



**DEVELOPING AN EVIDENCE-BASED
INTERVENTION TO IMPROVE AGITATION
FOR PEOPLE WITH DEMENTIA LIVING IN
CARE HOMES**

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*A thesis presented for the degree of
Doctor of Philosophy (PhD)*

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Declaration

I, Penny Lea Rapaport confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Date

Penny Lea Rapaport

Acknowledgements

I would like to thank my supervisors for encouraging me to pursue this PhD. Claudia, you have inspired me to persist with this challenge, even when it has all felt too much. Gill, I have looked to you for mentorship and inspiration and have learnt from how you both balance rigorous academic scholarship with warmth and commitment to improving the lives of people living with dementia and their families. I am fortunate to have been guided by such great leaders, and it is to you both that I owe the learning and personal distance I have travelled on my academic journey. Thank you to ESRC and NIHR supporting the project and for the NIHR CLAHRC support to maintain my focus on the PhD alongside other commitments.

Thank you to the MARQUE project team for all of your support in the development, delivery and testing of the intervention. Sarah, Adam, Leah and Olivia, I am sure much of the success of this project was a direct result of your facilitation and interpersonal skills; thank you for your honest reflections in supervision. It has given me such pleasure to see you all moving forward in your careers. Thank you to all of the care home staff, family carers and professionals who contributed to the development of the MARQUE intervention; I feel humbled that you trusted me with your knowledge and experience and I hope that my interpretations warrant your generosity. Thank you to Suzanne Reeves, Kathryn Lord and Natalie Marchant for nurturing me and for ensuring that I always had someone to laugh and eat with.

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Abstract

Background

Agitation is common, persistent and distressing and can lead to care home admission. There is a paucity of evidence for the sustained effects of interventions to manage agitation and little is known about how care home staff understand and respond to residents' agitation.

Aim

To co-produce and initially test the feasibility and acceptability of the MARQUE (Managing Agitation and Raising Quality of Life) intervention, an evidence-based, manualised training intervention to reduce agitation.

Methods

I conducted a systematic review of effective components of psychosocial interventions delivered by care home staff to people with dementia and a qualitative study of care home staff experiences of caring for agitated residents. I integrated these findings with additional stakeholder involvement, co-producing the intervention. I conducted a mixed methods feasibility and process evaluation in one home.

Results

Care home staff experienced agitation as diverse, unpredictable and persistent and tried to prevent agitation from emerging and manage episodes once they occurred. Responding to agitation was not a linear process and staff faced dilemmas when attempts to respond to residents' needs were inhibited by structural and procedural constraints. I co-produced a manualised training intervention with a system of on-going support to reduce agitation in people living with dementia in care homes. I

successfully recruited and retained staff and residents with dementia and delivered the intervention to eligible staff in the care home.

Conclusions

To ensure sustainability and maximise implementation, I developed an intervention to support staff to identify and respond to resident unmet needs, to look after themselves and to minimise the impact of agitation, building upon the approaches and strategies already being used by care home staff. In initial testing, I found that the co-produced MARQUE intervention was feasible to deliver, acceptable to staff and ready for testing in a randomised controlled trial (RCT).

Impact statement

Who will benefit from this work?

This PhD will potentially impact on: 1) people with dementia and their family carers through better understanding and care for those living in care homes and experiencing agitation. 2) those implementing health and social care policy and 3) the academic community.

1. Patient impact

People with dementia and their family and paid carers are the primary intended beneficiaries. In the short-term, I hope that the intervention developed in this project is fit for purpose and deliverable in the full cluster RCT, benefitting the people living with dementia and the care staff participating. If the intervention developed and initially tested in this project is subsequently clinically and cost-effective, there will be medium-term benefits, by improving the lives of people with dementia. An intended aim of this thesis was to develop an intervention that is not only effective but also sustainable and scalable in real world care home settings, with potential long-term social and economic benefits. Agitation is one of the commonest and most distressing neuropsychiatric symptoms of dementia, affecting functioning and relationships. People with dementia and significant agitation cost more than double to care for than those with dementia without agitation. The intervention has potential to reduce health and social care service use as well as to mitigate the devastating social, psychological and physical impacts of agitation.

2. Public health and policy impact

This project's outputs include new understandings on how to sustain non-pharmacological interventions for agitation and effect change in care home care-delivery more broadly. The work in this thesis will also contribute to understandings of how best to include those affected by dementia and other stakeholders in co-production. I have iteratively fed-back to a range of stakeholders in the MARQUE

community of interest and as the findings from the MARQUE RCT become available we will continue this process of dissemination. Together with the MARQUE team I will use existing relationships to communicate findings and help deliver changes in policy and practice at local, national and international levels. I have already begun to present the findings and by considering implementation throughout the research process, if the intervention is effective, we will be well placed to support translation and implementation across the care home sector.

3) Academic impact

The findings of this research are applicable to academics in psychology, medicine, nursing and sociology, government bodies, universities and other research centres. I have already published and presented the findings in peer-reviewed journals and at national and international conferences as well as contributing to an NIHR (National Institute for Health Research) podcast on research in care homes and how the findings of this project are helping understandings of agitation. I will be travelling to present these findings to our international collaborators (September 2018) and I am co-applicant on a submitted application on the long-term impact of the MARQUE intervention upon care home culture, extending the impact of these preliminary research findings.

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Statement of personal contribution

My PhD is embedded within the MARQUE programme, of which Professor Gill Livingston (GL) is Chief Investigator (ES/L001780/1). I also received funding from the NIHR Collaborations for Leadership in Applied Health Research and Care (CLAHRC) scheme. As will be discussed throughout this thesis, although I led the intervention development this was a collaborative process which drew upon extensive knowledge within and outside of the MARQUE team.

As principal researcher for this study, my contributions were as follows:

- I designed and wrote the PhD research proposal with input from academic supervisors.
- I contributed to the grant application process for the MARQUE programme of which this PhD is part. I contributed to the MARQUE stream three protocol development and ethics applications, including attending the ethics committee meeting.
- For my systematic review, I conducted the literature searches, data extraction, study quality appraisal and wrote the first draft of the published paper.
- For phase one, I conducted all individual qualitative interviews with care home staff. The data were professionally transcribed and I coded and analysed all the qualitative data. This was also independently coded by MARQUE research assistants. I wrote the first draft of the paper for publication.
- For phase two, I led the co-production of the MARQUE intervention. As part of this process I co-facilitated the focus groups with family carers. MARQUE research assistants and I interviewed care home staff and members of the MARQUE steering group and community of interest for feedback. I collated

and analysed this information and wrote the first draft of the intervention and revised subsequent drafts with feedback from the MARQUE team and academic and lay partners. I worked with Adam Kadri (research assistant) on the visual design of the intervention manual. I developed a training programme for the research assistants facilitating the intervention together with Dr Suzanne Reeves (consultant psychiatrist) and delivered this with colleagues in the MARQUE team.

- For phase three, I consented the care home for the feasibility study with Sian Cousins, MARQUE project manager. Baseline and follow-up quantitative assessments were collected by Aisling Stringer (research assistant) with support from other MARQUE research assistants. I facilitated the follow-up focus groups and interview. Qualitative data were transcribed by a professional company. I fully checked the data and I developed the qualitative and quantitative analysis plans with input from my supervisors. I analysed the qualitative and quantitative data. I clinically supervised the facilitators of the intervention and delivered post-training support in the care home. I drafted the final version of the MARQUE intervention and developed an implementation guide to support the full trial.
- I wrote all of the thesis content.

List of abbreviations

CBT	Cognitive Behavioural Therapy
CC	Claudia Cooper
CDR	Clinical Dementia Rating
CI	Confidence Interval
CLAHRC	Collaborations for Leadership in Applied Health Research and Care
CMAI	Cohen Mansfield Agitation Inventory
COPE	Coping Orientations to Problems Experienced
CQC	Care Quality Commission
DCM	Dementia Care Mapping
DICE	Describe, Investigate, Create a plan, Evaluate
ERIC	Expert Recommendations for Implementing Change
ESRC	Economic and Social Research Council
GL	Gill Livingston
MARQUE	Managing Agitation and Raising Quality of Life
MCTS	Modified Conflict and Tactics Scale
MRC	Medical Research Council
MBI	Maslach Burnout Inventory
NDB	Need-driven Dementia-compromised Behaviour
NICE	National Institute for Health and Care Excellence
NIHR	National Institute for Health Research
NVQ	National Vocational Qualification
PCC	Person Centred Care
PPI	Patient and Public Involvement
RCT	Randomised Controlled Trial
RNV	Alzheimer's Society Research Network Volunteers
SCIDS	Sense of Competence in Dementia Care Staff
SRQR	Standards for Reporting Qualitative Research
TDM	Theoretical Domains Model

Chapter 1 Introduction

Dementia is a major current and future global health challenge, with the number of people living with dementia worldwide set to triple from over 46 million to 131.5 million by 2050 (Prince et al., 2015). As disability and dependency increase, dementia profoundly impacts upon the person living with dementia, their family and carers as well as wider society, with the annual global cost of dementia estimated at 818 billion US dollars (Prince et al., 2015). The recent Lancet Commission on 'Dementia prevention, intervention, and care' highlights that although there is no known cure for the underlying illness, good quality care interventions can reduce the impact of cognitive, behavioural and psychological symptoms both on the person themselves and those caring for them (Livingston et al., 2017b).

It is estimated that one third of those living with dementia in the UK live in care homes (Department of Health, 2015) and over 70% of UK care home residents have dementia (Prince et al., 2015). People with dementia living in care homes experience high levels of physical co-morbidity and neuropsychiatric symptoms (Ballard et al., 2001, Livingston et al., 2017a) and staff are often ill equipped and lacking in the knowledge, skills and resources to effectively deal with these complexities (Franklin, 2014, Testad et al., 2010). Although there was a key commitment in the Prime Minister's challenge on dementia to improve standards in care homes by 2015 (Department of Health, 2012), echoed in the priorities of campaigning organisations (Alzheimer's Society, 2016), and accompanied by investment in dementia care research (Department of Health, 2012, Department of Health, 2015), this is not a simple task.

During my career as a clinical psychologist working with people with dementia in a range of service settings, I have experienced first-hand the challenge of delivering good quality evidence-based care to people with dementia, especially in residential settings. At the same time, I have seen how supporting care home staff to make

small changes to their practice can have a big impact on both them and the residents. However, even introducing small changes can be challenging.

In 2015 the James Lind Alliance Dementia priority setting partnerships identified three of the top ten agreed research priorities as:

- **How can the best ways to care for people with dementia, including results from research findings, be effectively disseminated and implemented into care practice?**
- **What non-pharmacological and/or pharmacological (drug) interventions are most effective for managing challenging behaviour in people with dementia?**
- When is the optimal time to move a person with dementia into a care home setting and **how can the standard of care be improved?** (Kelly et al., 2015)

In this PhD I hope to broadly contribute to understandings in these three areas. I will now briefly outline the structure of my thesis.

1.1 Thesis structure

1.1.1 Relationship to the MARQUE study

My PhD is embedded within the MARQUE programme led by GL and of which I am a co-applicant. This five-year programme is funded by the Economic and Social Research Council (ESRC) and the National Institute for Health Research (NIHR). MARQUE comprises six linked streams that aim to understand and reduce agitation and improve quality of life in people with dementia. My PhD research fits within stream three: Production of, testing for feasibility and then a cluster RCT of an evidence-based, manualised training intervention for staff in care homes aimed at reducing agitation in people with dementia. As co-lead of MARQUE stream three with GL, I have been involved in every stage of the research process and have led in the manual production and initial testing for my PhD. In this PhD, I will describe the process of co-producing (collaborating with multiple stakeholders from professional, academic and especially lay communities (Bovaird, 2007, Gove et al., 2017)) and initially testing the MARQUE intervention. The structure of this work is

informed by the Medical Research Council (MRC) guidance for the evaluation of complex interventions (Craig et al., 2008) (see Figure 1.1).

1.1.2 The MRC guidance for evaluation of complex interventions

The MRC guidance proposes a systematic process for intervention development and testing, including evaluating the existing evidence base and developing a theoretical understanding and approach, a period of feasibility testing and piloting, evaluation of the process and effectiveness of the intervention, followed by a period of implementation and dissemination. The authors of the guidance note key questions to address in the development and evaluation of complex interventions. These are firstly, whether the interventions are effective in everyday practice? And secondly, how the intervention works: what are the active ingredients and how do they exert their effect? These questions are especially pertinent to research in diverse and complex care home settings.

A number of authors have highlighted limitations to the framework including the need for a greater focus on early phase development work (Hardeman et al., 2005), recognition that complex interventions may need to be tailored to the local context rather than being completely standardised (Campbell et al., 2007) and increased integration of process and outcome evaluation (Oakley et al., 2006), including at early stages of testing (Moore et al., 2015). The benefits of using qualitative methods during both intervention development and testing, to elucidate complex contexts or key uncertainties, have also been emphasised (O’Cathain et al., 2015). Throughout this thesis, via a process of qualitative enquiry, co-production and process evaluation I have tried to address these limitations.

1.1.2.1 *Feasibility and pilot study definitions*

Although the MRC guidance refers to a period of feasibility testing and piloting, there is inconsistency in the use of the terms “pilot study” and “feasibility study” (Eldridge et al., 2016). The NIHR has recently published specific guidelines differentiating them (National Institute for Health Research, 2017). The NIHR defines a feasibility study as a piece of research done before a main effectiveness

study to answer the question “can this study be done”, which can be used to estimate important parameters needed in the design of the main study. Feasibility studies need not be randomised and do not evaluate the outcomes of interest. The NIHR defines a pilot study as a small-scale version of the main study to test whether the components of the main study can work together, including randomisation and assessment of the primary outcome measure. Within this thesis, I will present a feasibility study of the MARQUE intervention, answering the question “can this be done” alongside a qualitative process evaluation, with a particular focus upon the intervention components. During the thesis when I use the word “pilot”, this is not to suggest that I have conducted a formal pilot study, but rather, as the word is defined by the Oxford English Dictionary to describe the process of: “test[ing] (a scheme, project, etc.) on a small scale before introducing it more widely.”(OED, 2018).

I will now provide a more detailed summary of my thesis and in Figure 1.1 I outline how the different components of this thesis map onto the MRC framework.

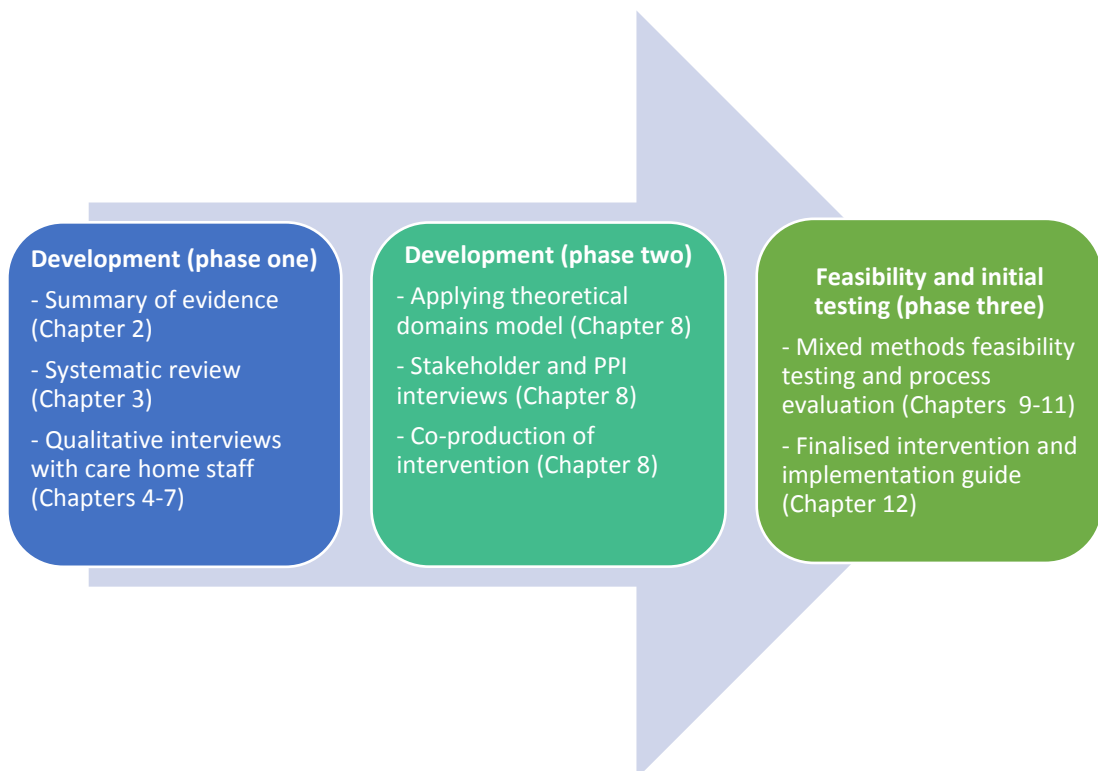


Figure 1.1: Structure of thesis mapped onto MRC processes for development and testing of complex interventions

1.1.3 Outline of the thesis

The overall aim of my PhD work described in this thesis is to develop and initially test the feasibility and acceptability of the MARQUE intervention, an evidence-based, manualised training intervention to reduce agitation in people with dementia living in care homes. Below I will summarise the three phases of this PhD.

1.1.3.1 *Phase one: Preliminary development work*

In the next chapter I present the background context for this research and evaluate the existing evidence base in terms non-pharmacological interventions for managing agitation in people living with dementia and training interventions for care home staff. Following this, in chapter three, I systematically review the effective components of psychosocial interventions delivered by care home staff to people with dementia in order to incorporate them into the manual. To further inform the intervention development, I conducted semi-structured interviews with care home staff about how they experience, understand and respond to agitation and what factors impact upon how this. In chapter four, I outline my methods for this qualitative study and in chapters five, six and seven I present the results.

1.1.3.2 *Phase two: co-production of the intervention*

In chapter eight, I describe phase two of the PhD, the co-production of the intervention. I discuss the 'theoretical domains model' (French et al., 2012, Michie et al., 2005) as applied to the process of co-producing the MARQUE intervention and the rationale for co-production in dementia care research. I integrate the findings from phase one and additional stakeholder and patient and participant involvement, presenting a manualised training intervention with a system of ongoing support for use in care homes to reduce agitation in people living with dementia.

1.1.3.3 *Phase three: Initial testing of the intervention*

In chapter nine, I present the methods for phase three of the research, a mixed methods feasibility and process evaluation of the intervention and in chapters 10

and 11 respectively I present the quantitative and qualitative evaluation of this initial testing.

In chapter 12, I discuss the key implications of my results, strengths and weaknesses of my thesis, plans for a pragmatic trial and future implementation of the intervention, including a draft implementation¹ guide to inform the MARQUE RCT and directions for future research. In chapter 13, I summarise my main conclusions.

According to the MRC guidance discussed above, systematic intervention development should begin with evaluation of the existing evidence base and development of a theoretically informed approach. In the next chapter, I will begin this process, exploring both theoretical understandings of managing agitation in people living with dementia in care homes and the existing evidence base.

¹ Throughout this thesis when I refer to implementation I am referring to the intervention being put into practice in the care home and to inform the full planned RCT. I am not assuming that the intervention is or will be effective, but am considering implementation throughout the process of intervention development.

Chapter 2 Summary of existing literature

In this chapter, I will provide an overview of dementia, agitation and care homes. I will then outline the existing evidence base regarding pharmacological and non-pharmacological approaches to managing agitation in people with dementia. Since I am particularly interested in developing a training intervention aimed at supporting staff to reduce agitation by making sustained changes in their practice, I will summarise what we know about training staff in care homes to work with people with dementia and how to translate evidence into practice in dementia care. In chapter three, I will present my systematic review, which identifies effective components of psychosocial interventions delivered by care home staff to people with dementia.

2.1 Dementia

According to the International Classification of Diseases (ICD-10) dementia is “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. The impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation” (World Health Organization, 1993). The most common type of dementia is Alzheimer’s disease, accounting for approximately 62% of cases, followed by vascular dementia (17%), mixed dementia (10%), Lewy body dementia (4%), frontotemporal dementia (2%), and Parkinson’s dementia (2%); 3% of cases comprise other rarer forms of dementia (Prince et al., 2014). Dementia is a major cause of disability and dependency worldwide and is often associated with stigma and barriers to diagnosis and support (World Health Organization, 2012). It is estimated that 47.5 million people have dementia worldwide with over half living in low and middle-income countries. This number is projected to increase to 75.6 million in 2030 with the increase largely being in low and middle-income countries (World Health Organization, 2016). There is currently no known cure for dementia,

although pharmacological and non-pharmacological symptomatic treatments are available (World Health Organization, 2016, Livingston et al., 2017b). Development of treatments to care for and cure dementia are a national (Department of Health, 2015) and global priority (World Health Organization, 2012).

2.2 Agitation

In 2015, the International Psychogeriatrics Association reached a provisional consensus definition of agitation in people with cognitive disorders. They broadly defined agitation as “(1) occurring in patients with a cognitive impairment or dementia syndrome; (2) exhibiting behaviour consistent with emotional distress; (3) manifesting excessive motor activity, verbal aggression, or physical aggression; and (4) evidencing behaviours that cause excess disability and are not solely attributable to another disorder (psychiatric, medical, or substance-related)” (Cummings et al., 2015). Agitation in dementia is common, persistent and distressing (Savva et al., 2009), with nearly half of people with dementia experiencing symptoms of agitation every month (Ryu et al., 2005). Symptoms of agitation are associated with lower quality of life in the community and higher care costs (Morris et al., 2015, Okura et al., 2010). It can lead to helplessness, anxiety and anger in family and paid carers resulting in care home admission (Draper et al., 2000, Morris et al., 1988). In the largest naturalistic care home study to date, carried out in an earlier stream of the MARQUE programme, 40% of residents with dementia had clinically significant levels symptoms of agitation and 86% had some symptoms of agitation. Care home residents experiencing agitation had a lower quality of life as rated by staff and relatives (Livingston et al., 2017a). Although severity of agitation was associated with severity of dementia, this association was not linear. Clinically significant levels of agitation were highest (45%) in those with moderately severe dementia. From this, we concluded that the symptoms labelled as agitation could not be entirely explained in terms of worsening brain pathology (Livingston et al., 2017a).

2.2.1 Agitation as unmet need

Agitation may increase the difficulties individuals with dementia face by impacting upon their 'personhood'; how they are perceived, understood and looked after by others, including family and paid carers (Higgs and Gilleard, 2016, Kitwood and Bredin, 1992). The Need-driven, Dementia-compromised Behaviour (NDB) theory suggests that a wide number of different behaviours in dementia often labelled as 'disruptive' arise from unmet needs or goals (Algase et al., 1996). This model is likely to be relevant to understanding agitation. Needs may be emotional (communication, comfort or physical contact), recreational and environmental (stimulation, including touch and music; enjoyable activities) and physical (pain relief, thirst, hunger or treatment of constipation or infection) (Livingston et al., 2014a). Agitation in residents with dementia has been found to be a greater predictor of distress among care staff than other neuropsychiatric symptoms (Zwijssen et al., 2014). Staff have reported finding behaviours that they perceived as aggressive, uncooperative and unpredictable most difficult to manage (Brodaty et al., 2003). When behaviours are perceived in this light, staff may be less likely to conceptualise them as expressions of an unmet need and more likely to attribute blame towards the person with dementia. As I will discuss below, further understanding of the relational aspects of agitation in care homes; of how staff in care homes make sense of and respond to agitation, is necessary to inform how best to respond.

2.3 Care homes

The National Institute for Health and Care Excellence (NICE) use the term 'care home' to refer to all the residential and nursing homes registered with the Care Quality Commission (CQC) offering accommodation and personal care to those who may not be able to live independently (NICE, 2015). There is wide variation in the size and quality of care homes across the UK with all homes providing 24-hour care and support and with staff assisting residents with personal care and activities of daily living. Nursing homes also have 24-hour support available from a qualified nurse. In 2013, there were 12,848 residential homes and 4,664 nursing homes

registered with the CQC (NICE, 2015). It is estimated that the UK care home market is worth £15.9 billion a year (Competition and Markets Authority, 2017), with around 80% of care homes privately run and smaller numbers of not-for-profit and local authority homes (Alzheimer's Society, 2013). Around 300,000 people in the UK live in care homes and over 70% of those living in care homes have dementia (Prince et al., 2014). The recent MARQUE stream two survey identified that 86% of residents in participating care homes had probable dementia (Livingston et al., 2017a); many have multiple and complex needs with high levels of neuropsychiatric symptoms (Ballard et al., 2001).

Public opinion about care homes is pervasively negative. In a survey commissioned by the Alzheimer's Society, 70% of UK adult respondents said that would be scared to move into a care home in the future and over half reported their greatest fear for a relative moving into a care home was that they would be abused (Alzheimer's Society, 2013). In the MARQUE stream two large survey of staff in English care homes, some abuse or neglect was reported in all but one of the 92 participating care home units, with neglect more common than physical or verbal abuse. Positive care behaviours were more prevalent, while specific person-centred interventions such as planning an activity around a residents interests were less frequent (Cooper et al., 2018).

2.4 Managing agitation in people with dementia

2.4.1 Pharmacological interventions

Although psychotropic medication has frequently been used to treat agitation and other neuropsychiatric symptoms, there is a drive towards reducing the prescribing of antipsychotic medication for people with dementia and increasing the use of high quality, evidence-based non-pharmacological interventions as an alternative (Department of Health, 2009b, 2009a, 2015). Antipsychotic drugs have low efficacy in treating agitation (Schneider et al., 2006, Ballard et al., 2009), with some evidence that risperidone is effective for agitation, particularly when there is severe aggression, in the short term (Ballard and Howard, 2006). Potential benefits are

offset by the increased risk of morbidity and mortality in people with dementia (Schneider et al., 2006, Ballard et al., 2009). Other psychotropic medications including donepezil and memantine do not reduce symptoms of agitation (Fox et al., 2012, Howard et al., 2007). Citalopram may reduce agitation in those with more mild dementia and with less severe agitation but can cause extra pyramidal and other side effects including prolonged QT interval (interference with conduction in the heart), cognitive impairment, falls and hyponatraemia (Coupland et al., 2011). Best-practice guidance suggests that psychotropic medication should only be prescribed to treat agitation in people living with dementia when there is a high risk of harm to self or others, other strategies have not worked and the person themselves is very distressed (Livingston et al., 2017b).

2.4.2 Non-pharmacological interventions

2.4.2.1 *Systematic reviews of non-pharmacological interventions to reduce agitation*

Before presenting my systematic review in Chapter 3, in which I focus on effective components of psychosocial interventions delivered by care home staff to people with dementia and what works to sustain implementation, I will now describe what is already known about how best to prevent and manage agitation in care homes.

A systematic review of non-pharmacological management of agitation in care homes highlighted interventions that reduced symptomatic and emergent agitation (Livingston et al., 2014a, 2014b). Group based activities reduced symptomatic agitation while in place, with no additional reductions in agitation when activities were individualised. Music therapy (delivered by trained music therapists to a specific protocol including listening and joining in with music) delivered in care homes resulted in a reduction in overall agitation immediately. Sensory interventions, such as massage, decreased symptomatic and clinically significant agitation whilst being delivered. Training paid carers in person-centred care (PCC) and to improve communication skills with people with dementia, with additional supervision after training, resulted in decreased symptomatic and severe agitation both immediately and up to six months later. Dementia care mapping (DCM), with

trained experts supporting care home staff to deliver the intervention resulted in a decrease in severe agitation, both immediately and four months later; these findings were not replicated in a more recent high quality RCT (van de Ven et al., 2013, 2014). No studies investigated or demonstrated evidence of benefits beyond a few months from the end of the intervention or for people with severe dementia (Livingston et al., 2014a). Livingston et al (2014b) and Morris et al (2015) found little evidence on the cost-effectiveness. They generated a model based on existing evidence, suggesting a high chance of benefit at low cost for non-pharmacological interventions to treat agitation.

A recent systematic review and meta-analysis of RCTs of non-pharmacological interventions for agitation and aggression in dementia included a narrower range of study designs (Brasure et al., 2016, Jutkowitz et al., 2016). They reported that overall, neither patient level interventions (delivered directly to residents) nor care-delivery level interventions (targeting how or the environment in which staff deliver care) were better than usual care, concluding that existing evidence is insufficient or of low strength with conceptual and methodological weaknesses. They argued that although individual studies show significant effects in reducing agitation, these effect sizes are unlikely to be clinically meaningful and current (quantitative) research provides little insight into how to improve clinical practice, especially how to sustain changes in staff practices.

Seitz et al (2012) looked at the efficacy and feasibility of non-pharmacological interventions in reducing neuropsychiatric symptoms in people with dementia in long-term care. They concluded that existing research interventions lack feasibility in real-world settings and rely heavily on access to highly specialist, external support and significant amounts of staff time. They suggested that greater understanding of the factors that contribute to embedding evidence-based interventions to reduce agitation into real-world care home practices over time is needed.

2.4.2.2 *Recent developments in non-pharmacological interventions to reduce agitation*

A small number of studies have been published since the reviews described above were undertaken, which I will now discuss. A randomised controlled trial conducted in 69 UK nursing homes compared intervention to usual treatment in 847 people with 573 followed up (Ballard et al., 2018). The intervention homes received staff training in person-centred care, social interaction and education regarding antipsychotic review followed by delivery through a care staff champion model with ongoing external support and consultation. The therapists were qualified occupational therapists or clinical psychologists. Those in the intervention group had higher quality of life and lower levels of agitation and overall neuropsychiatric symptoms compared to those receiving usual treatment at the end of a nine month intervention period. The intervention did not reduce antipsychotic use. Reported benefits were greatest for those with moderately severe dementia and the benefits were associated with reduced costs compared to usual care.

