 403-408.
- Bird, M., Llewellyn-Jones, R., Smithers, H., Andrews, C., Cameron, I., Cottee, A., Hutson, C., Jenneke, B., Kurrle, S. & Russell, B. (1998). Challenging Behaviours in Dementia: a Project at Hornsby/Ku-Ring-Gai Hospital. *Australasian Journal on Ageing*, 17(1), 10-15.
- Bird, M., Llewellyn-Jones, R. H. & Korten, A. (2009). An evaluation of the effectiveness of a case-specific approach to challenging behaviour associated with dementia. *Ageing & Mental Health*, 13(1), 73-83.
- Bird, M. & Moniz-Cook, E. (2008). Challenging behaviour in dementia: a psychosocial approach to intervention. In: Woods, B. & Clare, L. (eds.) *Handbook of the Clinical Psychology of Ageing*. 2nd ed. Chichester: John Wiley & Sons Ltd.
- Blaikie, N. (2000). *Designing Social Research*, Cambridge: Polity Press.
- Brechin, D., Murphy, G., James, I. A. & Codner, J. (2013). *Briefing Paper: Alternatives to antipsychotic medication: Psychological approaches in managing psychological and behavioural distress in people with dementia*. The British Psychological Society, Leicester.
- British National Formulary. (2011). *British National Formulary*. BMJ Group and Pharmaceutical Press.
- British National Formulary. (2013). *British National Formulary*. BMJ and Pharmaceutical Press.
- Brodaty, H. & Arasaratnam, C. (2012). Meta-analysis of nonpharmacological interventions for neuropsychiatric symptoms of dementia. *The American Journal of Psychiatry*, 169(9), 946-953.
- Brodaty, H., Draper, B., Saab, D., Low, L. F., Richards, V., Paton, H. & Lie, D. (2001). Psychosis, depression and behavioural disturbances in Sydney nursing home residents: prevalence and predictors. *International Journal of Geriatric Psychiatry*, 16(5), 504-512.
- Brodaty, H., Draper, B. M. & Low, L.-F. (2003). Behavioural and psychological symptoms of dementia: a seven-tiered model of service delivery. *The Medical Journal of Australia*, 178(5), 231-234.
- Brooker, D. (2003). What is person-centred care in dementia? *Reviews in Clinical Gerontology*, 13(03), 215-222.
- Brooker, D. (2005). Dementia Care Mapping: A Review of the Research Literature. *The Gerontologist*, 45(suppl 1), 11-18.
- Brooker, D. (2007). *Person Centred Dementia Care: Making services better*, London: Jessica Kingsley Publications.
- Bryman, A. & Burgess, R. G. (eds.) (1994). *Analyzing Qualitative Data*, Oxon: Routledge.
- Burns, A. (2009). Another nail in the coffin of the cognitive paradigm of dementia. *The British Journal of Psychiatry*, 194(3), 199-200.
- Burstow, P. (2009). *Breakthrough in ten year campaign to stop chemical cosh* [Online]. Sutton Liberal Democrats. Available: <http://paulburstow.org.uk/en/article/2009/013631/breakthrough-in-ten-year-campaign-to-stop-chemical-cosh-burstow> [Accessed 12/11/2013].
- Care Commission & Mental Welfare Commission. (2009). *Remember I'm Still Me*. Care Commission and Mental Welfare Commission for Scotland, Dundee.

- Care Quality Commission. (2011). *The Mental Capacity Act 2005 deprivation of liberty safeguards: Guidance for providers*. Care Quality Commission, London.
- Care Standards Act. (2000). *Care Standards Act 2000*. The Stationery Office, London.
- Castle, N., Ferguson-Rome, J. C. & Teresi, J. A. (2013). Elder Abuse in Residential Long-Term Care: An Update to the 2003 National Research Council Report. *Journal of Applied Gerontology*.
- Castle, N. G. & Engberg, J. (2005). Staff turnover and quality of care in nursing homes. *Medical Care*, 43(6), 616-626.
- Centre for Policy on Ageing. (2012). *A profile of residents in Bupa care homes: results from the 2012 Bupa census*. Centre for Policy on Ageing, London.
- Chambless, D. L. & Hollon, S. D. (1998). Defining empirically supported therapies. *Journal of Consulting and Clinical Psychology*, 66(1), 7-18.
- Chan, M. C., Chong, C. S., Wu, A. Y., Wong, K. C., Dunn, E. L., Tang, O. W. & Chan, W. F. (2010). Antipsychotics and risk of cerebrovascular events in treatment of behavioural and psychological symptoms of dementia in Hong Kong: a hospital-based, retrospective, cohort study. *International Journal of Geriatric Psychiatry*, 25(4), 362-370.
- Chang, E., Daly, J., Johnson, A., Harrison, K., Easterbrook, S., Bidewell, J., Stewart, H., Noel, M. & Hancock, K. (2009). Challenges for professional care of advanced dementia. *International Journal of Nursing Practice*, 15(1), 41-47.
- Charmaz, K. (2006). *Constructing Grounded Theory: A Practical Guide Through Qualitative Analysis*, London: SAGE Publications Ltd.
- Chen, Y., Briesacher, B. A., Field, T. S., Tjia, J., Lau, D. T. & Gurwitz, J. H. (2010). Unexplained variation across US nursing homes in antipsychotic prescribing rates. *Archives of Internal Medicine*, 170(1), 89-95.
- Chenoweth, L., King, M. T., Jeon, Y. H., Brodaty, H., Stein-Parbury, J., Norman, R., Haas, M. & Luscombe, G. (2009). Caring for Aged Dementia Care Resident Study (CADRES) of person-centred care, dementia-care mapping, and usual care in dementia: a cluster-randomised trial. *Lancet Neurology*, 8(4), 317-325.
- Cherryholmes, C. H. (1992). Notes on Pragmatism and Scientific Realism. *Educational Researcher*, 21(6), 13-17.
- Child, A., Clarke, A., Fox, C. & Maidment, I. (2012). A pharmacy led program to review anti-psychotic prescribing for people with dementia. *BioMed Central Psychiatry*, 12(155).
- CHMP. (2008). *Assessment Report on Conventional Antipsychotics*. European Medicines Agency (EMA), London.
- CHUMS. (2009). *Care Home Use of Medicines Study*. Department of Health,
- Cohen-Mansfield, J. (2001). Nonpharmacologic interventions for inappropriate behaviors in dementia: a review, summary, and critique. *American Journal of Geriatric Psychiatry*, 9(4), 361-381.
- Cohen-Mansfield, J., Jensen, B., Resnick, B. & Norris, M. (2012). Knowledge of and attitudes toward nonpharmacological interventions for treatment of behavior symptoms associated with dementia: A comparison of physicians, psychologists, and nurse practitioners. *The Gerontologist*, 52(1), 34-45.
- Cohen-Mansfield, J. & Mintzer, J. E. (2005). Time for Change: the role of nonpharmacological interventions in treating behavior problems in nursing home residents with dementia. *Alzheimer Disease and Associated Disorders*, 19 (1), 37-40.
- Connelly, P. J., Law, E., Angus, S. & Prentice, N. (2010). Fifteen year comparison of antipsychotic use in people with dementia within hospital and nursing home settings: sequential cross-sectional study. *International Journal of Geriatric Psychiatry*, 25(2), 160-165.

- Cooke, M. L., Moyle, W., Shum, D. H., Harrison, S. D. & Murfield, J. E. (2010). A randomized controlled trial exploring the effect of music on agitated behaviours and anxiety in older people with dementia. *Aging & Mental Health*, 14(8), 905-916.
- Coupland, C., Dhiman, P., Morriss, R., Arthur, A., Barton, G. & Hippisley-Cox, J. (2011). Antidepressant use and risk of adverse outcomes in older people: population based cohort study. *British Medical Journal*, 343.
- Creswell, J. W. (2003). *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches*, London: SAGE Publications Ltd.
- Creswell, J. W. & Plano Clark, V. L. (2011). *Designing and Conducting Mixed Methods Research*, London: SAGE Publications Ltd.
- Crotty, M. (1998). *The Foundations of Social Research: Meaning and Perspective in the Research Process*, St Leonards: Allen & Unwin.
- CSM. (2004). *Antipsychotic Drugs and Increased Stroke Risk* [Online]. Medications and Healthcare products Regulatory Agency (MHRA). Available: <http://www.mhra.gov.uk/Safetyinformation/Safetywarningsalertsandrecalls/Safetywarningsandmessagesformedicines/CON1004298> [Accessed 17.10. 2011].
- Curtis, J. & Capp, K. (2003). Administration of 'as needed' psychotropic medication: A retrospective study. *International Journal of Mental Health Nursing*, 12(3), 229-234.
- De Deyn, P. P., Carrasco, M. M., Deberdt, W., Jeandel, C., Hay, D. P., Feldman, P. D., Young, C. A., Lehman, D. L. & Breier, A. (2004). Olanzapine versus placebo in the treatment of psychosis with or without associated behavioral disturbances in patients with Alzheimer's disease. *International Journal of Geriatric Psychiatry*, 19(2), 115-126.
- De Vaus, D. A. (2002). *Surveys in Social Research*, Oxon: Routledge.
- Declercq, T., Petrovic, M., Azermai, M., Vander Stichele, R., De Sutter, A. I., van Driel, M. L. & Christiaens, T. (2013). Withdrawal versus continuation of chronic antipsychotic drugs for behavioural and psychological symptoms in older people with dementia. *Cochrane Database of Systematic Reviews*, 3.
- Dementia Action Alliance. (2011). *The right prescription: a call to action on the use of antipsychotic drugs for people with dementia*. [Online]. Dementia Action Alliance,. Available: http://www.dementiaaction.org.uk/news/article/6/the_right_prescription_a_call_to_action_on_the_use_of_antipsychotic_drugs_for_people_with_dementia [Accessed 16 June 2011].
- Dementia Care Matters. (2013). *Dementia Care Matters* [Online]. Available: www.dementiacarematters.com [Accessed 12.01. 2014].
- Denscombe, M. (2003). *The Good Research Guide: for small-scale research projects*, Maidenhead: Open University Press.
- Denzin, N. K. (1978). *The Research Act: A Theoretical Introduction to Sociological Methods*, New York: McGraw-Hill Book Company.
- Denzin, N. K. & Lincoln, Y. S. (2011). Introduction: The Discipline and Practice of Qualitative Research. In: Denzin, N. K. & Lincoln, Y. S. (eds.) *The SAGE Handbook of Qualitative Research*. London: SAGE Publications Ltd.
- Department of Health. (2010). 'Nothing Ventured, Nothing Gained': Risk Guidance for people with dementia. In: Department of Health (ed.). Crown Copyright: London.
- Deudon, A., Maubourguet, N., Gervais, X., Leone, E., Brocker, P., Carcaillon, L., Riff, S., Lavallart, B. & Robert, P. H. (2009). Non-pharmacological management of behavioural symptoms in nursing homes. *International Journal of Geriatric Psychiatry*, 24(12), 1386-1395.
- Devanand, D. P., Mintzer, J., Schultz, S. K., Andrews, H. F., Sultzer, D. L., de la Pena, D., Gupta, S., Colon, S., Schimming, C., Pelton, G. H. & Levin, B. (2012). Relapse risk after discontinuation of risperidone in Alzheimer's disease. *The New England Journal of Medicine*, 367(16), 1497-1507.

- Dewalt, K. M. & Dewalt, B. R. (2011). *Participant Observation: A Guide for Fieldworkers*, Plymouth: AltaMira Press.
- Dewing, J. (2008). Personhood and dementia: revisiting Tom Kitwood's ideas. *International Journal of Older People Nursing*, 3(1), 3-13.
- Dewing, J. (2010). Responding to agitation in people with dementia. *Nursing Older People*, 22(6), 18-25.
- Dickson, K., Lafortune, L., Kavanagh, J., Thomas, J., Mays, N. & Erens, B. (2012). *Non-drug treatments for symptoms in dementia: an overview of systematic reviews of non-pharmacological interventions in the management of neuropsychiatric symptoms and challenging behaviours in patients with dementia*. Policy Innovation Research Unit, London School of Hygiene and Tropical Medicine, London.
- Diniz, B. S., Butters, M. A., Albert, S. M., Dew, M. A. & Reynolds, C. F. (2013). Late-life depression and risk of vascular dementia and Alzheimer's disease: systematic review and meta-analysis of community-based cohort studies. *British Journal of Psychiatry*, 202(5), 329-335.
- Douglas, S., James, I. & Ballard, C. (2004). Non-pharmacological interventions in dementia. *Advances in Psychiatric Treatment*, 10(3), 171-177.
- Duffy, B., Oyebode, J. R. & Allen, J. (2009). Burnout among care staff for older adults with dementia: The role of reciprocity, self-efficacy and organizational factors. *Dementia*, 8(4), 515-541.
- Dunn, L. A., Rout, U., Carson, J. & Ritter, S. A. (1994). Occupational stress amongst care staff working in nursing homes: an empirical investigation. *Journal of Clinical Nursing*, 3(3), 177-183.
- Edvardsson, D., Winblad, B. & Sandman, P. O. (2008). Person-centred care of people with severe Alzheimer's disease: current status and ways forward. *The Lancet Neurology*, 7(4), 362-367.
- Eisenhardt, K. M. (1989). Building Theories from Case Study Research. *The Academy of Management Review*, 14(4), 532-550.
- Eisenhardt, K. M. & Graebner, M. E. (2007). Theory Building From Cases: Opportunities and Challenges. *Academy of Management Journal*, 50(1), 25-32.
- Epp, T. D. (2003). Person-centred Dementia Care: A Vision to be Refined. *The Canadian Alzheimer Disease Review*, 53, 14-18.
- Evans, D. (2003). Hierarchy of evidence: a framework for ranking evidence evaluating healthcare interventions. *Journal of Clinical Nursing*, 12(1), 77-84.
- Finkel, S. (2000). Introduction to behavioural and psychological symptoms of dementia (BPSD). *International Journal of Geriatric Psychiatry*, 15 (Suppl 1), S2-4.
- Finkel, S., Costa E Silva, J., Cohen, G., Miller, S. & Sartorius, N. (1997). Behavioral and psychological signs and symptoms of dementia: a consensus statement on current knowledge and implications for research and treatment. *International Journal of Geriatric Psychiatry*, 12(11), 1060-1061.
- Flicker, L. (1999). Review: Dementia Reconsidered: the Person Comes First. *British Medical Journal*, 318(7187), 880A.
- Food and Drug Administration (FDA). (2005). *Deaths with antipsychotics in elderly patients with behavioural disturbances* [Online]. U.S. Food and Drug Administration Public Health Advisory (FDA). Available: <http://www.fda.gov/Drugs/DrugSafety/PostmarketDrugSafetyInformationforPatientsandProviders/DrugSafetyInformationforHealthcareProfessionals/PublicHealthAdvisories/ucm053171.htm> [Accessed 13.11 2013].
- Food and Drug Administration (FDA). (2008). *Information for Healthcare Professionals: Conventional Antipsychotics* [Online]. U.S. Food and Drug Administration Public Health Advisory (FDA). Available:

<http://www.fda.gov/Drugs/DrugSafety/PostmarketDrugSafetyInformationforPatientsandProviders/ucm124830.htm> [Accessed 13.11. 2013].