A single blind cluster RCT in Norwegian nursing homes compared a multicomponent, interdisciplinary intervention to a control group (usual treatment plus a brief educational intervention) (Lichtwarck et al., 2018). The intervention included a physician led assessment, guided reflection based on PCC and cognitive-behavioural therapy (CBT) principles, and a detailed treatment plan and implementation phase. After an initial training period for all staff, implementation within the home was led by nursing staff and in house physicians. The authors report a reduction in agitation both in the intervention and the control group at 8 and 12 week follow-up, with a between groups difference in favour of the intervention group. They do not report on the cost-effectiveness.

Both of these interventions show significant results for a multi-component intervention promoting person-centred care using an in-house champion model to reduce agitation experienced by people living with dementia in nursing homes. The interventions were intensive and required ongoing support from highly qualified professionals and we do not yet know whether these effects were sustained after

the intervention period was completed. The authors do not report on changes in staff outcomes which makes it difficult to understand the potential mechanisms of impact in terms of changes in care practices within the homes.

2.5 Training interventions for care home staff

UK public policy calls for an 'informed and effective [care home] workforce' to support people with dementia, to improve the quality of care for people living with dementia in care homes (Department of Health, 2009a, Department of Health, 2015). However, care home staff are often poorly trained and paid little, with high staff turnover (Franklin, 2014, Testad et al., 2010). Numerous staff training interventions have been developed and used in residential care settings yet there is a lack of clear evidence supporting their efficacy in improving staff knowledge and practices and they are rarely based upon interventions and approaches that we know work (Fossey et al., 2014, Kuske et al., 2007, McCabe et al., 2007, Spector et al., 2013). Fossey et al (2014) conducted a quality and efficacy review of person centred care interventions and training manuals. They concluded that training staff in person-centred care led to reductions in agitation and anti-psychotic prescribing however, of the 170 interventions and training manuals reviewed only 30 followed good educational and person-centred principles, and only 4 had supporting evidence from clinical trials.

A systematic review of dementia care training interventions in nursing homes identified 21 studies, almost all of which reported some positive results, especially on staff skills and behaviours, but were methodologically weak. The included studies mainly measured staff outcomes (including knowledge, behaviour and attitudes); half included both staff and resident outcomes and two studies looked at resident outcomes alone. There was little or no evidence of efficacy for outcomes for residents or knowledge transfer for staff unless 'reinforcing' (e.g. additional supervision or individual skills training) or 'enabling' (e.g. having time made available to put learning into practice) strategies were incorporated into interventions (Kuske et al., 2007). There is a growing body of evidence that training

interventions for care home staff are only effective if they include on-going supervision or support post-training (Fossey et al., 2014, Spector et al., 2013, Livingston et al., 2014a, 2014b).

2.6 Translating evidence into practice in dementia care

Overall, despite some training and support interventions for staff in care homes demonstrating promising results, no evidence-based intervention has been integrated long-term in care home settings, so that they become part of the everyday practice of the whole staff team. This gap between research evidence and integration into everyday practice reinforces the need to consider the processes by which psychosocial interventions are implemented (Dopp et al., 2013) and how this knowledge can be translated into practice within the field of dementia research (Teri et al., 2012, Draper et al., 2009, Lourida et al., 2017).

What works in implementing evidence based dementia care was recently addressed in a broad based scoping review. Lourida et al (2017) reviewed studies about dissemination or implementation within dementia care including the barriers and facilitators to dissemination or implementation. The authors included 88 studies on implementation in dementia care, with training and education of professionals, development of stakeholder inter-relationships and use of evaluative and iterative approaches most commonly used to promote change in practice. They also highlight a paucity of strategies directly addressing the organisational barriers commonly identified in studies and the need for multifaceted approaches targeting different contextual levels.

2.7 Summary

Agitation is common, persistent and distressing neuropsychiatric symptom of dementia impacting upon the person with dementia and those caring for them both psychologically, socially and economically, resulting in breakdown in care and care home admission. Psychotropic medications have low efficacy when used to treat

agitation and can result in harmful side effects, therefore non-pharmacological approaches are seen as first-line treatment.

Findings suggest that in care home settings, supervised training and support interventions that promote better communication, interaction and understanding between care staff and people with dementia can reduce both symptomatic and severe agitation both immediately and for up to six months afterwards (Fossey et al., 2014, Livingston et al., 2014a, 2014b). However, reviews of the effectiveness of psychosocial interventions upon agitation in care homes have drawn mixed conclusions, reflecting the diversity of interventions, objectives and outcomes (Brasure et al., 2016, Jutkowitz et al., 2016, Livingston et al., 2014b, 2014c). Interventions have relied heavily upon expert delivery (Seitz et al., 2012) and have failed to become embedded into institutional practices (Jutkowitz et al., 2016).

To develop interventions for people with dementia living in care homes that will be effective in the long-term, we need to understand not just what works, but also how interventions work and can be sustained after the research team have withdrawn (Orrell, 2012), and consider the cost and staff needed to deliver them. In the next chapter, I present my systematic review of the effective components of psychosocial interventions delivered by care home staff to people with dementia, which I have used to inform the intervention development and initial testing presented in phase two and three of this thesis.

Chapter 3 Systematic Review

To develop effective interventions for people with dementia living in care homes, we need to understand both what works, and how intervention effects can be sustained and embedded into practice after training (i.e. implementation). Quantitative reviews of efficacy in relation to defined outcomes can inform the former but to date have not informed the latter. Qualitative syntheses can inform implementation and inform translation of interventions from research into practice (Orrell, 2012). To inform the development of the intervention, in line with the MRC framework, I conducted a systematic review of the effective components of psychosocial interventions delivered by care home staff to people with dementia and what works to sustain implementation.

Synthesis of qualitative and quantitative research is increasingly used to inform understandings of the processes by which complex interventions are successfully implemented in real-world settings (Dixon-Woods et al., 2005, Hannes et al., 2013). Two existing studies have reviewed how psychosocial interventions for people with dementia in care homes have been implemented. The first (up to 2011) only reviewed qualitative studies, (Lawrence et al., 2012) and the second (up to 2012) reviewed the effect of the interventions upon staff knowledge, attitudes and skills but not resident outcomes (Boersma et al., 2015).

To my knowledge, this is the first review to use this approach to consider the impact of care home interventions on both staff and residents. The review is registered with PROSPERO international prospective register of systematic reviews registration number CRD42015017621. A version of this review was published in BMJ Open in January 2017 (Rapaport et al., 2017) (see Appendix 1). I focused upon psychosocial interventions delivered by training the care staff to change their practices and implement new approaches, or interventions directly delivered by care home staff working with people with dementia. To develop sustainable, cost-effective interventions that can be delivered at scale, we need to understand approaches that do not solely rely upon highly paid, externally trained specialists (Seitz et al.,

2012). I reviewed papers reporting results for both staff and residents, as I was interested in interventions that made a difference to residents through changing staff practice.

3.1 Objectives

My objectives were to:

1. Review the evidence from quantitative intervention studies, delineating what works immediately and where there is evidence of sustained effects on outcomes for people with dementia and care staff.
2. Synthesise the qualitative research exploring what components of interventions were considered to have worked and to have been practicable to implement.

3.2 Methods

3.2.1 Search strategy

I searched Medline, PsychINFO and EMBASE with no restrictions on date of publication on the 6th June 2014 and updated the search on 20th May 2016. I used the terms “care home”, “institution”, “24 hour care”, “residential home”, “nursing home”, “assisted living residence” or “long-term care” together with “staff”, “care worker*”, “nursing staff”, “care staff”, “care assistant*” or “paid carer*” and “intervention”, “training”, “staff training”, “staff education” or “staff training intervention*” combined with “dementia”, “Alzheimer” or “vascular dementia”. I hand searched references of included papers and relevant systematic reviews for further papers.

3.2.2 Inclusion and exclusion criteria

I included primary research studies evaluating psychosocial interventions that trained care home staff to deliver a specific intervention *or* that sought to change how care home staff delivered care to residents with dementia. I included

quantitative studies with a control group that included both staff and resident outcome measures and qualitative studies that explored the impact of the intervention on both staff and residents. I defined psychosocial interventions as those which did not comprise a significant medical or drug care element e.g. review by pharmacists or physicians. I excluded studies where the intervention was delivered directly to older people by external health or social care professionals, single case studies and meeting abstracts. I screened titles and abstracts of studies and then my first supervisor and I independently read all retained papers. We agreed by consensus which papers to include or exclude.

3.2.3 Assessment of quality

Claudia Cooper (CC), an honorary research assistant and I rated the quality of papers independently, using operationalised checklists and criteria for defining higher quality studies developed by our group from standard quality criteria (see Table 3.1 for criteria) (Cooper et al., 2014, Lord et al., 2015, Mukadam et al., 2011, Critical Appraisal Skills Programme, 2006). We discussed discrepancies and reached consensus. Each quality checklist item scored one point; possible scores ranged from 0 to 6, with higher scores indicating better quality. For quantitative studies we categorised papers as higher quality (i.e. with low risk of bias) if they: allocated participants to intervention and control groups through independent randomisation, accounted for all participants who entered the trial and collected data and followed up participants in the same way (Table 3.2, validity criteria 1, 3 and 4). For qualitative studies we categorised papers as higher quality if they: used a clearly defined recruitment method, clearly stated inclusion and exclusion criteria, standardised data collection and involved two or more independent raters in data analysis (Table 3.3, validity criteria 2, 3 and 5).

Table 3.1: Tools used to rate the validity of studies

Quality assessment tool for qualitative studies	Quality assessment tool for intervention studies
(1) Were the aims of the research clearly stated?	(1) Were participants appropriately allocated to intervention and control groups? (Was randomisation independent?)
(2) Was a clearly defined method of recruitment used and explicit inclusion/exclusion criteria described?	(2) Were patients and clinicians, as far as possible, 'masked' to treatment allocation?
(3) Was the process of data collection explained clearly? Was data collection standardised?	(3) Were all patients who entered the trial accounted for and an intention-to-treat analysis used?
(4) Did the researchers attain saturation of data?	(4) Were all participants followed-up and data collected in the same way?
(5) Was the process of data analysis sufficiently rigorous, i.e. ≥2 raters, some method of resolving discrepancies?	(5) Was a power calculation carried out, based on one of our outcomes of interest?
(6) Have the findings been validated by participants?	

Criteria required for a paper to be rated higher quality are shown in bold.

3.2.4 Synthesis and analysis of data

For the quantitative studies, I prioritised results from higher quality studies and findings on primary reported outcome measures. As in previous work (Livingston et al., 2014a) I decided *a priori* to meta-analyse when there were three or more RCTs investigating sufficiently homogeneous interventions and outcomes. No intervention met these criteria. I included all the qualitative studies in the 'thematic synthesis' of qualitative findings, in line with previous, similar reviews (Lawrence et al., 2012, Thomas and Harden, 2008) and based on accepted methods (Dixon-Woods et al., 2005, Braun and Clarke, 2006). Thematic syntheses have been criticised for a lack of clarity and transparency in the analytic process (Dixon-Woods et al., 2005), Thomas and Harden address this concern by defining a procedure for thematic synthesis of qualitative data, which I used in the thematic synthesis outlined below (Thomas and Harden, 2008). The data I included in the synthesis was all of the 'findings' or 'results' sections of the qualitative papers. I extracted data from the qualitative papers' results sections into NVIVO 9 software and inductively coded it in an open-ended, exploratory manner. My first supervisor reviewed the

data and the coding frame; differences were discussed and the codes refined. I then developed overarching themes that related these descriptive themes to my question of what components of interventions were considered to have worked and to have been practicable to implement (French et al., 2012, Grol et al., 2007, Michie et al., 2005), discussing and further refining themes with my supervisors.

3.3 Results

I identified 2,537 unique, potentially eligible studies and included 49 relevant papers, categorising 6/27 qualitative papers and 6/22 quantitative papers as high quality (see Figure 3.1 for PRISMA diagram). Twelve of the included studies took place in the USA, nine in Sweden, eight in Australia, seven in the Netherlands, four in Norway, three in the UK, two in Portugal, two in Canada, one in Ireland, and one in Germany. Twenty describe training and delivery of person-centred and relationship focused care and dementia care mapping, ten describe creative and sensory interventions, eight describe communication skills and awareness training, five describe training in dementia and managing difficult behaviour, four describe staff support and supervision interventions, one describes a restraint minimisation intervention and one described a behavioural therapy intervention (further details are presented in Appendices 2 and 3).

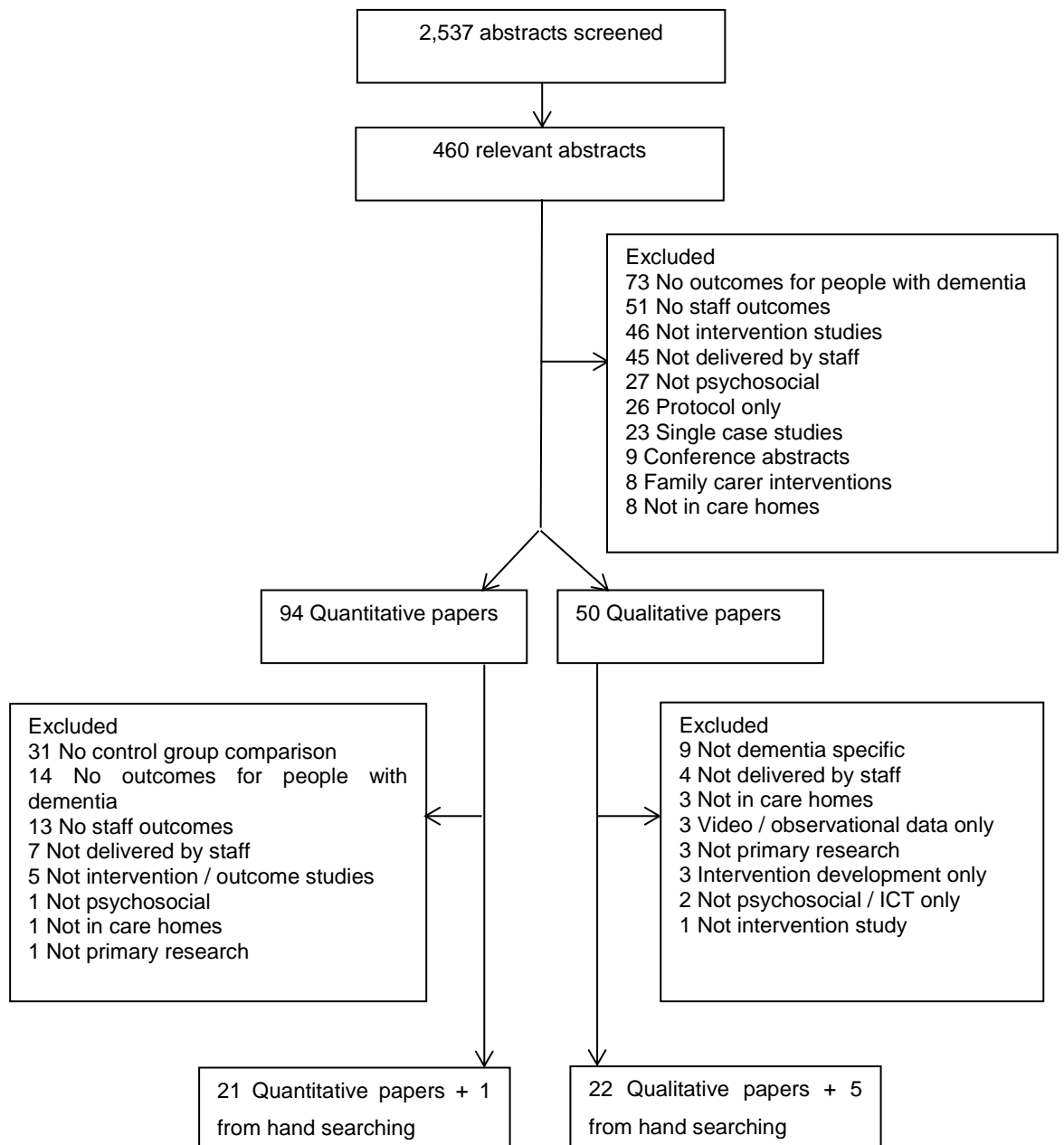


Figure 3.1: PRISMA diagram of included studies

3.3.1 Findings from high quality quantitative studies

The four high quality quantitative studies are described in Table 3.2. Lower quality quantitative studies are described in Appendix 2.

Table 3.2: Characteristics and quality ratings of high quality quantitative studies

Study	Recruitment source	Group training intervention	n		Control	n		Validity (answers to questions 1-5)				
			Staff	Resident		Staff	Resident	1	2	3	4	5
McCallion et al, 1999	Residents with ≥1 problem behaviour and nursing assistants on two US nursing facilities.	NA Communication Skills Program; 5x 45 minute didactic and interactive group (3-6 NAs) sessions, manual and videos; 4x 30 minutes individual, personalised training, practice and feedback. Individual catch up sessions offered. Monthly follow-up sessions with facilitator for three months. Delivered by Masters level social worker.	39	49	WLC crossover at 6 months (followed up at 9 months)	49	56	Y	Y	Y	Y	N
Pellfolk et al, 2010	40 group dwelling dementia units with high levels of restraint use.	Restraint minimisation education. 1 person per unit attended 2 days training delivered by the research team. 6x 30 minute video lectures for all staff with units facilitating group discussion of 3 vignettes.	156	149	WLC	133	139	Y	N	Y	Y	Y

CG = control group; DCM = Dementia Care Mapping; IG = Intervention group; NA = Nursing assistant; PCC = Person-centred Care; TAU = Treatment as usual; WLC = Wait list control.

Table 3.2 continued

Study	Recruitment source	Group training intervention	n		Control	n		Validity (answers to questions 1-5)				
			Staff	Resident		Staff	Resident	1	2	3	4	5
Chenoweth et al, 2009; Jeon et al, 2012	Staff and residents with need driven compromised behaviour in 15 Australian care homes using task focused not person-centred care.	PCC - 2 days of training for two staff / site by experienced researchers + training manuals. Trained staff supported to develop and implement resident care plans. Regular telephone contact +two visits during intervention.	56	77	TAU	23	64	Y	Y	Y	Y	Y
		DCM - two staff at each site, trained by expert, did DCM with researchers for 6 hrs / day for 2 days; developed care plans and helped staff to implement them with regular phone support.	45	95								
van de Ven et al, 2013; 2014	Nursing staff and residents with ≥1 NPS in 34 units in 11 Dutch nursing homes.	Training staff to implement DCM. Managers selected 2 staff per home to train and each home had a DCM briefing day with specialists. The trained mappers then completed at least two DCM cycles.	119	74	TAU	161	102	Y	N	Y	Y	Y

CG = control group; DCM = Dementia Care Mapping; IG = Intervention group; NA = Nursing assistant; PCC = Person-centred Care; TAU = Treatment as usual; WLC = Wait list control

3.3.1.1 *Group training interventions for care home staff with additional individual supervision*

One high quality study of group training for nursing assistants with additional individual skills training was included (McCallion et al., 1999). The training was designed to increase knowledge of dementia, verbal and non-verbal communication, and management of problem behaviours. It was delivered by Masters level social workers. It was tested in two US nursing homes in a crossover RCT. Resident physically aggressive behaviour in the intervention group decreased three months post-intervention ($F = 17.59, p < 0.001$) relative to the control group, but this was not maintained at six months. Verbally aggressive ($F = 14.23, p < 0.001$) and depressive symptoms ($p < 0.05$) were significantly lower in the intervention group versus the control group six months post-intervention. On reported secondary staff outcomes, knowledge of problem behaviours ($F = 5.35, p < 0.01$) and how to manage agitation ($F = 6.51, p < 0.01$) increased three months post-intervention relative to the control group. Six months post-intervention, staff turnover was lower in the intervention than the control group ($\chi^2 = 9.14, p = .003$).

3.3.1.2 *Dementia care mapping interventions*

Four papers described two high quality RCTs evaluating DCM a multi-component, person-centred intervention (Chenoweth et al., 2009, Jeon et al., 2012, van de Ven et al., 2013, 2014). CADRES (Caring for Aged Dementia Care Resident Study) compared PCC and DCM with usual care in a three arm RCT in 15 Australian care homes providing task focused care (Chenoweth et al., 2009, Jeon et al., 2010). The DCM intervention included systematic observations of people with dementia with detailed categorisation and scoring of the resident's observed well being fed back to staff to support person-centred care. Care mapping was performed both by expert study staff and by trained care home staff. At four month follow-up on primary reported outcomes, resident agitation was lower in the DCM (10.1, 95% CI = 0.7-21.1; $p = 0.04$) and the PCC (13.6, 95% CI = 3.3-23.9; $p = 0.01$) groups compared to the control group. On a secondary outcome for residents, less falls were recorded in the DCM group (0.24, 95% CI = 0.08-0.40; $p = 0.02$) and more falls recorded in PCC group compared to the control group four months post-intervention (0.15, 95% CI =

0.02–0.28; $p = 0.03$) Among staff, at four month follow-up on three subscales of the Maslach Burnout Inventory (MBI), a primary reported outcome for staff, emotional exhaustion was lower in the DCM group than in the PCC and control group ($F = 2.77$, $p = 0.03$), but there was no significant difference in depersonalisation or personal accomplishment.

In another high quality study testing DCM in a less tightly controlled setting, with care home staff delivering more of the intervention and without recruiting task focused homes, no significant differences were identified between the intervention and control group on primary staff or resident outcomes. On secondary reported outcomes residents experienced more neuropsychiatric symptoms in the intervention group relative to the control group ($p = 0.02$) and they identified lower hospital outpatient costs in the intervention group versus the control group post-intervention ($p < 0.02$). Staff in the intervention group reported fewer negative and more positive emotions during work post-intervention ($p = 0.03$) (van de Ven et al., 2013, 2014).

3.3.1.3 *Group training interventions for care home staff without additional supervision*

A cluster RCT evaluated a restraint minimisation group training programme without additional supervision in 40 Swedish dementia units. Immediately post-intervention, residents in the intervention group were restrained less than those in the control group ($OR = 0.35$, 95% CI = 0.15-0.83, $p = 0.02$). Among staff who received the intervention, knowledge of restraint use ($p = 0.02$) and dementia ($p = 0.01$) increased significantly compared to staff in the control group, but there was no difference in staff attitudes towards restraint use. Longer term outcomes were not reported (Pellfolk et al., 2010).

3.3.2 Findings from qualitative studies

I synthesised findings from all included qualitative papers with at least one higher quality paper contributing to each main theme. Higher quality studies contributed to more sub themes than lower quality studies. The findings from the high quality studies are presented in Table 3.3 and findings from lower quality qualitative papers are presented in Appendix 3. The key themes are summarised below in Figure 3.2.

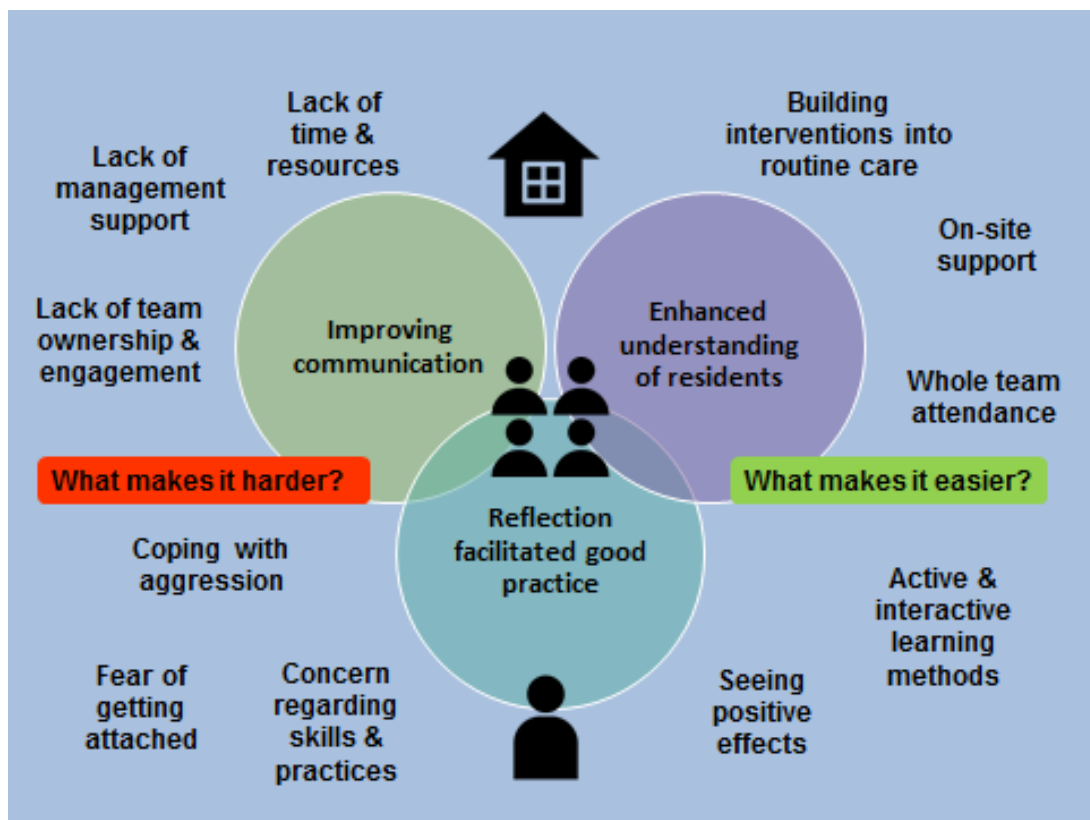


Figure 3.2: Summary of key findings of qualitative synthesis

Table 3.3 Characteristics and quality ratings of high quality qualitative studies

Study	Recruitment Source	Method	n	Type of intervention	Focus of analysis / key themes	Validity					
						1	2	3	4	5	6
Alnes et al, 2011; 2013	Staff in four Norwegian dementia care units.	Focus groups, semi-structured interviews, analysis of recorded intervention sessions and log kept by trainer.	24 staff in focus groups. 12 staff semi-structured interviews.	MMC (video-based counselling method to improve interaction skills). 7x 1.5 hr weekly sessions over 2 months with trainer.	2011 - Nurses perception of learning from MMC. Two overall themes were staff gaining new knowledge about themselves and the residents. 2013 - Factors that impact on learning outcomes of MMC intervention. Identified: 1. Establishing a common understanding of the content and form of MMC. 2. Ensuring that staff want to participate and have the opportunity to do so. 3. Creating an arena for discussion and interactions during and after MMC.	Y	Y	Y	N	Y	N
Figueiredo et al, 2013; Marques et al, 2013	Day staff in one Portuguese long-term care home.	Pilot evaluation of staff training intervention included analysis of recorded morning care and focus group with staff post-intervention.	Six staff took part in training and five participated in focus group.	8 psycho-educational sessions with staff with between session individual support. Intervention included staff support, multi-sensory stimulation and motor stimulation. Delivered by a multi-disciplinary team and included homework and hand-outs.	Figueiredo et al- Staff perspectives on structure and organisation and of benefits of the programme: 1. Acquisition of new knowledge and competencies. 2. Demystification of pre-existing beliefs. 3. Group cohesion 4. Self-worth feelings and 5. Positive coping strategies. Marques et al - The impact of the motor and multisensory care-based approach on care practices, suggestions for future programs, and difficulties implementing into practice.	Y	Y	Y	N	Y	N

CNA = Certified Nursing Aides; MMC = Marte Meo Counselling.

Table 3.3 continued

Study	Recruitment Source	Method	n	Type of intervention	Focus of analysis / key themes	Validity					
						1	2	3	4	5	6
Kontos et al, 2010	Staff in two Canadian nursing homes.	Post-intervention focus groups and semi structured interviews.	14 staff participated in two focus groups and 10 staff were individually interviewed.	12 week (2 hrs each week) arts/drama informed educational intervention to improve person-centred care. Used dialogue, critical reflection, role-play and dramatised vignettes.	Staff perspectives on intervention. Two main themes described: 1. Meaning beyond dementia – focused on how understanding behaviour facilitated care. 2. The influence of the approach to care -focused on how staff responses facilitate or inhibit person-centred care.	Y	Y	Y	N	Y	N
Veraik et al, 2011	Staff in nine psychogeriatric wards in Dutch nursing homes from RCT intervention group.	Semi-structured interviews, questionnaire analysis of meeting memos, session reports and observations.	98 CNAs were trained. 20 CNAs were interviewed including 10 of the most and 10 of the least positive about the intervention.	Guidelines for managing depression in dementia based on behaviour therapy and pleasant events. Included: Printed educational materials, three interactive team training sessions and setting up a promotion group on each ward.	Analysed data from successful, moderately successful and unsuccessful implementation sites – and analysed at multiple levels, nursing home, ward, CNA and resident levels. Presented case studies of successful / unsuccessful implementation and factors influencing successful introduction and application of the guideline intervention.	Y	Y	Y	N	Y	N

CNA = Certified Nursing Aides; MMC = Marte Meo Counselling.

3.3.2.1 *What works? Perceived beneficial components of interventions*

3.3.2.1.1 Improving communication

Staff across diverse studies described how training and support to improve interaction and communication with residents with dementia was useful. These included interventions that focussed on: initiating ‘meaningful conversation’ with residents during care (Brown et al., 2013, Figueiredo et al., 2013, Soderlund et al., 2012, Chenoweth et al., 2015), the emotional content of interactions (Brown et al., 2013, Gotell et al., 2012, Hammar et al., 2011, Hammar et al., 2010, Hansebo and Kihlgren, 2000, Soderlund et al., 2012, Soderlund et al., 2014, Lykkeslet et al., 2014), touch and physical contact (Alnes et al., 2011, Hansebo and Kihlgren, 2001, Soderlund et al., 2012, Viau-Guay et al., 2013, Chenoweth et al., 2015, Lykkeslet et al., 2014), maintaining eye contact and using simple clear instructions (Alnes et al., 2011, Hammar et al., 2010, Marques et al., 2013, Viau-Guay et al., 2013, Soderlund et al., 2014).