- Fossey, J., Ballard, C., Juszczak, E., James, I., Alder, N., Jacoby, R. & Howard, R. (2006). Effect of enhanced psychosocial care on antipsychotic use in nursing home residents with severe dementia: cluster randomised trial. *British Medical Journal*, 332(7544), 756-761.
- Foucault, M. (1973). *The Birth of the Clinic: An Archaeology of Medical Perception*, New York: Vintage Books.
- Foucault, M. (1977). *Discipline And Punish: The Birth of the Prison*, London: Penguin.
- Frank, L., Kleinman, L., Ciesla, G., Rupnow, M. F. & Brodaty, H. (2004). The effect of risperidone on nursing burden associated with caring for patients with dementia. *Journal of the American Geriatrics Society*, 52(9), 1449-1455.
- French, S. & Swain, J. (2012). *Working with disabled people in policy and practice: a social model*, Basingstoke: Palgrave macmillan.
- Froggatt, K. & Payne, S. (2006). A survey of end-of-life care in care homes: issues of definition and practice. *Health & Social Care in the Community*, 14(4), 341-348.
- Gage, H., Dickinson, A., Victor, C., Williams, P., Cheynel, J., Davies, S. L., Iliffe, S., Froggatt, K., Martin, W. & Goodman, C. (2012). Integrated working between residential care homes and primary care: a survey of care homes in England. *BioMed Central: Geriatrics*, 12(71).
- Gill, S. S., Bronskill, S. E., Normand, S.-L. T., Anderson, G. M., Sykora, K., Lam, K., Bell, C. M., Lee, P. E., Fischer, H. D., Herrmann, N., Gurwitz, J. H. & Rochon, P. A. (2007). Antipsychotic drug use and mortality in older adults with dementia. *Annals of Internal Medicine*, 146(11), 775-786.
- Gill, S. S., Rochon, P. A., Herrmann, N., Lee, P. E., Sykora, K., Gunraj, N., Normand, S.-L. T., Gurwitz, J. H., Marras, C., Wodchis, W. P. & Mamdani, M. (2005). Atypical antipsychotic drugs and risk of ischemic stroke: population based retrospective cohort study. *British Medical Journal*, 330(7489), 445-448.
- Gitlin, L. N., Kales, H. C. & Lyketsos, C. G. (2012). Managing Behavioral Symptoms in Dementia Using Nonpharmacologic Approaches: An Overview. *Journal of the American Medical Association*, 308(19), 2020-2029.
- Gold, R. L. (1958). Roles in Sociological Field Observations. *Social Forces*, 36(3), 217-223.
- Gray, R. J., Smedley, N. S. & Thomas, B. L. (1996). Administration of PRN medication by mental health nurses. *British Journal of Nursing*, 5(21), 1317-1322.
- Greene, J. C. (2002). With a Splash of Soda, Please: Towards Active Engagement with Difference. *Evaluation*, 8(2), 259-266.
- Guba, E. G. & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In: Denzin, N. K. & Lincoln, Y. S. (eds.) *Handbook of qualitative research* Thousand Oaks: CA: SAGE Inc.
- Health and Social Care Information Centre. (2012). *National Dementia & Antipsychotic Prescribing Audit 2012*. National Health Service, Leeds.
- Hoffmann, T. C., Erueti, C. & Glasziou, P. P. (2013). Poor description of non-pharmacological interventions: analysis of consecutive sample of randomised trials. *British Medical Journal*, 347(f3775).
- Hubbard, G., Downs, M. G. & Tester, S. (2010). Including older people with dementia in research: Challenges and strategies. *Aging & Mental Health*, 7(5), 351-362.
- Hurt, C., Bhattacharyya, S., Burns, A., Camus, V., Liperoti, R., Marriott, A., Nobili, F., Robert, P., Tsolaki, M., Vellas, B., Verhey, F. & Byrne, E. J. (2008). Patient and caregiver perspectives of quality of life in dementia: An investigation of the relationship to behavioural and psychological symptoms in dementia. *Dementia and Geriatric Cognitive Disorders*, 26(2), 138-146.

- Hussein, S. (2010). The Dementia Social Care Workforce in England. *Social Care Workforce Periodical* [Online]. Available: <http://www.kcl.ac.uk/sspp/kpi/scwru/pubs/periodical/issues/scwp9.pdf> [Accessed 13.11.2013].
- Huybrechts, K. F., Gerhard, T., Crystal, S., Olfson, M., Avorn, J., Levin, R., Lucas, J. A. & Schneeweiss, S. (2012). Differential risk of death in older residents in nursing homes prescribed specific antipsychotic drugs: population based cohort study. *British Medical Journal*, 344(e977).
- Innes, A., Macpherson, S. & McCabe, L. (2006). *Promoting Person-Centred Care at the Front Line*. Joseph Rowntree Foundation, York.
- Jibson, M. D. & Tandon, R. (1998). New atypical antipsychotic medications. *Journal of Psychiatric Research*, 32(3-4), 215-228.
- Johnson, B. & Gray, R. (2010). A History of Philosophical and Theoretical Issues for Mixed Methods Research. In: Tashakkori, A. & Teddlie, C. (eds.) *SAGE Handbook of Mixed Methods in Social & Behavioural Research*. Second ed. London: SAGE Publications Ltd.
- Johnson, J., Rolph, S. & Smith, R. (2010). *Residential Care Transformed: Revisiting 'The Last Refuge'*, Basingstoke: Palgrave Macmillan.
- Johnson, R. B. & Onwuegbuzie, A. J. (2004). Mixed Methods Research: A Research Paradigm Whose Time Has Come. *Educational Researcher*, 33(7), 14-26.
- Johnson, R. B., Onwuegbuzie, A. J. & Turner, L. A. (2007). Toward a Definition of Mixed Methods Research. *Journal of Mixed Methods Research*, 1(2), 112-133.
- Junker, H., J. (1960). The Fieldwork Situation: Social roles for observation. In: Seale, C. (ed.) *Social Research Methods: A reader*. London: Routledge.
- Kales, H. C., Kim, H. M., Zivin, K., Valenstein, M., Seyfried, L. S., Chiang, C., Cunningham, F., Schneider, L. S. & Blow, F. C. (2012). Risk of Mortality Among Individual Antipsychotics in Patients With Dementia. *American Journal of Psychiatry*, 169(1), 71-79.
- Kales, H. C., Valenstein, M., Kim, H. M., McCarthy, J. F., Ganoczy, D., Cunningham, F. & Blow, F. C. (2007). Mortality risk in patients with dementia treated with antipsychotics versus other psychiatric medications. *The American Journal of Psychiatry*, 164(10), 1568-1576.
- Katz, I., de Deyn, P.-P., Mintzer, J., Greenspan, A., Zhu, Y. & Brodaty, H. (2007). The efficacy and safety of risperidone in the treatment of psychosis of Alzheimer's disease and mixed dementia: a meta-analysis of 4 placebo-controlled clinical trials. *International Journal of Geriatric Psychiatry*, 22(5), 475-484.
- Killett, A., Hyde, P., Burns, D., Gray, R. & Poland, F. (2013). How organizational factors interact to influence the quality of care of older people in the care home sector. *Journal of Health Services Research & Policy*, 18(1 suppl), 14-22.
- Kitwood, T. (1997). *Dementia Reconsidered: The Person Comes First*, Buckingham: Open University Press.
- Knapp, M., Lemmi, V. & Romeo, R. (2013). Dementia care costs and outcomes: a systematic review. *International Journal of Geriatric Psychiatry*, 28(6), 551-561.
- Knapp, M., Prince, M., Albanese, E., Banerjee, S., Dhanasiri, S., Fernandez, J.-L., Ferri, C., McCrone, P., Snell, T. & Stewart, R. (2007). *Dementia UK: The Full Report*. London.
- Knight, P. T. (2002). *Small-Scale Research: Pragmatic Inquiry in Social Science and the Caring Professions*, London: SAGE Publications Ltd.
- Kolanowski, A., Fick, D., Frazer, C. & Penrod, J. (2010). It's about time: use of nonpharmacological interventions in the nursing home. *Journal of Nursing Scholarship*, 42(2), 214-222.
- Kushner, S. (2002). I'll Take Mine Neat: Multiple Methods but a Single Methodology. *Evaluation*, 8(2), 249-258.

- Kutsumi, M., Ito, M., Sugiura, K., Terabe, M. & Mikami, H. (2009). Management of behavioral and psychological symptoms of dementia in long-term care facilities in Japan. *Psychogeriatrics*, 9(4), 186-195.
- Kverno, K. S., Rabins, P. V., Blass, D. M., Hicks, K. & Black, B. S. (2008). Prevalence and Treatment of Neuropsychiatric Symptoms in Hospice-Eligible Nursing Home Residents with Advanced Dementia. *Journal of Gerontological Nursing*, 34(12), 8-17.
- Lawrence, V., Fossey, J., Ballard, C., Moniz-Cook, E. & Murray, J. (2012). Improving quality of life for people with dementia in care homes: making psychosocial interventions work. *The British Journal of Psychiatry*, 201(5), 344-351.
- Leone, E., Deudon, A., Maubourguet, N., Gervais, X. & Robert, P. H. (2009). Methodological issues in the non pharmacological treatment of BPSD in nursing home--the TNM study. *Journal of Nutrition, Health & Aging*, 13(3), 260-263.
- Leucht, S., Corves, C., Arbter, D., Engel, R. R., Li, C. & Davis, J. M. (2009). Second-generation versus first-generation antipsychotic drugs for schizophrenia: a meta-analysis. *Lancet*, 373(9657), 31 - 41.
- Lievesley, N., Crosby, G., Bowman, C. & Midwinter, E. (2011). *The changing role of care homes*. Bupa and Centre for Policy on Ageing, London.
- Liperoti, R., Gambassi, G., Lapane, K. L., Chiang, C., Pedone, C., Mor, V. & Bernabei, R. (2005). Cerebrovascular events among elderly nursing home patients treated with conventional or atypical antipsychotics. *Journal of Clinical Psychiatry*, 66(9), 1090-1096.
- Livingston, G., Johnston, K., Katona, C., Paton, J. & Lyketsos, C. G. (2005). Systematic review of psychological approaches to the management of neuropsychiatric symptoms of dementia. *American Journal of Psychiatry*, 162(11), 1996-2021.
- Lonergan, E. & Luxenberg, J. (2009). Valproate preparations for agitation in dementia. *Cochrane Database of Systematic Reviews*, (3).
- Lonergan, E., Luxenburg, J., Colford, J. M. & Birks, J. (2002). Haloperidol for agitation in dementia. *Cochrane Database of Systematic Reviews*, (2).
- Lopez, O. L., Becker, J. T., Chang, Y.-F., Sweet, R. A., Aizenstein, H., Snitz, B., Saxton, J., McDade, E., Kamboh, M. I., DeKosky, S. T., Reynolds, C. F. & Klunk, W. E. (2013). The Long-Term Effects of Conventional and Atypical Antipsychotics in Patients With Probable Alzheimer's Disease. *The American Journal of Psychiatry*, 170(9), 1051-1058.
- Luckhaus, C., Jacob, C & Reif, A. (2003). Mirtazapine completely relieves severe insomnia in a patient with Lewy body dementia. *International Journal of Psychiatry in Clinical Practice*, 7(2), 139-141.
- Luengo-Fernandez, R., Leal, J. & Gray, A. (2010). *Dementia 2010: The economic burden of dementia and associated research funding in the United Kingdom*. Alzheimer's Research Trust, Cambridge.
- Luff, R. 2008. *The emotion work of care assistants working with older people living in a care home*. PhD, University of Surrey.
- Luff, R., Ferreira, Z. & Meyer, J. (2011). *Care Homes*. NIHR School for Social Care Research, London.
- Lyketsos, C. G., Steele, C., Galik, E., Rosenblatt, A., Steinberg, M., Warren, A. & Sheppard, J.-M. (1999). Physical aggression in dementia patients and its relationship to depression. *American Journal of Psychiatry*, 156(1), 66-71.
- Lyketsos, C. G., Steinberg, M., Tschanz, J. T., Norton, M. C., Steffens, D. C. & Breitner, J. C. (2000). Mental and behavioral disturbances in dementia: findings from the Cache County Study on Memory in Aging. *American Journal of Psychiatry*, 157(5), 708-714.
- MacDonald, A. (2005). Care homes and dementia. *Aging & Mental Health*, 9(2), 91-92.

- Macdonald, A. J. D., Carpenter, G. I., Box, O., Roberts, A. & Sahu, S. (2002). Dementia and use of psychotropic medication in non-'Elderly Mentally Infirm' nursing homes in South East England. *Age & Ageing*, 31(1), 58-64.
- Maguire, A., Hughes, C., Cardwell, C. & O'Reilly, D. (2013). Psychotropic medications and the transition into care: a national data linkage study. *Journal of the American Geriatrics Society*, 61(2), 215-221.
- Maher, A. R., Maglione, M., Bagley, S., Suttorp, M., Hu, J. H., Ewing, B., Wang, Z., Timmer, M., Sultzer, D. & Shekelle, P. G. (2011). Efficacy and Comparative Effectiveness of Atypical Anti-psychotic Medications for Off-Label Uses in Adults - A Systematic Review and Meta-analysis. *Journal of the American Medical Association*, 306(12), 1359 - 1369.
- Margallo-Lana, M., Swann, A., O'Brien, J., Fairbairn, A., Reichelt, K., Potkins, D., Mynt, P. & Ballard, C. (2001). Prevalence and pharmacological management of behavioural and psychological symptoms amongst dementia sufferers living in care environments. *International Journal of Geriatric Psychiatry*, 16(1), 39-44.
- Martinez, C., Jones, R. W. & Rietbrock, S. (2013). Trends in the prevalence of antipsychotic drug use among patients with Alzheimer's disease and other dementias including those treated with antidementia drugs in the community in the UK: a cohort study. *British Medical Journal Open*, 3(1).
- Maslow, A. H. (1943). A Theory of Human Motivation. *Psychological Review*, 50, 370-396.
- Mason, J. (1996). *Qualitative Researching*, London: SAGE Publications Ltd.
- Matrix Evidence. (2011). *An economic evaluation of alternatives to antipsychotic drugs for individuals living with dementia*. South Tees Hospitals Foundation Trust, Coventry.
- Maxcy, S. J. (2003). Pragmatic Threads in Mixed Methods Research in the Social Sciences: The Search for Multiple Modes of Inquiry and the end of the Philosophy of Formalism. In: Tashakkori, A. & Teddlie, C. (eds.) *Handbook of Mixed Methods In Social & Behavioural Research*. 1st ed. London: SAGE Publications Ltd.
- Medical Research Council. (2008). *Developing and evaluating complex interventions: new guidance*. MRC, London.
- Mental Capacity Act. (2005). (c.9). HMSO: London.
- Merton, R. K. (1972). Insiders and Outsiders: A Chapter in the Sociology of Knowledge. *The American Journal of Sociology*, 78(1), 9-47.
- MHRA. (2008). *Antipsychotic Drugs* [Online]. London: The Medicines and Healthcare Products Regulatory Agency (MHRA). Available: <http://www.mhra.gov.uk/Safetyinformation/Generalsafetyinformationandadvice/Product-specificinformationandadvice/Product-specificinformationandadvice-A-F/Antipsychoticdrugs/index.htm> [Accessed 17.06. 2013].
- Milton, J., Lawton, J., Smith, M. & Buckley, A. (1998). Hidden high-dose antipsychotic prescribing: effects of p.r.n. doses. *Psychiatric Bulletin*, 22,675-677.
- Miyamoto, Y., Tachimori, H. & Ito, H. (2010). Formal caregiver burden in dementia: impact of behavioral and psychological symptoms of dementia and activities of daily living. *Geriatric Nursing*, 31(4), 246-253.
- Moniz-Cook, E. D., Swift, K., James, I., Malouf, R., De Vugt, M. & Verhey, F. (2012). Functional analysis-based interventions for challenging behaviour in dementia. *Cochrane Database of Systematic Reviews*.
- Morgan, D. G., Stewart, N. J., D'Arcy, C., Forbes, D. & Lawson, J. (2005). Work stress and physical assault of nursing aides in rural nursing homes with and without dementia special care units. *Journal of Psychiatric and Mental Health Nursing*, 12(3), 347-358.
- Morgan, D. L. (2007). Paradigms Lost and Pragmatism Regained: Methodological Implications of Combining Qualitative and Quantitative Methods. *Journal of Mixed Methods Research*, 1(1), 48-76.

- MY Home Life. (2014). *My Home Life* [Online]. Available: <http://myhomelife.org.uk/> [Accessed 12.01. 2014].
- National Health Service and Community Care Act. (1990). *National Health Service and Community Care Act*. The Government of England and Wales,
- National Minimum Wage Act. (1998). *National Minimum Wage Act 1998*. The Stationery Office, London.
- Netten, A., Darton, R. & Williams, J. (2002). *The Rate, Causes and Consequences of Home Closures*. Personal Social Services Research Unit (PSSRU), Canterbury.
- NICE and SCIE. (2006, revised 2012). *Dementia: supporting people with dementia and their carers in health and social care*. National Institute for Health and Clinical Excellence & Social Care Institute for Excellence, London.
- Nolan, M. R., Brown, J., Davies, S., Nolan, J. & Keady, J. (2006). The Senses Framework: improving care for older people through a relationship-centred approach. *Getting Research into Practice (GRiP)*, Report No 2. Project Report. University of Sheffield.
- Nolan, M. R., Davies, S., Brown, J., Keady, J. & Nolan, J. (2004). Beyond 'person-centred' care: a new vision for gerontological nursing. *Journal of Clinical Nursing*, 13(suppl s1), 45-53.
- Nursing & Midwifery Council. (2007, 2010). Standards for medicines management. London: NMC.
- Nyth, A. L. & Gottfries, C. G. (1990). The clinical efficacy of citalopram in treatment of emotional disturbances in dementia disorders. A Nordic multicentre study. *The British Journal of Psychiatry*, 157(6), 894-901.
- O'Donnell, B. F., Drachman, D. A., Barnes, H. J., Peterson, K. E., Swearer, J. M. & Lew, R. A. (1992). Incontinence and troublesome behaviors predict institutionalization in dementia. *Journal of geriatric psychiatry and neurology*, 5(1), 45-52.
- O'Neil, M. E., Freeman, M., Christensen, V., Telerant, R., Addleman, A. & Kansagara, D. (2011). *A Systematic Evidence Review of Non-pharmacological Interventions for Behavioral Symptoms of Dementia*. Department of Veterans Affairs, Washington.
- Onishi, J., Suzuki, Y., Umegaki, H., Nakamura, A., Endo, H. & Iguchi, A. (2005). Influence of behavioral and psychological symptoms of dementia (BPSD) and environment of care on caregivers' burden. *Archives of Gerontology and Geriatrics*, 41(2), 159-168.
- Onwuegbuzie, A. J. & Leech, N. L. (2004). Enhancing the Interpretation of "Significant" Findings: The Role of Mixed Methods Research. *The Qualitative Report*, 9(4), 770-792.
- Onwuegbuzie, A. J. & Leech, N. L. (2005). On Becoming a Pragmatic Researcher: The Importance of Combining Quantitative and Qualitative Research Methodologies. *International Journal of Social Research Methodology*, 8(5), 375 - 387.
- Opie, J., Doyle, C. & O'Connor, D. W. (2002). Challenging behaviours in nursing home residents with dementia: a randomized controlled trial of multidisciplinary interventions. *International Journal of Geriatric Psychiatry*, 17(1), 6-13.
- Orrell, M. (2012). The new generation of psychosocial interventions for dementia care. *The British Journal of Psychiatry*, 201(5), 342-343.
- Owen, T. & Meyer, J. (2009). *Minimising the Use of 'Restraint' in Care Homes: challenges, dilemmas and positive approaches*. Social Care Institute for Excellence, London.
- Pillemer, K., Chen, E. K., Van Haitsma, K. S., Teresi, J., Ramirez, M., Silver, S., Sukha, G. & Lachs, M. S. (2012). Resident-to-Resident Aggression in Nursing Homes: Results from a Qualitative Event Reconstruction Study. *The Gerontologist*, 52(1), 24-33.
- Prince, M., Bryce, R., Albanese, E., Wimo, A., Ribeiro, W. & Ferri, C. P. (2013a). The global prevalence of dementia: a systematic review and metaanalysis. *Alzheimer's & Dementia: the journal of the Alzheimer's Association*, 9(1), 63-75.
- Prince, M., Guerchet, M. & Prina, M. (2013b). *Policy Brief for Heads of Government: The Global Impact of Dementia 2013–2050*. Alzheimer's Disease International, London.

- Purandare, N., Burns, A., Challis, D. & Morris, J. (2004). Perceived mental health needs and adequacy of service provision to older people in care homes in the UK: a national survey. *International Journal of Geriatric Psychiatry*, 19(6), 549-553.
- Rainer, M., Haushofer, M., Pfolz, H., Struhala, C. & Wick, W. (2007). Quetiapine versus risperidone in elderly patients with behavioural and psychological symptoms of dementia: efficacy, safety and cognitive function. *European psychiatry: AEP*, 22(6), 395-403.
- Richter, T., Meyer, G., Möhler, R. & Köpke, S. (2012). Psychosocial interventions for reducing antipsychotic medication in care home residents. *Cochrane Database of Systematic Reviews*, 12.
- Ritchie, J. & Lewis, J. (eds.) (2003). *Qualitative Research Practice: A Guide for Social Science Students and Researchers*, London: SAGE Publications Ltd.,
- Ritchie, J. & Spencer, L. (1994). Qualitative data analysis for applied policy research. In: Bryman, A. & Burgess, R. G. (eds.) *Analyzing Qualitative Data*. New York: Routledge.
- Robinson, L., Hutchings, D., Corner, L., Finch, T., Hughes, J., Brittain, K. & Bond, J. (2007). Balancing rights and risks: Conflicting perspectives in the management of wandering in dementia. *Health, Risk & Society*, 9(4), 389-406.
- Robson, C. (2002). *Real World Research*: Blackwell Publishing, Oxford.
- Rodriguez, N. A., Sackley, C. M. & Badger, F. J. (2007). Exploring the facets of continence care: a continence survey of care homes for older people in Birmingham. *Journal of Clinical Nursing*, 16(5), 954-962.
- Rosenheck, R. A., Leslie, D. L., Sindelar, J. L., Miller, E. A., Tariot, P. N., Dagerman, K. S., Davis, S. M., Lebowitz, B. D., Rabins, P., Hsiao, J. K., Lieberman, J. A. & Schneider, L. S. (2007). Cost-benefit analysis of second-generation antipsychotics and placebo in a randomized trial of the treatment of psychosis and aggression in Alzheimer disease. *Archives of General Psychiatry*, 64(11), 1259-1268.
- Rossum, R. C., Rector, T. S., Lederle, F. A. & Dysken, M. W. (2010). Are all commonly prescribed antipsychotics associated with greater mortality in elderly male veterans with dementia? *Journal of the American Geriatrics Society*, 58(6), 1027-1034.
- Royal College of Nursing. (2012). *Persistent challenges to providing quality care: An RCN report on the views and experiences of frontline nursing staff in care homes in England*. Royal College of Nursing, London.
- Saczynski, J. S., Beiser, A., Seshadri, S., Auerbach, S., Wolf, P. A. & Au, R. (2010). Depressive symptoms and risk of dementia: The Framingham Heart Study. *Neurology*, 75(1), 35-41.
- Sarantakos, S. (2005). *Social Research*, Basingstoke: Palgrave Macmillan.
- Savva, G. M., Zaccai, J., Matthews, F. E., Davidson, J. E., McKeith, I. & Brayne, C. (2009). Prevalence, correlates and course of behavioural and psychological symptoms of dementia in the population. *British Journal of Psychiatry*, 194(3), 212-219.
- Schneeweiss, S., Setoguchi, S., Brookhart, A., Dormuth, C. & Wang, P. S. (2007). Risk of death associated with the use of conventional versus atypical antipsychotic drugs among elderly patients. *Canadian Medical Association Journal*, 176(5), 627-632.
- Schneider, J., Kezia, S., Simon, B. & Joanne, L. (2010). *Challenging care: the role and experience of Health Care Assistants in dementia wards*. National Institute for Health Research
- Schneider, L. S., Dagerman, K. & Insel, P. S. (2006a). Efficacy and adverse effects of atypical antipsychotics for dementia: meta-analysis of randomized, placebo-controlled trials. *The American Journal Of Geriatric Psychiatry: Official Journal Of The American Association For Geriatric Psychiatry*, 14(3), 191-210.
- Schneider, L. S., Dagerman, K. S. & Insel, P. (2005). Risk of death with atypical antipsychotic drug treatment for dementia: meta-analysis of randomized placebo-controlled trials. *Journal of the American Medical Association*, 294(15), 1934-1943.

- Schneider, L. S., Pollock, V. E. & Lyness, S. A. (1990). A Metaanalysis of Controlled Trials of Neuroleptic Treatment in Dementia. *Journal of the American Geriatrics Society*, 38(5), 553-563.
- Schneider, L. S., Tariot, P. N., Dagerman, K. S., Davis, S. M., Hsiao, J. K., Ismail, M. S., Lebowitz, B. D., Lyketsos, C. G., Ryan, J. M., Stroup, T. S., Sultzer, D. L., Weintraub, D. & Lieberman, J. A. (2006b). Effectiveness of atypical antipsychotic drugs in patients with Alzheimer's disease. *New England Journal of Medicine*, 355(15), 1525-1538.
- Seitz, D. P., Brisbin, S., Herrmann, N., Rapoport, M. J., Wilson, K., Gill, S. S., Rines, J., Le Clair, K. & Conn, D. (2012). Efficacy and Feasibility of Nonpharmacological Interventions for Neuropsychiatric Symptoms of Dementia in Long Term Care: A Systematic Review. *Journal of the American Medical Directors Association*, 13(6), 503-506.e2.
- Shah, S. M., Carey, I. M., Harris, T., DeWilde, S. & Cook, D. G. (2011). Antipsychotic prescribing to older people living in care homes and the community in England and Wales. *International Journal of Geriatric Psychiatry*, 26(4), 423-434.
- Shah, S. M., Carey, I. M., Harris, T., DeWilde, S., Hubbard, R., Lewis, S. & Cook, D. G. (2010). Identifying the clinical characteristics of older people living in care homes using a novel approach in a primary care database. *Age and Ageing*, 39(5), 617-623.
- Singleton, R. A. & Straits, B. C. (2005). *Approaches To Social Research*, Oxford: Oxford University Press.
- Sörensen, S., Duberstein, P., Gill, D. & Pinquart, M. (2006). Dementia care: mental health effects, intervention strategies, and clinical implications. *The Lancet Neurology*, 5(11), 961-973.
- Spira, A. P. & Edelstein, B. A. (2006). Behavioral interventions for agitation in older adults with dementia: an evaluative review. *International Psychogeriatrics*, 18(2), 195-225.
- Stake, R. E. (1995). *The Art Of Case Study Research*, London: SAGE Publications Ltd.
- Stake, R. E. (2005). Qualitative Case Studies. In: Denzin, N. K. & Lincoln, Y. S. (eds.) *The Sage handbook of qualitative research*. 3rd ed. Thousand Oaks: Sage Publications Ltd.
- Stokes, G. (2000). *Challenging Behaviour in Dementia: A Person-Centred Approach*, Bicester: Winslow Press Ltd.
- Strassnig, M. & Ganguli, M. (2005). About a Peculiar Disease of the Cerebral Cortex: Alzheimer's Original Case Revisited. *Psychiatry (Edgmont)*, 2(9), 30-33.
- Street, J. S., Clark, W. S., Gannon, K. S., Cummings, J. L., Bymaster, F. P., Tamura, R. N., Mitani, S. J., Kadam, D. L., Sanger, T. M., Feldman, P. D., Tollefson, G. D. & Breier, A. (2000). Olanzapine treatment of psychotic and behavioral symptoms in patients with Alzheimer disease in nursing care facilities: a double-blind, randomized, placebo-controlled trial. The HGEU Study Group. *Archives of General Psychiatry*, 57(10), 968-976.
- Sultzer, D. L., Davis, S. M., Tariot, P. N., Dagerman, K. S., Lebowitz, B. D., Lyketsos, C. G., Rosenheck, R. A., Hsiao, J. K., Lieberman, J. A. & Schneider, L. S. (2008). Clinical symptom responses to atypical antipsychotic medications in Alzheimer's disease: phase 1 outcomes from the CATIE-AD effectiveness trial. *American Journal of Psychiatry*, 165(7), 844-854.
- Tan, L. L., Wong, H. B. & Allen, H. (2005). The impact of neuropsychiatric symptoms of dementia on distress in family and professional caregivers in Singapore. *International Psychogeriatrics*, 17(2), 253-263.
- Tariot, P. N., Erb, R., Podgorski, C. A., Cox, C., Patel, S., Jakimovich, L. & Irvine, C. (1998). Efficacy and tolerability of carbamazepine for agitation and aggression in dementia. *American Journal of Psychiatry*, 155(1), 54-61.
- Tashakkori, A. & Teddlie, C. (1998). *Mixed Methodology: Combining Qualitative and Quantitative Approaches*, London: SAGE Publications, Ltd.

- Teddlie, C. & Tashakkori, A. (2010). Overview of Contemporary Issues in Mixed Methods Research. In: Tashakkori, A. & Teddlie, C. (eds.) *SAGE Handbook of Mixed Methods in Social & Behavioural Research*. Second ed. London: SAGE Publications Ltd.
- Testad, I., Auer, S., Mittelman, M., Ballard, C., Fossey, J., Donabauer, Y. & Aarsland, D. (2010). Nursing home structure and association with agitation and use of psychotropic drugs in nursing home residents in three countries: Norway, Austria and England. *International Journal of Geriatric Psychiatry*, 25(7), 725-731.
- The Data Protection Act. (1998, amended 2003). *The Data Protection Act*. Crown Copyright, London.
- Theison, A.-K., Geisthoff, U. W., Förstl, H. & Schröder, S. G. (2009). Agitation in the morning: symptom of depression in dementia? *International Journal of Geriatric Psychiatry*, 24(4), 335-340.
- Thomas, G. (2011). *How to do Your Case Study: a Guide for students & Researchers*, London: SAGE Publications Ltd.
- Townsend, P. (1964). *The Last Refuge: A Survey of Residential Institutions and Homes for the Aged in England and Wales*, London: Routledge & Kegan Paul.
- Turner, S. (2005). Behavioural symptoms of dementia in residential settings: a selective review of non-pharmacological interventions. *Aging & Mental Health*, 9(2), 93-104.
- University of Bradford. (2012). *Dementia Care Mapping* [Online]. Bradford: University of Bradford. Available: <http://www.bradford.ac.uk/health/career-areas/bradford-dementia-group/dementia-care-mapping/> [Accessed 12.01. 2014].
- Usher, K., Baker, J. A. & Holmes, C. A. (2010). Understanding clinical decision making for PRN medication in mental health inpatient facilities. *Journal of Psychiatric & Mental Health Nursing*, 17(6), 558-564.
- Warden, V., Hurley, A. C. & Volicer, L. (2003). Development and Psychometric Evaluation of the Pain Assessment in Advanced Dementia (PAINAD) Scale. *Journal of the American Medical Directors Association*, 4(1), 9-15.
- Whitaker, R., Ballard, C., Stafford, J., Orrell, M., Moniz-Cook, E., Woods, R. T., Murray, J., Knapp, M., Woodward Carlton, B. & Fossey, J. (2013). Feasibility study of an optimised person-centred intervention to improve mental health and reduce antipsychotics amongst people with dementia in care homes: study protocol for a randomised controlled trial. *Trials*, 14(1), 1-10.
- Wood-Mitchell, A., James, I. A., Waterworth, A., Swann, A. & Ballard, C. (2008). Factors influencing the prescribing of medications by old age psychiatrists for behavioural and psychological symptoms of dementia: a qualitative study. *Age and Ageing*, 37(5), 547-552.
- Woods, R. T., Bruce, E., Edwards, R. T., Elvish, R., Hoare, Z., Hounsborne, B., Keady, J., Moniz-Cook, E. D., Orgeta, V., Orrell, M., Rees, J. & Russell, I. T. (2012). REMCARE: reminiscence groups for people with dementia and their family caregivers - effectiveness and cost-effectiveness pragmatic multicentre randomised trial. *Health Technology Assessment*, 16(48), 1-116.
- World Health Organisation. (2010). *International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10) Version for 2010* [Online]. World Health Organisation. Available: <http://apps.who.int/classifications/icd10/browse/2010/en#/F00-F09> [Accessed 14.11.2013].
- Yin, R. K. (2003). *Applications of case study research*, London: SAGE Publications LTD.
- Yin, R. K. (2009). *Case Study Research: Design and Methods*, London: SAGE Ltd.