Staff judged that this not only improved their own communication but led to positive changes in residents’ responses; they noticed residents were more alert, responsive, happier and cooperative (Gotell et al., 2012, Hammar et al., 2010, Soderlund et al., 2012, Chenoweth et al., 2015, Cooney et al., 2014). Giving residents time and space to respond and communicate was perceived as beneficial. Staff observed that by taking time to understand residents’ responses, residents seemed more able to make decisions and actively participate in their care. (Alnes et al., 2011, Hansebo and Kihlgren, 2000, Hansebo and Kihlgren, 2001, Soderlund et al., 2012, Van Weert et al., 2004, Viau-Guay et al., 2013, Chenoweth et al., 2015, Lykkeslet et al., 2014). Staff who participated in singing based interventions (which involved them singing to residents during routine care) found themselves talking and instructing less, and residents understood and expressed themselves more effectively (Gotell et al., 2012, Hammar et al., 2011, Hammar et al., 2010).

3.3.2.1.2 Enhanced understanding of the residents

Staff described how interventions enhanced their understanding of residents’ needs. They felt more able to put themselves ‘in the client’s shoes’ (Viau-Guay et

al., 2013) and empathise with people with dementia (Alnes et al., 2011, Alnes et al., 2013, Brown et al., 2013, Cooke et al., 2014, Figueiredo et al., 2013, Hansebo and Kihlgren, 2000, Hansebo and Kihlgren, 2001, Hansebo and Kihlgren, 2004, Kontos et al., 2010, Moyle et al., 2013, Rosvik et al., 2011, Soderlund et al., 2012, Viau-Guay et al., 2013, Chenoweth et al., 2015, Cooney et al., 2014), which was intrinsically rewarding (Hansebo and Kihlgren, 2000, Moyle et al., 2013). Staff reflected that this extended to understanding relatives' perspectives (Chenoweth et al., 2015, Hansebo and Kihlgren, 2000, Moyle et al., 2013), resulting in improved relationships between staff and relatives, which was echoed in relatives' responses where elicited (Moyle et al., 2013, Chenoweth et al., 2015, Cooney et al., 2014).

Staff across a range of studies recognised the importance of getting to know the person with dementia in order to provide individualised and 'person-centred' care (Brown et al., 2013, Gotell et al., 2012, Guzman-Garcia et al., 2013, Hansebo and Kihlgren, 2000, Hansebo and Kihlgren, 2001, Kontos et al., 2010, Moyle et al., 2013, Soderlund et al., 2012, Viau-Guay et al., 2013, Chenoweth et al., 2015, Lykkeslet et al., 2014, Cooney et al., 2014). This was achieved both by engaging people with dementia in activities through which they could express their individuality such as dancing, singing and sensory activity (Gotell et al., 2012, Guzman-Garcia et al., 2013, Hammar et al., 2011, Hammar et al., 2010, Lykkeslet et al., 2014), and through interventions which encouraged staff through training, supervision and experiential learning to find out more about care recipients (Brown et al., 2013, Hansebo and Kihlgren, 2000, Hansebo and Kihlgren, 2004, Kontos et al., 2010, Moyle et al., 2013, Chenoweth et al., 2015).

Developing staff knowledge of residents facilitated their understandings of the potential meaning of residents' behaviours, enabling them to alter their responses accordingly (Alnes et al., 2011, Alnes et al., 2013, Brown et al., 2013, Kemeny et al., 2004, Kontos et al., 2010, Moyle et al., 2013, Soderlund et al., 2012, Chenoweth et al., 2015, Cooney et al., 2014, Lykkeslet et al., 2014, Soderlund et al., 2014) . Staff identified this as important for identifying residents' strengths and weaknesses (Alnes et al., 2011, Cooke et al., 2014, Figueiredo et al., 2013, Hansebo and Kihlgren,

2000, Hansebo and Kihlgren, 2001, Kontos et al., 2010, Marques et al., 2013, Moyle et al., 2013, Chenoweth et al., 2015, Cooney et al., 2014) and promoting independence when providing care (Gotell et al., 2012, Guzman-Garcia et al., 2013, Hammar et al., 2011, Hammar et al., 2010, Hansebo and Kihlgren, 2000, Kontos et al., 2010, Soderlund et al., 2012, Viau-Guay et al., 2013, Chenoweth et al., 2015, Cooney et al., 2014, Lykkeslet et al., 2014, van Haefthen-van Dijk et al., 2015).

3.3.2.1.3 Reflection facilitates good practice

A common process underlying improved communication and understanding is an emphasis within interventions on staff reflecting on their practices. Staff appreciated the opportunity to consider their own and residents' actions and interactions within experiential learning (Kontos et al., 2010), interactive training (Figueiredo et al., 2013, Marques et al., 2013, Moyle et al., 2013), formal supervision (Hansebo and Kihlgren, 2000, Hansebo and Kihlgren, 2001, Hansebo and Kihlgren, 2004, Lykkeslet et al., 2014), or video based feedback (Alnes et al., 2011, Alnes et al., 2013, Soderlund et al., 2014). This enabled them to identify patterns in their own and residents' behaviours, consider alternative reactions (Alnes et al., 2011, Hansebo and Kihlgren, 2000, Hansebo and Kihlgren, 2001, Kontos et al., 2010, Lykkeslet et al., 2014, Soderlund et al., 2014), feel validated and reassured about practices that were working well whilst recognising unhelpful practices and assumptions (Cooney et al., 2014, Marques et al., 2013, Moyle et al., 2013, Teri et al., 2009, Verkaik et al., 2011, Viau-Guay et al., 2013).

3.3.2.2 *Individual factors*

3.3.2.2.1 What gets in the way?

3.3.2.2.1.1 Coping with verbal and other aggression

Staff across studies described the negative impact on themselves of providing care to people with dementia in certain situations. Providing personal care to residents was experienced as particularly challenging (Hammar et al., 2011, Hansebo and Kihlgren, 2001, Hansebo and Kihlgren, 2004, Soderlund et al., 2012, Lykkeslet et al., 2014). When faced with resistance and verbal and physical aggression, staff described frustration and distress (Hammar et al., 2011, Hammar et al., 2010,

Hansebo and Kihlgren, 2001, Teri et al., 2009). One carer described this struggle: “I wonder how long you can do this... It is hard to fight every morning and only get anger back...What should we do, we just have to live with it, right? I hide in the laundry room to catch my breath before caring for her.” (Hammar et al., 2011) (p.104).

3.3.2.2.1.2 Concern about becoming attached

Staff were sometimes reluctant to engage with interventions. For some, interventions that promoted emotional and physical closeness led to fears of becoming attached to residents and being emotionally vulnerable to loss (Guzman-Garcia et al., 2013, Soderlund et al., 2012, Soderlund et al., 2014).

3.3.2.2.1.3 Concern regarding skills and new practices

Staff expressed doubts about their own ability to implement interventions, either in terms of having specific skills, such as being able to sing (van Haeften-van Dijk et al., 2015, Gotell et al., 2012), or having the ability to adopt new roles, such as approaching relatives (Kemeny et al., 2004, Chenoweth et al., 2015) or coordinating care (Rosvik et al., 2011). There was initial scepticism from staff about engaging with new interventions, especially if they were perceived to involve additional work, changes to existing ways of working (Gotell et al., 2012, Hansebo and Kihlgren, 2001, Moyle et al., 2013, Van Weert et al., 2004, Verkaik et al., 2011, Chenoweth et al., 2015) or unfamiliar techniques (Alnes et al., 2013, Hansebo and Kihlgren, 2001, Soderlund et al., 2014, van Haeften-van Dijk et al., 2015). Negative responses towards interventions were more apparent when staff felt they did not accommodate the varying levels of education and experience within a team (Alnes et al., 2011, Alnes et al., 2013, Hansebo and Kihlgren, 2001, Verkaik et al., 2011, Chenoweth et al., 2015) or the complex needs of those cared for (Rosvik et al., 2011, Soderlund et al., 2012, Verkaik et al., 2011, van Haeften-van Dijk et al., 2015).

3.3.2.2.2 What makes it easier?

3.3.2.2.2.1 Seeing positive effects

A key facilitator of staff engagement was seeing interventions benefit staff and residents rather than being told of potential benefits by trainers. This was especially true when staff saw positive changes in residents' mood or abilities (Alnes et al., 2011, Cooke et al., 2014, Figueiredo et al., 2013, Gotell et al., 2012, Guzman-Garcia et al., 2013, Hammar et al., 2011, Hansebo and Kihlgren, 2000, Kemeny et al., 2004, Marques et al., 2013, Moyle et al., 2013, Soderlund et al., 2012, Van Weert et al., 2004, Verkaik et al., 2011, Chenoweth et al., 2015, Cooney et al., 2014, van Haften-van Dijk et al., 2015). In numerous studies staff reported decreased agitation and aggressive behaviours, which they associated with the interventions (Gotell et al., 2012, Guzman-Garcia et al., 2013, Hammar et al., 2010, Soderlund et al., 2012, Van Weert et al., 2004, Chenoweth et al., 2015, Cooney et al., 2014). Staff identified a link between the positive impact of interventions on residents, and fewer difficulties providing care, a calmer and more relaxed atmosphere and improved relationships with residents and relatives (Brown et al., 2013, Cooke et al., 2014, Figueiredo et al., 2013, Gotell et al., 2012, Guzman-Garcia et al., 2013, Hammar et al., 2011, Hansebo and Kihlgren, 2000, Hansebo and Kihlgren, 2001, Hansebo and Kihlgren, 2004, Kemeny et al., 2004, Kontos et al., 2010, Marques et al., 2013, Soderlund et al., 2012, Van Weert et al., 2004, Viau-Guay et al., 2013, Chenoweth et al., 2015, Cooney et al., 2014, Lykkeslet et al., 2014, Soderlund et al., 2014, van Haften-van Dijk et al., 2015, Moyle et al., 2013).

3.3.2.2.2.2 Active learning methods

Using active and interactive learning methods was integral to staff making changes to their practice. Staff reported that group based activities facilitated discussion and generated shared learning within teams (Cooke et al., 2014, Figueiredo et al., 2013, Verkaik et al., 2011) and that role play, the use of clinical vignettes and analysis of filmed interactions supported understanding (Figueiredo et al., 2013, Hansebo and Kihlgren, 2001, Kontos et al., 2010, Soderlund et al., 2014, van Haften-van Dijk et al., 2015). Access to written materials including manuals, tip sheets and hand-outs was perceived to support learning if the materials were appropriate to the

educational level of the staff (Cooke et al., 2014, Figueiredo et al., 2013, Rosvik et al., 2011, Soderlund et al., 2012).

3.3.2.3 *Social and team factors*

3.3.2.3.1 What gets in the way?

3.3.2.3.1.1 Lack of team ownership of intervention

Lack of cooperation within staff teams was cited as a barrier to implementing interventions, with staff identifying colleagues' unwillingness to help each other and poor communication as obstacles to applying new learning or changing existing practices (Marques et al., 2013, Van Weert et al., 2004, Verkaik et al., 2011, Viau-Guay et al., 2013). Staff reported difficulties in sharing new approaches with staff who had not attended training, especially those who had opted not to participate or held negative attitudes (Alnes et al., 2013, Moyle et al., 2013, Rosvik et al., 2011, Verkaik et al., 2011, Chenoweth et al., 2015, Soderlund et al., 2014). Staff did not wish to be seen as telling colleagues what to do or felt that they lacked authority to do so (Alnes et al., 2013, Moyle et al., 2013, Rosvik et al., 2011, Verkaik et al., 2011). Lack of ownership of new interventions within the care team was cited as a barrier to initial implementation (Rosvik et al., 2011, Van Weert et al., 2004, Verkaik et al., 2011, Viau-Guay et al., 2013, Chenoweth et al., 2015, Soderlund et al., 2014, van Haften-van Dijk et al., 2015) and maintaining positive changes after research trials (Moyle et al., 2013, Chenoweth et al., 2015, van Haften-van Dijk et al., 2015). This was noted when staff felt that changes were being imposed in a top down way by managers or external professionals (Verkaik et al., 2011, Chenoweth et al., 2015).

3.3.2.3.2 What makes it easier?

3.3.2.3.2.1 Whole team attendance

Participants suggested that all staff should be included in training or introduction of new interventions in the hope that this would promote shared learning and help to sustain new practices (Alnes et al., 2013, Marques et al., 2013, Moyle et al., 2013, Soderlund et al., 2012, Verkaik et al., 2011, Viau-Guay et al., 2013, Chenoweth et al., 2015, Soderlund et al., 2014). Staff also valued the opportunity to share learning within the team (Alnes et al., 2013, Cooke et al., 2014, Figueiredo et al., 2013,

Kontos et al., 2010, Rosvik et al., 2011, Van Weert et al., 2004, Verkaik et al., 2011, Chenoweth et al., 2015, Soderlund et al., 2014, van Haften-van Dijk et al., 2015). Some interventions included formal structures promoting shared learning, such as a 'digital database' for sharing ideas (van Haften-van Dijk et al., 2015) or structured 'consensus meetings' led by team members whilst others built discussion into existing forums or had informal discussions during routine care (Rosvik et al., 2011, Van Weert et al., 2004, Verkaik et al., 2011).

3.3.2.3.2.2 Additional on-site support

Common across studies was the importance placed upon on-site, individual support to put new skills into practice. This reinforced learning and gave staff the opportunity to refine strategies and troubleshoot (Alnes et al., 2013, Cooke et al., 2014, Figueiredo et al., 2013, Van Weert et al., 2004, Verkaik et al., 2011, Chenoweth et al., 2015, van Haften-van Dijk et al., 2015). Most studies included some element of support outside of formal training either as supervision and direct feedback on care practices (Alnes et al., 2011, Alnes et al., 2013, Figueiredo et al., 2013, Hansebo and Kihlgren, 2000, Hansebo and Kihlgren, 2001, Hansebo and Kihlgren, 2004, Kemeny et al., 2004, Marques et al., 2013, Rosvik et al., 2011, Soderlund et al., 2012, Teri et al., 2009, Lykkeslet et al., 2014, Soderlund et al., 2014, van Haften-van Dijk et al., 2015), or through on-site mentoring (Cooke et al., 2014, Kemeny et al., 2004, Moyle et al., 2013, Van Weert et al., 2004, Verkaik et al., 2011, Viau-Guay et al., 2013, Chenoweth et al., 2015). Having on-site mentors trained as part of the intervention has the benefit of being sustainable post-intervention but relies upon committed individuals within the home who require additional support and supervision in order to sustain implementation (Kemeny et al., 2004, Moyle et al., 2013, Van Weert et al., 2004, Verkaik et al., 2011, Chenoweth et al., 2015).

3.3.2.4 *Organisational factors*

3.3.2.4.1 What gets in the way?

3.3.2.4.1.1 Lack of time and resources

Lack of time was raised as a barrier across most of the studies both in relation to finding time to attend training sessions and to put learning into practice. Staff found fitting in training or supervision sessions stressful (Alnes et al., 2013, Rosvik et al., 2011, Soderlund et al., 2012, Van Weert et al., 2004, Cooney et al., 2014, Soderlund et al., 2014), especially if the training was felt to be 'too long' (Soderlund et al., 2012, Soderlund et al., 2014). When interventions required staff to set up additional project meetings these happened infrequently and more intensive interventions, requiring additional activities, such as detailed notes or care plans and in depth observation of residents, were seen as difficult to sustain (Rosvik et al., 2011, Soderlund et al., 2012, Van Weert et al., 2004, Verkaik et al., 2011, Chenoweth et al., 2015, Soderlund et al., 2014, van Haften-van Dijk et al., 2015). This was particularly so when staff felt that the research teams had been unclear upfront about the time commitment (Soderlund et al., 2014, van Haften-van Dijk et al., 2015). Staff identified an incompatibility between their busy, pressurised shifts and interventions that required them to spend more time engaging with residents at a slower and more relaxed pace, shifting from a task focused to a relationship centred approach (Moyle et al., 2013, Viau-Guay et al., 2013, Cooney et al., 2014, Soderlund et al., 2014). High staff turnover and low staffing ratios were also highlighted as a barrier. In addition to an increased workload, lack of consistency in staffing resulted in less opportunity for sharing of new learning, less coordination within teams and less familiarity with the residents (Alnes et al., 2013, Hansebo and Kihlgren, 2000, Marques et al., 2013, Van Weert et al., 2004, Verkaik et al., 2011, Viau-Guay et al., 2013, Chenoweth et al., 2015, van Haften-van Dijk et al., 2015).

3.3.2.4.1.2 Lack of management support

Parallel change, such as restructuring of units or management, new IT and reporting systems or new training initiatives were seen to hinder implementation (Verkaik et al., 2011, Viau-Guay et al., 2013, Moyle et al., 2013). Although management and care home policy may have promoted a 'person-centred' approach, in practice staff

felt that task completion remained a priority over promoting individualised approaches with managers and with peers (Guzman-Garcia et al., 2013, Moyle et al., 2013, Teri et al., 2009, Verkaik et al., 2011, Chenoweth et al., 2015, Soderlund et al., 2014). One staff member commented: “I would rather be doing my care plans... because that is probably judged by others, whereas the project is not judged.”(Moyle et al., 2013). Overall, when staff felt unsupported by management they found it difficult to prioritise new ways of working (Cooke et al., 2014, Guzman-Garcia et al., 2013, Marques et al., 2013, Moyle et al., 2013, Van Weert et al., 2004, Chenoweth et al., 2015, van Haeften-van Dijk et al., 2015) and teams were unmotivated if they felt they lacked the power to implement changes (Alnes et al., 2013, Rosvik et al., 2011, Verkaik et al., 2011). Staff noted that management engagement through attending training, contributing to project meetings or arranging staff cover had a positive effect (Alnes et al., 2013, Rosvik et al., 2011, Van Weert et al., 2004, Verkaik et al., 2011, Chenoweth et al., 2015), but in most studies this did not happen.

3.3.2.4.2 What makes it easier?

3.3.2.4.2.1 Building interventions into routine care

Being able to build the interventions into routine care was reported as an important facilitator. Spending time talking to a resident about their interests, reminiscing, singing to them or putting on a residents’ jewellery did not require additional time or resources and often made care provision more enjoyable for staff and residents (Teri et al., 2009, Brown et al., 2013, Gotell et al., 2012, Hansebo and Kihlgren, 2000). Sharing information via booklets left in a resident’s room or in team discussions resulted in new strategies being sustained and again did not require major changes to existing practices (Brown et al., 2013, Hansebo and Kihlgren, 2000, Van Weert et al., 2004). Interventions consistent with or built on existing approaches were valued (Figueiredo et al., 2013, Hansebo and Kihlgren, 2001, Moyle et al., 2013, Teri et al., 2009, Van Weert et al., 2004, Verkaik et al., 2011, Viau-Guay et al., 2013, Cooney et al., 2014, van Haeften-van Dijk et al., 2015). Benefits of new approaches were reinforced when staff felt that giving more time to care for and interact with residents rather than rushing to complete tasks, saved

time overall as residents were more engaged, cooperative and less distressed and agitated (Alnes et al., 2011, Hansebo and Kihlgren, 2001, Kontos et al., 2010, Soderlund et al., 2012, Teri et al., 2009, Van Weert et al., 2004, Viau-Guay et al., 2013, Chenoweth et al., 2015, van Haften-van Dijk et al., 2015).

3.4 Discussion

3.4.1 Key findings

In line with earlier reviews, I found a paucity of higher quality evidence that effects could be sustained after care home psychosocial interventions had stopped and no interventions were shown to work after six months. In one higher quality study, an individual and group programme with monthly follow-up sessions decreased resident physical aggression after three months but not at six months and resident depressive symptoms and verbal aggression up to six months later (McCallion et al., 1999). This continuing effectiveness may relate to their inclusion of monthly top-up sessions in addition to the group and individual skills training, highlighting the benefits of 'reinforcing' strategies (Kuske et al., 2007). This is consistent with the findings from the qualitative papers, with staff across studies referring to the benefits of individualised support to put new approaches into practice and to sustain interventions after initial training is completed. In one higher quality trial, training a staff champion to implement a video and case vignette training programme increased staff knowledge and decreased restraint use immediately with no long-term evidence (Pellfolk et al., 2010), while evidence for DCM and PCC was mixed, with positive findings from an Australian study not replicated in a more pragmatic, real-world care home environment (van de Ven et al., 2013, 2014).

Although multi-component interventions and implementation strategies are important in effecting change in complex healthcare systems (Dopp et al., 2013, Craig et al., 2008), such complexity relies heavily on the staff delivering the interventions and the care home systems surrounding them. In the qualitative synthesis, I found that staff judged interventions that focused upon staff getting to know, understand and connect with residents with dementia as useful and valued.

This is consistent with previous reviews (Fossey et al., 2014, Testad et al., 2014). Interventions perceived to be too intensive and complex for staff to put into practice, or separate to rather than building on existing practices were difficult to sustain. Staff described a number of beneficial 'enabling' practices (Kuske et al., 2009) such as having on-site mentors and champions and opportunities to share new learning within the team. Having management support to implement new approaches was key to success.

3.4.2 Implications for clinical practice

Sustaining effects of psychosocial interventions in real-world care home environments after research teams move on is challenging and we do not know if it is ever achieved. The qualitative synthesis highlighted the components and characteristics of interventions that staff considered important for achieving this. Interventions should be interactive and staff should retain materials after the groups are finished. All of the high quality, quantitative studies reporting positive outcomes for people with dementia identified positive outcomes for staff on a range of measures including staff knowledge, decreased burnout and reduced staff turnover, reinforcing the need for an explicit focus within interventions upon staff needs. Focusing upon the benefits of the interventions for both staff, residents and their relatives within training and giving staff opportunities to experience the impact of interventions by practicing skills between sessions and reflecting upon what works, may motivate staff to continue to use and embed skills within routine care provision. Interventions need to fit into daily care provision, avoid lengthy record keeping or intensive observations and should save more time than they take. Including management in training and holding separate sessions with management and senior staff can support implementation. Having management support to train all staff is likely to make the role of on-site mentors or champions more beneficial, increasing shared responsibility across teams.

3.4.3 Strengths and Limitations of this review

I reviewed studies testing a broad range of interventions, using qualitative and quantitative methods. Heterogeneity and lack of data meant that it was not possible to meta-analyse quantitative data. By only including quantitative studies that report outcomes for both staff and residents, I have excluded high quality RCTs that may have provided further insights into the questions being addressed in the review. However, without considering the effects of interventions upon both residents and staff, it is difficult to understand how altering staff practices impacts upon care home residents with dementia. Integrating findings from effective quantitative findings and qualitative studies I have addressed criticisms of a previous qualitative review (Lawrence et al., 2012) that it provided limited insight into what works and how to practically implement interventions (Orrell, 2012).

3.4.4 Conclusions

Within this review I highlight some of the beneficial intervention components and the potential barriers and facilitators to implementing psychosocial interventions in care homes. Future RCTs in this area should consider implementation strategy from the outset and can draw on these findings to address the inherent challenges of embedding psychosocial interventions into care home settings (Vernooij-Dassen and Moniz-Cook, 2014). I have used this approach to inform the intervention development within my PhD. In line with MRC guidance, having now reviewed the literature, I will now present my qualitative study used to further inform the intervention development. In the next chapter I will present my qualitative methods (Chapter 4) followed by the results from qualitative interviews with care home staff (Chapters 5-7).

Chapter 4 Method: Phase one qualitative interviews

In this chapter I present the methods I used to collect and analyse semi-structured interviews with care home staff to inform subsequent intervention development. My specific objectives were to:

1. Explore and describe staff understanding and current practice in management of agitation and consider what knowledge, skills and support they require to manage agitated behaviour among residents with dementia.
2. To understand what factors determine how agitation is managed in care homes and what can facilitate a shift in these factors.

I presented a poster of this work at the Alzheimer's Association International Conference (AAIC) 2017 and a paper from this qualitative analysis has been published in *BMJ Open* (Rapaport et al., 2018) (see Appendix 4). I have also co-authored two papers incorporating secondary analyses of this data; one on conceptualisation of the personhood of staff, published in *PLOS ONE* (Kadri et al., 2018) and another on the relationship between speaking English as a foreign language and agitation in people with dementia living in care homes, published in *International Journal of Geriatric Psychiatry* (Cooper et al., 2017b) (see Appendix 5).

4.1 Setting, participants and procedures

4.1.1 Ethical approval

Ethical approval was given by the National Research Ethics Service (NRES) committee (London, Queen's Square, June 2014). (See Appendix 6 for approval letter).

4.1.2 Recruitment and sampling

I recruited staff from six care homes participating in MARQUE Stream two. I purposively recruited staff from varied care home settings: residential and nursing; differing sizes; private and charity sector; and situated in urban and rural areas.

Research assistants with existing relationships with the care homes approached the care home managers and explained the purpose of the interviews, asking if they were happy for me to contact them to discuss this further. All of the homes we approached agreed to participate. I then contacted managers to discuss the interviews and to arrange to interview staff without impacting on care provision or staff break times. The MARQUE study budget covered replacement staff costs so that staff could participate in interviews.

After managers had agreed to participate, the researchers approached individual staff members, explaining the purpose of the study and providing information sheets (see Appendix 7 for patient information sheet). I included staff providing direct care and support to residents with dementia, including care assistants, senior carers (who had additional responsibilities), team leaders, activities coordinators, registered nursing staff and managers. I did not interview staff in solely domestic, catering or administrative roles. I used purposive sampling to ensure I interviewed staff of either sex and differing ages, ethnicities, nationalities and different roles and experience.

4.1.3 Data collection

I interviewed staff in private rooms in the care homes, obtaining informed written consent (see Appendix 8 for informed consent form). I used my clinical skills both in setting up a comfortable and safe space for discussion and during and after the interview to maintain engagement and put participants at ease. I collected demographic information.

I conducted interviews using a semi-structured interview schedule (see Appendix 9). I developed this schedule based on the research literature, consultation with family carers of people with dementia via a focus group and expert opinion within the MARQUE team. I used open-ended questions to elicit staff perceptions of current care and I revised questions iteratively, further exploring issues raised. After completing each set of interviews (in one care home), I listened to the recordings, reflected on initial themes and revised the interview schedule to incorporate new ideas expressed by care staff, and as part of an ongoing reflective process based upon both the emerging perspectives of the participants and the interviewer (Agee, 2009). This also allowed us to check that the

questions made sense to the participants, especially since over half did not speak English as a first language.

I ceased interviews at thematic saturation, defined as the point at which reflections on additional interviews and iterative discussions with my supervisors resulted in no further emergent themes (Guest et al., 2016). All interviews were digitally recorded and transcribed verbatim by a professional transcription company. Identifying information was removed to preserve anonymity; on completion of the analysis all recordings were deleted. Transcripts were password protected and stored on a secure network.

4.2 Data analysis

4.2.1 Analytic approach

I have taken a thematic analytic approach based upon the work of Braun and Clarke (2006) who argue that thematic analysis represents a flexible standalone method which can be used as a tool to develop a rich and complex account of qualitative data (Braun and Clarke, 2006). Braun and Clarke highlight that although thematic analysis is not wedded to a particular epistemological position, it is important for researchers to be clear what their position is, why they have chosen a particular method and how they have undertaken the analysis. I would locate this research within a 'contextualist' or 'critical realist' position which neither denies the impact of social context upon peoples' experiences nor overlooks their material or lived experiences (Bentall, 2009, Houston, 2001). I would see this approach as particularly fitting in care home research where the day to day experiences of staff are undeniably framed by institutional culture and social context but where the uniqueness of staff experiences in relating to people with dementia in their care can be easily overlooked (McEvoy and Richards, 2006).

I decided together with my research supervisors that this method was most appropriate to meet my research objectives. In relation to my objective to explore and describe staff understanding and management of agitation and consider what knowledge, skills and support they would need to manage agitated behaviour among residents, I have taken an inductive approach to the analytic process. This is because I am interested in the subjective

experience of care staff and what I can learn from the data about these experiences to inform our general understanding of how agitation is managed in care homes.

In contrast, in relation to my objective to understand what factors determine how agitation is managed in care homes and what can facilitate a shift in these factors, I have taken a more deductive approach drawing upon existing theoretical understandings of what informs implementation in complex healthcare settings (French et al., 2012, Grol et al., 2007, Michie et al., 2005).

4.2.2 Analytic procedure

After listening to each interview, familiarising myself with the data and checking the transcription against the audio recording, I entered all transcribed interviews into NVivo 9 software package for qualitative data analysis. I then systematically coded the transcripts into meaningful fragments and labelled these initial codes. Each transcript was independently read and fully coded by a research assistant and we discussed and resolved any discrepancies (Barbour, 2001). I then organised the data into preliminary themes, displaying in matrices and diagrams until I had a comprehensive picture of all the phenomena in question. I discussed the coding frames within my supervisors and the research assistants involved in coding, using the constant comparison method (Glaser, 1965), identifying similarities and differences in the data in an iterative process closely grounded in the data. I sought respondent validation (Mays and Pope, 2000) on the thematic analysis by sending participants summaries of the findings, allowing them to comment on the accuracy and credibility of interpretations (see Appendix 10). In the next three chapters I will present my analysis of these interviews.

Chapter 5 What is agitation? Staff experiences and understandings

I begin this chapter by describing who I interviewed and the care homes they were working in, giving the context for the analysis presented (Chapters 5-7). I will then describe the behaviours staff perceived as agitation in residents and consider its impact upon staff. Finally, I will describe their explanations of what causes agitation.

5.1 Care home and staff demographics

I conducted 25 semi-structured interviews with staff in six care homes; four in London, one in Kent and one in Cambridge between July 2014 and January 2015. Interviews lasted between 32 and 71 minutes. Five of the care homes were privately run and one was run by a charity. Three of the care homes were nursing homes, two were residential homes and one provided residential and nursing care. At their most recent routine CQC inspection prior to participating in the study, four of the six homes met all assessed quality standards, one required action on three out of five quality standards and one required action on one of seven quality standards. Staff demographics and employment characteristics are presented below in Table 5.1.