Appendix A: List of non-pharmacological interventions with brief definitions

A list of the Non-Pharmacological Interventions included in the survey with brief definitions

Music Therapy

Music therapy can involve people with dementia either listening to songs or music, or actively playing instruments or singing. It can be provided for individuals or for groups. The therapy works by increasing social interaction, relaxation, well-being, autobiographical memory and quality of life. Music therapy occupies people with dementia, preventing them from becoming bored and music can help relax them to ease frustration; meaning, less BPSD occur.

Massage

Massage can be anything from firm deep-tissue bodywork to a more soothing touch based session. Often for people with dementia a comforting session is provided, which may involve massage, touch, stroking or/and deep listening or encouragement. Massage can be provided to a small area of the body such as, the hands or feet or large areas such as, the back, shoulders, arms, legs or head. Massage works by relaxing the person with dementia so they feel calm, therefore BPSD are less likely to occur.

Doll Therapy

Doll therapy involves the use of a doll or teddy as a therapeutic comfort for the person with dementia. The person gains comfort from being with, and looking after, the doll. Doll therapy works by fulfilling a person with dementia's need to be useful, needed and to be able to care for others. In this way the doll is used to meet attachment needs and as such, alleviates distress and provides comfort. Being able to hug a doll can also provide security in an uncertain world. Doll therapy reduces the likelihood of BPSD occurring by fulfilling unmet needs and comforting people with dementia.

Animal/Pet Therapy

Animal therapy involves either having a pet live where the person with dementia lives or by animals/pets visiting and spending time with them. Animal/pet therapy can involve dogs, cats, fish in tanks, smaller animals or even horses. Dogs are used most commonly. Animal/pet therapy works by providing a non-judgemental companion offering unconditional love. This helps the person with dementia feel pleasure, respond affectionately, increase physical activity and improve social interaction. The benefits of animal therapy are improved mood, more social interaction, and a calming effect; these consequently reduce the likelihood of BPSD.

Reality Orientation

Reality orientation involves reminding people with dementia of facts about themselves and their environment. This helps them minimise their their memory loss and the

Appendix A: List of non-pharmacological interventions with brief definitions

feelings of panic, distress and anxiety that accompany disorientation. Reality orientation can be used with individuals or groups and can utilise a range of materials and activities. Signposts, notices and other memory aids can be incorporated to assist in orientating a person with dementia to their current reality. Reality orientation works to minimise BPSD by making people with dementia aware of their situations, thereby reducing feelings of anxiety or distress.

Behavioural Therapy

Behavioural therapy has developed from classical conditioning and learning theory. Behavioural therapy is a type of therapy that focuses on trying to find out the reasons difficult behaviours occur and then changes the physical or social environment so that the behaviours are not triggered or reinforced anymore. A thorough assessment is needed to identify the antecedents, behaviours and consequences (ABC) before strategies are put into place to remove, offset, circumvent or reduce these occurrences. These strategies should then reduce instances of BPSD occurring.

Multisensory Stimulation

Multisensory stimulation usually involves the use of a specialist room with sensory equipment in it. The equipment often includes lights, some of which can be fibre optic so they are flexible and safe to touch; textures of any sort, but can include cushions or vibrating pads; smells such as essential oils, and sounds such as music or wildlife. Multisensory stimulation is usually adapted to the individual and used for people in the moderate to later stages of dementia. Multisensory stimulation helps with BPSD by calming an individual, thereby reducing distress or agitation.

Validation Therapy

Validation therapy involves empathising with the feelings of the person with dementia through communication, thereby validating their emotions and beliefs at that time. It can also be seen as going along with the person's reality by not orientating them to the present situation or circumstance. For example, by not telling the person with dementia that the person they are asking for is dead, but saying that they are late and then distracting them from the topic. Validation therapy works by promoting contentment, making the person with dementia feel valued, and acknowledging and validating their thoughts and feelings. People with dementia then feel less stress and distress, which works to reduce instances of BPSD occurring.

Aromatherapy

Aromatherapy involves the use of essential oils; usually lavender and melissa balm for people with dementia. The oils can be administered through massage, bathing, inhalation or by the topical application of a cream. The therapy is usually aimed at individuals and can be tailored to suit their needs. Aromatherapy works to reduce

Appendix A: List of non-pharmacological interventions with brief definitions

BPSD by increasing social interaction, and relaxing and calming a person through a sensory experience. This can reduce agitation, distress and anxiety.

Reminiscence Therapy

Reminiscence therapy involves assisting a person with dementia to revisit or relive positive experiences in their past. Reminiscence is flexible and adaptable; it can be used with individuals or groups. The sessions can involve props, music, artefacts or activities to help stimulate the reminiscence. Reminiscence works by improving well-being, social interaction and providing cognitive stimulation and pleasure. BPSD can be reduced in this way since people with dementia can be less frustrated, bored or agitated after reminiscence.

List and brief definitions compiled with reference to:

Ballard, C. G., Gauthier, S., Cummings, J. L., Brodaty, H., Grossberg, G.T., Robert, P. & Lyketsos, C. G. (2009). Management of agitation and aggression associated with Alzheimer disease. *Nature Reviews Neurology*, 5(5), 245-255.

The Alzheimer's Society website (www.alzheimers.org.uk)

The NHS website (www.nhs.uk/Conditions/dementia-guide/Pages/dementia-treatment.aspx)



Thank you for agreeing to complete this survey.

Please answer all of the questions.

If you have any questions please contact:

Tamara Backhouse

Postgraduate Research Student

0.27 Queen's Building,

University of East Anglia,

Norwich, Norfolk,

NR4 7TJ

Email: Tamara.Backhouse@uea.ac.uk

Tel:

Please return the survey in the enclosed pre-paid envelope by 2nd December 2011

Appendix B: Questionnaire for postal survey

Dementia Care Survey

1. How many residents doescurrently have?

.....

2. Does your home currently care for people with dementia?

Yes No

3. Do you admit people into your care home with challenging behaviour?

Yes No

4. Thinking about the past week have there been any episodes of challenging behaviour in your care home?

Yes No

❖ **4 a. If yes, thinking about the challenging behaviour that you experience in your care home, which three behaviours do you find most difficult? Please specify**

.....
.....
.....

5. Which of the following, if any, therapies or treatments do you use to help you care for people with challenging behaviour? Tick all that apply

Music Therapy	<input type="checkbox"/>	Massage	<input type="checkbox"/>	Doll Therapy	<input type="checkbox"/>
Animal/Pet Therapy	<input type="checkbox"/>	Reality Orientation	<input type="checkbox"/>	Behavioural Therapy	<input type="checkbox"/>
Multisensory Stimulation	<input type="checkbox"/>	Validation Therapy	<input type="checkbox"/>	Aromatherapy	<input type="checkbox"/>
Reminiscence Therapy	<input type="checkbox"/>	None used	<input type="checkbox"/>		

Other, please specify.....

6. Thinking about the current residents in your care home, approximately how many are prescribed antipsychotic medication?

.....

❖ **6 a. Thinking about those residents on antipsychotic medications, approximately how many are prescribed antipsychotics as PRN (as required) medication?**

.....

Thank You for Your Time

Appendix C: Categorised free text responses – difficult behaviours

Q4a, If yes, thinking about the challenging behaviour that you experience in your care home, which three behaviours do you find most difficult? Please specify

Categorised free text responses from survey: behaviours reported as difficult

Behaviour category		Category Includes	
Aggression		Physical and verbal aggression categories Aggression Violence Biting Scratching Hitting	Slapping Kicking Anger Spitting Lashing out Pinching Threatening
Physical Aggression		Physical Hitting Acting aggressively Physical abuse Physical assault Lashing out Throwing missiles Damage to property Destructive behaviour	Slapping Kicking Violence Spitting Pinching Biting Scratching Disruptive Behaviours Throwing items
Verbal Responses	Verbal Aggression	Verbal Abusive Swearing	Verbal Violence Talking aggressively
	Verbal Sounds	Noisiness Screaming Shouting out Calling out	Name calling Loud crying Vocalisation Continual calling
Persistent or Unpredictable Behaviours		Continual behaviours that cannot be appeased Unpredictability	
Inappropriate Sexual Behaviour		Sexual disinhibition Masturbation Sexual inappropriateness	
Impact on others		Putting others at risk Impact on staff or residents In other residents' rooms Taking other residents' possessions Keeping others awake Bullying Aggression towards staff or other residents Stalking Following staff	
Risk to Self		Constantly trying to stand, which endangers them Putting themselves in danger Throwing/putting self on floor Self harm Injury to self Falls Inability to recognise risk – results in falls	
Deprivation of liberty		Attempting to leave the building	

Appendix C: Categorised free text responses – difficult behaviours

	Absconding Deprivation of liberty – physical and sexual	
Agitation	Agitation Restlessness Anxiety Anxious OCD type symptoms, now part of behaviour	
Wandering	Wandering	
Resisting Care	Lack of co-operation with personal care Refusing care, advice or help Non-compliance Aggression during intervention Inability to accept personal care Opposition to care Fighting against care/equipment Unpredictable behaviour during care interventions Lack of compliance with medication Medication Non-compliance	
Night Time Waking	Sleep disturbance Shouting at night	Wandering at night Night time traumas
Communication Difficulties	Communication difficulties Failure to communicate needs Communication when a person is confused Frustration from communication difficulties	
Looking for Attention	Demanding Wanting attention all the time Banging on tables	
Emotional Responses	Emotions Crying Withdrawn Unsettled Sadness Possessiveness	Despair Depression Distress Mood swings Frustration Perseveration
Inappropriate Incontinence/Undress	Inappropriate toileting Enters other's rooms in a state of undress Coping with incontinence	
One-to-One	Behaviours requiring one-to-one care	
People's Attitudes	Discrimination Other people's attitudes Clients with full capacity	
Different Reality	Residents asking about Mum or Dad Asking for friends who are dead Asking for care that has already been given	
Eating Issues	Refusal of diet/fluids Ability to eat or drink in later stages	
Severe Memory Loss Confusion	Repeated questioning Confusion Repetition of words	Severe memory loss Short term memory loss

Appendix C: Categorised free text responses - NPIs

Q5, Which of the following, if any, therapies or treatments do you use to help you care for people with challenging behaviour? Other Please Specify Responses:

Categorised free text responses from survey: non-pharmacological interventions used

Therapy/NPI Name	Category includes	
Reminiscence*	Life histories	
Multisensory Stimulation*	Sonas	
Aromatherapy*		
Behavioural Therapy*		
Validation Therapy*		
Reality Orientation*	Timelines	
Music Therapy*		
Massage*	Hand Massage	
Pet/Animal Therapy*		
Doll Therapy*		
Exercise	Exercise Keep fit	Passive exercise
Art Therapy	Art Therapy Art	Painting
One-to-One Time	One-to-one time Sessions	Services Talking to residents
Occupational Therapy	Occupational Therapy Giving a specific occupation Washing up Helping maintenance man	Help make beds Light chores Past occupations
Cause of Behaviour	Trying to find the cause of behaviour Intervene before issue Assess pain	
Psychotherapy	Psychotherapy	
Distraction	Distraction	Diversional tactics
Arranged Activities	Board Games Bingo Balloon Gardening Routine activities for residents	Activities Hobbies – specific interests Crafts Cooking
Dementia Care matters	David Sheard – Dementia Care Matters (butterfly)	
Outings	Outings Out shopping Trips out of home Walks outside	Out to pub Drive out Outdoor
Social or Recreational Activities	Tea dance Circle dancing Entertainers Clothes party Children Religious meetings	Sing-a-longs Sing Reading Dolls house therapy Old films Charity work
Reflexology	Reflexology	

*Therapies provided as tick box options on survey

Appendix D: Indicative observation guide

Indicative Observation Guide – context and processes

BPSD

- Types of BPSD – environment effects
- Severity of BPSD - action - **Antecedents – Behaviour – Consequences (ABC)**
- Which BPSD enact which strategies
- BPSD after intervention
- Impact of BPSD on resident, other residents and staff
- Nature of BPSD

STATEGIES

- What strategies used?
- Levels at which things operate
 - Organisational approach - generally and towards individual residents
 - Care team
 - Individual staff member
 - Pharmacological
- Strategies formal or informal
- Types of strategies
- When strategies used
- How strategies work
- 1 or more strategies used at a time?
- If strategies successful – for whom?
- Compromise – for who?
- Context of strategy use
- Residents reactions to strategies
- Issues with strategies
- Tensions between organisational constraints and individualised care

SUPPORT/RESOURCES

- Support for care staff? - Where/who is it from?
- Resources for staff
- How are resources or support used?
- Relatives

Appendix D: Indicative observation guide

CARE HOME DYNAMICS

- Review and reassessment of residents
- Flexibility of staff and strategies
- Relationships between staff – residents – care home
- Use of space
- Philosophy of care? Group norms – taken for granted assumptions/understandings shaping practices

MEDICATION

- Place of antipsychotics/psychotropics in care homes (reliance on – resident or staff)
- How psychotropic agents are used in relation to non-pharmacological interventions
- Psychotropic PRN use
 - When
 - For what behaviour
 - How decision made? Who by?
 - Why
 - Successful? For whom? Problems with taking?
 - 1st or last resort?
- Resident keep own med or not – is generic or dementia different?

STAFF

- Staff reactions to BPSD
- Staff approaches to people with BPSD

POSSIBLE INFLUENCING FACTORS

- Time
- Staff levels
- Strategies not working
- Flexibility?
- Other residents reactions
- Team work
- Type of care approach
- Environment

(1 GP for care home?/referrals/admission to secondary care/ GP requests)

Appendix E: Indicative interview topic guide

Indicative Interview Topic Guide

Demographics

- Gender?
- Age Range? 18-30, 31-40, 41-50, 51-60, 61+
- Ethnicity?
- Length of time working as a care worker?
- Length of time working in this CH?
- Length of time working with PWD? Training? Role/responsibility? PT/FT?

Attitudes towards people with BPSD

- Describe Job. Enjoy job?
- What like/dislike about looking after PWD? PWD compared to other residents?
- BPSD? How often? Impact on self/others (staff/residents/visitors)?
- Resident behaviours difficult to cope with? Why difficult?
- How BPSD affect PWDs' lives?
- Are there any aspects that worry you about looking after people with BPSD?

Strategies Used

- Describe last time you experienced challenging behaviour – what did you do?
- How know what to do? Who decides? How decide?
- How find out about ways to cope with BPSD? Manager/staff/self/other
- Formal NPIs used? Training? Successful? How chosen? Who uses? When?
- Different strategies for different behaviours? E.g.s. How work? Prompt....
- Successful ways of coping- how work? Always successful?
- Unsuccessful strategies – why?
- Residents moved on? Referrals
- All staff act the same?
- Difficulties with strategies Time/resources? Staff numbers?
- What makes it hard to manage BPSD? What could make it easier?
- Tensions – Knowledge/time/experience?
- Welfare of/impact on other residents – duty to care for all

Review – reassessment

- Changing needs of resident – how respond/change care – flexibility/responsiveness

Medication Knowledge

- Psychotropic medications? Antipsychotics? GP helpful/reluctant?
- PRN use/decision – Describe the last time you used PRN antipsychotics. Who?/how decide? How often used?
- Successful – resident reactions
- 1st/last resort – with other strategies?

Available Support

- Do you discuss ways to cope with BPSD within the staff team? Stress?
- Support available? How used? Staff team/MH team/GP/Training
- Where/how can you access it?
- Is there enough support? Does it help?
- What support would help?
- Resources available? For what?