Table 5.1: Staff demographics and employment characteristics

Staff characteristic		<i>n</i> (%)
Sex	Female	17 (68)
	Male	8 (32)
Ethnicity	Asian or Asian British	6 (24)
	Black or Black British	6 (24)
	White British	6 (24)
	White other	5 (20)
	Mixed other	2 (8)
English as first language	No	13 (52)
	Yes	11 (44)
	Not stated	1 (4)
Highest level of education	Diploma or NVQ	12 (48)
	Degree	8 (32)
	Postgraduate	3 (12)
	GCSE	1 (4)
	Not stated	1 (4)
Staff role	Care assistant	9 (36)
	Senior carer	5 (20)
	Manager / deputy manager	5 (20)
	Team leader/unit manager	2 (8)
	Activities coordinator	2 (8)
	Nurse	2 (8)
Shift pattern	Days	18 (72)
	Days and nights	7 (28)
Time working in care home	Less than 1 year	4 (16)
	1 to 5 years	13 (52)
	6 to 10 years	8 (32)

GCSE (General Certificate of Secondary Education); NVQ (National Vocational Qualification)

5.2 Qualitative analysis

In exploring staff experiences and understandings of agitation, I identified four overarching themes: 1 Symptoms of agitation: No two residents are the same; 2. The course of agitation: Persistent and unpredictable; 3. The impact of agitation on staff and 4. What causes agitation? Unpredictable but not inexplicable. These are discussed in turn below.

5.2.1 Theme one: Symptoms of agitation: No two residents are the same

Table 5.2 shows the different symptoms of agitation detailed by care home staff. Throughout their accounts, staff stressed the varied presentation and individual nature of what was labelled as agitation and how this reflected their general experiences of caring for residents with dementia:

Everyone's different really and you get it [agitation] in different ways. (Deputy manager; CH1)

Staff reported a range of behaviours that they labelled as agitation. Staff rarely spoke of one discrete symptom, often describing symptoms as co-occurring or developing from one to another, for example, verbal aggression escalating into physical aggression and leading to staff injury. They most commonly described verbal and physical aggression directed towards staff as occurring when they were providing intimate care, such as washing, dressing or assisting a resident to the toilet:

Like when you do the personal care he just goes with you for a while and then suddenly he'll react, it's like if you are not taking care of yourself the carers can be hit or sometimes those kinds of things, he'll just smash you like that. (Team leader; CH2)

Table 5.2: The symptoms of agitation described by care staff

Staff description	
Verbal and physical aggression	Starting from the morning, when we have to carry out our personal tasks and that kind of resolves into really, you know, aggression that just manifest itself through verbal abuse or even physical. You know, there is spitting. There is kicking. There is swearing. (Care assistant 1; CH3) We try to follow most of the techniques correctly what they teach us, but still we get injured bruised and slapped on the face and all from the residents. (Team leader; CH2)
Screaming crying and emotional distress	There was a resident who passed away – he was just screaming non-stop and was not able to say what was going on. (Manager; CH5) She will just say, I want to go home, I want to die, but that's... and then, but she doesn't have anybody, do I call it agitation... (Care assistant 1; CH6)
Repetitive behaviour	She likes to do what the staff call "cuckooing". She'll be in her room, she'll close her door, she'll probably lock it and then she'll open her door and she'll open it and she'll look up and down the corridor, she'll close the door, go back in. (Unit manager; CH4)

5.2.2 Theme two: The course of agitation: Persistent and unpredictable

Agitation was sometimes unpredictable and fluctuating from moment to moment and over longer periods of time:

It fluctuates frequently; she can go from being content, engaging well with others, jovial and making, you know, making jokes to then becoming completely disorientated, anxious, pacing up and down, calling out for help, not knowing where she is. (Unit manager; CH5)

There was a sense that episodes can escalate very quickly into aggression, both for individuals and between residents. Staff spoke about having to be constantly vigilant so as not to be taken by surprise:

...they're holding hands and they're walking up and down the corridor, chatting away, and then the next minute is, 'Why are you following me? Get away'. And that can turn so quickly into a hitting or pushing, so, you're just on high alert. (Unit manager; CH4)

Staff also experienced agitation as unrelenting and persistent, especially when residents displayed repetitive behaviours. These behaviours were seen as problematic if they impacted either upon the individual, staff or the other residents on a unit, for example, when people went into other residents' bedrooms or took other residents' belongings:

Every single door he will open. So he just burst into somebody's room and that will start somebody else up... (Senior carer 1; CH3)

Behaviours not perceived as harmful to the person themselves or to others were not conceptualised as problematic. For example, the behaviour of a resident who paced persistently did not concern staff until she became lost in a basement:

There's nothing stopping her doing it, she's not doing any harm or anything. Occasionally she's managed to end up in the basement, once she ended up in the basement, and got quite distressed because it was completely unfamiliar. (Manager; CH2)

5.2.3 Theme three: The impact of agitation on staff

The violent nature of behaviours described by some staff in rather matter of fact terms is striking. These staff appeared to perceive it as part of their job or as routine:

I've got so many punches and slaps and spits and kicks and everything, I'm used to it. (Care assistant; CH2)

I had my glasses broken, and I had to go and pay for them. This place wouldn't pay for them. The resident hit me round the face... It was so funny because she was stroking my hair, saying, oh, you're so lovely. (Care assistant 1; CH4)

However, other staff talked about how difficult they found it to manage residents' agitation, especially when it was persistent or it involved more than one resident, which was often the case. Staff recounted how an episode of agitation could have an emotional effect upon them which continued after they finished a shift:

I've made my journey home and I've missed two stops because of a situation that happened that day at work with a resident that was agitated. (Unit manager; CH5)

5.2.3.1 *Staff feeling powerless and disheartened*

Staff frequently described a sense of powerlessness, especially when they felt that attempts to reduce agitation or alleviate the resident's distress were not working or if they felt unable to make sense of a resident's behaviour:

But to have someone distressed in front of you, then you realise that someone else is getting distressed. Maybe someone is complaining about it. They are looking at you to try and do something, and you can't do anything. (Deputy manager; CH6)

At these times, staff described finding it difficult to make decisions or think clearly:

What will be the next step they going to do, so what's the reaction from them, so kind of, where do you stand, like, take them away or leave them for a while to calm down, that kind of confusion we have. (Team leader; CH2)

Being unable to resolve agitation often resulted in staff feeling as if they were not 'doing a good job' and seemed to undermine their identity as caring professionals whose role it was to help others:

It can make you feel sometimes, when things aren't working, that you feel you've failed... sometimes you do go home disarmed, because you feel that you haven't been able to do the best for that person that you can. (Activities coordinator; CH4)

You could tell, even if they tried to hide but you could tell, you know. You would ask are you all right? No it's so and so and I'm not able to handle her or him. (Nurse; CH3)

Feeling disheartened at not being a 'good enough' carer was recounted both in terms of staff judging themselves *and* as feeling judged by others, especially by relatives and by managers:

Like, obviously they shouldn't be in bed if the managers come or their family comes. And they'll say, why is my mum being in bed? And, you know, I... obviously we tried our best and that... it does annoy. (Care assistant 2; CH3)

5.2.3.2 *Staff feeling frightened and unprotected*

Staff also spoke about feeling frightened of being harmed by residents which was connected to the feelings of powerlessness, especially in relation to episodes of physical and verbal aggression. This anticipation of harm affected how staff approached and responded to residents:

They are scared. It doesn't mean they don't do it, but, you know what I mean? While you're doing things, you're not doing with all the openness and things, you do it with an 'oohf'. (Care assistant 1; CH3)

Although staff narrated aggressive acts as ‘part of the job’, they highlighted how difficult it was to fear for your own safety in the workplace:

Sometimes it is quite traumatic to be slapped or to be kicked or to be scratched or... you know, it’s not an easy thing to say, okay, I’ll brush it off.
(Deputy manager; CH6)

Staff were often faced with difficult decisions, balancing their own safety with that of the residents and feeling that they were not afforded protection in the same way as the residents:

It can be very awkward for both of you, and sometimes you can feel very scared of a resident because, you know, they can do whatever they want to you. They can hit you, but you can’t restrain here. (Care assistant 1; CH4)

Safeguarding is both ways...it’s also when the resident abuses us. (Care assistant 1; CH3)

5.2.3.3 *Feeling angry but trying not to react*

Staff commented that although residents’ behaviours were not intentional and dealing with agitation was part of their job, they and other staff sometimes reacted to it in ways they knew they should not:

It may make you react at a time in a way that you don’t want to react, because you know these residents can’t help their behaviours, but then you’re stressed and whatever, you know, and you may say something that you know you shouldn’t say, or you may raise your voice at a resident, which you know you shouldn’t do, but at that moment, you’re thinking, oh, no, again. (Unit manager; CH4)

Staff described needing to think and respond quickly, often facing ethical dilemmas and balancing multiple needs of different residents and potential risks. This tension was apparent in the discussion of attempts ‘not to react’ in response to agitation and aggression and the effort required to stay calm themselves:

But I think being calm is a big thing, and not reacting because, you know, when you're getting smacked in the face, you know, some people's natural reaction would be to say something, usually. (Care assistant 1; CH4)

Staff accounts highlighted a sense of having to do something quickly in order to prevent a crisis:

So, that's... if somebody get agitated you can't just say, oh I don't have time, I'll leave you like this because it will get worse for the person. (Care assistant 2; CH6)

5.2.4 Theme four: What causes agitation? Unpredictable but not inexplicable

Staff suggested a number of possible medical, environmental and interpersonal reasons for agitation, however they also described how agitation can feel like a 'guessing game', unpredictable but not inexplicable:

Often it's just a guessing game, and often you just get it wrong, because you think, oh, this is what happened, and instead it's completely... it might be completely off the mark. (Deputy manager; CH6)

Although staff sometimes described feeling that there were 'no triggers' for episodes of agitation, their accounts contained numerous hypotheses as to what may be causing agitation, which I will now discuss.

5.2.4.1 *It is part of the disease*

Dementia itself, was often given as an explanation for agitation by staff. This included brain damage causing agitation directly, and through cognitive impairment making it harder for people to understand and be understood:

Well, obviously I do understand they've got dementia. It's they're not, like, fully complete in their, what do you call it, brain... (Care Assistant 2; CH3)

We understand her behaviour because they have cognitive impairment, they don't see things the way we see them...When I'm trying to offer something to

drink she might not see that as something to drink, something else, I don't know it's hard to read someone else's mind really. (Nurse; CH3)

5.2.4.2 *Agitation is interpersonal*

Staff highlighted the relational aspects of agitation, with particular responses and interactions, especially between staff and residents escalating agitation:

I think if you keep insisting yourself, like if you keep doing what she don't want you to do, it will more aggravate her, yes. (Senior carer 1; CH2)

Staff described how agitation tends to spread within the care home, with other residents affected both directly and indirectly:

I don't quite know why but, it seems there's a domino effect with other residents. When they know you're trying to cope with one situation, then another resident will start shouting out in the corridor, trying to get your attention away from the other person. (Care assistant 1; CH4)

In addition to the complex interactions between staff and residents, staff frequently spoke about the impact of relatives. Generally, staff spoke of relatives as a trigger for agitation in the residents, especially if they perceived relatives to lack understanding or have unrealistic expectations of their relative's abilities:

The relative would trigger that behaviour by being too pushy or insist for that resident doing things which she doesn't want to do. (Senior carer 2; CH3)

Other staff reflected upon the absence of relatives, and the effect upon residents at the end of a family visit, when they notice that their family are no longer there:

After they leave they look left and right they notice the family's gone, nobody's around, so a few minutes they're coming and visiting, they make them happy, later on they make them unhappy. (Senior carer; CH6)

5.2.4.3 *Agitation as unmet need*

An additional subtheme was that of agitation being an expression of unmet, emotional, physical or environmental need, which the person with dementia can no longer resolve themselves:

They might not be able to express what they want – their wishes, their preferences – or if they don't want it. (Manager; CH5)

5.2.4.3.1 Unmet physical need

Many staff thought that agitation could be a consequence of physical factors that needed consideration. They realised that residents were often unaware or unable to communicate that they are in pain or feeling unwell:

Like maybe they have pain in their legs, but they can't explain themselves. That is why I say you need patience, because they're shouting, they don't know where the pain is. (Senior carer 1; CH3)

Identifying the cause of distress or agitation involved a process of elimination and consideration of a number of factors such as hunger, thirst or medication. Some managers and nursing staff commented that these causes may be overlooked by care staff:

But you'll find a lot of... Someone might be shouting out and instead of asking, are you in pain, or investigating why, you'll find a lot of, well, I'll do you a cup of tea and that should do you for a little bit. (Deputy manager; CH4)

5.2.4.3.2 Unmet emotional need

Many of the staff understood resident agitation as an expression of emotional distress and they drew on their knowledge of residents' past and present experiences to make sense of their current emotional state:

He feels he's been... I think he feels he's not wanted, he feels maybe they [his family] left him. I understand how he feels, how come I'm here, where are they, you know, I do understand. (Senior carer 1; CH3)

Staff often attributed meaning to how a person in their care was responding, for example that they were feeling ashamed or embarrassed during personal care or were experiencing distress at a loss of independence:

He's in a horizontal position, someone is trying to change his pad and he doesn't like that, because he doesn't like to be touched behind, for example, because he feels embarrassed. He would never realise how to express the embarrassment. He would kick and spit, but in his mind he's telling you, every bloody time. (Care assistant 1; CH3)

Staff also highlighted how this distress was often made worse because of the other deficits that result from dementia including cognitive and physical decline, for example that a person could no longer remember that they could not walk.

That he can't get up and do anything he wants. He's tried a couple of times, but we have to stop him, because he thinks, he remembers walking, but he doesn't know that... he can't walk, so we have to, like, plug his chair back or keep checking on him. (Care assistant 1; CH5)

Some staff considered that emotional needs were not always taken as seriously as more tangible physical needs, especially when staff are under pressure with limited time or resources and suggested that some 'needs' were viewed as more valid or real or as less deserving of staff responses:

Unfortunately, what it comes to is you start to think to yourself, well, these people have real needs, where her needs aren't real. Yes, they are real, because she wants the companionship, but, you know, we do have a hierarchy in terms of - is the person pain free, are they well hydrated, are they fed well, are they comfortable, and then maybe you can get to the social needs. (Deputy manager; CH4)

Some staff described agitated residents as engaging in a behaviour to gain attention:

It's a bit of a game sometimes for him I think...There's a lot of play-acting getting involved. This guy probably has lot more capacity than he thinks. (Care assistant 2; CH5)

5.2.4.3.3 Unmet environmental need

Staff also described a number of environmental, social and external factors that could exacerbate or alleviate agitation. A common thread was that people need, and good care provides, interaction and stimulation at both an environmental and individual level:

Just the whole idea of them sitting in a chair is no good. I don't like that. The brain must be stimulated, even if it is a small amount it must be stimulated.
(Care assistant 2; CH5)

Throughout the accounts, there was an assumption that the more institutional aspects of care home environments contributed to agitation:

I mean, if you walk into the lounge in a care home it isn't like your home. There isn't a sofa, there's single chairs, and who has single chairs? And something that small can make a big part on someone, especially if someone is affectionate, they want to sit next to somebody. (Care assistant 1; CH4)

A number of staff made a direct link between residents feeling trapped inside and becoming agitated, evoking striking images of imprisonment:

Well, there is one. Like xxx. He find that this home - can I use that word? Prison...He finds this home that it's a prison, because he likes to go out each day. (Activities coordinator; CH5)

Many highlighted that resident's freedom was curtailed because of concerns about residents coming to harm when going outside or even moving around within the home, and that this caused staff and residents distress:

And it's not like us. I can open the door. I can have a walk outside. It's not for them. They are always going, either in this left corridor, or to the far end of the right one, or in the lounge, or in the dining area. That's it. Finished.
(Care assistant 1; CH3)

5.3 Summary

In this chapter, I have recounted how the staff perceived agitation as phenomenologically diverse, persistent and unpredictable. Staff were often caring for residents experiencing severe agitation as part of their routine work and this had a direct impact upon how staff felt about themselves, the residents and their jobs. I also described how staff make sense of agitation as multifactorial, encompassing the disease process itself, the interaction between staff, residents and relatives, and as an expression of unmet physical, emotional and environmental needs. In the next chapter, I will synthesise what staff told me about the approach and methods that they use to manage agitation. I will highlight how the emotional impact of agitation on staff and how they themselves make sense of residents' agitation, influences how they respond and what they feel able and unable to do.

Chapter 6 How do staff manage agitation?

In this chapter, I will describe staff accounts of how they were managing agitation. I have organised this into two main themes (see Figure 6.1):

Theme one - Preventative approaches: Responding to individual need: This theme highlights how staff try to meet residents needs and reduce the likelihood that they become agitated. It describes the overall approach taken by staff in caring for people with dementia.

Theme two - Strategies to reduce agitation: This theme focuses upon the methods and techniques staff draw upon when residents become agitated.

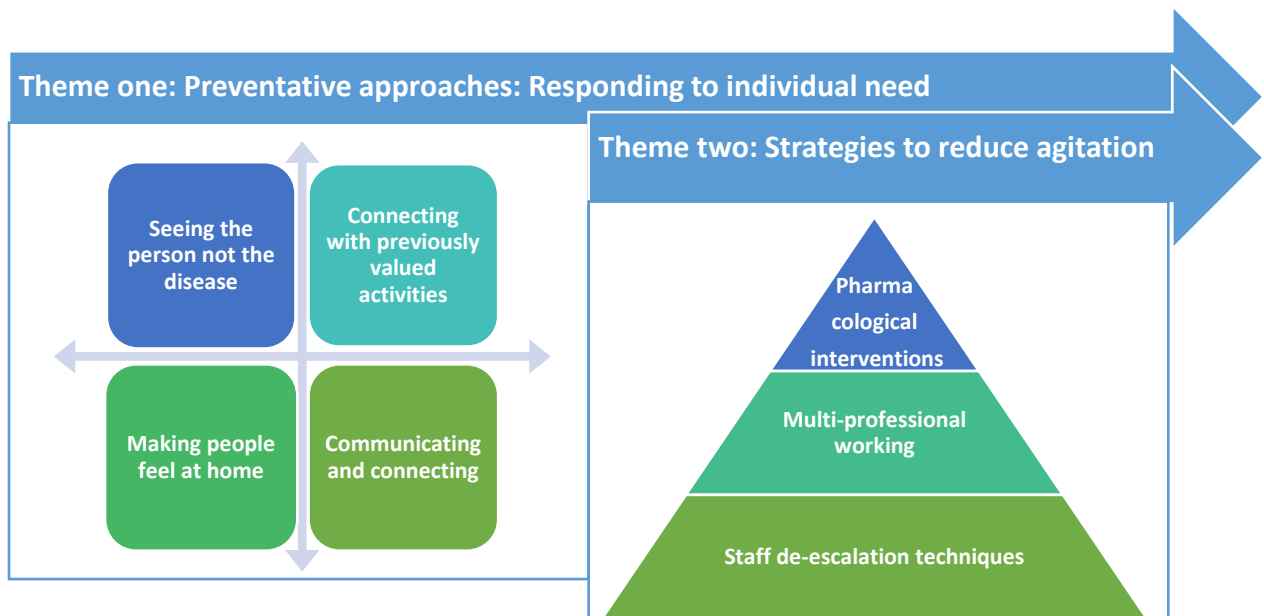


Figure 6.1: How do staff manage agitation?

6.1 Theme one: Preventative approaches: Responding to individual need

Staff highlighted aspects of their care that they felt prevented or reduced the likelihood of residents becoming agitated. Having time to get to know and understand a resident's specific needs and desires was considered important in helping them to know how best to respond or approach care, and to help the residents to build trust and familiarity with care home staff:

And, also, it makes... well it gives hope, put it that way, from our point of view, that the person can learn, slowly, slowly, to, you know, be confident and familiar with us and with our words, with our voice. (Care assistant 1; CH3)

This theme included four sub-themes: seeing the person not the disease, connecting with previously valued identities, making people feel at home and communicating and connecting.

6.1.1 Seeing the person not the disease

Well, I think they should be able to come in, yes, do the personal care, but while you're doing the personal care, look at the rest of the person, not only the bit you're washing and dressing, remember that they're a human being, remember that they've lived a life. (Unit manager; CH4)

Staff described taking a 'person centred approach' as essential to getting to know the person with dementia and discussed how this informed their responses during care. They talked about seeing the residents as equals and trying to imagine how they would feel in a similar situation:

Is there a person who doesn't get stressed, doesn't get angry over a silly little thing? You know, someone spills a drink and they shout at them, and just because they've got dementia it doesn't mean they haven't still got those feelings. (Care assistant 1; CH4)

Staff drew upon notions of shared humanity to describe how they maintained empathy and compassion. This was a complex process which involved staff navigating between connection with the 'personhood' of individuals and seeing agitation and aggression as part of the dementia and separate to the person. At times, staff seemed to weave between these different, arguably contradictory, positions. When responding to severe agitation, this was a difficult path to tread:

I think the person, will, be normal like, you know, how he used to be. He will don't do this one, he will not pinch you, or... So, you just try to understand how, you know, the person is now so if we will be, like, normal like myself he will don't do it to me because I know, because having dementia and he's

agitated so... Just try to, you know, explain to the person just please don't do something and I know that person still can do it like this. (Care assistant 2; CH6)

Tension was particularly apparent when staff recalled attempts to talk directly to residents about behaviours viewed as challenging or unacceptable. Where staff viewed residents with dementia as being fully in control of, and therefore to blame for their behaviour, this sometimes appeared to undermine rather than promote 'personhood':

We said that you have to apologise to your wife because it was not nice how you swearing at her. So, after maybe he realise but he say, I don't want to, I'm not going to apologise, because he didn't, maybe he just doesn't remember, like, maybe when he was swearing. (Care assistant 2; CH6)

6.1.2 Connecting with previously valued identities

Staff discussed the importance of developing a sense of a person's past and building this knowledge into how they engage and respond during care.

Well, I always like to know what did you used to do in your time. What work do you like doing, you know. All the different things, really, in life... (Activities coordinator; CH5)

This was perceived as a respectful way to approach care and sometimes as a way to 'calm' agitated residents and ease the process of delivering care:

She's a lady that likes to look nice and, I guess, sometimes it does work just to sit her down in her bedroom, so a calmer environment and just to encourage her to put makeup on... but the actual process of her doing it can, can, sort of, help settle her again a bit. (Unit manager; CH5)

Staff spoke about times when they perceived agitation to be caused by an unmet emotional need, such as a loss of independence or feeling lost or insecure. They spoke of the importance of supporting individuals to reconnect with preferred identities in new ways. A staff member describes her approach to a resident who likes to 'pay her way':

You don't want to give up your independence, and that is a way of showing your independence. I'm still able to do this. Whereas, if you... if you just sort of say, well, here you are, you can have this. There's no charge. She feels that she's not entitled to that. So allowing... giving her the paper money that she can pay with, she feels that she's paid for it and that it... she's worthy to have that sort of thing. (Activities coordinator; CH4)

For many staff, finding out more about people's past and finding creative ways to build this into day-to-day care was also a way for them to feel that they were making meaningful connections with the residents. This was not always straightforward or easy to do, especially with residents with more severe dementia:

But when we talk about the previous things, you know, past things, I think they know when they get... showing the photographs and everything, when they talk about it. They will talk with them, you know? They get more relaxed, we can see that. (Senior carer 2; CH3)

6.1.3 Making people feel at home

Staff attempted to create a homely environment for residents reflecting how they perceived the residents would wish to be cared for and tailoring their responses to meet individual preferences:

Pottering, you know, they're used to certain things in their 'home-home'. (Activities coordinator; CH5)

It's a 24 hour process and this is their home, they can get up when they like, as long as they eat and they feel comfortable, that's the most important. (Senior carer; CH6)

Staff described multiple ways in which they tried to prevent and reduce physical and emotional discomfort for residents. They described using music, touch and sensory stimulation, particularly with more impaired residents. A number of staff talked about the effect of 'touch' upon agitated residents and how often a small act could seem to make a big difference to a resident's mood:

So what we'd do is, literally, pick up the guinea pig, take it down. Look at this and the crying would stop. Oh, you love me and it was just that comfort of having something just laid there, cuddling with her. (Deputy manager; CH1)

Some staff considered how touching residents in an affectionate way prevented personal care being the only situation in which residents were touched. Staff would often qualify their comments about touch outside of care delivery with reference to their professional boundaries or role. They would mention that touch was not always appropriate, highlighting that this is a tricky area to navigate:

I'll say to him, do you want to dance? Because he always says he used to dance. He'll take me really close and we'll have a little bit of a dance... But something silly and trying to be more of a friend than, I'm a carer, you are a resident and this is my profession. (Care assistant 1; CH4)

6.1.4 Communicating and connecting

Underpinning staff accounts of how they try to prevent residents from becoming agitated was the central importance of communication to building and maintaining relationships, delivering care and alleviating distress. This included drawing upon a range of different communication skills to understand residents and to facilitate being understood.

If he can't understand you then you will show, you will try to explain by showing it to him or her. But with him it's very easy, if you explain verbally step by step what you want to do then he will understand, and I told you, 90% he will accept everything. (Care assistant; CH2)

Staff required patience and skill to continue to find ways to communicate and even then, the strategies being used were not always successful:

And sometimes we'll explain to him what we're going to do before we do it, but by the time we start doing it, he might sort of forgotten, so then that's when he gets angry again. And we will explain again. Sometimes he will accept it; sometimes he will still be angry... And then it can go over and over until he allows us to carry on. (Care assistant 1; CH5)

Many staff talked about 'one-to-ones' as protected time to spend with residents without being engaged in other care tasks, both as a way to get to know and connect with residents but also as a strategic response to agitation. Based upon their experiences, staff explained that it was important for residents to feel that they were being listened to and given undivided attention. This was seen as separate to the interactions that took place during routine care tasks or activities. 'A cup of tea and a chat' was a common way for care staff to describe this form of interaction. In practice, there was some tension as to when, where and how this should happen, as is described by this deputy manager talking about staff sitting with residents and showing them pictures on their mobile phones:

They [the residents] couldn't, kind of, figure out what was happening on the phone, but these staff were actually involving the residents. They were maybe lazing [?] for a minute, you know, just, kind of, skiving a bit of work and saying, okay, I'm sitting down for ten minutes, but they were doing it with the residents. (Deputy manager; CH6)

6.2 Theme two: Strategies to reduce agitation

At times when the preventative approaches outlined above were unsuccessful, staff used a wide range of strategies to reduce and manage agitation, ranging from direct, 'hands on' approaches aimed at de-escalating episodes of agitation, to pharmacological and multi-disciplinary interventions that involved specialist input from outside agencies.

6.2.1 Staff de-escalation techniques

Staff described a range of strategies and techniques that they used to de-escalate episodes of agitation. Staff highlighted that the process had to be flexible and adaptive, based on what works with a particular resident at a particular time. Many staff described a process of 'trial and error':

There's no hard and fast rules, it's just really sort of trying to read the situation really. (Care assistant 2; CH5)

6.2.1.1 *Distraction vs reassurance*

Distracting or diverting residents' attention was described as key to managing episodes of agitation by staff at all levels. This process of redirecting the person was often complex and based upon staff knowledge and understanding of the individual, for example, redirecting a resident who was a doctor by asking him medical questions or enabling a woman anxious about feeding her children to pick out store cupboard items to take back to her room:

He was getting really agitated and one of the staff said 'oh, do you mind if you have a look at my back, it's been quite bad?' And it immediately distracted him and he went 'certainly, of course.' And, you know, went along and they had a little poke around, 'I can't see anything wrong here, are you sure... it might be muscular.' (Manager; CH2)

Frequently staff described how they would sit and talk with people as they were trying to deliver personal care or help at mealtimes, in order to change the atmosphere or reduce anxiety, particularly if they felt that agitation was being caused by an unmet emotional need. One activities coordinator described how they would attempt to distract a resident searching for her husband:

We try to engage her in as much as we can to try and sort of take her mind off looking for [her husband] and going home. (Activities coordinator; CH4)

She then compared this to the less successful strategy of offering repeated reassurance:

Even though you assure her five minutes before, he's been here, she won't believe you. So that tends to increase the agitation. (Activities coordinator; CH4)

Reassurance was usually experienced as a temporary solution with limited effect:

She will carry on, even if you say he's coming, then she will listen to you for a bit, and again, after one minute or two minutes she will ask again. (Care assistant 1; CH6)

6.2.1.2 *Playing along with rather than correcting*

A dilemma faced by staff was knowing how best to respond to residents who were distressed or disoriented in time and place, especially when the reality of delivering care was at odds with the perceptions of the people they were caring for. Staff at all levels talked about 'playing along with' or 'entering their reality', often describing how this is better than trying to orient people to their present reality:

While you standing arguing with someone saying, no, you're 90 and your kids are all grown up, to them they're not. They're still at school. They need help so we just say to them... so just go in their reality with them. If they're looking for their kids, the kids are at school. They're all right. (Deputy manager; CH1)

Although staff described feeling this was the right way to respond to residents, it was clear from their accounts that this was not a simple process and that it did not always have a positive effect upon agitated residents:

She paces and she wants to get up and leave the room, she will start talking but the conversation is very, very rambling and confused, so even though you might try and participate you will get lost somewhere so that's not an effective strategy. (Care assistant 2; CH5)

Staff explained that they can find it hard to think how best to respond in the moment and described how it can be challenging to know when to stop 'going along with residents', potentially leading to increased confusion or feeling uncomfortable that they are 'lying' to residents:

You're not saying... You wouldn't go as far as saying, oh, they've just gone to the shop. They'll be back in a minute because then that minute they could still be, well, where is she? (Deputy manager; CH1)

6.2.1.3 *Giving agitated residents space*

Staff stressed that giving people space away from others or the focus of distress was an important response when residents became agitated, as well as a basic right:

Giving them their own privacy, giving them their own time and just... so that, you know, she will make her peace, and then just come back when she's ready, something like that. (Senior carer 1; CH2)

It was also a practical response which involved staff helping residents to find space when they were unable to achieve this for themselves:

So, if it's because somebody is getting annoyed because of the noise that's going on or the music that's playing then try and bring them out of it. So, get them out of the situation. (Senior carer 2; CH2)

This frequently involved trying to separate the agitated resident from the perceived trigger, for example, another resident or an overstimulating environment. Separating an agitated resident had several purposes: minimising the impact (and potential risk) on other residents, distracting the agitated person from the source of the agitation and as a strategy to manage the situation:

You just separate them, so that can be easier for us and good for the residents not throwing the glass and breaking the head, you know? (Senior carer; CH6)

Although staff wanted to maximise freedom and space, they had to balance this with perceived potential impact on both the agitated residents and the other residents in the home:

So the best thing is just give him that freedom, but the problem is we don't really want him going into the residents' rooms, which is depriving them from their own privacy. (Senior carer 1; CH3)

6.2.1.4 *Walking away*

Staff often talked about 'walking away' from residents as a useful strategy, particularly if they were trying unsuccessfully to provide hands on care or if a resident was becoming verbally or physically aggressive:

Sometimes I think leave them for some time, then come back and talk to them. If they get agitated, whatever we tell them, they can't understand it... (Senior carer 2; CH2)

However they faced a dilemma of leaving a vulnerable resident who wanted to be left but may then come to harm, and the perception that their actions were neglectful:

He doesn't like to have a shower in the morning, at the same time he's covered with faeces or urine, we cannot leave him in his bed, that's kind of abuse. (Senior carer; CH6)

One activities coordinator, who did not provide direct personal care, spoke disparagingly of her colleagues in this respect:

Just walk away. You can't walk away... Yes, I see it...I will report the danger and the abuse part. (Activities coordinator; CH5)

Staff try hard to 'stay calm' and 'not react' as a way of minimising unhelpful responses such as getting angry or impatient with residents (See Section 5.2.3.3).

6.2.2 Multi-professional working

When strategies such as distraction or giving people space did not work, staff described how they would involve team colleagues and senior staff. They tried working in pairs or introducing a different staff member for a 'change of face'. They sometimes referred to specialist teams for assessment and intervention.

6.2.2.1 *Consulting a senior colleague or team member*

When there were potential risks to residents or staff, or if there were difficult ethical decisions to be made, staff would involve a team member or a senior colleague to validate choices or share responsibility for actions:

Especially if a resident was wet in bed and they were lashing out to you, you need to walk away and call someone else...Whereas a lot of people would see it as abuse, you need to have confidence. That is a big thing, you know, and you need to have a team to back you up. (Care assistant 1; CH4)

Many accounts explicitly highlighted the existing hierarchies within the care home and the clear delineation around roles, such as who was able to refer to a doctor and who was responsible for writing a care plan. Care assistants spoke about how they would defer to senior colleagues and senior staff. Managers described their expectations of when care staff should seek support:

I mean, we teach staff here to back off, keep them within your sights, let somebody else know so you're not on your own, let somebody else know and we'll come up and deal with it. (Manager; CH2)

We just tell the nurse if they're in pain, because we... obviously, we can't do anything. (Care assistant 2; CH3)

Staff talked about how they would make a shared plan about how to manage a resident's agitation. This was sometimes informal, based on discussions between staff. At other times, this was formalised in a written plan shared across the team. These plans would evolve with staff experience of what did or did not work:

So someone might say, well, actually, I tried that but that didn't work but I tried this and that did work so they share each other's ideas. So that'll be a case of, all right, well, we'll try that next and we'll see how it gets on and then they just do it that way. (Deputy manager; CH1)

6.2.2.2 *Referring to external agencies*

When staff felt that they could not manage agitation themselves, that a crisis was imminent or a risk could not be managed, referrals would be made to external agencies or specialist professionals:

Other residents were distressed, other families were distressed, and obviously then professionals were brought in and the usual things were attempted, which is medications, because... she wasn't responding to anything else. (Deputy manager; CH6)

Overall staff spoke in rather negative terms about input from specialist teams. Sometimes this related to feeling that ultimately the staff in the home were the ones caring for

agitated residents and that specialist teams were not responsive or available at the right time:

but it's just down to us on the unit and, you know, we try to get psychiatric team, the GP, people involved, but when things are happening, she hits somebody or something like that, still nothing, and it's just left, you're on the unit, it's just left there (Unit manager; CH4)

Others described feeling that input from specialists was ultimately unsuccessful because the advice they gave was unachievable in practice, for example telling staff to 'never say no' to a resident with agitation or because of a belief that sometimes nothing can be done:

They try... we try to call the social worker, but you know, guess what, hallelujah, social worker is not God. He can sit with you and with the residents and think, but if there is no logical thinking in there. (Care assistant 1; CH3)

However for some, having a different perspective or having certain strategies suggested or reinforced by specialists was perceived as valuable, even if the agitation persisted:

It helps the staff to feel, okay, there is someone I can actually ask something and we're not completely alone, which is important, I think. (Deputy manager; CH6)

6.2.3 Pharmacological interventions

When staff spoke about using medication to treat agitation, they often qualified their comments by explaining that they generally had negative views of medication, based upon past experiences, and that medication was not an alternative to good quality care:

Because sitting in one place, the same place, the same building, the same food...they're going to get depressed, depression, what do the doctors give, the doctor gives tablets and they deteriorate, deteriorate, deteriorate...(Senior carer; CH6)

Medication tended to be framed as a last resort, to avert a crisis or to minimise harm:

I understand in a crisis where somebody is at risk of harming themselves or harming someone else you have to do something pretty immediately. I mean that's usually pills until things settle. (Manager; CH2)

However, staff spoke about how medication effects were often limited or temporary leading to different medications being trialled or dosages being increased. This often resulted in side effects which led some staff to see medication as more likely to worsen rather than improve agitation, for example by causing drowsiness or increased confusion:

We have had points come up where she's had it for a couple of days in a row, and it's just no longer had any kind of effect on her, but aside from that we try not to use it because she's got a history of falls as well. (Deputy manager; CH4)

6.3 Summary

Staff at different levels described working flexibly to prevent agitation and to respond when agitation occurred. Underpinning staff responses was the importance of getting to know the person with dementia and finding ways to meet their needs, thus preventing or reducing distress, which staff enacted in various ways. In response to agitation, staff described a stepped response which included trying to respond directly by de-escalating episodes through giving space or distraction. They described taking a multi-professional approach for more persistent agitation, sometimes calling upon external agencies and pharmacological interventions in more severe cases. This was not a straightforward linear process. Staff described tensions and dilemmas which they faced in their responses to agitation where strategies were often unsuccessful. In the next chapter, I will analyse what factors influence how staff are able to use these approaches when residents with dementia experience agitation.

Chapter 7 What factors influence staff management of agitation?

In the last two chapters, I outlined how staff make sense of agitation amongst residents, experiencing it as unpredictable, variable and persistent. I discussed the range of explanations and strategies they draw upon to manage and prevent agitation. As noted throughout the accounts, strategies do not always work and staff often feel unable to manage agitation, feeling overwhelmed, powerless and frustrated. In this chapter, I will explore, through analysis of my qualitative interviews, what factors staff feel make it harder or easier for them to manage agitation and put successful strategies into practice. Based upon existing approaches that highlight how considering multiple factors at different contextual levels is important to understanding how best to effect changes in care settings (Grol et al., 2007), I have organised these into individual, social and team, organisational and socio-political factors. Although I present themes in distinct categories, there is overlap and interaction across them, which I will highlight. Figure 7.1 gives an overview of the main themes at each level.

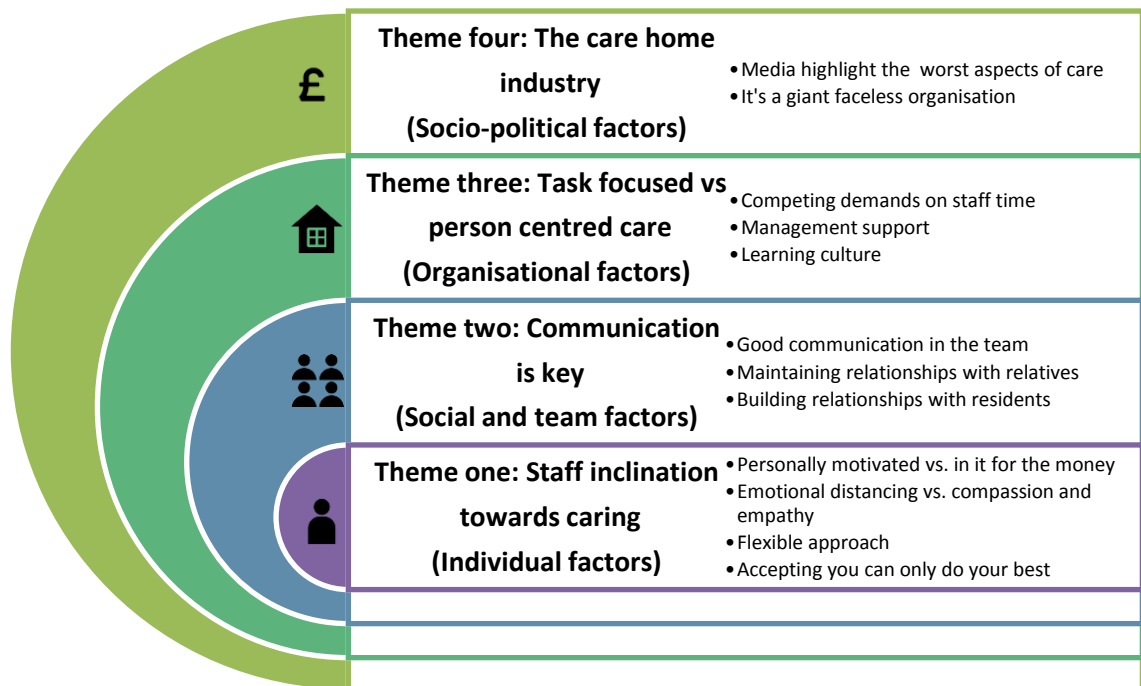


Figure 7.1: What factors impact on staff managing agitation?

7.1 Theme one: Staff inclination towards caring (Individual factors)

I just can't understand sometimes why they've chosen to do the job because they don't show any inclination towards caring or getting to know the person so that you can then treat them in the best way. (Unit manager; CH4)

A key theme was that staff perceived that individuals had personal qualities which made them more or less able to manage agitation effectively. Generally, staff spoke in terms of there being *other staff* who did not have the right sort of attitude or personality for providing care and compared this to the qualities that they felt made *them* or others better suited to the role. There was clear sense that some individuals' intrinsic character meant they did not have what it takes to be a 'good carer'. This quality or attitude was seen as innate and unlike other skills could not be taught:

I find that anyone can fake it, but because people don't realise how stressful the job is, particularly in the dementia and confused units, that it's very difficult for them to sustain it. (Deputy manager; CH4)

So, there are certain things you can teach staff to do but you can never teach them the attitude to do it in. (Manager; CH2)

The staff interviewed perceived specific qualities to make staff more or less inclined to care and more or less able to manage agitation. I describe these next.

7.1.1 Personally motivated vs in it for the money

Staff described how they felt personally motivated to work in care homes and that this enabled them to cope with the more stressful aspects of the role:

And what else gives us hope through the day? ...I love my job, very much, and there is no explanation for that. You either have that or not... I go through the day because I feel sorry for these people, simple as that... and I want to instinctively make it better. (Care assistant 1; CH3)

They spoke in terms of caring being 'vocational' and drew upon different aspects of their identities and experiences to justify their dedication. Some staff talked about their personal experiences of caring for parents or grandparents with dementia:

Before I came here, my grandmother had this illness... So I can see my grandma, while I am looking after these people. (Care assistant 1; CH6)

Whilst others spoke explicitly about religious faith as a motivating factor as well as a way to cope with the job:

My personal... my private, my, my - you know, my church; yes, I mean my personal relationship with God, with Jesus. This really helps me a lot. (Senior carer 1; CH2)

Staff compared this personal motivation to other staff being motivated by money:

I know they're here just for the money, just to earn a wage. It is only a very few, I hasten to add. But that makes it so... I'm not saying they don't do their job properly. They do do their job properly, but that's as far as they go. (Activities coordinator; CH4)

Interestingly, staff condemned the attitude of being 'only in it for the money' in colleagues as unreasonable: they felt that good quality care could only be provided by staff willing to exceed the expectations of their paid role: 'when you're coming only for the money then you can't do proper work.' (Care assistant; CH2). Perhaps unsurprisingly, none of the staff interviewed described themselves as seeing the job solely as a source of income, however some managers acknowledged that although not an unreasonable position, it can make it harder to sustain the challenging aspects of the role:

If you do it because this is what you have to do because you have a family and you need to support them and this is not your first choice, working is incredibly difficult in these situations. (Deputy manager; CH6)

7.1.2 Emotional distancing vs Compassion and empathy

Being compassionate and empathic was seen by staff to facilitate both the caring process and how they felt able to cope. For many, compassion was closely linked to the personal motivation described above and the more intrinsic and vocational nature of the work for some:

If you don't have those traits of kindness and caring and compassion and the ability to see things from the other person's point of view. I would say anybody who can't do that shouldn't be in caring. (Manager; CH2)

Being empathic was closely linked in staff accounts of 'seeing the person not the disease' (see Section 6.1.1):

You know, in five hours I'm going to be home watching telly. They are not. They're not guaranteed to be in their own place. They don't have choice of doing, you know, things, and that must be horrible...I can read it in their eyes. (Senior carer 2; CH3)

However, it was not always possible or realistic for staff to sustain this approach all of the time:

From a selfish point of view, I can understand it. If you work for 12 hours you want to have ten minutes to yourself, so in a way I can understand it, but it's... yes, it would be better the other way. (Deputy manager; CH6)

Some staff described witnessing others becoming emotionally distant, depersonalising or even blaming residents:

Yes, the staff get upset, they say, oh, that dirty old man, leave it, eating and dying there, I've heard it so many times, so that means they're not interested. (Senior carer; CH6)

Staff considered that actions of carers who distanced themselves from the residents, particularly those who were agitated or whose behaviour was difficult to manage, was understandable but not justified and sometimes linked to more overtly abusive behaviours:

If you slam the door behind you, you're likely to abuse or create a chain of reactions, or things that could possibly result in situations, they are not ideal. (Care assistant 1; CH3)

7.1.3 Flexible approach

A common theme was the importance of being flexible and open-minded, particularly in relation to staff experiences of agitation as persistent, diverse and fluctuating (see Section 5.2.2). Below, one manager describes the importance of this quality in general and then a care assistant describes what this looks like in front-line practice:

You know, push button A, push button B, but you'll never be able to do it in any other order other than you've been told try this first, try that next. Yes, there's no flexibility with it. So I do think for dementia clients particularly they need someone who can. (Manager; CH2)

You may be going to the suite or something and on the way you could be looking so if there's someone getting frustrated or agitated with something. You can go back to the other carer if you're doing personal care, 'sorry I had to stop and sort out, you know, Mr. B' or whatever on the way. (Care assistant 2; CH4)

Generally, management and senior staff expressed frustration at more junior staff being unwilling or unable to change their approach, whereas non-management staff were more likely to identify organisational and social barriers (see Section 7.3 below). Some managers acknowledged the challenges staff experienced in changing their approach or putting new learning into practice:

I think it's find a way to change the approach, which is not an easy thing...it's really people being willing to say, okay, I've always done this, let me try something else, and that's the difficult part to change. (Deputy manager; CH6)

Other managers expressed more frustration about some staff not being open to new approaches introduced by their colleagues, for example describing 'idea squashing' and the effect that this can have on the team:

If you're the person that's bringing the ideas and actually doing something positive, and you find something that works but you're not getting the support for it, that can also rip you to shreds and you think, well, why bother? (Deputy manager; CH4)

7.1.4 Accepting you can only try your best

Staff spoke of the importance of finding ways to help them persevere without becoming overwhelmed, particularly when feeling disheartened that agitation cannot be reduced (see Section 5.2.3.1). This often involved recognising the limits of what could be changed:

But as I always say, as long as you can honestly say you've tried your hardest and tried your best, you shouldn't feel bad about it. (Care assistant 1; CH4)

Implicit in this approach was accepting the limits of problem-solving approaches and acknowledging the need for more acceptance-based and emotion-focused coping strategies for carers:

I don't think your goal should be taking agitation away. I think it should be equally part coping mechanism for the staff looking after the residents as well as dealing with agitation when it presents, rather than them trying to remove it completely. (Deputy manager; CH4)

7.2 Theme two: Communication is key (Social / team factors)

Agitation was often conceptualised as interpersonal (see Section 5.2.4.2) and staff saw understanding residents' needs and adapting interactions accordingly as key to a successful response (see Section 6.1.4). It is unsurprising, therefore that staff felt that good team communication and building relationships with the team and residents influenced how they managed agitation.

7.2.1 Good communication in the team

All staff interviewed highlighted the importance of good communication within the staff team as key to providing good quality care and managing agitation; both to ensuring the smooth running of the home at a procedural level and to fostering trust and respect between team members, promoting a positive atmosphere and consistent care for residents:

If you can get that sort of mutual respect going so they can recognise maybe the pressures that each are under I think that makes a big difference...But it's very important for dementia clients because any sort of break within staff or separation of how they're thinking or what they're ... that can become very confusing for dementia clients and for me. (Manager; CH2)

Staff highlighted the need for clear, open lines of communication between staff about residents. Some spoke of the importance of having team meetings or ways to share information in notes and care plans, whilst others described more informal conversations between staff about residents. Although staff were able to describe what they felt worked well and was important, they also highlighted what happened when teams did not function well:

So you do need sort of a like-minded workforce, in a way, if you're going to function effectively in this sort of environment. Otherwise it's like everything, you imagine if you've got three people and they're pulling together you're getting something harmonious, if the three people are all pulling that way there is a bit of like fracture. (Care assistant 2; CH5)

I will now discuss some of the specific strategies that staff described as underpinning good communication in the team.

7.2.1.1 *Sharing the load – working in partnership*

Ultimately for staff, how well they felt able to manage and respond to agitation related to feeling that they were not working in isolation; that colleagues would help with a resident if needed. They described how sharing tasks made working quicker, safer and more rewarding:

If the team is built very good, we can give more time to the residents, then the work is done properly on time we can sit with the residents one to one. We can talk to them, we'll make them happy, you know, take them sometimes into the garden. (Senior care; 05.04)

However, staff explained that this successful collaboration relied upon staff feeling that colleagues worked to the same standard or took a similar approach, and having the confidence to ask for assistance when needed and a confidence others will provide it:

When I'm doing the job, I want it to be a certain standard, but actually finding people who work the same is very difficult, and I find that stressful because then I'm going around behind you, finishing off your job and I want to know why can't you just do the whole job? (Unit manager; CH4)

Front-line staff often referred to the challenges of working with staff who did not seem to have the same level of dedication. They perceived certain colleagues as unprepared to work as hard and therefore were less likely to approach them:

If you are working with staff that are just... it's just work, like in/out, then you might feel, not scared, but don't want to ask them for help. (Care assistant 1; CH5)

7.2.1.2 *It's everybody's responsibility – flexibility in roles*

Linked to staff valuing the ability to 'share the load', they stressed the importance of being able to take on multiple roles; seeing management of agitation as everybody's responsibility, including managers, activities staff and domestic staff. This did not just involve individual staff showing flexibility, but was connected to having flexibility built into team processes:

Although we're assigned all different tasks the ability to sort of just flit in and out. (Care assistant 2; CH5)

Some managers gave examples of how staff were over-reliant on calling in external professionals in response to agitation as they did not feel it was part of their role.

This made it difficult to manage agitation within the teams. This was framed as staff unwillingness rather than lack of skills or confidence to manage:

Yes, they really think... not all of them. Some of them, they think that, well, not my job. Call the...Yes, call CMHT, tell them to come, give them medication. (Manager; CH5)

One manager linked this lack of flexibility in roles to the wider organisational culture in the care home and how divisions or 'factions' develop (see also Section 7.3):

Yes. In a perfect world, like, we get a lot of people, oh, I'm just a night carer, or I'm just the cleaner, or I'm just the chef, and I think part of that has to do with the fact that it's a large home and it's sliced and diced. It's broken up into lots of different factions so you get a lot of 'us and them'. (Deputy manager; CH4)

7.2.1.3 *Staff supporting each other*

When they were communicating well as a team they were in a better position to understand each other's needs and therefore to support each other when stressed. A number of staff described how they recognised when colleagues were struggling or upset and would offer support without having to be asked:

Yes I've seen my staff when they are not able to manage something. You could tell, even if they tried to hide but you could tell, you know. You would ask are you all right? No, it's so and so and I'm not able to handle her or him. (Nurse; CH3)

Staff described how colleague's support, such as having a brief 'moan' or 'an arm round their shoulder' made them feel more able to cope:

You do sometimes wonder why you have actually come in in the morning because you think to yourself, I don't know if I can cope with this today but then, you know, you take five minutes, you have a chat with one of the other carers and then we sort it out. (Care assistant 2; CH4)

Staff talked generally about the benefits and sometimes the necessity of removing themselves from a situation and taking 'time off the floor'. This relied upon other

staff stepping in or noticing a need and was seen to make it easier for staff to keep going:

I do see staff becoming stressed with different situations and again that's when we would tag team so to speak and change, change over. And just give, you know, give someone that time away from that person and someone else will then go and, sort of, support the resident. (Unit manager; CH5)

7.2.2 Maintaining relationships with relatives

Sometimes it's very hard to be with the relatives, harder with the relatives than with the residents. (Care assistant; CH2)

Throughout their accounts staff at all levels, across all the care homes described the complexity involved in maintaining relationships with the residents' relatives. One of the most challenging aspects of this was meeting relatives' expectations, especially when they did not match those of the staff or the residents. When staff understood the relatives' perspectives, and responded accordingly, they were then able to develop more collaborative and productive relationships.

7.2.2.1 *Unrealistic expectations*

Staff described struggling to balance the needs of residents with those of the relatives, especially when they thought relatives' expectations were unrealistic and unattainable:

It can make you feel you're not doing your job but then also it can annoy me because I think to myself well, you know, they're here for a reason, step back and think what that person wants to do because I'm not here for you, I'm here for that resident. (Care assistant 2; CH4)

Staff perceived relatives as having expectations about the level of care that should be available, for example one-to-one care, that could not be met:

It's expectations, managing expectations, because we get people who think a care home should either be the Ritz, or what they see in the Mirror every other week, and they can't grasp that it's neither. (Deputy manager; CH4)

Staff attributed relatives' unrealistic expectations to their lack of understanding or acceptance of how dementia had changed their relatives. Staff described difficult interactions with relatives who would insist that residents had certain tastes, interests or abilities that did not fit with staff knowledge of current preferences:

Say, they've never drunk coffee all their life. Well, I made them coffee and they drank it, and to me, their reaction that this coffee is nice, is better than you saying to me they don't like it. (Care assistant 1; CH4)

These differences were most apparent when residents were agitated or staff had difficulties in caring for them, for example, if residents did not accept a change of clothes or medication. Staff felt that relatives may not see the context or extent of behaviours that challenged staff because they visit for short periods of time:

You know, when someone is refusing their tablets and I had one of the sons saying, but he must take his tablets and I'm saying, well if you'd like to come in and try. That's not my job, you're paid to do that... So sometimes they get, you know ... well ... I mean what sort of a care place is it if they can't even give him his tablets? (Manager; CH2)

Staff felt that these unrealistic expectations sometimes had a direct effect upon resident agitation:

And his family are constantly on at him, sit down, sit down, what are you doing, you're disturbing so and so. And yet I feel, if he doesn't want to sit down, we can ask him to but it's fine, let him go. (Care assistant 1; CH4)

7.2.2.2 Understanding relatives' perspectives

Staff tried to understand the distress that they imagined relatives must feel at having a relative placed in a care home or at the changes they saw in their relative:

I can understand their expectation as well that, you know, nobody would be able to care for their relative the same way that they would if they lived at home (Unit manager; CH5)

The family was incredibly distressed because they didn't recognise her. They could see their mother being incredibly distressed. (Deputy manager; CH6)

Some thought that relatives feel guilt at not being able to care for their relative themselves:

They have to perhaps, answer to their sense of guilt of having one of their relatives in the home. They put him in the home because they couldn't cope. They feel guilty and so they show you that they care. (Care assistant 1; CH3)

As a consequence of their perceptions of relatives' feelings, staff described how they would position themselves to support the relatives and attempt to build relationships.

7.2.2.3 *Collaborating with relatives*

Although staff undoubtedly found that it could be more difficult to care for residents if their relatives were actively involved, many staff explained that having relatives around often made it easier for them to care. A common thread was that residents were calmer when their relatives were with them and that even more impaired residents benefitted from familiarity and personal connection:

No, when family comes, I think they get more relaxed, because even though they have dementia, some people know their wife, their children, and so they are a bit relaxed, I think, with them. (Senior carer 2; CH3)

Staff explained that relatives facilitated the process of getting to know residents, by sharing biographical information and explaining what helps when residents become agitated or distressed. At times, having relatives around allowed staff to take a break from residents with the highest level of need:

The family stays with him, so at least she calms down. It helps. So when xxx is out, so at least we have peace, we don't need to be... (Care assistant 1; CH6)

Collaborating with relatives and communicating directly about resident care also seemed to benefit the relationships between staff and relatives, overcoming some of the challenges. Staff described how they would try and engage relatives by being

transparent about the care they were providing but also by being open rather than defensive in how they communicated with relatives:

So it's trying to find ways to show the families, look, this person can do this. Would you like to come along and participate with us, you know, so you can see what they can do? (Activities coordinator; CH4)

7.2.3 Building relationships with residents

Staff felt that it was intrinsically rewarding when residents expressed affection or appreciation:

but we had a resident who always, when I was working only three days, always after four days I was coming back, where have you been, why didn't you come in, I was missing you, so it's a very, very good feeling, and me personally, it helps me a lot. (Care assistant; CH2)

When staff felt a personal connection with the residents then it seemed easier for them to care for them, and although some residents could express appreciation and recognition directly, with others a positive non-verbal response or reaction could also feel rewarding:

If you can see what you're [doing] is making a difference, I think. Like if they're happy. (Care assistant 1; CH5)

The challenge for some staff was that when caring for some of the more severely impaired residents or those who could not express themselves clearly, it was harder to establish these connections, or indeed to communicate at all:

She still didn't respond to outside stimuli. Whether they were positive or negative, she didn't give any response of any kind that could guide us toward, okay, she likes this better than the other, or she doesn't like this. (Deputy manager; CH6)

Making connections with residents was also sometimes difficult because of language differences between staff and residents. Over half of those interviewed did not have English as a first language. Many staff talked about language barriers with those that they were caring for:

That all seems to have changed; we do have a lot of carers here that are now from overseas, a lot of them are fantastic, but occasionally you will have someone where, I think, sometimes maybe communication is difficult. (Unit manager; CH5)

Staff also connected this to people with dementia reverting back to their first language, and although there was an acknowledgement that this was a part of dementia, there was also frustration in some staff accounts:

What they start saying is something that nobody understands, and that is dementia, they become a kid, a child, and they start saying... I go, can you just say it in English so we can know how to help you. (Senior carer 1; CH3)

As well as language differences, staff also spoke about the socio-demographic differences between staff and the residents. Sometimes this was explicit: for example, certain residents preferred male or female staff to provide care. Staff also spoke about more subtle cultural and class based differences which they felt may make it harder for staff and residents to relate to each other:

Most of the staff come from the local areas. There are about five estates around here, and the reason I'm touching on that is there's not a very broad mixture of education and social skills in the building, whereas the residents come from far and wide. Some of them are very noted and published professionals. (Deputy manager; CH4)

7.3 Theme three: Task focused vs person-centred care (Organisational factors)

A central theme underpinning staff accounts was that understanding and responding to residents' individual needs was integral to preventing and responding to agitation (see Section 6.1). This is consistent with notions of 'person-centred' care and was often labelled as such by the staff, and named as an approach to strive for. A deputy manager described how she has seen a shift in the home culture and approach as the proportion of residents with dementia and higher levels of need has increased:

Your personal care is still important, obviously, but you need that person-centred approach which is more important because, by having

that, you actually get to know your resident and that's when you can stop all the agitation and the aggression because you know why they're upset, you know what's going to upset them. (Deputy manager; CH1)

Although a person-centred approach was valued, it was also acknowledged by many that care delivery was often divided into a series of tasks, with an inherent tension between the two approaches:

So you know you've got to get things done, making the beds, keeping the place clean, tidying the wardrobes and all that sort of stuff... but still see the client, still looking out for the client, still caring but they're getting other things done at the same time. (Manager; CH2)

This tension was apparent in the accounts of care assistants whose work was often clearly organised around tasks. Managers and senior staff acknowledged that more junior staff did not have the autonomy to take a different approach:

Changing in that [person-centred] direction, I think, is very difficult, because people start thinking, oh, if I do that, I might get told off. If I do that, then I won't be able to fill in the dishwasher by quarter past 11, or if I do this instead of that, then they're going to tell me off because I didn't take the bin, so it's all this kind of balancing act. (Deputy manager; CH6)

Below I will outline some of the organisational and procedural factors that influence how able staff feel to deliver person-centred care and manage agitation in residents with dementia.