Appendix F: Medication mapping form

Resident Number:

Age:

Gender:

Psychotropic Prescribed	Type	Dose	Freq per day	Route	Usually Taken	Type of Prescription	PRN	PRN – Times Given	PRN - Max daily dose

Reasons given for PRN use

Any anomalies in regards to administration (on back of MAR sheet)

Reasons and frequency of non-administration (for example, “initial” options on MAR sheet, such as E = refused and destroyed)

Appendix F: Medication mapping form

Psychotropic prescribed: Medication name

PRN: Y/N

Type: Type of Medication-

Times Given: Times of day and frequency over month (eg, evening x 12)

- Typical Anti-psychotic: TAP
- Atypical Anti-psychotic: AAP
- Anti-depressant: AD
- Mood Stabiliser: MS
- Anti-obsessive: AO
- Anti-anxiety: AA
- Anti-panic: AP
- Stimulants: S

PRN Maximum Dose: In figure and measurement

Dose: In figures and measurement (eg, 2mg)

Frequency per day: x Figure: Morning: M Noon: N Tea: T Bed: B

Route:

- Oral: PO
- Intramuscular Injection: IM

Usually Taken: .../28

Type of Prescription:

- Regular: R
- PRN: PRN
- Temporary: T
- Variable Dose: V

Appendix G: Survey cover letter to care home managers

Address of care home

Faculty of Medicine and Health Sciences
School of Allied Health Professionals,
University of East Anglia,
Norwich, NR4 7TJ
United Kingdom
Email: Tamara.Backhouse@uea.ac.uk

Tel: -----

Date

Dear Manager of,

I am a postgraduate student at the University of East Anglia in Norwich, conducting a research project about dementia care in care homes. The research aims to gain an understanding of the strategies used in care homes to care for people with behavioural and psychological symptoms of dementia, such as, wandering, repeated questioning, aggression and agitation. With the prevalence of dementia rising, care homes are increasingly encountering these symptoms when caring for older people. To explain this situation it is important to gain an understanding of the strategies care homes are using to care for people with dementia. As part of my study I am inviting every care home in Suffolk, Norfolk, Essex and Peterborough to fill in a short survey.

From my own experience working as a carer in residential, nursing and very sheltered accommodation homes I am very aware how busy and demanding it can be and I do not want to take up too much of your time. Therefore, the survey is very short with just 6 simple questions to answer. I would really appreciate it if you as care home manager, or another appropriate person, were able to fill it in and return it in the post within the next 2 weeks. It should only take a few minutes of your time. I have enclosed the survey, along with a pre-paid addressed envelope for you to return it in once completed.

The surveys will provide information to allow the study to gain an overview of dementia care in care homes in the Eastern region. All responses will be analysed collectively and anonymously and any identifying information will be kept confidential. The findings from the survey will identify how many care homes care for people with symptoms

Appendix G: Survey cover letter to care home managers

of dementia and the approaches used to care for these people. I will be carrying out follow-up research, in a small number of care homes in the region (4-6), about how care homes care for people with dementia. It will be important for the research to be carried out in homes with different approaches to caring for people with dementia and the survey findings will also allow identification of these differences.

This study has been reviewed by the Social Care Research Ethics Committee and has been given a favourable opinion. I would like to thank you in advance for your response to the survey. If you have any questions or need more information about the study, please feel free to contact me.

Yours faithfully,

Tamara Backhouse

Postgraduate Research Student

Tamara.Backhouse@uea.ac.uk

Appendix H: Aging & Mental Health publication

This article was downloaded by: [Tamara Backhouse]

On: 26 July 2013, At: 03:28

Publisher: Routledge

Informa Ltd Registered in England and Wales Registered Number: 1072954 Registered office: Mortimer House, 37-41 Mortimer Street, London W1T 3JH, UK



Aging & Mental Health

Publication details, including instructions for authors and subscription information:

<http://www.tandfonline.com/loi/camh20>

Behavioural and psychological symptoms of dementia and their management in care homes within the East of England: a postal survey

Tamara Backhouse^a, Anne Killett^a, Bridget Penhale^b, Diane Burns^c & Richard Gray^d

^a School of Rehabilitation Sciences, University of East Anglia, Norwich, United Kingdom

^b School of Nursing Sciences, University of East Anglia, Norwich, United Kingdom

^c Sheffield University Management School, University of Sheffield, Sheffield, United Kingdom

^d Department of Nursing and Midwifery, University of the West of England, Bristol, United Kingdom

Published online: 26 Jul 2013.

To cite this article: Aging & Mental Health (2013): Behavioural and psychological symptoms of dementia and their management in care homes within the East of England: a postal survey, Aging & Mental Health

To link to this article: <http://dx.doi.org/10.1080/13607863.2013.819834>

PLEASE SCROLL DOWN FOR ARTICLE

Taylor & Francis makes every effort to ensure the accuracy of all the information (the "Content") contained in the publications on our platform. However, Taylor & Francis, our agents, and our licensors make no representations or warranties whatsoever as to the accuracy, completeness, or suitability for any purpose of the Content. Any opinions and views expressed in this publication are the opinions and views of the authors, and are not the views of or endorsed by Taylor & Francis. The accuracy of the Content should not be relied upon and should be independently verified with primary sources of information. Taylor and Francis shall not be liable for any losses, actions, claims, proceedings, demands, costs, expenses, damages, and other liabilities whatsoever or howsoever caused arising directly or indirectly in connection with, in relation to or arising out of the use of the Content.

This article may be used for research, teaching, and private study purposes. Any substantial or systematic reproduction, redistribution, reselling, loan, sub-licensing, systematic supply, or distribution in any form to anyone is expressly forbidden. Terms & Conditions of access and use can be found at <http://www.tandfonline.com/page/terms-and-conditions>

Appendix H: Aging & Mental Health publication

Behavioural and psychological symptoms of dementia and their management in care homes within the East of England: a postal Survey

Abstract

Objectives: To determine the prevalence of antipsychotic use in care homes. To explore which behaviours care home staff can find difficult to manage and which non-pharmacological interventions are currently used within care homes to help cope with behavioural and psychological symptoms of dementia.

Method: A postal survey sent to all care homes registered as specialising in the care of older people or/and older people with dementia within four counties in the East of England ($n = 747$).

Results: Questionnaires were returned from 299 care home managers (40%). The vast majority ($n = 200$, 73%) reported having at least one resident with an antipsychotic prescription in their home. Twelve percent ($n = 1027$) of care home residents were reported to be prescribed antipsychotic medications. Aggression was most frequently reported, by 37% ($n = 109$) of care home managers, as a difficult behaviour to manage. Non-pharmacological interventions were reported to be used in 87% ($n = 253$) of care homes. The interventions most commonly used in care homes to manage difficult behaviours were reminiscence (75%, $n = 219$) and music therapy (73%, $n = 213$).

Conclusion: This survey was a first attempt to estimate the use of antipsychotics in care homes. Despite measures to reduce antipsychotic use for all people with dementia in England, we found that 12% of care home residents were still prescribed antipsychotic medication. Around half of all care home managers reported they had experienced behaviours they found difficult. Antipsychotic medications and a variety of non-pharmacological interventions appear to be used concurrently in many care homes.

Keywords

- care homes,
- homes for the aged,
- antipsychotic agents,
- non-pharmacological interventions,
- behavioural and psychological symptoms of dementia (BPSD)

Introduction

Behavioural and psychological symptoms of dementia (BPSD) is a term used to group a range of issues potentially distressing to the person with dementia and those around them. BPSD such as psychosis, aggression, apathy and anxiety are common in people with dementia (Lyketsos et al., 2000), particularly in care home populations (Ballard et al., 2001; Brodaty et al., 2001). These symptoms are likely to arise from a range of neurological, environmental and social factors. Predominantly, antipsychotic agents have been used to manage BPSD. The majority of these medications are not licensed

Appendix H: Aging & Mental Health publication

by the Medicines and Healthcare products Regulatory Agency in the UK for the treatment of BPSD and their use for this purpose is therefore 'off label'.

In 2010, because of the concerns about the safety of antipsychotic medications highlighted in a Government commissioned report (Banerjee, [2009](#)) the Department of Health in England pledged to reduce the use of these medicines for people with dementia by two-thirds by November 2011. Banerjee estimated that around 180,000 people with dementia were prescribed antipsychotics in the UK. The prevalence of dementia in over 65s was estimated at 6%, and the prevalence of over 65s on antipsychotics was estimated to be 5.3%, Banerjee concluded, conservatively, that at least 50% of people with dementia were likely to be prescribed antipsychotic medications. There was not enough evidence for him to estimate the prevalence of antipsychotic use in care homes.

The National Dementia and Antipsychotic Prescribing Audit conducted in 2011 obtained data showing antipsychotic prescriptions for all patients diagnosed with dementia from 46% ($n = 3850$) of general practitioner (GP) practices in England. The audit found 7% of people diagnosed with dementia were prescribed an antipsychotic medication, a reduction from 17% in 2006 (Health and Social Care Information Centre, [2012](#)). One study set in Medway Primary Care Trust in England found that 26% of the people on the dementia register who live within care homes are prescribed antipsychotic medications (Child, Clarke, Fox, & Maidment, [2012](#)). Neither of these studies provides an estimate of the prevalence of antipsychotic use in care homes. Several disparate studies show the prevalence of antipsychotic prescriptions for residents within UK care homes of different types, regardless of diagnosis, ranging from 15% to 58% (Allred, Petty, Bowie, Zermansky, & Raynor, [2007](#); Connelly, Law, Angus, & Prentice, [2010](#); Fossey et al., [2006](#); Macdonald, Carpenter, Box, Roberts, & Sahu, [2002](#); Shah, Carey, Harris, DeWilde, & Cook, [2011](#)).

As an alternative to antipsychotic medication use, non-pharmacological interventions such as aromatherapy, reminiscence, multisensory stimulation and massage are recommended as appropriate first line treatments for BPSD, due to the range of implicated triggers for these symptoms (NICE and SCIE, [2006](#)). Non-pharmacological approaches have been viewed as working to reduce BPSD in one of two ways (Brechin, Murphy, James, & Codner, [2013](#)). Some approaches, such as functional analysis (see Moniz-Cook et al., [2012](#) for a recent Cochrane review) and staff training in communication techniques are aimed directly at the reduction of BPSD. Other interventions, such as music therapy (Vink, Bruinsma, & Scholten, [2003](#)) and exercise (Teri, Logsdon, & McCurry, [2008](#)), have a more indirect effect on BPSD, for example by improving people's quality of life. A briefing paper published by the British Psychological Society outlines possible alternative approaches to antipsychotic medication and introduces a four-stage stepped care model to manage BPSD. The model advocates an individualised approach focusing on thorough assessment and a hierarchical approach to interventions, with antipsychotic medications only introduced at step four, if necessary and as part of a specialist intervention (Brechin et al., [2013](#)). This approach could provide a possible way forward for clinical and care practice in this area.

Appendix H: Aging & Mental Health publication

Yet, although there is a developing evidence base for non-pharmacological interventions (see, for example, Moniz-Cook et al., [2012](#); Whitaker et al., [2013](#)), at present it is still relatively limited. Using non-pharmacological interventions may require different approaches, skills and attitudes to be employed by care homes and their staff, and can be time-consuming, which shifts costs onto the care provider and raises challenges for their widespread incorporation into care settings.

With much attention focused on the reduction of antipsychotic medications and the use of non-pharmacological interventions to manage BPSD, current practice within care homes may be undergoing an important transformation. To inform the development of dementia care and assess how far the landscape has changed, it is necessary to establish how BPSD are managed in homes at this time. The term 'manage' in the context of this paper refers to the tools or interventions utilised by care home staff to assist them to cope with or address BPSD. The objectives of this study were to estimate the prevalence of antipsychotic prescriptions in care homes. In addition, we sought to explore the behaviour managers perceive as causing difficulty in the care home setting, since this may affect decisions about 'as required' (pro re nata or PRN) use of medication, and which non-pharmacological interventions or therapies are being utilised within care homes to manage BPSD. At the time of this study, to our knowledge this was the first survey to estimate the prevalence of antipsychotic use within care homes.

Methods

To address the objectives, a postal survey of care homes was employed. Four counties within the East of England (Norfolk, Suffolk, Essex and Peterborough Unitary Authority) were chosen to represent affluent, poor, rural and urban areas. Within the target counties, all care homes ($n = 747$) identified from directories in the public domain registered as specialising in older people and/or dementia were included in the study sample. The sample included nursing, non-nursing, dual registered, elderly mentally infirm, elderly severely mentally infirm and residential homes. In November 2011, a postal questionnaire, information sheet and prepaid return envelope were sent to all care home managers within the sample.

The questionnaire (available from the authors on request) was specifically designed to be quick and easy for care home managers to fill in to maximise the response rate. It comprised eight questions on one page; information about caring for people with dementia, antipsychotic use, perceived difficult behaviours and interventions used within the home to manage difficult behaviour was sought. Consent for participation was assumed on return of the questionnaire. The wider study, of which this phase is part, was reviewed and given a favourable opinion by the Social Care Research Ethics Committee (Reference number: 11-IEC08-0028).

Analysis

Data were analysed using SPSS18 (Statistical Package for the Social Sciences). Basic descriptive statistics were employed. Correlations and *t*-tests were applied as appropriate.

Appendix H: Aging & Mental Health publication

Results

Survey response

Survey responses were received from $n = 299$ (40%) care home managers; six responses were from managers declining to take part in the study and two were from respite only units and were excluded from the analysis, this left $n = 291$ (39%) completed questionnaires to be analysed. [Table 1](#) shows categories of the original sample and of the participating care homes. Categories reflect those used in the care home directories from where the sample was derived. Responses were proportionate across ownership, specialism and type of home. Homes that were registered as specialising in old age and dementia, those not providing nursing care or those privately owned were the majority in both the original and responding samples.

Table 1: Sample and response care home categories

	Original Sample $n = 747$		Response Sample $n = 291$		% of Responses from Original Sample
	Frequency	%	Frequency	%	
Ownership					
Private	661	88	247	85	37
Local Authority	20	3	9	3	45
Voluntary	66	9	35	12	53
Registered as specialising in					
Old age	247	33	99	34	40
Dementia	73	10	29	10	40
Old age and Dementia	427	57	163	56	38
Type of Home					
Home without nursing care	563	75	211	73	37
Home with nursing care ^a	184	25	80	27	43

^aIncludes dual registered homes

The sum of all residents from the 291 care homes was 9244 (mean = 32, sd = 17.66). As shown in [Table 2](#), 80 (27%) of the responding care homes provided qualified nursing care (including dual registered homes). In all, 85% ($n = 246$) of care homes reported caring for people with dementia even though only 66% ($n = 192$) of them were registered to provide this type of specialist service. Just over half of the responding managers ($n = 149$, 52%) reported they would admit people with challenging behaviour into their home and 124 (43%) managers reported experiencing an episode of challenging behaviour within the last week.

Appendix H: Aging & Mental Health publication

Table 2: Care home factors by home type (Nursing includes dual-registered)

	Home Type		Total n = 291	Missing Data n
	Residential n = 211	Nursing n = 80		
Number of homes				
Caring for people with dementia n(%)	178(84)	68 (85)	246 (85)	
Admitting people with challenging behaviour n(%)	108 (51)	41 (53)	149 (52)	4
Experiencing challenging behaviour in the last week n(%)	86 (41)	38 (49)	124 (43)	4
Using at least one non-pharmacological intervention n(%)	182 (86)	71 (89)	253 (87)	
Identifying 1 or more difficult behaviours n(%)	95 (45)	41 (51)	136 (47)	
Number of residents				
Total number of residents	5843	3401	9244	
Mean(sd) number of residents per home	28(14.4)	43(20.8)	32 (17.7)	
Total number of residents prescribed antipsychotic medication (regular and/or 'as required') n ^a	640	387	1027	17
Mean(sd) number of residents prescribed antipsychotic medication (regular and/or 'as required') per home	3(3.89)	5(7.34)	4(5.13)	17
Total number of residents prescribed 'as required' antipsychotic medication n ^b	190	128	318	14
Mean(sd) number of residents prescribed antipsychotic medications 'as required' per home	1(1.79)	2(3.63)	1(2.45)	14

^aData of prescribed antipsychotics were available for 274 care homes with 8579 residents

^bData of 'as required' (PRN) prescribed antipsychotics were available for 277 care homes with 8684 residents

Out of the homes caring for people with dementia ($n = 246$) only 58% ($n = 140$) would admit people with challenging behaviour and just under half (49%, $n = 118$) had experienced an episode of challenging behaviour in the last week. Homes that provided qualified nursing care had significantly more residents (mean = 42.51 (sd = 20.82) versus mean = 27.69 (sd = 14.39); $t = -5.86$, $p < .01$) than residential homes with a medium to large ($r = .49$) effect size.