7.3.1 Competing demands on staff time

Having more time would really help, if you actually had time to spend with the residents when they're agitated and if they're accepting to your presence and you can probably just sit and talk... (Unit manager; CH4)

Unsurprisingly, staff commonly referred to not having enough time to spend with residents as a result of multiple and competing demands. Below, a care assistant

describes how since the home had been remodelled into smaller, home-like units to try make the environment less institutional, care staff had been given additional duties that were previously done by separate domestic staff, paradoxically making care delivery less personal. Most of the staff interviewed in that nursing home mentioned this change and suggested that it had reduced time available to spend with the residents by increasing their workload:

Because, like, before...we didn't do, like, here, we don't have open kitchen, so we don't have to do the washing up and put the dishes to the dishwasher empty. Everything was bringing from the kitchen. So, now, like, we're having more job for our carers to do. (Care assistant 2; CH6)

7.3.1.1 *Balancing need/hierarchy of need*

Staff explained that often the most challenging aspect of managing episodes of agitation came when they had to minimise the impact on other residents or visitors and take care of the agitated resident. At times they reported being unable to give space to a resident or let them express discomfort, as they wanted to minimise the impact on others:

So it can be very difficult if he shouts all night. It's not fair on them because he's disrupting somebody and they don't sleep. Alright fair enough, he's got his got his own problems but what about the other residents. But we can't lock him up, we can't. So where does that fair come into? (Senior carer 1; CH3)

Balancing the needs of multiple residents was described by many as a source of stress:

If too many people are agitated at the same time, because they have to reassure them; they have to manage other people all around as well, and they have their... the other workload to be tackled. So, yes, it makes them panic, makes them stressed out. (Manager; CH5)

There seemed to be an implicit hierarchy of how staff should be responding to residents' needs. This meant that they could not always respond to residents' agitation as they would prioritise basic needs over a need for company or

interaction, or a physical need over an emotional one (see Section 5.2.4.3.2). Staff related this to feeling that they did not have the time to engage residents in activities themselves, relying on activities coordinators for this:

And you might be doing an activity with someone, the guy in one of the rooms pressed the emergency, we have a guy who presses the...he is almost like needs one-to-one care so you might be rushed off to attend to him really. It really is, the activities really does demand an extra carer I think, to be honest. (Care assistant 2; CH5)

7.3.1.2 *Staffing levels*

Staff spoke explicitly about how they felt that the levels of experienced staff available in the homes were inadequate. Having 'bank' or agency staff, or new inexperienced carers on a shift meant that although the staff to resident ratio was acceptable, working was more difficult than working with an experienced and established team:

If there's a ratio of 20 residents and four carers, if one of the carers is a new carer, the carer they are paired up with has got more pressure now because, in the room, they've got to take that strain from a carer that knows nothing. (Care assistant 1; CH4)

Staff at different levels spoke about feeling that staffing levels were insufficient to manage people with dementia experiencing agitation, but that this reflected government set ratios:

The sort of RCN staff ratio for residential dementia clients is something like 10 to one. Are you kidding? Or eight to one... If I have one staff member with eight dementia clients and they're supposed to survive the day it just... that doesn't make sense; that really doesn't make sense at all. (Manager; CH2)

7.3.2 **Management support**

Both managers and junior staff described how management practices affected their day-to-day work and their responses when they did not feel that available support matched their needs or expectations. I will explore this further below.

7.3.2.1 *Staff feeling devalued by managers*

Staff spoke poignantly about the distress caused by feeling devalued by their managers, giving examples of not feeling consulted, listened to or taken seriously, particularly when they raised concerns. A number of staff spoke about changes to their working practices, for example shift patterns, being imposed in a top-down way:

But decisions have to be made sometimes without consultation...just imposing them, just taking a decision and we're just literally herded into one room and just told it's all going to change (Care assistant 2; CH5)

Staff explained that because it was a difficult job and they did not feel valued in their role by residents and relatives, feeling appreciated by managers took on additional importance:

I guess sometimes you don't always feel valued for the job that you're doing; it is a very difficult job. It does have an effect on, on, on, on your working practise... what we are doing is just caring for people all day and it doesn't always feel as though staff are really cared for. (Unit manager; CH5)

Small gestures by managers, for example, a validating comment, a thank you or an immediate response, could make a big difference:

Now the suite manager will say at the end of the evening "thank you very much" or will even sort of like say my name or whatever as she's going through and it does make a difference, you feel like you've done a good job. (Care assistant 2; CH4)

7.3.2.2 *We sort it out ourselves*

Staff described a culture of seeking support from their immediate team and were often reluctant to approach managers. This was particularly in relation to managing agitation, as they did not perceive that it would make any difference or that actions would be taken by management whom they perceived as unsupportive:

We just, we don't tell the higher ones, that it's too much, we just keep it to ourselves...They won't listen anyway, I don't know, we just...keep it to ourselves, yes. (Care assistant 1; CH6)

Some staff felt that managers cannot understand what they are experiencing as front-line carers and cannot contribute to finding solutions:

Well, even if I told somebody, I don't know what they could do. What could they do? (Care assistant 1; CH5)

7.3.2.3 *Hands-on and available managers*

Direct care staff spoke about what management support they felt would be useful, and they (and the managers interviewed) highlighted examples of good practice. This often related to staff feeling that managers were willing to get involved if there was a problem. Being 'hands on' connected to staff feeling that managers could understand, by having done the job or had similar experiences themselves:

If it's a case of we need to go and mop the bathrooms or jump on cleaning, cooking, I mean, both me and xxx both started here as housekeepers and we've both worked our way up from there so we know what it's like to do all of the jobs in the house. (Deputy manager; CH1)

Staff appreciated having managers that knew the residents well and would get involved and deliver care if there was a problem. Managers spoke of the importance of leading by example and *showing* rather than *telling* staff how they would manage an episode of agitation:

We ourselves go and check and ask to help, we shower sometimes, the residents, with the help of them, like, we make sure that somehow it's done. (Team leader; CH2)

In addition to being approachable and available to staff, managers that were open to new practices, where staff felt they had permission to try out new strategies or approaches or who offered solutions to problems were seen to facilitate the successful management of agitation:

But on the whole, xxx's very open minded. She sort of gives us carte blanche as to what we want to do. I mean, obviously, we have to run things past her first, but she's... very rarely does she put an idea down. (Activities coordinator; CH4)

7.3.3 Learning culture

Staff described how working in an organisation where learning was valued made it easier for them to work effectively and manage when residents were agitated. Staff valued having high quality, formal training as well as informal opportunities for learning and reflection.

7.3.3.1 *Learning on the job is key*

Staff at all levels highlighted the importance of learning from both peers and senior staff through discussion, observation and delivering care together:

But, you know, whenever you get new staff you explain, you show the way how it is and they see it works. And I say, you see? The resident was not aggressive, no one was shouting, no one was aggressive, everything went very smoothly. (Senior carer 2; CH3)

Staff explained that learning by gaining experience themselves, finding out what works and what does not, was essential to becoming a better carer:

Even though I have had training and people have helped, I've gone to management and they've taught me a different way to try and cope with it, I feel being there, dealing with it, doing it, is actually the best training you can have. (Care assistant 1; CH4)

7.3.3.2 *Opportunities for reflection and discussion*

Staff valued the opportunity to reflect upon their work with colleagues. The senior staff also described how they would offer staff the chance to reflect and discuss challenging situations and interactions; sometimes this seemed to be providing the opportunity for debriefing:

So she'll come in, she'll shut the door, she'll moan, she'll be completely inappropriate with what she's saying but it's behind closed doors, it's

private but instead of her trying to get her words out so it sounds all proper and correct, she'll just say it how it is. (Deputy manager; CH1)

Others described a more formal supervision process, encouraging learning and change in practices. This tended to be mentioned by managers rather than care assistants and sometimes the manager's commented about this also being an opportunity to identify and challenge problematic practices or gaps in skills:

Because, when there is aggressive episode, it will be documented as an incident. Then we will see who is involved and, if there is one person involved more than other people, so, we just think that there is something wrong with that person. Then we try to do supervision to see if they need some more training, or we try to reassure the staff. (Manager; CH5)

Interestingly, what was often described as supervision or reflection, seemed rather directive:

They sit down and say, okay, I think this should be improved, and I think people should be more tempted... do this. Do this. Do that. But, yes, fine, thank you. But... So, I mean, no I believe there is no reflective practice in this place. (Care assistant 1; CH3)

7.3.3.3 *Training gives you tools to cope*

Staff described how they found that good quality formal training enabled them to develop new skills to manage agitation:

They will tell them more techniques to cope... how to deal with the residents... with agitated people...(Senior carer 2; 03.04)

Seeing positive effects upon their interactions with residents when putting new learning into practice motivated staff to use what they had learnt:

For me the communication, when I saw, when they explained what you can achieve with the communication, what you can do for that resident, that opened my eyes and I really enjoyed it. (Care assistant; CH2)

Staff discussed how training could help build confidence as well as knowledge:

That's why I'm saying it needs to... rather than be... to create this kind of situation, it would be good to actually train someone to feel really secure, so that even if there is a dominant personality, they feel secure enough to say, you know, I see, but this is the way we have to do it. (Deputy manager; CH6)

In Figure 7.2 I summarise the components of training staff perceived as most useful and what they felt helped them to put new learning into practice:

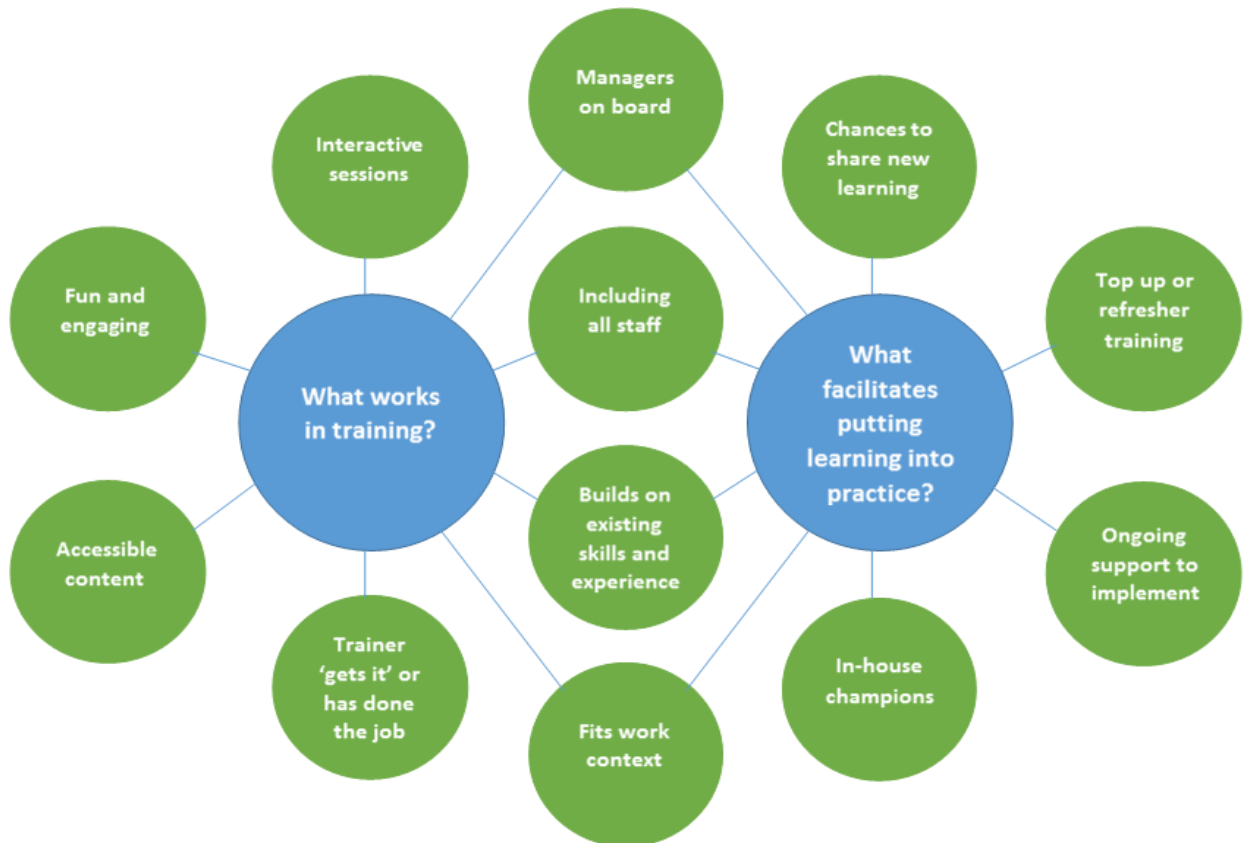


Figure 7.2: What works in training and facilitates putting learning into practice

7.4 Theme four: The care home industry (Socio-political factors)

Staff in all roles discussed their perceptions of how care homes were perceived in the media, as well as the impact that they felt a profit-driven business had upon how care could be delivered in care homes. Generally staff described how negative external perceptions of care homes eroded staff morale and motivation.

7.4.1 Media highlight the worst aspects of care

Staff often referred to widely held negative perceptions of care homes, particularly related to abuse and neglect. They referred to specific television programmes or newspaper articles and the impact that they felt this had. Staff were keen to highlight that the mainstream media focus upon the negative aspects of care and overlook both the good practice that they see in their day-to-day work and the impact of aggression from residents towards staff:

Sometimes it would be so lovely to hear a nice story about dementia, and staff, and what people do, and also it feels like, you know, you don't hear things about residents lashing out at carers. (Care assistant 1; CH4)

This general negative view added to a sense of not being valued and had a direct impact upon how they were seen by relatives:

I find that quite distressing because I think, you know, just because people have done stuff like that it's like you're being tarred with the same brush, that it's happening to their loved ones and I do find that quite upsetting. (Care assistant 2; CH4)

7.4.1.1 *Culture of fear*

Many staff described how they were afraid of making mistakes, or of getting into trouble with senior staff or relatives and therefore were cautious in their practice:

So we have to persuade him, to take him there and take him to the lounge or garden, so we can go, because if we go and he might follow us and we would get in trouble as well, yes. (Care assistant 2; CH3)

Although taking care to minimise risks to residents is important, staff often described a culture of fear which potentially stifled more creative and flexible approaches to managing agitation:

You know, there's the cover your back kind of fear to people, that... I think that translates back into the negative thing from before, where you don't want to try a new thing in case it hurts someone or in case it puts them at risk, or...(Deputy manager; CH4)

7.4.1.1.1 Feeling under scrutiny: Appearances matter

Often junior staff described how they felt under scrutiny both from relatives, questioning their care and from more senior staff who they felt would prioritise relatives' wishes over residents' needs, leaving front-line staff in an untenable position:

Like, obviously they shouldn't be in bed if the managers come or their family comes. And they'll say, why is my mum being in bed? And, you know, I... obviously we tried our best and that... it does annoy. We're always writing it down and just inform the Nurse so we don't get in trouble. (Care assistant 2; CH3)

Some managers recognised the tensions that staff face and the impact that this level of scrutiny can have upon their actions:

I'm not going to spend time with this person because I need to do that, otherwise I'm going to be told off. It's always this, kind of, I'm-going-to-be-told-off kind of attitude, which obviously damages the way you work a lot. Because then it becomes, like, obviously task based. (Deputy manager; CH1)

Others described how managers would increase the level of scrutiny that staff were under as a direct result of media coverage:

Yes, because when we see these things in Panorama or other programmes, we will have meeting with the staff and we warn them about their own behaviour when they are in the resident's room, because sometimes they do not realise what... the way that they speak with the resident or the way that they even re-position a resident. (Manager; CH5)

Staff felt that appearances were sometimes valued more than minimising resident distress, for example managers insisting a resident changed a dirty top or came out of their room even when this resulted in escalation in agitation:

Sometimes it's more about the look of things. You know, like, if someone is getting agitated in their room, it's more like why is everything in a mess? Because they're making a mess, but you can just tidy it up. (Care assistant 1; CH4)

7.4.2 'It is a giant faceless organisation'

Staff across homes, including those in a charity run home and in a small family run home as well as those in large chains, commented on the financial challenges facing the sector and business culture impacting on how care is delivered. They suggested that the business model did not fit with being able to deliver personalised care, particularly when it impacted upon staffing levels:

Sometimes it can be challenging because if the budget doesn't meet, or if you go a bit over, then the staff needs to be reduced, and there is always the stage where the needs of the residents take second place because you need to reduce the staff and that becomes a problem. (Deputy manager; CH6)

Other staff also suggested that bigger homes with more corporate structures resulted in less personal care with less time available to spend with the residents. Staff also spoke about how, when working in a home that was part of a big chain, they felt anonymous or disconnected from those higher up in the organisation. This connected for some with the general sense of being undervalued:

And, I think, with these big homes where there are 109, 110 beds, it's too much. I know they split them into smaller units but the staff are stretched so thin, it is just a conveyor belt; who's next, who's next, who's next? (Deputy manager; CH1)

7.4.2.1 *Poor terms and conditions*

Staff felt they were inadequately paid for the job. They spoke about being paid a minimum wage. Financial pressures from this added stress and it also increased the feeling of being undervalued, making it harder to maintain the level of care and dedication that was expected:

But I think if the staff feel valued and I think there would be a huge improvement in the industry but just to put staff on a minimum wage and then just chuck stuff at them and expect them to respond in sometimes very difficult situations. (Care assistant 2; CH5)

You know, bin men get paid more than carers, and a carer is in charge of someone's life. (Care assistant 1; CH4)

In addition to commenting on the impact that poor pay had upon their motivation, staff also highlighted how working 12 hour shifts (a common pattern in the homes I visited) made the job difficult to sustain, especially when they were caring for very agitated and impaired residents.

Because one of the things that I have found, for example on the fourth floor, if you put someone on a long day on the fourth floor they are knackered and I'm not sure if they'd be able to come in the next day. (Manager; CH2)

7.4.2.2 *Lack of regulation*

Staff commented upon the lack of regulation in the industry. In particular they noted that a lack of consistency in the training new carers received, and the absence of mandatory qualification across the sector, had a direct impact upon the quality of the care and how able staff felt to do the job:

It should be harder to get into care. They need to have the qualifications, and have the training. I feel a lot of carers are thrown into care, you know, like they have one day shadowing a carer, and they go in, and think, oh, my god, what am I going to do? (Care assistant 1; CH4)

7.5 Summary

In this chapter, I have summarised factors that staff felt impacted upon how they manage agitation. The key themes included staff personal inclination towards caring, the importance of communication, task focused versus person centred care and the care home industry. Within these themes, staff described both barriers and facilitators to their practice. In the next chapter, I will describe the process of co-producing the MARQUE intervention. I will highlight how the findings from this and the previous chapters informed the content, form and process of the intervention as well as a range of strategies aimed at addressing the barriers described above.

Chapter 8 Phase two: Intervention development

I led the process of co-producing the MARQUE intervention for initial testing, which I will now outline. I was recently awarded a prize for my lay summary of this work at an NIHR infrastructure doctoral training camp. I will begin by outlining the rationale for the chosen approach and the theoretical underpinnings. I will then summarise the process of intervention development and summarise key content of the MARQUE intervention manual for initial testing.

8.1 Rationale for the chosen approach

8.1.1 The Theoretical Domains Model

As described in section 1.1, in developing the intervention, I used the MRC guidelines for the development and testing of complex interventions (Craig et al., 2008). Although useful as a broad approach to intervention design, the guidance does not specify in detail a process for developing interventions in a theoretically informed and systematic way (French et al., 2012). The ‘Theoretical Domains Model’ (TDM), a set of behavioural change domains agreed by expert consensus, has been used to inform systematic, complex intervention development and I have drawn upon it in the process of developing the MARQUE intervention. The TDM highlights twelve behavioural change domains to be considered when designing interventions. Each of these domains incorporates a number of psychological constructs which can be used to develop theoretically informed questions to aid intervention development (French et al., 2012, Michie et al., 2005). Table 8.1 below summarises the model and how I used it as a guide to develop the first draft of the intervention and to inform the process.

Table 8.1: Applying the Theoretical Domains Model (TDM) to intervention development

Theoretical domain	Questions to consider	Source of information	Proposed MARQUE intervention component
Knowledge	<ul style="list-style-type: none"> • What do we already know works? • What do staff already know? • What do staff need to know? 	<ul style="list-style-type: none"> • Agitation systematic review (Livingston et al., 2014a, 2014b). • Qualitative staff interviews. 	<ul style="list-style-type: none"> • Focus on communication / getting to know the person with dementia. • Focus on pleasant activities. • Focus on preventing and managing agitation.
Skills	<ul style="list-style-type: none"> • What skills do staff already have? • What skills do staff need to develop? 	<ul style="list-style-type: none"> • Qualitative staff interviews. • Systematic review (Rapaport et al., 2017). 	<ul style="list-style-type: none"> • Skills practice within and between intervention sessions. • Post training troubleshooting and support.
Social and professional role and identity	<ul style="list-style-type: none"> • How does the proposed intervention fit with how care staff see themselves / are seen? 	<ul style="list-style-type: none"> • Qualitative staff interviews. • Systematic review. 	<ul style="list-style-type: none"> • Valuing existing skills of staff in sessions. • Using quotations from care staff. • Framing managing agitation as fitting with all aspects of care. • Group based learning.
Beliefs about capabilities	<ul style="list-style-type: none"> • How confident are staff about managing agitation and delivering interventions? 	<ul style="list-style-type: none"> • Qualitative staff interviews. • Systematic review. • Focus group with family carers. 	<ul style="list-style-type: none"> • Facilitators reinforcing good practices and troubleshooting difficulties. • Providing written resources & tools to make it easier e.g. Call to Mind game • Focus on communication.
Beliefs about consequences	<ul style="list-style-type: none"> • What do staff / managers perceive the consequences of delivering intervention will be? 	<ul style="list-style-type: none"> • Agitation systematic review. • Qualitative staff interviews. • Systematic review. 	<ul style="list-style-type: none"> • Focus in training on what we know works. • Between session practice and follow-up support. • Reflecting on positive effects of intervention on staff and residents.
Motivation and goals	<ul style="list-style-type: none"> • What will make staff more likely to put what they learn into practice? 	<ul style="list-style-type: none"> • Qualitative staff interviews. • Systematic review. 	<ul style="list-style-type: none"> • Reflecting on the benefits of the intervention. • Action planning and setting SMART goals in sessions. • Making the sessions fun and engaging e.g. having refreshments, relaxation exercises, providing resources.
Memory, attention and decisional processes	<ul style="list-style-type: none"> • Will staff remember to use interventions? • How will staff understand and decide what to do? 	<ul style="list-style-type: none"> • Qualitative staff interviews. • Systematic review. • Work on DICE approach (Kales et al., 2014) 	<ul style="list-style-type: none"> • Having champions in the home to prompt staff and support practice. • Having manuals, audio files, resources, tip sheets and posters to aid learning. • Making the training simple, clear and

Theoretical domain	Questions to consider	Source of information	Proposed MARQUE intervention component
			<ul style="list-style-type: none"> easy to follow. • Having troubleshooting and follow-up support.
Environmental context and resources	<ul style="list-style-type: none"> • What resources would staff need to be able to use the intervention? • What will make it harder/easier for staff to engage with training? 	<ul style="list-style-type: none"> • Qualitative staff interviews. • Systematic review. 	<ul style="list-style-type: none"> • Having protected time to attend training and follow-up sessions. • Minimising the demand on staff time outside of sessions. • Focusing on ways to build interventions into routine care. • Demonstrating that changing practices can make it easier to provide care.
Social influences	<ul style="list-style-type: none"> • How do wider relationships facilitate or hinder staff management of agitation? E.g. management, peers, relatives, residents. 	<ul style="list-style-type: none"> • Qualitative staff interviews. • Focus group with family carers. • Systematic review. 	<ul style="list-style-type: none"> • Including all staff in training • Focus on communication within team and with relatives. • Focus on sharing of information and techniques. • Having staff champions.
Emotion	<ul style="list-style-type: none"> • How will the intervention affect staff emotionally? How do emotions impact on how staff respond? 	<ul style="list-style-type: none"> • Qualitative staff interviews. • Systematic review. 	<ul style="list-style-type: none"> • Including stress reduction techniques in training sessions. • Focus on staff support and self-care. • Focus on understanding how staff reactions impact on residents and vice versa.
Behaviour regulation	<ul style="list-style-type: none"> • What preparation or processes will facilitate implementation? 	<ul style="list-style-type: none"> • Qualitative staff interviews. • Systematic review. 	<ul style="list-style-type: none"> • Including management and senior staff in set up. • Flexible delivery and catch up sessions. • Focus on developing action plans in final session with follow-up support. • Having staff champions.
Nature of behaviour	<ul style="list-style-type: none"> • What staff behaviours do we want to promote / change? • What will facilitate long-term behaviour change? 	<ul style="list-style-type: none"> • Agitation systematic review. • Qualitative staff interviews. • Systematic review. • Work on DICE approach. 	<ul style="list-style-type: none"> • Focus practice within and between sessions. • Giving practical tools like Call to Mind or DICE approach. • Focus on small changes having an impact. • Focus on sharing learning within teams and with relatives. • Follow-up support sessions. • Having staff champions.

DICE = (Describe, Investigate, Create a plan, Evaluate the effectiveness); SMART = (Simple, Measurable, Achievable, Relevant, Timely)

8.1.2 Co-production in dementia research

Co-production is the process of collaborating with multiple stakeholders from professional, academic and especially lay communities (Bovaird, 2007, Gove et al., 2017) and is advocated as a means to ensure the relevance and acceptability of interventions in diverse settings (Wherton et al., 2015, Davies et al., 2016). Dementia charities, along with national and international research networks' policies, promote meaningful involvement of those affected by dementia in research (Alzheimer's Europe, 2011, Alzheimer's Research UK, 2016, Alzheimer's Society, 2017, Department of Health, 2005b). The Alzheimer's Europe position paper on involving people with dementia in research highlights that co-production with people living with and affected by dementia can enhance intervention quality and relevance (Gove et al., 2017) and is a way to ensure that interventions and services meet the target population's needs (Elliott et al., 2017, Boyle and Harris, 2009). However, stakeholder involvement alone is not sufficient for intervention development. O'Brien et al (2016) highlight that a range of methods are integral to the process of complex intervention development, including consideration of the existing relevant evidence as well as qualitative research to provide in-depth understanding of contextual issues. Figure 8.1 outlines the key elements which I combined to develop the MARQUE intervention.

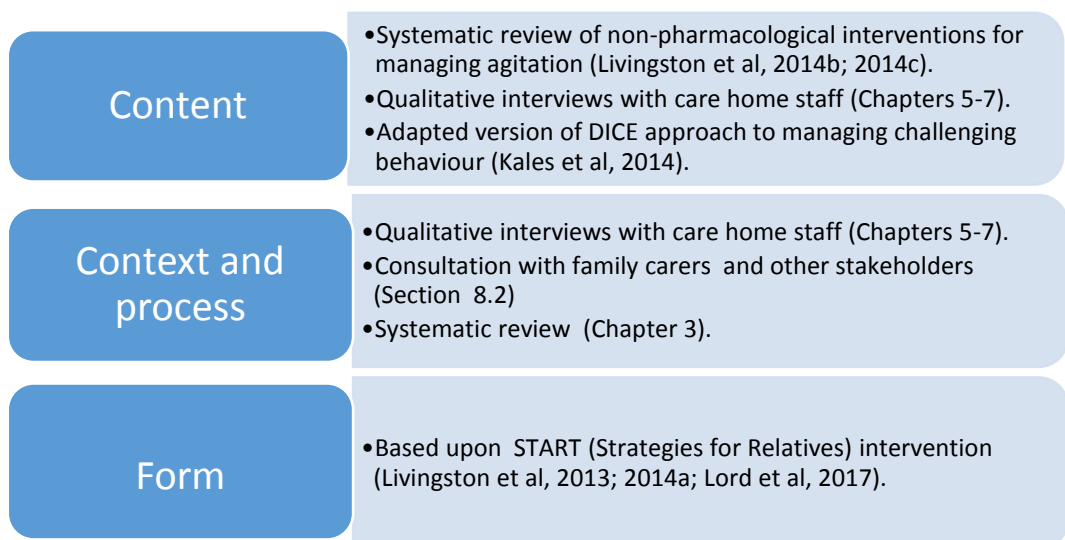


Figure 8.1: Key components informing MARQUE intervention co-production

8.2 Process of intervention development

Over the course of the intervention development, we brought together experts in the development and testing of manualised interventions in dementia care, experts and professionals in the organisation and delivery of care to people living with dementia in care homes and Alzheimer’s Society research network volunteers (RNVs) whose lives had been affected by dementia. We adopted an iterative and collaborative process throughout, summarised in Figure 8.2 below (see Appendix 11 for a detailed timeline and summary of specific contributors during the process of intervention development). When focus groups or individual interviews were conducted, in line with NRES approval, those contributing gave written, informed consent to audio recording. It was then professionally transcribed, and I entered the data into NVivo 9 software and analysed using thematic analysis (Braun and Clarke, 2006).