Antipsychotic use

Seventy-three percent of care homes ($n = 200$) reported having at least one resident with an antipsychotic prescription within their home. Antipsychotic medications were prescribed to over 5 residents in 23% of homes and to over 10 residents in 8% of homes. One thousand and twenty-seven residents were prescribed at least one antipsychotic medication across the 274 care homes (mean = 4 (sd = 5.13), range 0–40), amounting to 12% of all residents ($n = 8579$). Of the 12% of residents prescribed antipsychotic medications, 8% represent regular prescriptions and 4% represent 'as required' prescriptions. Four percent ($n = 318/8684$) of care home residents in the sample and 31% ($n = 318/1027$) of those residents prescribed antipsychotic medications are having 'as required' antipsychotics administered based on the judgement of qualified nurses or unqualified care home staff. In all, 38% of care homes ($n = 105$) reported having at least one resident prescribed an 'as required' antipsychotic (mean = 1 (sd = 2.45), range 0–20).

Appendix H: Aging & Mental Health publication

We explored whether residents in homes providing qualified nursing care were more likely to be prescribed antipsychotics than residents in homes that did not. A significant difference was observed ($t = -2.264$, $p < .05$, $r = .23$), suggesting that homes providing qualified nursing care have on average (mean = 5.23, sd = 7.34) more residents prescribed antipsychotic medications than homes that do not (mean = 3.20, sd = 3.89). There was no significant difference between the type of home and 'as required' prescriptions. On average, the number of antipsychotic prescriptions was higher in those homes that indicated they were caring for people with dementia than those not caring for people with dementia. This difference was significant (mean = 4.13 (sd = 5.31) versus mean = 1.44 (sd = 2.89); $t = 4.66$, $p < .01$), with a medium effect size $r = .44$. This difference was also significant for 'as required' prescriptions (mean = 1.29 (sd = 2.57) versus mean = 0.33 (sd = 1.23); $t = 3.76$, $p < .01$, $r = .34$) where homes caring for people with dementia were found to have more residents prescribed antipsychotics than those that did not.

We also examined if care homes using non-pharmacological interventions had a lower number of residents prescribed antipsychotics than those not using them. The difference was found to be significant (mean = 4.07 (sd = 5.32) versus mean = 1.34 (sd = 2.16); $t = -5.31$, $p < .01$) with a large effect size $r = .47$, suggesting that, in the wider population, care homes using non-pharmacological interventions are likely to have more residents prescribed antipsychotics than homes not using them. This was the same for 'as required' prescriptions (mean = 1.28 (sd = 2.57) versus mean = 0.18 (sd = 0.53); $t = -5.82$, $p < .01$, $r = .35$) where care homes using interventions were found to have significantly more residents with 'as required' prescriptions for antipsychotics than homes not using them. The number of residents in care homes was significantly correlated with the number of antipsychotic prescriptions in care homes ($r = .43$, $p < .01$).

Behaviours and related issues care home staff found difficult to manage

Forty-seven percent ($n = 136$) of care home managers identified one or more behaviours or related issues that they or their staff found difficult to manage (totalling 329); 95% of these behaviours were reported from homes caring for people with dementia ($n = 130$). The free text answers were grouped into categories and are shown in [Table 3](#). Aggression was reported by 109 (37% of all homes) managers; 104 of these were from homes caring for people with dementia. The category aggression included the number of homes stating aggression and/or physical aggression ($n = 73$) and/or verbal aggression ($n = 33$).

The impact of difficult behaviours on either other residents or staff was reported by 34 (12%) care homes as being a difficult issue to manage; all of these homes were caring for people with dementia. Resisting care was reported as difficult to manage by 25 (9%) care home managers.

Appendix H: Aging & Mental Health publication

Table 3: The frequency of reported difficult to manage behaviours and related issues by care home

Behaviours and Issues	Homes that provide care for people with dementia		All homes	
	n ^a	%	n ^b	%
Aggression	104	42	109	37
Impact on Others	34	14	34	12
Resisting Care	25	10	25	9
Verbal Sounds	22	9	24	8
Agitation	16	7	17	6
Inappropriate Incontinence, Undress or Sexual Behaviour	17	7	17	6
Memory Loss or Confusion	14	6	16	5
Risk to Self (resident with BPSD)	13	5	15	5
Wandering	13	5	13	4
Emotional Behaviours	11	4	12	4
Persistent or Unpredictable Behaviours	8	3	9	3
Absconding	8	3	8	3
Night Time Waking	6	2	7	2
Eating Issues	7	3	7	2
Looking for Attention	5	2	5	2
Communication Difficulties	4	2	4	1
Other Peoples' Attitudes	3	1	3	1
Different Reality	3	1	3	1
Behaviours Requiring One-to-one Care	1	.4	1	.3
Deprivation of liberty	1	.4	1	.3

^a=246 homes ^b=291 homes

The use of non-pharmacological interventions

Care home managers were asked which non-pharmacological interventions they used to help care for people with BPSD. In all, 253 (87%) care homes used at least one intervention to help manage behaviour (mean = 4). Ninety-four percent (1045/1113) of these interventions were used in homes that were caring for people with dementia. [Table 4](#) shows the interventions reported to be used by homes. The interventions used in the most homes were reminiscence ($n = 219$; 75%), music therapy ($n = 213$; 73%) and animal/pet therapy ($n = 185$; 64%).

Appendix H: Aging & Mental Health publication

Table 4: Non-pharmacological interventions used by care home

Interventions used	Homes that provide care for people with dementia		All homes	
	n ^a	%	n ^b	%
Reminiscence	203	83	219	75
Music Therapy	200	81	213	73
Animal/Pet Therapy	172	70	185	64
Massage	102	41	108	37
Doll Therapy	91	40	92	32
Aromatherapy	53	22	56	19
Multisensory Stimulation	51	21	55	19
Reality Orientation	48	20	52	18
Behavioural Therapy	30	12	32	11
Validation Therapy	30	12	32	11
Other	65	26	69	24
No Therapies Used	13	5	38	13

^a=246 homes ^b=291 homes

Free text responses reported as 'other' included many categories, such as arranged activities, one-to-one activities, trips out, occupational therapy and physical exercise. Thirteen percent of homes ($n = 38$) did not use any non-pharmacological therapies; of these 66% ($n = 25$) were homes not caring for people with dementia.

Discussion

Contextualising the findings

Despite the recent strategy by the Department of Health in England to reduce the use of antipsychotic medicines for people with dementia, 12% of care home residents in the East of England were reported in late 2011 to still be prescribed these medications. Judgements over whether the Department of Health in England have met their original target of reducing antipsychotic use by two-thirds within this sector are impossible to determine, since there was not enough evidence to estimate a baseline prevalence within care homes. The prevalence of antipsychotic use for people in care homes appears to have reduced in comparison to the range of 15% up to 58% found in previous studies (mentioned above). Two care homes in our sample reported having 40 residents prescribed antipsychotic medications, these were large homes, even so, between 40% and 50% of their residents were reported to be prescribed antipsychotics, which is extremely high in comparison to the majority of homes responding to the survey. Our findings show that 27% of care home managers reported having no residents prescribed antipsychotic medication within their home; yet, this could reflect the homes in our sample that did not admit people with challenging behaviour (48%) and/or those only specialised in only old age (34%) where many residents may not have dementia.

Appendix H: Aging & Mental Health publication

The non-pharmacological interventions used in the most care homes were those whose primary aim could be described as improving quality of life (reminiscence, music therapy, animal/pet therapy). Reminiscence was the most frequently cited non-pharmacological intervention used, although its use is not evidence-based for the treatment of BPSD (Ballard et al., [2009](#); Woods et al., [2012](#)). It is noteworthy that 87% of homes reported that they were using some form of non-pharmacological intervention and that those homes using interventions were likely to have more residents prescribed antipsychotic medications than those not. This was a surprising finding and could indicate a high prevalence of BPSD in some homes; for example, in nursing homes where there are more likely to be residents with complex needs, which then require multiple management strategies. Conversely, it could indicate that the use of non-pharmacological interventions does not necessarily offset the need for such medications.

The management of BPSD is a topical area. There are many negative value judgements associated with the use of antipsychotics. Non-pharmacological interventions are recommended by NICE (NICE and SCIE, [2006](#)) as first line treatments for BPSD and there is some evidence that they could be cost effective (Matrix Evidence, [2011](#)). Yet, the evidence base for non-pharmacological interventions is poor (Ballard et al., [2009](#)) and, at this time, the authors cannot recommend one specific intervention. Until the costs for these interventions are covered by outside sources, care home managers may struggle to incorporate them into their homes.

Constraints when conducting care home research – limitations of the study

Care home research can be problematic. The multitude of different companies, organisations and individuals owning care homes makes them a very disparate group. Negative media representations, the stigma of antipsychotic use and its assumed association with suboptimal care could make care home managers reluctant participants in a survey of this kind. Care home managers (our target participants) are also busy people. It is likely that these factors had an impact on the survey response rate. Online and telephone surveys were considered by the authors, but postal surveys were chosen, since the directories from which the sample was derived did not include email addresses for care homes and the sample size of $n = 747$ made telephone surveys unfeasible.

Taking this into account, the 40% response rate, which could be viewed as a low level of compliance, is actually a satisfactory response rate for a survey of this type within the care home sector. This is particularly so since care home surveys, typically, have low response rates (for example, Gage et al., [2012](#)). Additionally, care homes are a difficult population to engage in research (Froggatt & Payne, [2006](#)), with other postal surveys sent to care home managers, without follow ups, typically generating 35%–38% response rates (Purandare, Burns, Challis, & Morris, [2004](#); Rodriguez, Sackley, & Badger, [2007](#)). The 40% response rate for this survey is at the higher end of this range. The survey has connected with a difficult group and elicited some important and useful observations to start to illuminate this under researched population in this very topical area.

Appendix H: Aging & Mental Health publication

Ignoring the response rate of 40% would be a mistake since non-response bias could be an issue in the data set. For example, it is possible only those care homes with low antipsychotic use responded to the survey. However, the demographics in [Table 1](#) indicate a proportionate response, providing some evidence that non-response bias was random and not systematic. Nevertheless, the results of this survey must be interpreted with caution.

The research team were keen to validate the survey in regard to antipsychotic use. Initially, the study design included a medication-mapping phase in a subset of care homes to verify antipsychotic prescription rates against the survey results. To adhere to ethical principles, consent is needed from each resident to read their medication administration record. For residents lacking the capacity to consent to the research, guidance has to be sought from a potential personal consultee (close family member or friend). The consultee has to be contacted and be asked for their opinion of whether the resident in question would have wanted to participate if they had mental capacity (Mental Capacity Act, [2005](#)). These factors made the 100% participation rate needed to determine an accurate antipsychotic prescription prevalence within care homes improbable, and also made the prospect of verification in the time available to the researchers untenable. This option was also made unsuitable by additional factors connected to the nature of care homes, such as changes in prescriptions, changes in residents' conditions and changes in the care home population since the survey was sent.

There is also likely to have been subjectivity and some ambiguity over issues, such as the use of non-pharmacological interventions, which are generally difficult to standardise (Leone, Deudon, Maubourguet, Gervais, & Robert, [2009](#)). Therefore, interpretations of what constitutes an intervention could have been varied; for example, reminiscence could mean an informal chat about the past or a formal session. The survey also relied upon the self-reporting of care home managers, who may have wished to portray their home in a certain way. Care home staff cannot prescribe antipsychotic medications themselves; however, prescription levels could have been under reported by managers due to the stigma associated with their use.

Conclusions

This paper highlights the difficulties inherent in self-completion postal surveys and in gaining prevalence information from individualised personal data. Twelve percent of care home residents in the East of England were reported to be prescribed antipsychotic medications. Aggression is reported to be the most difficult behaviour for care home staff to manage. A multitude of interventions, both pharmacological and non-pharmacological, are already employed by care home staff to manage BPSD.

Sponsor: This work was supported by the University of East Anglia; however, the university played no role in the design, execution, analysis, interpretation of data or the writing of this paper.

Appendix H: Aging & Mental Health publication

References

1. Alldred, D.P., Petty, D.R., Bowie, P., Zermansky, A.G., & Raynor, D.K. (2007). Antipsychotic prescribing patterns in care homes and relationship with dementia. *Psychiatric Bulletin*, 31, 329–332.
2. Ballard, C.G., Gauthier, S., Cummings, J.L., Brodaty, H., Grossberg, G.T., Robert, P., & Lyketsos, C.G. (2009). Management of agitation and aggression associated with Alzheimer disease. *Nature Reviews Neurology*, 5(5), 245–255.
3. Ballard, C.G., Margallo-Lana, M., Fossey, J., Reichelt, K., Myint, P., Potkins, D., & O'Brien, J. (2001). A 1-year follow-up study of behavioral and psychological symptoms in dementia among people in care environments. *Journal of Clinical Psychiatry*, 62(8), 631–636.
4. Banerjee, S. (2009). *The use of antipsychotic medication for people with dementia: Time for action*. London: Department of Health.
5. Brechin, D., Murphy, G., James, I.A., & Codner, J. (2013). *Briefing paper: Alternatives to antipsychotic medication: Psychological approaches in managing psychological and behavioural distress in people with dementia*. Leicester: The British Psychological Society.
6. Brodaty, H., Draper, B., Saab, D., Low, L.F., Richards, V., Paton, H., & Lie, D. (2001). Psychosis, depression and behavioural disturbances in Sydney nursing home residents: Prevalence and predictors. *International Journal of Geriatric Psychiatry*, 16(5), 504–512.
7. Child, A., Clarke, A., Fox, C., & Maidment, I. (2012). A pharmacy led program to review anti-psychotic prescribing for people with dementia. *BMC Psychiatry*, 12(115), 1–6.
8. Connelly, P.J., Law, E., Angus, S., & Prentice, N. (2010). Fifteen year comparison of antipsychotic use in people with dementia within hospital and nursing home settings: Sequential cross-sectional study. *International Journal of Geriatric Psychiatry*, 25(2), 160–165.
9. Fossey, J., Ballard, C., Juszczak, E., James, I., Alder, N., Jacoby, R., & Howard, R. (2006). Effect of enhanced psychosocial care on antipsychotic use in nursing home residents with severe dementia: Cluster randomised trial. *British Medical Journal*, 332(7544), 756–761.
10. Froggatt, K., & Payne, S. (2006). A survey of end-of-life care in care homes: Issues of definition and practice. *Health & Social Care in the Community*, 14(4), 341–348.
11. Gage, H., Dickinson, A., Victor, C., Williams, P., Cheynel, J., Davies, S.L., ... Goodman, C. (2012). Integrated working between residential care homes and primary care: A survey of care homes in England. *BioMed Central: Geriatrics*, 12(71), 1–10.
12. Health and Social Care Information Centre. (2012). *National dementia & antipsychotic prescribing audit 2012*. Leeds: National Health Service.
13. Leone, E., Deudon, A., Maubourguet, N., Gervais, X., & Robert, P.H. (2009). Methodological issues in the non pharmacological treatment of BPSD in nursing home – the TNM study. *Journal of Nutrition, Health & Aging*, 13(3), 260–263.
14. Lyketsos, C.G., Steinberg, M., Tschanz, J.T., Norton, M.C., Steffens, D.C., & Breitner, J.C. (2000). Mental and behavioral disturbances in dementia: Findings

Appendix H: Aging & Mental Health publication

from the cache county study on memory in aging. *American Journal of Psychiatry*, 157(5), 708–714.

15. Macdonald, A.J., Carpenter, G.I., Box, O., Roberts, A., & Sahu, S. (2002). Dementia and use of psychotropic medication in non-‘Elderly Mentally Infirm’ nursing homes in South East England. *Age & Ageing*, 31(1), 58–64.

16. Matrix Evidence. (2011). *An economic evaluation of alternatives to antipsychotic drugs for individuals living with dementia*. South Tees Hospitals Foundation Trust.

17. Mental Capacity Act. (2005). (c.9). London: HMSO.

18. Moniz-Cook, E.D., Swift, K., James, I., Malouf, R., De Vugt, M., & Verhey, F. (2012). Functional analysis-based interventions for challenging behaviour in dementia. *Cochrane Database of Systematic Reviews*, 2, Art. No.: CD006929. pub3.

19. NICE and SCIE. (2006). *Dementia: Supporting people with dementia and their carers in health and social care*. London: National Institute for Health and Clinical Excellence & Social Care Institute for Excellence.

20. Purandare, N., Burns, A., Challis, D., & Morris, J. (2004). Perceived mental health needs and adequacy of service provision to older people in care homes in the UK: A national survey. *International Journal of Geriatric Psychiatry*, 19(6), 549–553.

21. Rodriguez, N.A., Sackley, C.M., & Badger, F.J. (2007). Exploring the facets of continence care: A continence survey of care homes for older people in Birmingham. *Journal of Clinical Nursing*, 16(5), 954–962.

22. Shah, S.M., Carey, I.M., Harris, T., DeWilde, S., & Cook, D.G. (2011). Antipsychotic prescribing to older people living in care homes and the community in England and Wales. *International Journal of Geriatric Psychiatry*, 26(4), 423–434.

23. Teri, L., Logsdon, R.G., & McCurry, S.M. (2008). Exercise interventions for dementia and cognitive impairment: The Seattle Protocols. *Journal of Nutrition, Health and Aging*, 12(6), 391–394.

24. Vink, A.C., Bruinsma, M.S., & Scholten, R.J.P.M. (2003). Music therapy for people with dementia. *Cochrane Database of Systematic Reviews*, 4, Art.No.: CD003477. pub2.

25. Whitaker, R., Ballard, C., Stafford, J., Orrell, M., Moniz-Cook, E., Woods, R.T., ... Fossey, J. (2013). Feasibility study of an optimised person-centred intervention to improve mental health and reduce antipsychotics amongst people with dementia in care homes: Study protocol for a randomised controlled trial. *Trials*, 14(13), 1–10.

26. Woods, R.T., Bruce, E., Edwards, R.T., Elvish, R., Hoare, Z., Hounscome, B., ... Russell, I.T. (2012). REMCARE: Reminiscence groups for people with dementia and their family caregivers – effectiveness and cost-effectiveness pragmatic multicentre randomised trial. *Health Technology Assessment*, 16(48), 1–116.

Appendix I: Negotiations with care homes for case study phase

Care home negotiations for case studies

DATE 2012	CH	ACTION
16 th January	199	Letter sent
16 th January	102	Letter Sent
26 th January	199	Rang and arranged a visit with the manager
26 th January	102	Rang and arranged a visit with the manager
27 th January	102	Visited CH and met manager – manager to ring me
30 th January	199	CH manager rang me and cancelled appointment – said to ring them back in March
22 nd February	102	Rang CH left a message for the manager
24 th February	126	Letter sent
24 th February	1	Letter sent
6 th March	102	Rang CH – manager busy – left a message with another staff member
6 th March	126	Rang CH – manager not in today
6 th March	1	Rang CH – manager busy with a resident
7 th March	126	Rang CH – manager on phone to someone else. Rang back – manager not available
7 th March	1	Rang CH – phone engaged. Rang CH – left message with another staff member for the manager
8 th March	126	Rang CH – left a message on answer phone
9 th March	1	Rang CH – manager not in – try Monday
9 th March	126	Rang CH – spoke to manager – head of dementia unit should ring me. Head of dementia unit rang me. As no BPSD in unit at moment ring back in 3-6 months to see what the unit is like then.
9 th March	102	Rang CH – manager stated to ring back at 3.30pm. I rang back at 3.30pm – manager out.
12 th March	1	Rang CH – spoke to manager who declined to take part in the study
12 th March	63	Letter sent
12 th March	102	Rang CH – manager in meeting – staff member told me to ring back tomorrow
13 th March	145	Letter Sent
13 th March	199	Rang no answer x3. Rang – manager busy, another staff member asked me if I could ring back Thursday morning
13 th March	102	Rang – Staff member told me the manager was busy
15 th March	199	Rang and spoke to manager who had handed in her notice – no new manager appointed at the moment – probably best to exclude this home
16 th March	102	Manager rang me and invited me to start a case study on 26 th March
23 rd March	145	Rang CH – a staff member told me she thinks the manager said that they would be unable to take part at this time – she will get the manager to contact me
23 rd March	63	Rang CH – manager away – try next week Mon/Tue
27 th March	63	Rang CH – manager declined to take part
28 th March	290	Letter sent
28 th March	64	Letter sent
28 th March	60	Letter sent
12 th April	290	Rang CH – manager off this week – told to ring back next week
12 th April	64	Rang CH – message left with another staff member for manager
12 th April	60	Rang CH – manager out – left a message with another staff member

Appendix I: Negotiations with care homes for case study phase

16 th April	64	Rang CH – spoke to manager – maybe interested – ring back in middle of May
16 th April	60	Rang CH – spoke to a staff member who took my number and said the manager will ring back if they are interested – staff member sounded uninterested
23 rd April	290	Rang CH – spoke to manager arranged a meeting for 2 nd May 10am
2 nd May	290	Visited CH – arranged to start case study 10 th May 10am
21 st May	64	Rang CH – manager in a meeting – told to try tomorrow after 2pm
22 nd May	64	Rang Ch – manager not there – at other home she manages – I was told to ring her there – Rang other home and arranged a meeting for next Wednesday 11 am
30 th May	64	Visited CH – arranged to start case study 18 th June 10.30am
28 th June	126	Rang CH – no answer
3 rd July	126	Rang CH – new manager and new dementia nurse – not know of my study – new manager not there
7 th August	126	Rang CH – new manager in a meeting – busy all day – left my number with admin lady
8 th August	126	Rang CH – Manager said will pass me on to dementia nurse at her new place – Manager not interested in me going there
4 th September	127	Letter sent
14 th September	127	Rang CH, left a message for manager and my phone number
17 th September	127	Rang CH, Spoke to manager arranged a meeting for 24 th September 1pm
24 th September	127	Visited CH – arranged to start case study 1 st October 10.30am with an induction 28 th September 2pm

CH – care home

Appendix J: Interview and interviewee characteristics

Bullace View: Interview and interviewee characteristics

Role of Interviewees	Age Range	Gender	Length of Interview	Time and Venue
Assistant manager (S9)	18-30	F	52.04	11pm: Lounge
Assistant manager (S5)	41-50	F	35.09	11am: Manager's office
Senior carer (S7)	31-40	F	42.52	2pm: after lunch when cleaning up kitchen
Carer (S4)	41-50	F	21.54	11am: Coffee lounge during break
Carer (S6)		M	26.10	2pm: Dining room while setting up tables
Night carer: black African (S8)	41-50	F	28.48	10 pm: During night shift in entrance hall
Activity coordinator/carers (S1)	18-30	F	51.20	10am: Lounge

Gage Hill: Interview and Interviewee characteristics

Role of Interviewees	Age range	Gender	Length of interview	Time and Venue
Manager (S10)	41-50	F	28.03	2pm: Staff room
Team leader (S9)	41-50	F	39.09	3pm: Staff room after shift
Team leader (S13)	51-60	F	Joined S12's interview	10.30am: Staff room during break
Senior carer (S5)	51-60	F	16.57	4.30pm: Dining room
Carer (S6)	18-30	F	23.13	3.45pm: Kitchen while preparing tea
Carer (S7)	41-50	F	23.07	3.45pm: Kitchen while preparing tea
Carer (S4)	18-30	F	26.19	3.45pm: Kitchen while preparing tea
Carer (S12)	31-40	F	20.45	10.30am: Staff room during break
Activity coordinator/laundry (S3)	31-40	F	17.30	10am: Laundry room while ironing

Appendix J: Interview and interviewee characteristics

Mirabelle Way: Interview and interviewee characteristics

Role of Interviewees	Age range	Gender	Length of interview	Time and Venue
Manager (M1)	51-60	F	1.09.54	11.30pm: Main lounge
General Nurse (S4)	51-60	F	Joined S10's interview	9pm: Small unit lounge
Psychiatric nurse (S6)	41-50	F	26.09	4pm: Back office
General nurse (S7)	41-50	F	52.04	2pm: Activities room – day off
Night carer (S9)	51-60	F	50.02	1am: Staff room
Carer (S8)	51-60	F	43.29	12.30pm: Corridor on unit
Carer (S3)	18-30	M	30.53	12.30pm: Corridor – moving to spare bedroom
Carer (S10)	18-30	F	26.45	9pm: Small unit lounge
Carer (S13)	31-40	F	18.03	3pm: Activity room
Carer/activity coordinator (S2)	18-30	F	39.02	1pm: Staff room
Activity coordinator (S5)	31-40	F	24.39	2pm: Activity room

Cherry-Plum: Interview and interviewee characteristics

Role of Interviewees	Age range	Gender	Length of interview	Time and Venue
Manager (M1)	41-50	M	28.52	3.45pm: Empty bedroom
General nurse (S3)	51-60	F	18.00	2.30pm: Empty bedroom
General nurse (S4)	41-50	F	31.02	2.50pm: Empty bedroom
Psychiatric Nurse - nights (S8)	51-60	M	45.56	12.25am: Nurses station
Lead senior carer (S13)	51-60	F	20.35	3.45pm: Outside in smoking area
Senior carer (S6) joint interview with S7	41-50	F	24.12	1.45pm: Hairdresser's room
Senior carer (S7) joint interview with S6	41-50	F	24.12	1.45pm: Hairdresser's room
Carer (S2)	31-40	F	26.08	2pm: Staff room over lunch
Carer (S9)	51-60	F	24.06	9.45am: Staff room, then hairdresser's room
Carer/cleaner (S10)	31-40	F	22.47	12.50pm: Green lounge while on duty as cleaner
Night carer (S11)	51-60	F	1.27.30	2.30pm: Staff room – day off
Social care manager (S5)	41-50	M	26.34	3.25pm: Hairdresser's room
Social care (S1)	51-60	F	18.38	12noon: Dining room

Appendix K: Framework for analysis

The Framework

1 Monitoring/Surveillance/Protection

- 1.1 Communication
- 1.2 Documentation
- 1.3 Technology
- 1.4 Failed systems
- 1.5 Security/safety
- 1.6 Reviews

2 Staff Team Factors

- 2.1 Knowledge/experience/training
- 2.2 Individual characteristics/attitudes
- 2.3 Hierarchy/responsibilities
- 2.4 Cohesiveness
- 2.5 Role blurring
- 2.6 Confidence
- 2.7 Emotions
- 2.8 New staff

3 Care Home Dynamics

- 3.1 Environment effects
- 3.2 Ownership
- 3.3 Management
- 3.4 Admission criteria – resident cohort
- 3.5 Ethos/care style
- 3.6 Strengths/weaknesses
- 3.7 Care home journey/changes

4 Risk

- 4.1 Protect staff
- 4.2 Protect resident
- 4.3 Autonomy vs risk
- 4.4 Restrictions/DoLs

5 Impact of behaviour on others

- 5.1 Impact on residents
- 5.2 Impact on staff
- 5.3 Impact on self (person with BPSD) by other residents

6 Management of BPSD – issues/tensions

- 6.1 Interrupted work
- 6.2 Staff judgements – prioritising
- 6.3 Staff duty factors
- 6.4 Competing demands – duty to care for all
- 6.5 Staff uncertainty
- 6.6 When to intervene

7 Support

- 7.1 For care home
- 7.2 For staff
- 7.3 For residents
- 7.4 External agencies

8 Medication

- 8.1 PRN
- 8.2 Review/monitor
- 8.3 Instating
- 8.4 Administration
- 8.5 Knowledge of
- 8.6 Perception of

9 Strategies/Interventions/Approaches

- 9.1 Person centred care
- 9.2 Lack of PCC
- 9.3 Knowing the resident
- 9.4 Communication techniques
- 9.5 Flexibility
- 9.6 Hierarchy of interventions
- 9.7 Routine
- 9.8 Trial and error
- 9.9 Non-pharmacological interventions
- 9.10 Activities/trips
- 9.11 Segregation/positioning
- 9.12 Avoidance/ignoring
- 9.13 Coercion/reasoning
- 9.14 Staff/resident relationships
- 9.15 Moving on
- 9.16 Timing of intervention

Appendix K: Framework for analysis

- 9.17 Balance – neglect/forced care
- 9.18 Staff approach
- 9.19 Distraction
- 9.20 Perception of intervention
- 9.21 Strategy helps who?
- 10 Resources**
- 10.1 Financial
- 10.2 Physical
- 10.3 People
- 10.4 External Agencies
- 11 Behaviours**
- 11.1 Aggression
- 11.2 Resisting care
- 11.3 Verbal sounds
- 11.4 Agitation
- 11.5 Inappropriate incontinence, undress or sexual behaviour
- 11.6 Memory loss/confusion
- 11.7 Wandering
- 11.8 Emotional behaviours
- 11.9 Persistent or unpredictable behaviours
- 11.10 Absconding
- 11.11 Night time waking
- 11.12 Eating issues
- 11.13 Looking for attention
- 11.14 Communication difficulties
- 11.15 Different reality
- 11.16 Patterns of behaviour
- 11.17 Changes in behaviour
- 11.18 Perception of Behaviour
- 11.19 Perception of cause of behaviour
- 12 Reflexivity**
- 12.1 My role
- 12.2 Interviews
- 12.3 Ethics
- 12.4 Data access

Appendix L: Example excerpt of an indexed interview transcript

<p>64 Interview S13 – In activity room after shift – I had nearly lost my voice, S13 needed to go in a short while so it was a rushed interview</p> <p>Age: 31 – 40</p> <p>Your length of time as a care worker</p> <p>Um, in total or here?</p> <p>In total</p> <p>In total, um, oh my God three, three, three years like consecutive, but then before that I, I'd stopped doing caring then probably for about four years before that, so I supp, do you know what I mean, so I done like that four years then stopped for a bit and then gone back into it so for a while.</p> <p>Oh fantastic and how about here?</p> <p>Um, April, four months now is it, April, May, June, July, August, yeah four months.</p> <p>Can I just ask about your training in regards to looking after people with dementia?</p> <p>Um, what training I've received here? Um, there's loads of training I think the training here is amazing, I really do, um, already I've had safeguarding, um, I've got dementia training coming up, I've had all fire, um, health and safety, um, all them um, and they are in detail and they're not always done from people here, sometimes it's head office, people from the head office come down, which I think is good 'cause you get to know everyone from every aspect of the place instead of just this home.</p> <p>Oh that's really good then</p> <p>Yeah</p> <p>So have you had to do an NVQ or are they?</p> <p>I've already done my NVQ2 um, yeah and when I, I did say to M when I came for interview that I, even if I can't be, because obviously I can't be a senior here because it's nurses um so I said 'obviously I understand I can't be a senior but I'd still like to do my NVQ3 'cause then that will give me that knowledge' so fingers crossed (laughs).</p> <p>Ah that's really good (laughs). Okay I'll jump to like the crux of the things, um, first of all what behaviours do you find difficult to manage?</p> <p>Um, behaviours, I suppose it's when they get aggressive and angry, um, because you kind of like, you want to help, but you don't want to get hurt (laughs) you know, so, for instance if someone was to, to lose their temper um and they had something that could be dangerous, that's when you, you'd obviously be a bit scared but you need to try and calm them down to be able to, but yeah I'd say that's the only one I worry about, anger.</p> <p>So what would you do to calm them down? (laugh at my voice)</p> <p>(laughs) Just try and talk to them to start off with, try and talk to them or deter them away from that situation, so maybe 'shall we go and have a cup of tea?' or 'shall we walk out in the garden?' to, to, to try and change that, that the way they're thinking 'cause obviously the, the way they're thinking is just anger and um, yeah, just want to hurt someone maybe or to get that anger out, whereas by totally changing it, or sometimes go and get someone else because a totally new face can work so different to you trying to do it.</p> <p>Yeah. Thanks. Thinking about, you've worked at other places and then you've come here and I found that an interesting thing, can you talk about the differences...</p> <p>What in what I've had before to here?</p> <p>Yeah</p> <p>Here, this place, I think this place is very um, person centred, definitely, definitely, all about what, what they want, what they want to do, what they want to wear, what they want to eat, um, and everyone is, is an individual, they, if they don't want to eat</p>	<p>12.2</p> <p>2.1</p> <p>2.1</p> <p>2.1</p> <p>2.1</p> <p>3.2</p> <p>2.1</p> <p>11.1</p> <p>6.6</p> <p>4.1</p> <p>5.2</p> <p>9.18</p> <p>9.4</p> <p>9.19</p> <p>11.19</p> <p>9.5</p> <p>9.1</p> <p>9.7</p>
---	---