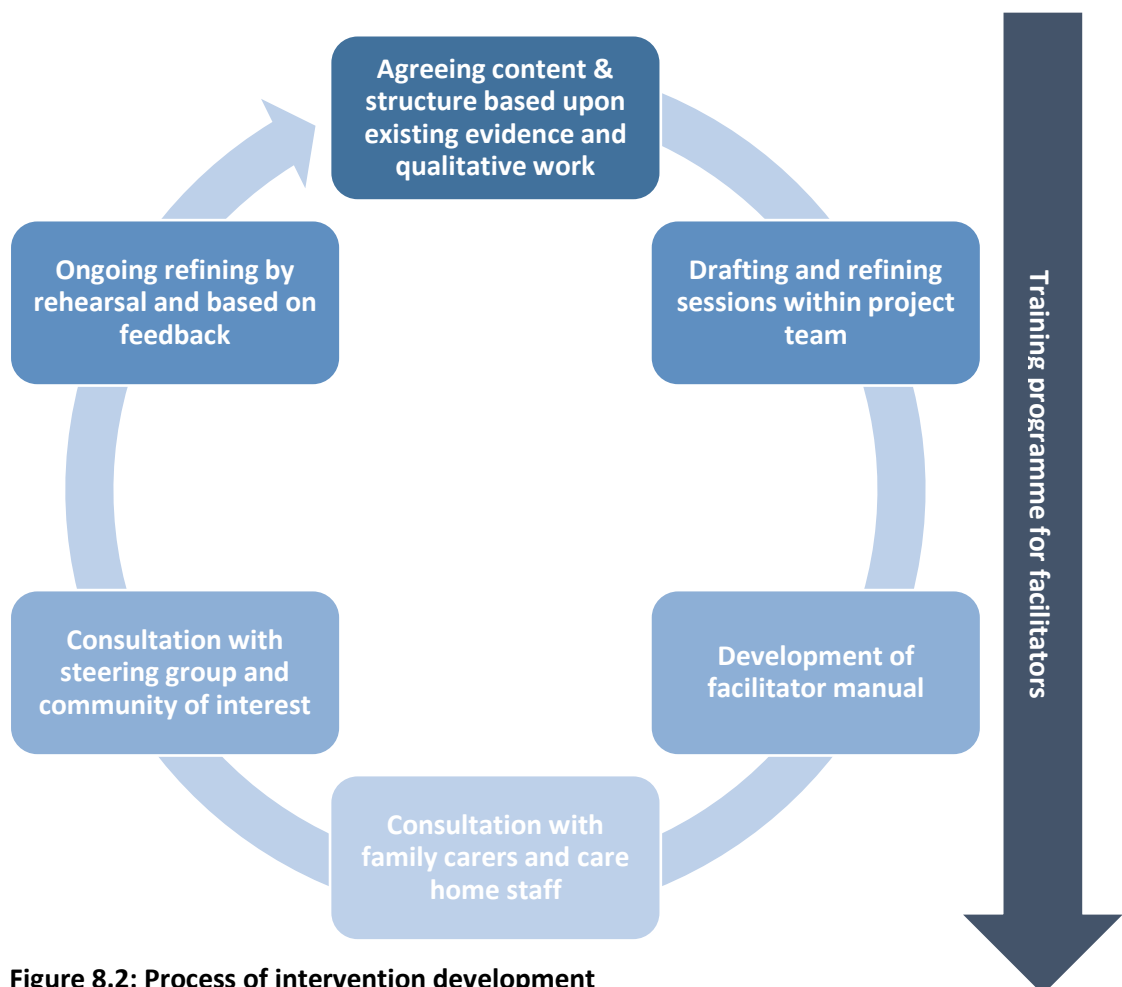


Figure 8.2: Process of intervention development

8.2.1 Developing the initial draft

We began the writing process with a consensus meeting attended by the MARQUE stream three researchers in March 2015. At this meeting we discussed the key initial findings from the relevant evidence base (Chapters 2 and 3) and the qualitative interviews with care home staff (Chapters 5-7) and we agreed an overall plan, the basic principles underpinning the intervention and skeleton content and structure. We agreed that it would be a six-session, group based, interactive intervention, with sessions lasting two hours, followed by a three-month period of supervision within the home. We agreed to adopt a non-prescriptive model, explicitly encouraging care home staff to build upon their experience of what works, and to develop and use new techniques and behavioural strategies. In line with the earlier START intervention, each session included a stress reduction exercise, a practice task between the sessions, a recap on the previous session, and troubleshooting around putting strategies into practice.

I developed an initial structure based upon this discussion and I then wrote initial drafts of each session which were refined iteratively, based on feedback from the team. Each session of the intervention incorporated theoretical components, clinical vignettes and practical exercises based upon the care home staff's experiences. We avoided chunks of technical information and presented information in visually engaging ways. We also included an adapted and simplified version of the DICE approach and integrated the use of an interactive game, Call to Mind. The DICE approach is an evidence-informed algorithm which supports care providers in deciding which non-pharmacological interventions to use and how to build them into a usable plan (Kales et al., 2014). Call to Mind is a board game designed and tested in collaboration with our team which facilitates communication and encourages staff to get to know and understand residents better (Wadlow, 2013). Both these elements were included as tools to support staff to translate learning into changes in care practices. At this point, I also wrote a facilitator version which included additional detail on the delivery process.

8.2.2 Consultation with care home staff and managers

MARQUE research assistants and I met with two care home managers, three senior care home staff and two care assistants working across four care homes to show them the draft manual and obtain their feedback (see Appendix 12 for interview schedule). All staff were asked to comment upon the design, layout, content and structure of the manual and managers were also asked to comment on the practicality of delivering it. Their feedback is summarised in Table 8.2.

Table 8.2: Care home staff feedback on the draft intervention

	What people liked	Suggestions for changes
Content	<ul style="list-style-type: none"> • Topics are specific and clear. • DICE model is easy to understand. • Helpful to make action plans. • Using examples from care staff. • Stress management for staff. • Recognising pain as cause of agitation. • Including massage, touch and music. • Focus on getting to know people with dementia. • Gives practical strategies. • Order of sessions works well. • Call to Mind is fun and interactive. • Not just focused on severe agitation. 	<ul style="list-style-type: none"> • Add more ways to work with relatives. • Add finding out about preferences of person on admission. • Communication is key and should come earlier and throughout. • More on managing distress. • More about sensory impairment. • More about sharing information within the team. • More about people with severe dementia. • More on dementia and the causes of agitation.
Structure and language	<ul style="list-style-type: none"> • Simple language, good for people with poor literacy or who do not speak English as a first language. • Direct quotes from staff. • Clearly laid out. • Key points and text easy to understand. • Focus on seeing what works and putting into practice. • Focus on small changes making a big difference. • Focus on trial and error. • Review of previous session each week. • Summary and recap. • Builds on staff knowledge and experience. • Practical interactive exercises. 	<ul style="list-style-type: none"> • Don't include tests as it will put off staff. • Take out complex terms like 'progressive supranuclear palsy' or explain. • Stress the importance of building activities into existing routines. • Make exercises clearer to understand. • Give more context for the quotes.
Design and layout	<ul style="list-style-type: none"> • Appealing to the eyes...draws you in. • Pictures look like real nursing homes. • Visual prompts bright and engaging. • Good balance of words and images. 	
Delivery	<ul style="list-style-type: none"> • Good to have two facilitators. • Including management in set up and sessions. • Having champions in the home. • Weekly sessions give people time to put into practice and consolidate learning. • Group process allows staff to reflect and share concerns and experiences. • Group will suit different levels of experiences. • Good to have breaks and refreshments. 	<ul style="list-style-type: none"> • Give care homes time to set up rotas and staffing. • Need to work with the home about how to arrange attendance e.g. two sessions run on same day. • Deliver in mixed groups of staff. • Train staff from different units separately. • Give out session manuals one at a time. • Have more champions in bigger homes. • Should train night staff and non-care staff.

DICE = (Describe, Investigate, Create a plan, Evaluate the effectiveness)

8.2.3 Consultation with family carers of people with dementia

As part of the MARQUE stream three Patient and Public Involvement (PPI), I facilitated three focus groups with family carers of people with dementia who were RNVs. The first two focus groups (May and September 2014) were attended by six and five family carers, respectively, and focused upon their experiences of having a relative who had experienced agitation whilst living in a care home. A key theme to emerge from this group was the importance of the relationship between the care home staff and relatives, particularly in how all parties responded to agitation, acting as both a barrier and a facilitator. The family members also highlighted what they felt worked more generally to manage and prevent agitation, based upon their personal experiences. The key findings from these focus groups informed the development of the qualitative interview schedule described in Section 4.1.3 (see Appendix 9). The third focus group (September 2015) attended by four family carers was to consult with them on the draft manual (see Appendix 11 for detailed timeline). Their feedback on the draft manual was generally positive and corresponded closely with what care home staff liked about the draft. Consequently, here I will only present the suggestions from the focus groups about how the intervention could be improved. These included:

- Making sure there are pictures on all pages and no large chunks of text.
- Good for facilitators to keep a record of what works.
- Getting managers involved and attending at least some of the sessions.
- Marking which pleasant events could be done in the course of routine care.
- Keeping the same champions throughout the course of the intervention.
- Inviting family carers to observe.
- Clarifying that asking multiple questions is not the same as giving choice.
- Highlighting the importance of sharing what works within teams.
- Adding in 'smiling' to the communication section.
- Having a one page summary of each session for those who do not read and write English well with key points and using pictures.

8.2.4 Consultation with MARQUE steering group and community of interest

In parallel to consulting with care home staff and family carers, I sought feedback from a range of professionals and other stakeholders from the MARQUE steering group and our community of interest group (a network of academic researchers, policy makers, community stakeholders and PPI representatives). In addition to presenting the overview of the intervention to the community of interest group, I also met in person or had telephone conversations with six of the members who were a geriatrician, a sociologist, a research nurse, an occupational therapist, an academic psychologist and a clinical psychologist to get feedback on the draft facilitator version of the manual.

Feedback was more specific and detailed than that of care home staff and family carers, with some giving written as well as verbal feedback on the drafts. They made suggestions about changes to make it easier for the facilitators to deliver the manual and detailed comments on the formatting and language. Additionally, individuals suggested areas that were missing or which they felt needed to be emphasised, this would often link to their professional or academic background. For example, the occupational therapist noted that we should include more about weighing up the risks of certain behaviours and how that can impact on how staff respond to agitation and the geriatrician was concerned that we had not included enough focus upon pain and illness as causes for agitation.

8.2.5 Finalising the intervention

I used the stakeholder feedback to develop a full second version of the manuals. Senior members of the MARQUE team worked with the research assistants who would be delivering the intervention to try it out and made further suggestions regarding timing, content and structure. I coordinated feedback and developed finalised versions of the manual and a champion's guide for piloting by March 2016 (see Appendix 13 and Appendix 14, respectively).

Sessions one to five all included one or two key topics for discussion, a specific plan or activity to try out between sessions, a stress reduction exercise with an accompanying CD/MP3 file and a record form for staff to fill in for monitoring progress between sessions. Although manualised, during each session, the participants shared examples from their practice to ensure that the intervention was individually focused and relevant.

The six MARQUE sessions covered:

- 1. Getting to know the person with dementia:** This session included psychoeducation about dementia and staff experiences of managing agitation including what works. It also introduced the key theme that getting to know and understand the person with dementia can help staff to manage and prevent agitation from occurring. The session also included a focus on managing the stress that caring can bring.
- 2. Pleasant events:** This session focused on the importance of pleasant events for residents. It included a focus on how to plan for and include those with more severe dementia and how to build activities into day-to-day care. It introduced the idea that even small interactions could be pleasant events.
- 3. Improving communication:** This session discussed communicating with people with dementia, with a particular focus on how to respond when residents are distressed. It also included discussion and exercises on effective communication, within the team and with relatives.
- 4. Understanding agitation:** This session introduced the DICE approach, focusing upon 'describing' and 'investigating' episodes of agitation. The content is framed in terms of recognising and understanding the unmet needs of residents experiencing agitation.
- 5. Practical responses and making a plan:** This session focused on creating strategies to manage agitation, including practical and environmental changes and when to ask for additional help. The session also introduced the importance of building these strategies into a plan which can be evaluated.
- 6. What works? Using skills and strategies in the future:** This session recapped on earlier sessions and focused upon what staff have found useful and what worked. It included the development of a specific action plan, individual to each home, to enable staff to continue to use helpful strategies and approaches and to inform the supervision phase of the intervention.

Key elements of the process for intervention delivery included:

- Staff having their own copy of the manual
- Practice within and between the sessions
- Two psychology graduate facilitators running each group
- Combining information giving, group discussion, practical exercises and practicing new skills
- Training all daytime staff and offering 'catch up' sessions
- Each care home having at least two 'champions'
- Separate facilitator / staff and champion guides
- A period of post-training supervision with a clinical psychologist and reinforcement sessions with facilitators

8.2.6 Training and supervising the facilitators

In collaboration with the team, I developed a training programme for the research assistants who would be delivering the intervention (summarised in Appendix 15). We focussed upon both clinical and practical skills and the knowledge and understanding necessary to effectively and safely deliver it. Training involved didactic teaching, small group discussion and reflection, role-play and practical exercises. All training emphasised the importance of asking for help and how to use supervision.

Alongside this training, I supervised the research assistants to learn to deliver the manualised intervention confidently and with fidelity to the manual through self-directed learning, role-play and troubleshooting sessions. Before delivering the intervention in the participating care home, research assistants were required to demonstrate their competence in delivering each session through role-play; I developed a specific checklist for each session; they were assessed on this in pairs by at least two senior MARQUE team members. During the intervention delivery I offered the research assistants weekly clinical supervision.

8.2.7 Summary

Informed by the TDM, I integrated findings from relevant literature, my systematic review and extensive qualitative interviews with care home staff to produce an initial draft of the MARQUE intervention manual. I then undertook an iterative co-production process to produce the version of the intervention trialled in the feasibility study described in the next part of this thesis.

Chapter 9 Phase 3 Methods for feasibility testing and process evaluation

In this chapter, I describe the quantitative and qualitative methods used to initially test the MARQUE intervention.

My overall aim was to test the feasibility of the intervention and the outcome measures and conduct a process evaluation of how it was put into practice to inform the final intervention and implementation guide for use in the full trial.

9.1 Ethics committee approval

London (Queen's Square) (14/LO/0697) NRES committee approved this (see Appendix 6 for ethics permission letter, Appendix 16 for information sheets and Appendix 17 for consent forms).

9.2 Setting and sample

I tested the MARQUE intervention in one care home, from January to August 2016. Because most English care homes are residential and privately owned (NICE, 2015, Alzheimer's Society, 2013), I selected a suburban, residential London care home owned by a small private chain that had participated in an earlier stream of MARQUE to undertake this study. We reimbursed the care home for staff time taken to complete measures and participate in training.

9.3 Procedures

9.3.1 Consenting the care home

The study manager, research assistant who would be collecting the data, and I met with the care home manager and the care home group lead for staff training, to explain the purpose and nature of the study. At this meeting we obtained informed, written consent from the care home manager for the home's participation.

9.3.2 Identifying residents with dementia

At our initial meeting we collected lists of residents and asked the care home manager which residents had a formal diagnosis of dementia on medical records and were therefore potentially eligible for the study. We then screened the remaining residents to identify possible dementia using the Noticeable Problems Checklist (Levin, 1989), a carer proxy measure (see Appendix 18) We indirectly assessed this rather than screening residents themselves with a cognitive measure, as it does not cause distress and is independent of culture and education. In addition, it does not require contacting relatives and residents who will not be in the study. In this checklist, a score of two or more out of five indicates probable dementia and this has been validated against clinical diagnosis (Moriarty and Webb, 2000). Residents were not required to be agitated to be included in the study as the intervention aims to prevent agitation as well as treating existing symptoms.

9.3.3 Consenting residents with dementia

We invited all residents with (probable) dementia to participate, abiding by the Mental Capacity Act (Department of Health, 2005a). If care home staff considered that a resident had capacity to decide whether to take part, they approached the resident and asked them if they agreed to talk to researchers about the study. The researchers, who were trained in assessing capacity, then met with these individuals and judged whether they had capacity to consent. If they did not they asked the staff to contact the relative/friend in closest regular contact. When care home staff considered a resident to lack capacity to decide whether to take part, they contacted the relative/friend who visited most often and asked if they were happy to be contacted by researchers. If the relative/friend agreed to be contacted, researchers approached them. If no family member or friend was available to act as a personal consultee, the team identified a professional consultee, who knew the resident well, through the care home manager and in line with procedures agreed with the NRES committee.

9.3.4 Staff eligibility criteria and consent

Staff were eligible to consent to the study if they:

- Provided direct care for residents at least some of whom have dementia.
- Were permanently employed or expected to be working in the home for the next three months.
- Worked some weekday, daytime shifts, and therefore would be able to attend training.

At the initial meeting the care home manager compiled a list of eligible staff. Staff gave written informed consent to participate in post-intervention focus groups, individual interviews or complete quantitative staff measures. The training was included as part of the home's mandatory training provision for all eligible staff, so staff were not required to consent to attend as it was not part of the research study.

9.3.5 Relative eligibility criteria and consent

Primary family carers of eligible and consenting residents who indicated to care home staff that they were willing to be approached by the research team, were invited to participate in the study by researchers. The researchers sent the information sheet and arranged a meeting to obtain written informed consent. Frequently, the family carer was also the personal consultee for a resident who lacked capacity.

9.4 Delivering the intervention

I visited the care home with the project manager and two of the researchers due to facilitate the sessions three weeks prior to the planned intervention delivery. We met with the home manager, senior staff and two named champions, chosen by the care home manager, in order to engage senior staff in the process and ensure that there was senior 'buy in' and commitment that all eligible staff, including managers, would be expected to attend training, and subsequent supervision and troubleshooting sessions. At this meeting, the practicalities of delivering the

sessions were agreed, with plans made for how staff would be released to attend the sessions. I gave the champions a “champions guide” (see Appendix 14) and discussed with them how to best support the intervention delivery. The week before the intervention sessions started, the four researchers who would be facilitating the sessions in pairs visited the care home to make final arrangements.

I met with the researchers weekly for group clinical supervision during the intervention. The researchers kept details of staff attendance and worked closely with the senior staff and champions to ensure that all staff could attend sessions. The sessions were repeated three times across three days each week to maximise attendance. The manager allocated staff to each group, but staff could attend any group to increase flexibility. If staff were unable to attend any of the three repeated sessions, the researchers offered individual or small group “catch up” sessions.

Towards the end of the training sessions, I met with the home’s training manager (the manager was on leave for three weeks) to arrange the supervision and troubleshooting period, and the focus groups (see below). We agreed that I would offer scheduled supervision sessions for staff on three occasions; these would focus upon managing agitation in specific residents and applying learning from the training sessions. The research assistants would visit in between my visits to offer more informal troubleshooting sessions, focused on putting the MARQUE action plans into practice.

9.5 Study baseline and outcome measures

9.5.1 Data collection

Research assistants who were not involved in the intervention delivery collected data at baseline and 8 months. Staff completed study measures, either during their shifts or at staff meetings arranged to discuss the research project. Senior and experienced staff who knew the residents with dementia well were asked to

complete proxy measures. Staff did not need to consent to complete proxy measures for the residents as the resident or their consultee had agreed to this.

I collected qualitative data post-intervention together with research assistants who had not facilitated the intervention sessions. We did not start the follow-up supervision until after the post-intervention focus groups had been completed. This was so that those providing feedback on their experience of the intervention were not doing so to those who had delivered it or to me after having built up a relationship during supervision, thus reducing the risk of bias.

9.5.2 Care home measures

At baseline, research assistants used a home census (see Appendix 19) to record characteristics of the care home, including: number of residents, staff:resident ratios, CQC ratings, whether public, charity or private sector, whether residents with dementia have a specific staff team, and whether there has been dementia specific training in the previous six months.

9.5.3 Resident measures

At baseline research assistants interviewed a paid carer involved in the day to day care of each participating person with dementia. We recorded the age, sex, ethnicity, first language, level of education, and last occupation of the person with dementia. We completed the Clinical Dementia Rating (CDR)(Berg, 1988)(see Appendix 20) to measure dementia severity (Hughes et al., 1982). This 5-point scale measures six domains: Memory, Orientation, Judgment & Problem Solving, Community Affairs, Home & Hobbies, and Personal Care. These items are used to generate an overall dementia severity score: 0, “none”, 0.5, “questionable” or very mild for those with a diagnosis; 1, “mild”, 2, “moderate”, or 3, “severe”.

At baseline and 8 months we asked the same paid carer where possible to complete the following measures about each resident:

1. Cohen-Mansfield Agitation Inventory (CMAI)(Cohen-Mansfield and Billig, 1986, Cohen-Mansfield et al., 1989) (see Appendix 21); a 29-item measure of agitation shown to have satisfactory construct validity and reliability. Each item relates to an agitated behaviour present over the last two weeks and is scored from 1–7 with one meaning “never” and seven “several times per hour”. The overall score is the sum of the individual items and possible scores range from 29-203. Clinically significant agitation is usually regarded as a total score of > 45 (Fox et al., 2012, Livingston et al., 2017a).

2. DEMQOL-Proxy (Smith et al., 2007); a 31 item interviewer-administered questionnaire answered by a caregiver to measure quality of life (see Appendix 22). The DEMQOL-Proxy was also completed by consenting relatives for all residents for whom we could identify a family member who visited at least once a month. If possible, residents also completed the DEMQOL (Smith et al., 2007) a 28 item interviewer-administered questionnaire answered by the person with dementia. Both DEMQOL versions include three sections: feelings, memory problems and everyday life. Items are rated on a Likert scale, with four choices of either “A lot, Quite a Bit, A little, or, Not at all”. The final question on the DEMQOL asks the participant how the individual would rate their quality of life overall and offers the choices “Very Good, Good, Fair, or, Poor”. The DEMQOL and DEMQOL proxy have psychometric properties at least as good as other dementia-specific quality of life instruments (Smith et al., 2007, Banerjee et al., 2004).

3. The Neuropsychiatric Inventory (NPI)(Cummings et al., 1994) (see Appendix 23); a validated instrument which assesses 12 behavioural domains over the last four weeks: hallucinations; delusions; agitation/aggression; dysphoria/depression; anxiety; irritability; disinhibition; euphoria; apathy; aberrant motor behaviours; sleep and night-time behaviour change; appetite and eating change. The domain total scores are the product of the frequency (0-4) score multiplied by the severity score (0-3) for that symptom and ranges from 0-12. These are summed to obtain a total score out of 144.

9.5.4 Staff measures

At baseline we recorded staff sex, ethnicity, first language, role, years of experience, shift pattern (day, night shifts or mixed), qualifications and recent training.

At baseline and 8 months we asked staff to complete the following measures:

1. Brief Coping Orientations to Problems Experienced (COPE) (Carver, 1997) (see Appendix 24): a self-report measure of staff coping strategies with fourteen subscales describing different coping strategies, (with two items per scale). Each strategy is scored on a Likert scale from 1 “not doing it at all” to 4 “doing it a lot”. The scale can be divided into three subscales for which adequate psychometric properties in dementia carers are reported (Cooper et al., 2008a): problem-focussed (active coping, instrumental support and planning), emotion-focussed (acceptance, emotional support, humour, positive reframing and religion) and dysfunctional coping (behavioural disengagement, denial, self-distraction, self-blame, substance use and venting).
2. Maslach burnout inventory (MBI) (Firth et al., 1985) (see Appendix 25) is one of the most commonly used measures of burnout in care home staff, and has adequate psychometric properties (Maslach et al., 1986, Poghosyan et al., 2009). It has 22 items scored from 0 “never” to 6 “everyday” and comprises three subscales: emotional exhaustion (being emotionally overextended and exhausted by work), depersonalisation (measuring unfeeling and impersonal response toward recipients of one’s service, care treatment or instruction) and personal accomplishment (measuring feelings of competence and successful achievement in one’s work).
3. Sense of Competence in Dementia Care Staff (SCIDS) scale (see Appendix 26); a self-report measure of sense of competence in care staff. The SCIDS has 17 items scored from 1 “not at all” to 4 “very much”. It has four subscales (Professionalism, Building Relationships, Care Challenges, and Sustaining Personhood) with adequate psychometric properties (Schepers et al., 2012).

4. Revised Modified Conflict Tactics Scale (MCTS) (see Appendix 27): a measure of helpful and potentially abusive behaviour perpetrated or witnessed by staff. The measure was developed and piloted with care home staff and has been found to be acceptable and to have content validity (Cooper et al., 2013). It was found to be acceptable in MARQUE stream two (Cooper et al., 2018) and is based on a previous measure that has been extensively used among people with dementia and family carers (Beach et al., 2005, Cooper et al., 2008b, Cooper et al., 2009). It comprises 10 potentially abusive items and six positive care items. Care staff were asked to self-complete whether each item had, in the last three months happened “never”, “almost never”, “sometimes” “most of the time” or “all of the time”. The carers self-completed this questionnaire anonymously, in private and sealed it in a blank envelope which they returned to the researcher in the home. We were not able to identify individual participants, but notified the care home manager if any staff member reported in the questionnaire that the residents had been hit or shaken. If residents or staff reported or we witnessed potentially abusive behaviour, this was handled according to our protocol and UK safeguarding procedures.

9.5.5 Family carer measures

We recorded family carer age, sex, relationship to the person with dementia and how many times a week or month they visited their relative.

9.5.6 Intervention only measures

9.5.6.1 *Quantitative measures*

9.5.6.1.1 Attendance

We recorded attendance at each intervention session, attendance at individual catch up sessions and reasons for non-attendance. We also recorded the number of staff who attended follow-up support or supervision sessions.

9.5.6.1.2 Fidelity

As a measure of fidelity to the intervention for each of the three groups delivered each week, one of the six sessions was audio recorded and rated using a fidelity

checklist (see Appendix 28). I developed this checklist for each session, which included a yes/no item for each section of the manual being covered by facilitators as well as four items rating process factors (keeping to time, keeping the group focused on the manual, keeping the group engaged in the session, and managing group dynamics). These were rated separately for each facilitator on a Likert scale ranging from 1 “not at all” to 5 “Very much”. Each of the fidelity recordings was checked by at least 5 research assistants who had not facilitated the session. These ratings were then checked for any notable discrepancies between raters and to refine the fidelity forms for use in the main RCT.

9.5.6.2 *Qualitative measures*

The facilitators invited all staff at the end of the final training sessions to attend focus groups in the care home within the next month. The home requested that we run the focus groups at the same times and in the same room where we had run the group training sessions, with the same mixed groups of staff invited to attend. We agreed that the focus groups would be approximately 1-1.5 hours long. Posters were put up around the home reminding staff about the focus groups. On the day of each scheduled focus group, care home champions and senior staff encouraged staff to attend. Once a group of staff had arrived I went through the information sheet and explained the purpose of the group. At this point either a research assistant or I took written consent from those who wished to participate and made clear that those who did not wish to attend the group could be interviewed individually. To facilitate the focus groups I used a semi-structured topic guide which I developed in consultation with the MARQUE team (see Appendix 29). I used open-ended questions to elicit staff perceptions and revised questions iteratively.

To inform the process evaluation as well as the supervisory process, the facilitators of the intervention wrote a reflective log after each session (see Appendix 30) and made written notes after each supervision session in the home. During the final session of the training, SMART (Specific, Measurable, Achievable, Realistic, Timely) action plans were developed based upon what the staff felt worked well and would

like to keep going in the future. The plans were integrated across the three groups and agreed with the home manager.

9.6 *A priori* analysis plan

9.6.1 Quantitative analysis plan

I performed all statistical analyses using SPSS 22 software package (IBM, 2013).

The main objectives were:

1. To report the proportion of eligible care home staff and residents with dementia recruited and retained in the study.

I report the proportion of care home residents and care home staff eligible to participate in the feasibility study and the proportion of staff and residents who consented to participate in the study. Additionally I report the proportion of people that completed baseline interviews who also completed the 8 month follow-up measures and where available, reasons for non-completion. We did not collect demographic information on the residents or staff who did not consent to participate in the study.

For the main MARQUE RCT, in order to maintain 90% power to detect a clinically significant change in the primary outcome, in each care home cluster we must recruit a minimum of 15 residents (assuming an ICC =0.088 and 30% loss to follow-up). To account for the possibility that two homes may drop out, each cluster should consist of 17-18 participants. Additionally, in the main RCT, 60% of the eligible staff must consent to the study after the care home manager has agreed to the study but before randomisation. These criteria are prerequisites for care home participation. Therefore, predetermined criteria for successful recruitment during the study were agreed as:

- Recruitment rate of at least 60% of all eligible staff.
- Recruitment of at least 17 residents with dementia.

2. To report socio-demographic characteristics and main outcome measure scores at baseline and 8 months.
3. To report the acceptability of main and secondary outcome measures completed by staff at baseline and 8 months.

I summarise resident and staff characteristics and rating scale scores at both time-points as well as the proportion of completed outcome measure for staff and residents at baseline and 8 months. I report mean and standard deviations for continuous (approximately) normally distributed variables, medians and inter-quartile ranges for non-normally distributed variables and frequencies and percentages for categorical variables. In line with standard practice, I defined a skewness statistic of between -1 and 1 as within the acceptable limits for approximating the normal distribution. I have described but not analysed this data (or the staff measures below) as the study is not powered for this.

4. To obtain estimates of the acceptability and feasibility of the MARQUE intervention, specifically to estimate the proportion of participants offered the intervention that completed it.

I report the number of eligible staff who attended all six sessions of the intervention and the mean/median number of sessions staff attended. I report the staff role of those who did and did not attend sessions and reasons for non-attendance. As the manager agreed to the intervention being “mandatory” training our predetermined criteria for success of this feasibility study was completion of all 6 MARQUE intervention sessions (either attendance at group training or an individual catch up) by 80% of all eligible staff.

5. To report therapist fidelity to the intervention and fidelity checklist interrater reliability.

I report the mean percentage of components of the intervention covered on the checklist, the mean rating for process factors and an overall fidelity rating for each session (the average score of the four process factors for both facilitators for each session). To maintain the anonymity of the facilitators I present a combined rating for each session rather than ratings for individual facilitators. I computed inter-rater reliability for the fidelity ratings using a two-way mixed, average measures intra-

class correlation (McGraw and Wong, 1996). I interpreted inter-rater agreement in accordance with Cicchetti's (1994) classification ($< 0.4 =$ poor, $0.40 - 0.59 =$ fair; $0.60 - 0.74 =$ good; $\geq 0.75 =$ excellent) (Cicchetti, 1994). For the intra-class correlation I only compare raters where a full set of fidelity ratings is available for all three recorded sessions.

9.6.2 Qualitative analysis plan

The main objective of the focus groups was to qualitatively explore the acceptability and feasibility of the MARQUE intervention, focusing specifically upon staff experiences of the intervention, what helped them to put learning into practice and any suggested changes to the intervention. All focus groups and individual interviews were digitally recorded and transcribed verbatim and identifying information was removed to preserve participant's anonymity. I used thematic qualitative analysis methods based upon the approach outlined by Braun and Clarke (2006).