Appendix L: Example excerpt of an indexed interview transcript

Um, I don't know, I guess you need lots of patience and also again it's down to that, you try and, like for instance with 'resident's name' um, I mean I had her screaming at me the other day right in my face, in, like almost intimidating me because I was like 'she's going to wack me in a minute'	9.8 5.2 9.4
She's a lot taller than you	
Yeah but I was firm, but nice, you know, because I was like ''resident's name' it's rude to scream at me and shout at me in the face' and once, after a little while she did actually say 'oh I didn't mean to be rude' even though she was still shouting at me, she was like 'I didn't mean to be rude' and I was like 'but you need to come out of here because you're upsetting everyone' you know, but again we don't just 'out' and ignore them, it's like 'out, let's talk about it' and, and again try and calm them down. Often obviously for 'resident's name' it was for a cigarette so you'd take her for a cigarette and she'd be totally different, but um, but yeah we do try and say to them 'you cannot scream and shout like that because there are other people living here, um, go out in the garden if you want to, if you want to be loud (laughs)	5.1 9.18 5.3 9.11 9.1 6.4 3.1 9.11
(laughs) yeah	4.4
But to be fair it is only really 'resident's name' and 'resident's name' yeah sometimes 'resident's name' upsets people so, but again try and shut the door um for a little while if she's obviously keep doing it, but you just keep trying to change, if she looks uncomfortable we put her in the bed or chair and just to try and, they're obviously shouting for a reason, so to try and sort that, that problem out.	9.12 9.8 11.19 11.19
Yeah, so look underneath it a bit	9.8
Yeah, yeah, instead of just thinking 'oh my God they're screaming, it's doing my head in' actually like why is she screaming, is she uncomfortable, does she need the toilet and because she's sitting in the chair it's you know, so we put them to the bed and maybe the bed, she's still screaming so it's like maybe the drink, you know, so you go through everything to try and...	9.11
Try and sort of alleviate it	
Yeah	
One of the issues, um that you've mentioned is like the impact on others and that seems to be a big factor with a lot of the behaviours, perhaps a factor that makes them difficult in a way because	5.1 11.3
Yeah, yeah, because like, because sometimes like, I don't know, 'resident's name' can get upset because 'resident's name' is shouting, so then that will start 'resident's name' off and then, so you do try and like ''resident's name' let's go, we'll go this way' because we know that's going to kick 'resident's name' off. Um, so yeah some of them do start each other off. Um, but yeah again it's just trying to, to calm them, split them, seper, you know, we used to when 'resident's name' was around we'd try and keep 'resident's name' away and vice versa, um whereas we don't really have that problem with 'resident's name' and 'resident's name' and stuff	9.11 R 9.18 9.11 6.4 6.6
No	
Um, they are in there room and, yeah..	
Okidoke. Another, um are you alright it's 9 minutes?	12.2
Yeah you're alright	
Just a couple more?	
Yeah	
Um another one um that comes up time and time again is resistance to care, so perhaps somebody's wet and they need to be changed but they're	
They don't want to be	2.6
Anti, yeah can you talk me through because it's a dilemma everywhere it's not just here	11.2

Appendix L: Example excerpt of an indexed interview transcript

Yeah, yeah, um, we're pretty good 'cause most of them, they'll either tell you they're wet or they'll want to, um, my experience, if I try because someone's wet and they really don't want it I'll leave them and get someone else straight away because obviously they're wet, it needs to be dealt with, um, on a couple of occasions um people have got really aggressive so we have actually left them wet just for a little while, maybe 10, 15 minutes, gone back and then they've let us do it, um I've never, ever had to restrain someone or anything like that um, eventually they've always been willing to let me change them, you know, even if it is within that half an hour um, I do know obviously sometimes there are people that, er, 'cause 'resident's name' was resistant I think one time she didn't want to have, but they used the towels and explained why they'd used towels because they didn't want to grab her and hurt her and bruise her and, and she accepted that and she was fine um, but yeah I've never had anything like that, that's always been if they, like for instance like 'resident's name' I asked one night, he was like 'no, I'm fine that will be alright' so I was like 'okay' walked off, a little while later asked him again, he was alright 'yeah I'll do that' so that's within that, within that 5, 10 minutes um, they can totally change so therefore it's yeah, so much easier.	9.5 9.17 11.1 11.2 9.8 11.17 4.4 9.17 9.5 11.17
Oh that's really good. Um, I'll just ask you about the support, you've talked about the training you get here, what other sources of support are available to you?	7.2 2.4
Um, I think there's loads of support here from everyone, team, obviously you're all a big team so there's always that help, 'M's name' is amazing, if ever you needed anything 'M's name', even 'admin's name' the admin you know there's many a questions I've asked 'admin's name' because I'm like 'oh I'm a bit worried about going to 'M's name'' she's like 'don't be silly' but yeah, so the support is, is, is amazing and, and they also tell you that, there's also numbers in the staff room for like head office or um, if you want to speak to anyone at of them you know, um, so yeah that is really good here.	3.3 2.3 7.2 2.4
That's what I've seen	6.3
Yeah definitely, definitely and there's always someone ready to help, I don't think I've ever heard anyone like bitching or arguing or being horrible about someone and um it's always been support 'can you help me with this?' 'yeah of course' you know or even the shifts, I've never swapped a shift yet, but I often hear people keep saying 'oh I really need to swap that shift' and 'oh yeah I'll do it' you know so everyone's so helpful.	7.2
And also in regards to saying 'I can't get anywhere with that resident can you have a go?' do you know what I mean?	9.8
Yeah, yeah, yeah, yeah	
Is that seen as okay? Not like you're shirking your job?	9.6
No, no everyone is like if you can't, as long as obviously you've tried, I think if I just saw someone go 'do you want to go to the toilet?' um, and the bloke or the woman saying 'no' I mean then they didn't actually try anything, then I'd be a little bit annoyed, but no it's not, it is literally like 'I have tried my hardest' it's kind of 'okay, well I'll have a go' um and if not we'll try again later, you know um, and the same with like medications, sometimes the nurses don't get anywhere but they give them to us and we go 'here you are' and they'll take it and they're absolutely fine.	9.5 8.4 2.4 7.2 2.5 2.2 9.14
So individual personalities and relationships	
Yeah and I guess they're, the residents are the same as us, there's people they do and don't like (Continued)	9.18

Appendix M: Example of charting analysis phase – interviews from 1 case study care home

Chart 3: Issues and Tensions				
CH 290	4.1 Protect Staff	4.2 Protect Resident	4.3 Autonomy VS Risk	4.4 Restriction/DoLS
S3 Int				
S4 Int	Try to get res off you without hurting them p4, 2 staff if res will fight them p4,	Keep down stairs if wander as secure p3, Try to get res off you without hurting them p4, 2 staff for res safety p4,	Staff can hold res if need to p1,	Shut doors to stop res go in other's bedrooms p2, locked doors to make secure area p3, lock on other side of lift – create secure area p3, if res wander = keep in secure area of home p3,
S5 Int		Staff monitor res at all times – one on floor p3, if not safe = refer – MH team – change meds –if not work = move on p4,		PC – resistive res – staff try to be gentle p1, staff monitor and lead away from risks – move lift to first floor = res not able to open door p3, shut doors to other res bedrooms = restrict wanderers p4,
S6 Int	Defend self without hurting res p3,	Defend self and not hurt res – here to look after them p3,	Stairs – res able to walk up there – can't take away every risk p2,	Stop res absconding p2,
S7 Int		Push res back in doors to protect from road/outside world p4, step in R to protect both res p5, PC can't be left not done p6,		Stop from absconding – got to stay in home p4, can't leave in entrance hall as stairs risk – res have to stay in shared secure area so staff know if okay – freedom in restricted area p4,
S9 Int		Safe because of secure area p5, pressure mats for quick alerts to res p6, Not give R1 a cup of tea unless seated p9, authoritative voice – stops res in tracks p10,	Wandering is fine if res safe p8,	Hold hands during PC or use handling belt p2,3, res upset as want to go home p4, secure area – res no access to stairs or front door p5, others not allowed in res

Appendix M: Example of charting analysis phase – interviews from 1 case study care home

				bedrooms in living bit p6, night staff shut fire doors in corridor to slow res down p6, used to have a big gate at front before secure area p6, safety rails on beds p6, tone of voice to stop resident causing damage p10,
S10 Int M		Absconding res – scary = secure unit = protect res from getting out/road p6,		Free range home – but within restriction p6,
S12 Int		March res out of way = stop hurt self p5,	Risk assessments done by M p5, march res away from where she was hurting herself p5, R1 wanted cup of tea, but not sit – weighing up the risk p5,	1 res can go up stairs on own, others you say come down and they're fine with it p2, physical restraint – physical restraint forms in care plan – march off with 2 carers if lashing out R p5, trained in physical restraint – working here = need it p6,

Chart 3: Issues and Tensions

290	5.1 Impact on Residents	5.2 Impact on Staff	5.3 Impact on Self	6.1 Interrupted Work
S3 Int		Feels uneasy – gets carers p3,		
S4 Int		R1 can kick staff, hit staff = difficult p1, Emotional when res get ill p3, if R1 grabs you = allow it as if pull away he tightens p3, fighting staff, spit on staff p4, Stressful when short staffed or when visitors or competing demands or		Res interruption Int, alarm – emergency p1, staff interruption int p7, visitors = want drink = interrupt usual routine p7,

Appendix M: Example of charting analysis phase – interviews from 1 case study care home

		someone's playing up p7,		
S5 Int	D res = danger to other res = refer p4,	Mentally and physically exhausting – conducting PC when res is resisting p1, worn out after PC if res resists p2,	Refer res if danger to others = new meds = move on p4,	Res takes pad off = int paused p1, S56 goes to intervene in argument R in next room during int p3, res tries to get in lift S5 informs res it is lift and tells res where loo is p3,
S6 Int	Res in other res rooms p3,	Job hard going and can be stressful – need a good team p3,		Staff interruption to int p4,
S7 Int		R1 nearly broke S7 finger – p1, get hurt now and then by res p5, hit S7 and she cried – walloped S7 = shocked – cry – bashed in face = wary p5,	Resist care = more staff – abscond = restrictions put in place	Staff interruption to int p2, res interruption p2, emergency alarm p4, res interruption p6,
S9 Int	If res unsettled others get unsettled too p1, res in other res bedrooms = difficult p6, wandering and touching others things = upset other res p8,	Get upset or can't deal with p3, stressful job so need good team p3, secure area – helps staff = less worry – before res could get out p6, carer feel as though they failed if another carer can do it p9, hard for carers when hit etc p9, carers hurt with wounds – but take it off the res p9, staff put up with a lot p9 staff get hurt p10, can feel why them p10,	Res gets agitated – if no med given = res upset and tearful p1,	Carers used to do activities but kept getting called away ACs better p7,
S10 Int	Secure garden – res complain when doors to it are open though p6, res have to have D to tolerate Bs at 290 p2,			
S12 Int	Risk of R1 hurting res p5,	Scary working with D at first p1, everyday = sworn at, hit or nipped p1,	Res lashing out at door = blamed carers for bruises =	Staff interruption in int p2,

Appendix M: Example of charting analysis phase – interviews from 1 case study care home

		know not mean it, but against us p1, just walk away = hard to do, but do it p1, 2 scratches on face – leaning down and got grabbed and scratched p4, res hurt carers p3,	marched away from door to protect p5,	
--	--	--	---------------------------------------	--

Chart 3: Issues and Tensions				
290	6.2 Staff Judgements	6.3 Staff Duty Factors	6.4 Competing Demands	6.5 Staff Uncertainty
S3 Int		2 laundry girls to cover each other – hols, sickness p1,		Not told what activities to do = uncertain p1, uncertain as to whether she should have training for activity role p1, hard to find ideas of what to do with res p2, need to sort out resources p2, not sure of activity budget – came and got on with it p2, worried about doing wrong thing with res = B = get carer asap p2, S3 = uncertain if res needs loo or has CB – uneasy – no training or experience - gets carer p3, not sure would like job, but love it p4,
S4 Int		Lunch time and shift change time = hard parts of day with B p4, nothing to do = activity p6, short staff = hard = guilty as no time p6, holiday = short staff p6, 5 new staff = only 2 left p6, try to get as many to bed as can or change res ready	short staffed = juggling – stress p7, short staff = hard = guilty as no time p6,	

Appendix M: Example of charting analysis phase – interviews from 1 case study care home

		in late shift p6, short staffed = juggling – stress p7, 1 staff does teas in kitchen		
S5 Int				
S6 Int	Try to look after both res when R – decide who to lead away p3,	Part time staff only evenings p1, not enough staff – people don't want the job p4, mornings busier but res worse in eve – activities in am – staff prepare teas in eve p4,	Trying to look after both res R p3,	
S7 Int	Chose to push res back into secure unit!	3 staff need to be free to PC with R1 p2, floor has to have a staff member on at all times – break times = no toileting for other res as take staff off floor p3, prepare tea by carers – do early in case get busy p4, carers = not time to do activities p5,		Res wanting to go home = S7 – hard to know what to say p3,
S9 Int	Weigh up res and see what like each day as to what to do p5, got to learn over time and take in your stride p5, risk assess on a day to day basis p9,	Discuss problem at time rather than leave for staff meeting p4, help out on nights if desperate p7,	Let res wander but not upset the others p8,	
S10 Int		Staffing levels – owner thinks are too high, but res cohort needs them p4, carers no time to do activities – role on it's own p4, kitchen a pain – hot – no storage p6,		
S12 Int	Weigh up risks eg tea for R1 if walking p4, monitor – keep eye on – judge when to step in p5, find a balance – judges how to	Full time S12 p5, 2 carers on floor at all times p3, stagger breaks p3, night staff = stay on floor as only 2 here p3,		

Appendix M: Example of charting analysis phase – interviews from 1 case study care home

	approach res p6, 7,		
--	---------------------	--	--

Chart 3: Issues and Tensions				
290	6.6 When to Intervene			
S3 Int				
S4 Int	Start fighting R = intervene p5, res = shouting, voices raised = intervene – when going to be a scrap p5, depends when intervene – if res just call each other names and walk past = okay p5,			
S5 Int	Change of tone in voice = intervene p3,			
S6 Int				
S7 Int	Hitting R grabbing = intervene p5, if goes too far = split up p5,			
S9 Int	If res needs PC p4,			
S10 Int				
S12 Int	When res get fisticuffs or lash out p4, monitor if too verbal or start physical = step in p4, physical restraint if that far p5, if lashing out at each other – march off p5,			