After listening to each recording, familiarising myself with the data and checking the transcription against the audio recording, I entered all transcribed interviews into NVivo 11 software package. I initially systematically coded the transcripts into meaningful fragments and labelled these initial codes. To increase reliability, each transcript was independently read and fully coded by a MARQUE research assistant and any discrepancies were discussed and resolved (Barbour, 2001). I then organised the data into preliminary themes, displaying these in matrices and diagrams until I had a comprehensive picture of all the phenomena in question. I discussed the coding frames within the team using the constant comparison method to identify similarities and differences in the data (Glaser, 1965).

Following initial inductive open coding, I integrated the data from the focus groups and interviews with the facilitators' reflective logs, action plans from the care home and quantitative findings to inform a mixed methods process evaluation of the initial intervention testing based upon the MRC guidance on process evaluation for complex interventions (Moore et al., 2015, Holle et al., 2014). Table 9.1 describes

the framework I adapted for the process evaluation. The quantitative results related to the acceptability and feasibility of the intervention, in terms of the coverage and reach, frequency and duration, and fidelity of the intervention. They are presented in Chapter 10 and the qualitative findings related to the impact and factors affecting implementation during initial testing are presented in Chapter 11.

Table 9.1: Framework for process evaluation of the initial intervention testing

Domain	Research question	Data source	Data analysis
Implementation			
Coverage and reach	What proportion of target staff participated in the intervention? (Reasons for non-attendance)	Attendance records demographics	Descriptive statistics
Fidelity, frequency and duration	To what extent was the intervention implemented as planned? Was the intervention implemented as often and as long as planned?	Attendance records Fidelity recordings	Descriptive statistics Fidelity analysis
Impact and factors affecting implementation			
Participant responses	How did the participants engage with the intervention? How did the participants perceive impact of the intervention? How did participants put learning into practice? Which learning & change processes took place?	Reflective logs Staff focus groups Action plans	Thematic analysis
Strategies to facilitate implementation	What strategies were used to support implementation? How were these strategies perceived and adopted by staff involved in the project?	Attendance records demographics Reflective logs Staff focus groups	Descriptive statistics Thematic analysis
Quality of delivery	How was the quality of delivering the intervention?	Reflective logs Staff focus groups Fidelity recordings	Descriptive statistics Thematic analysis
Context	What factors at political, economic, organisational, and work group level affected the implementation?	Reflective logs Staff focus groups	Thematic analysis

Chapter 10 Quantitative results

10.1 Care home description and demographics

The care home was privately managed and registered to provide personal care to residents and care to people with dementia. It had 56 places available for residents. During baseline data collection 55 beds were occupied, with one resident in hospital. It was rated 'good' overall at the most recent CQC inspection. It was not registered as a dementia specialist home but had a specialist unit for people with dementia experiencing behavioural difficulties. The care staff in the home had received one three hour session of dementia training in the past six months. Overall the home employed 41 permanent care staff and 2 permanent registered nurses. The daytime staff: resident ratio was 1:2.8.

10.2 Study recruitment and retention

10.2.1 Resident recruitment and retention

Full details of resident recruitment and retention to the study are presented in Figure 10.1. 32/55 (58%) residents in the care home were eligible to participate in the study (either had a documented or probable diagnosis of dementia, scoring ≥ 2 on Noticeable Problems Checklist (Levin, 1989)). Of the 32 eligible residents, 17 participated (53%). Of these 17, only one had capacity to consent and so were approached directly, and the remaining 16 were consented by relative consultees. The demographics of the participating residents are presented in Table 10.1. At baseline the mean age of residents was 88.9 years (S.D = 8.39) and the median length of stay was 27 months (IQR 17,67). Follow-up data was collected for 13 residents (76% overall retention; 95% Confidence Interval (CI) 50% to 93%); three had died and one left the home between baseline and 8 months.

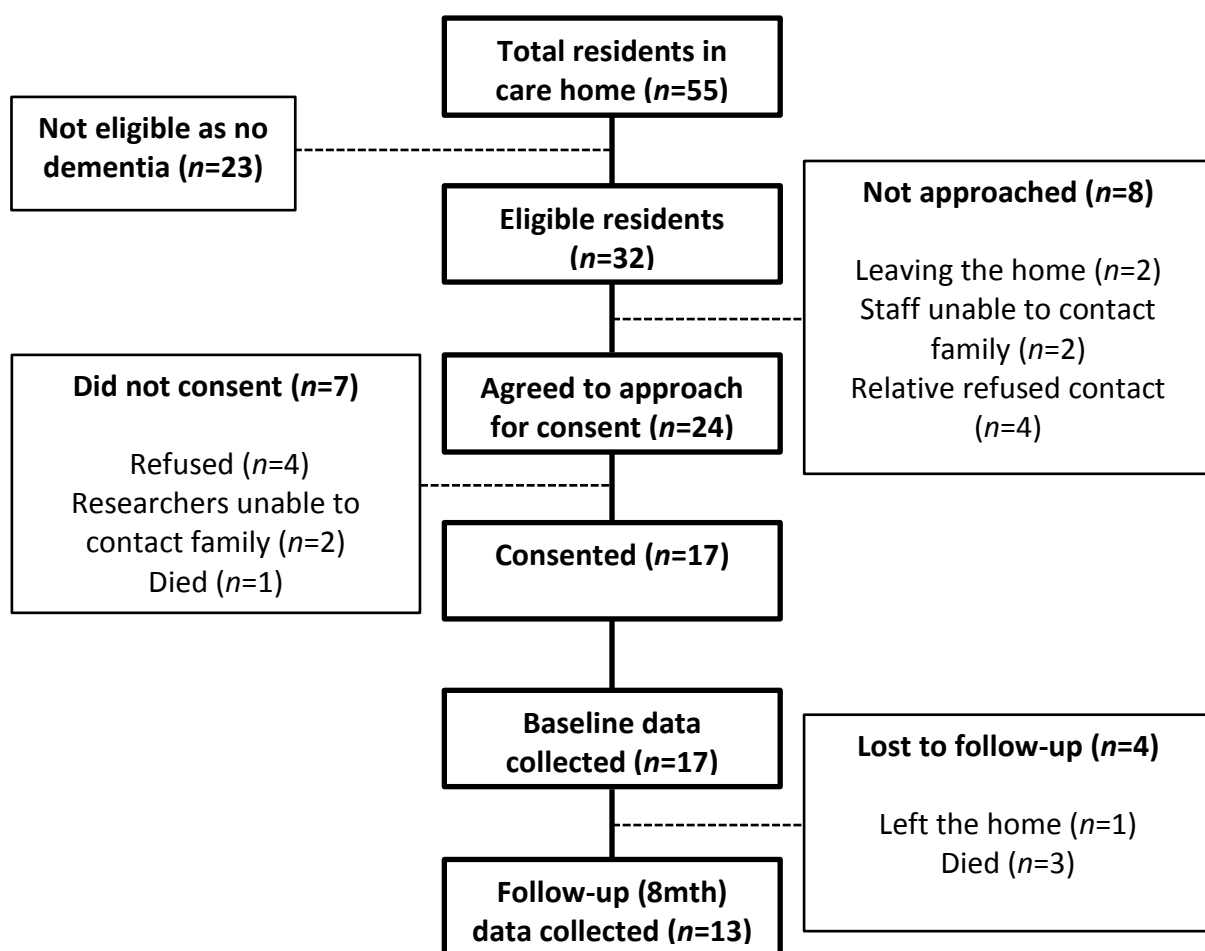


Figure 10.1: Resident recruitment and retention

Table 10.1: Resident demographic characteristics

Resident Characteristic		<i>n</i> (%)
Sex	Female	16 (94.1)
Age	65-74	1 (5.9)
	75-84	3 (17.6)
	85-94	9 (52.9)
	95-102	4 (23.5)
Ethnicity	White British	14 (82.4)
	White other	2 (11.8)
	Black Caribbean	1 (5.9)
English as a first language	Yes	16 (94.1)
	No	1 (5.9)
Dementia Severity	Very mild/Mild	2 (11.8)
	Moderate	7 (41.2)
	Severe	8 (47.1)

10.2.2 Staff recruitment and retention

Full details of staff recruitment and retention to the study are presented in Figure 10.2. At baseline there were 43 members of staff working in the care home and 30 (70%) were eligible to participate. 22 (73%) of the eligible staff consented to participate at baseline. Sex and role of staff who completed baseline measures compared to those that did not are presented in Table 10.2. Demographic and employment characteristics of staff that consented at baseline are presented in Table 10.3. The mean age of staff was 45.9 years (SD=12.01) and 3 of the staff were registered general nurses. Follow-up data was collected from 17 staff members (77% retention rate; 95% Confidence Interval (CI) 55% to 92%).

Table 10.2: Sex and role of staff who did and did not participate in the study

Staff characteristic		Participant <i>n</i> (%)	Non- participants <i>n</i> (%)
Sex	Female	20 (90.9)	8 (100)
Role	Care assistant	9 (40.9)	6 (75)
	Senior carer	6 (27.3)	0 (0)
	Team leader	3 (13.6)	0 (0)
	Deputy manager	1 (4.5)	2 (25)
	Manager	1 (4.5)	0 (0)
	Activities coordinator	2 (9.1)	0 (0)

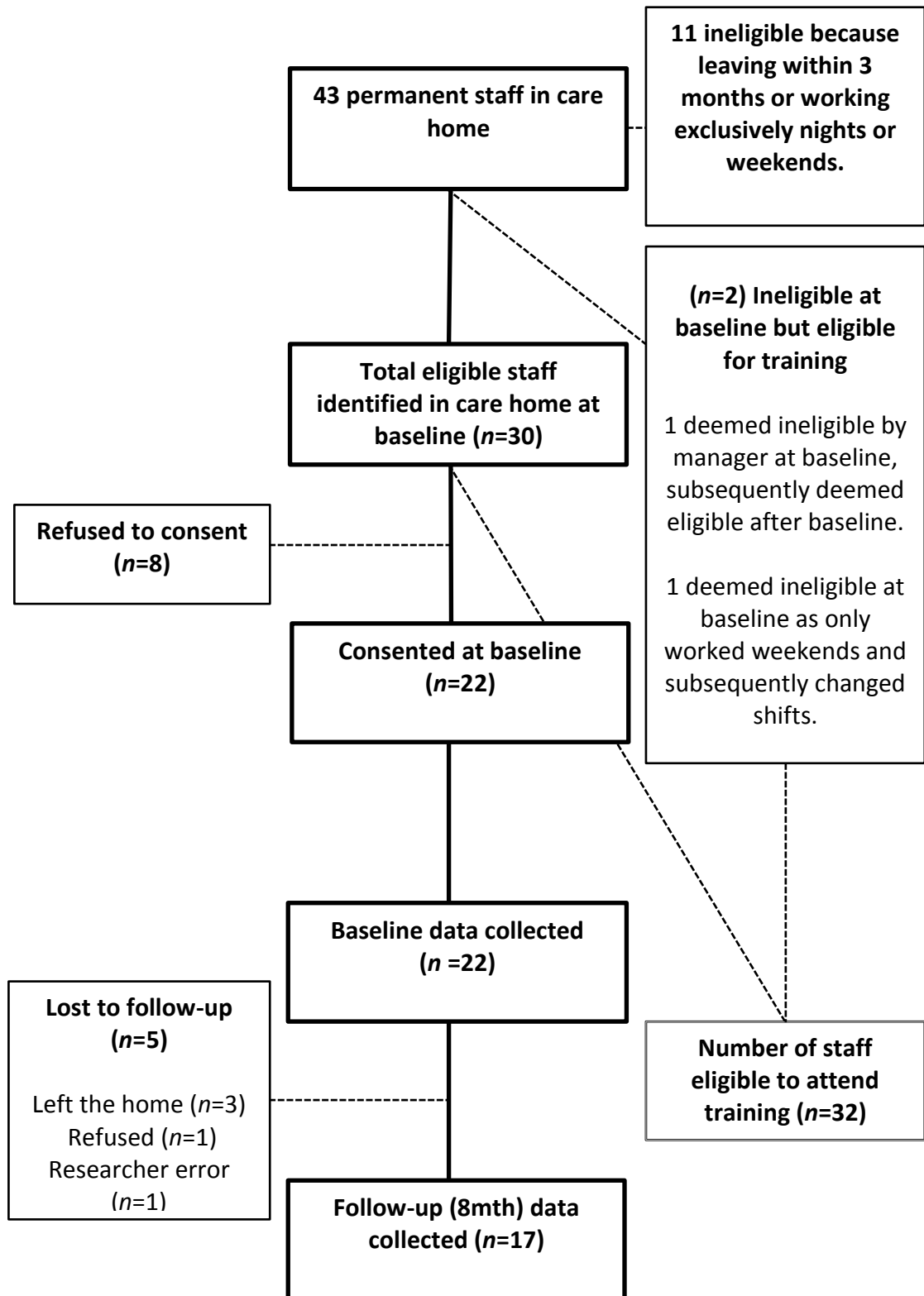


Figure 10.2: Staff recruitment and retention

Table 10.3: Staff demographics and employment characteristics

Staff Characteristic		<i>n</i> (%)
Sex	Female	20 (90.9)
Age	20-34	4 (18.2)
	35-44	6 (27.3)
	45-54	5 (22.7)
	55-64	6 (27.3)
	Not known	1(4.5)
Ethnicity	White British	2 (9.1)
	White other	3 (13.6)
	Black African	4 (18.2)
	Black Caribbean	2 (9.1)
	Asian Indian	3 (13.6)
	Asian Chinese	2 (9.1)
	Asian other	3 (13.6)
	Mixed other	3 (13.6)
English as a first language	Yes	10 (45.5)
	No	12 (54.5)
Highest level of education	No qualifications	1 (4.5)
	O Levels/GCSE/NVQ Level 1or 2	2 (9.1)
	A Levels/NVQ Level 3-5	10 (45.5)
	Degree	5 (22.7)
	Other	3 (13.6)
	Not known	1 (4.5)
Staff role	Care assistant	9 (40.9)
	Senior carer	6 (27.3)
	Team leader	3 (13.6)
	Deputy manager	1 (4.5)
	Manager	1 (4.5)
	Activities coordinator	2 (9.1)
Years in current care home	Less than 1 year	7 (31.8)
	1-5 years	8 (36.4)
	More than 5 years	7 (31.8)
Shift pattern	Days only	18 (81.8)
	Days and nights	4 (18.2)

GCSE (General Certificate of Secondary Education); NVQ (National Vocational Qualification)

10.3 Acceptability and feasibility of the MARQUE intervention

10.3.1 MARQUE training session

At the beginning of the intervention there were 32 staff members eligible to attend training sessions. Of the eligible staff, 16 (50%) were care assistants, 6 (19%) were senior carers, 4 (13%) were team leaders, 3 (9%) were activities coordinators, 2 were deputy managers (6%) and 1 (3%) was the home manager. Overall, 27 (84.4%) of these 32 staff members completed all 6 of the intervention sessions (either attending group sessions or receiving an individual catch up). Three (9.4%) members of staff (2 care assistants and 1 team leader) completed 5 sessions, 1 (3.1%) care assistant completed 4 and 1 care assistant (3.1%) completed 2 sessions. The median number of sessions attended was 6 (IQR 6,6). The proportion of staff attending each session (including the numbers attending a group session or an individual catch up) are described in Table 10.4. Each group session was repeated three times on different days of the week. The reasons given for non-attendance at the group sessions are described in Figure 10.3.

Table 10.4: Staff attendance at each session

	Attendance <i>n</i> (%)					
	Session 1	Session 2	Session 3	Session 4	Session 5	Session 6
Group Session	25 (78)	27 (84)	26 (81)	23 (72)	26 (81)	26 (81)
Individual catch up	7 (22)	4 (13)	4 (13)	7 (22)	5 (16)	3 (9)
Overall attendance	32 (100)	31 (97)	30 (94)	30 (94)	31 (97)	29 (90)

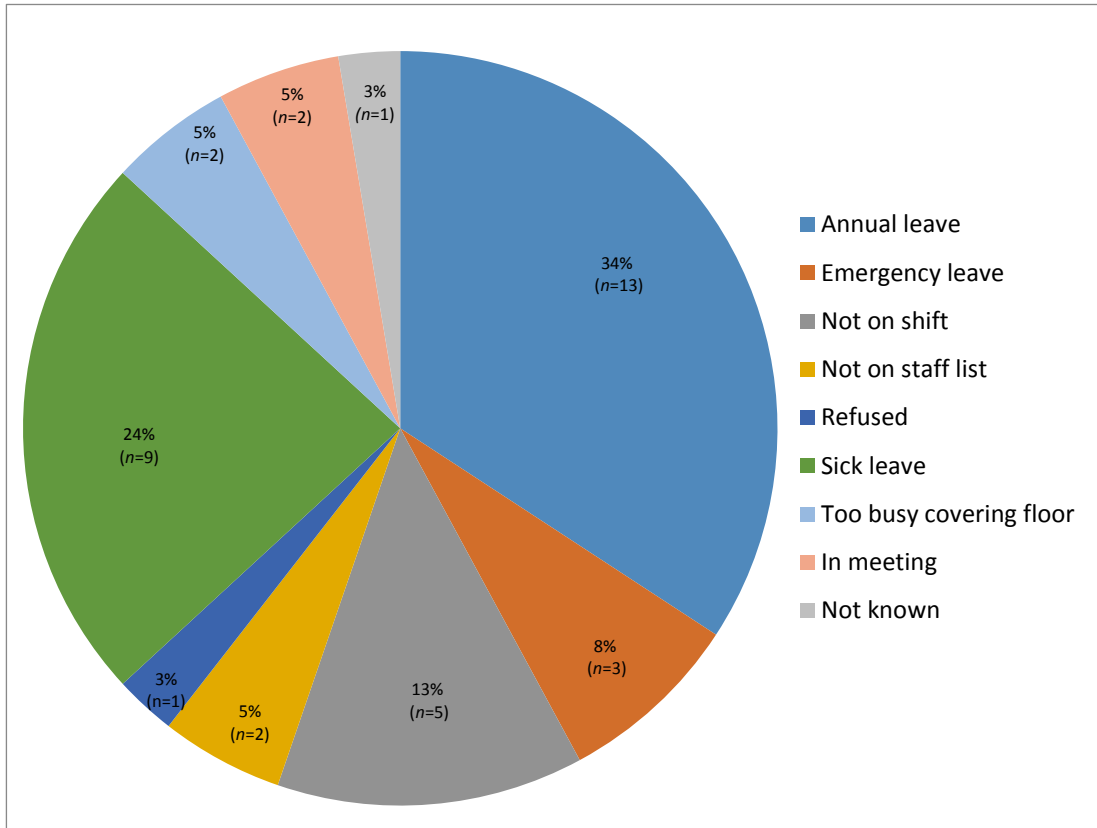


Figure 10.3: Reasons given for not attending a group training session

10.3.2 Supervision and troubleshooting period

The supervision period lasted for six weeks and began after the post intervention focus groups described in Chapter 11. During this time I delivered three, one hour clinical supervision sessions in the home. I met with 12 members of staff once and three members of staff twice. Staff role of those attending clinical supervision sessions is detailed in Table 10.5. Additionally, the research assistants who facilitated the sessions visited the home on four other occasions and offered informal troubleshooting sessions on the care home floors. They spoke with 24 members of staff over the course of these visits.

Table 10.5: Staff role of attendees at clinical supervision

Clinical Supervision session	Staff role of attendees	n (%)
Session 1	Care assistants	6 (60)
	Senior carer	2 (20)
	Team leader	1 (10)
	Activities coordinators	1 (10)
Session 2	Senior carer	2 (50)
	Team leader	1 (25)
	Care assistant	1 (25)
Session 3	Care assistant	1 (33)
	Activities coordinator	1 (33)
	Team leader	1 (33)

10.4 Fidelity to the intervention

One session was recorded (MARQUE session 2, 4, and 6) for each of the three groups being delivered in the care home and rated for fidelity by up to 9 research assistants (8 rated sessions 2 and 6, 9 rated session 4). Five research assistants rated all three of the sessions. The intra-cluster correlation was 0.77 which indicates excellent agreement (Cicchetti, 1994). The overall mean fidelity score for session 2 was 4.33 (SD=.37), for session 4 was 4.85 (SD=.12) and for session 6 was 4.73 (SD=.21). The mean percentage of session components covered for session 2 was 91.2% (SD= 5.42, range 84-96%), for session 4 was 94.3% (SD= 4.94, range 87.5-100%) and for session 6 was 93.4% (SD= 5.65, range 85.7-100%). The mean rating for each process factor for the three recorded sessions is presented in Table 10.6.

Table 10.6: Mean fidelity rating of process factors for recorded sessions

	Fidelity rating		
	Session 2	Session 4	Session 6
	Mean (SD)	Mean (SD)	Mean (SD)
Keeping the session to time	3.86 (.63)	5 (0)	4.5 (.52)
Keeping focussed on the manual	4.44 (.51)	4.72 (.46)	4.75 (.45)
Keeping the group engaged	4.75 (.45)	4.89 (.32)	5 (0)
Managing group dynamics	4.25 (.77)	4.78 (.43)	4.69 (.48)

10.5 Descriptive study outcomes

10.5.1 Resident outcomes

Resident total outcome scores are presented in Table 10.7. Only three residents were able to complete DEMQOLs at baseline and none at 8 month follow-up. Therefore I do not present the results. The main resident outcome measures (CMAI and DEMQOL staff proxy) were completed by staff proxy for 100% of residents at baseline and 8 month follow-up. Of the thirteen residents who remained in the study at 8 month follow-up, at baseline only one had a clinically significant level of agitation (scored ≥ 45 on CMAI) and at 8 month follow-up four residents had clinically significant level of agitation.

Table 10.7: Resident outcome scores at baseline and 8 months

Resident measure (Score range)	Baseline			8 Month Follow-up		
	<i>n</i>	Skew	Median (IQR)	<i>n</i>	Skew	Median (IQR)
CMAI total (29-203)	17	0.79	36 (30,39)	13	2.13	31 (29,51)
DEMQOL Proxy (staff) total (31-124)	17	-2.47	106 (102,111)	13	-1.18	109 (89,111)
DEMQOL Proxy (Relatives)	13	-1.285	104 (93,107)	11	.23	101 (94,106)
NPI total (0-144)	17	1.16	6 (0,25)	13	0.86	16 (0,26)

CMAI = Cohen Mansfield Agitation Inventory; NPI = Neuropsychiatric Inventory

10.5.2 Staff outcomes

Staff outcome measures at baseline and at 8 month follow-up are presented in Table 10.8 below. 20/22 (91% completion; 95% Confidence Interval (CI) 71% to 99%) staff at baseline and 16/17 (94% completion; 95% Confidence Interval (CI) 71% to 99%) staff at follow-up completed all of the main outcome measures (Brief COPE, MBI and SCIDS). On the MCTS at baseline 53% of staff reported that they had witnessed or perpetrated at least one abusive behaviour at least sometimes in the last three months. This was 47% at 8 months. Details of the number and proportion

of care home staff reporting that they had seen or carried out each potentially abusive or positive behaviour included in the MCTS are presented in Appendix 31.

Table 10.8: Staff outcomes at baseline and 8 months

Staff measure (Score range)	Baseline				8 month follow-up			
	<i>n</i>	Skew	Mean (SD)	Median (IQR)	<i>n</i>	Skew	Mean (SD)	Median (IQR)
Brief COPE subscales								
Problem focussed coping (6-24)	20	-.37	15.50 (4.03)	-	17	-.31	16.65 (4.40)	-
Emotion focussed coping (10-40)	21	-.025	24.73 (5.90)	-	17	0.20	26.12 (7.90)	-
Dysfunctional coping (12-48)	21	.55	21.90 (5.67)	-	16	-.13	19.38 (4.37)	-
MBI subscales								
Emotional exhaustion (0-54)	22	.61	-	22.5 (15,30)	17	.38	-	20.2 (5,29)
Personal accomplishment (0-48)	21	-.76	-	41 (38,47)	17	-.75	-	42 (36,45)
Depersonalisation (0-30)	22	1.32	-	3 (1,6)	17	1.67	-	1 (0,6)
SCIDS subscales								
Professionalism (5-20)	21	-.26	-	18 (15,20)	17	-.35	-	18 (16,19)
Building relationships (4-16)	21	-.60	-	11 (11,12)	17	.50	-	12 (11,13)
Care challenges (4-16)	20	-.21	-	12 (11,13)	17	-1.3	-	14 (12,15)
Sustaining personhood (4-16)	21	-.33	-	13 (12,14)	17	.19	-	14 (13,16)
SCIDS total (17-68)	20	-.89	-	55 (48,56)	17	.21	-	57 (52,60)

COPE = Coping Orientations to Problems Experienced; MBI = Maslach Burnout Inventory; SCIDS = Sense of Competence in Dementia Care Staff

Chapter 11 Qualitative process evaluation of feasibility study

In this chapter, I qualitatively explore what the participants and facilitators judged to be the impact of the MARQUE intervention and the factors that affected staff putting it into practice. I will present findings from the post-intervention focus groups and individual interview, the facilitator reflective logs and the action plans created by the staff during training. I will present the data according to the framework I used to analyse it in the methods section analysis plan (Table 9.1).

I will first describe the demographics of the focus group and individual interview participants, and the facilitators of the intervention, and summarise the content of the action plans developed. I will then set out results of the main qualitative analysis of focus groups, interview and reflective data and describe the main suggestions for changes that were then integrated into the final version of the intervention tested in the MARQUE RCT.

11.1 Descriptives

11.1.1 Demographics of staff participants

Overall, 16/32 (50%) of the staff who attended the training sessions contributed to a focus group or had an individual interview; 15 attended one of the three focus groups and one staff member, who was unable to attend any of the focus groups but wished to contribute, was interviewed individually. Those who did not contribute were either not available or did not wish to participate. The staff role and sex of those participating and for all staff eligible to attend the training are compared in Table 11.1 and were similar. Participants included people of either sex and from all the staff roles. A director from the care home chain also contributed to the first focus group. Although I suggested to her that as “the boss” she might make some people less able to talk openly, she decided that she would stay and contribute. The focus groups had seven, five and four participants respectively and lasted between 43 and 53 minutes. The individual interview lasted 18 minutes.

Table 11.1: Role and sex of focus group/interview participants compared to eligible staff

Staff characteristic		<i>n</i> (%) contributing to focus group or interview	Total <i>n</i> (%) of staff eligible to attend training
Sex	Female	14 (87.5)	29 (90.6)
Role	Care assistant	7 (43.8)	16 (50)
	Senior carer	3 (18.8)	6 (18.8)
	Team leader	2 (12.5)	4 (12.5)
	Deputy manager/manager ²	2 (12.5)	3 (9.4)
	Activities coordinator	2 (12.5)	3 (9.4)

11.1.2 Demographics of MARQUE facilitators

The intervention training sessions were delivered by four trained psychology graduates who received weekly group based clinical supervision from me. They were three women and one man, who were ethnically white British (3) and white Asian British (1) all in their mid-20s.

11.1.3 Additional materials included in analysis

Overall I analysed 28 separate facilitator reflective logs from the training sessions and 14 written notes from the troubleshooting sessions. Overall, across the three training groups five separate action plans were developed based on integrating the plans made in each group, which were agreed with the care home manager. The main focus of each action plan is summarised below in Table 11.2 (copies of the action plans are in Appendix 32).

² As there was only one manager and one assistant manager and one director interviewed I will describe them as manager 1, 2 and 3 in the analysis to reduce identifiability and when referred to by other staff in quotations I will insert [management].

Table 11.2: Main focus of action plans developed in final session of training

What?	How often?	Facilitating strategies?
1. To use the troubleshooting with MARQUE researchers to look through the MARQUE folders and address any issues. To maintain these meetings after the researchers stop coming in.	Initially fortnightly and then monthly	<ul style="list-style-type: none"> • Reminders on message board and in communication book. • Support from managers and researchers • Talking about it in home • Commitment to MARQUE
2. To keep using Call to Mind with residents regularly.	Twice a week (on two separate units)	<ul style="list-style-type: none"> • Carers allocated and names put on schedule and message board • Activities staff will organise • Will discuss in MARQUE supervision
3. To use the DICE model to create strategies to manage agitation and communicate these strategies within the team. This will be done by writing record forms for agitated residents and creating care plans.	When a resident is agitated record forms will be completed. DICE model will be used in handovers and MARQUE supervision meetings.	<ul style="list-style-type: none"> • Folders kept on each floor with record form and care plan for each resident • Discussed in handover and MARQUE supervision
4. For staff to keep taking time to practise relaxation, either in small groups or individually.	When morning and afternoon shifts overlap, at least once a week.	<ul style="list-style-type: none"> • Staff reminding each other • Discussed in supervision • CDs available and accessible • Champions will encourage and remind people • Management support (to take time out)
5. To write down successful communication strategies and pleasant events that worked with residents.	When new information is identified and when there is time	<ul style="list-style-type: none"> • Champions to look in folders remind staff • Discussed in MARQUE supervision

11.2 Qualitative analysis

I will now outline my qualitative findings from focus groups, individual interview and reflective log data on the potential impact and factors affecting the initial implementation of the MARQUE intervention. I will present the findings in relation to four main themes. I will begin by describing participant responses to the intervention, and will then discuss the strategies used to facilitate implementation,

the quality of the intervention delivered and the impact of the context upon implementation.

11.2.1 Participant responses to the intervention

11.2.1.1 *How did the participants engage with the intervention?*

Staff spoke about how the MARQUE sessions differed from previous training in homes they had worked in. They appreciated the greater opportunities for interaction and action rather than been given information alone:

It's always like theory, like this, this, this, this, this, this, this and this and you're like, okay...Whereas, we actually got to like talk and do stuff in these and it wasn't like we were being told something. It was like we actually got to discuss it with each other rather than a normal training day that we'd go on where they would just say to you, "this is what you have to know... goodbye" (laughs). (Care assistant 1)

Staff compared the MARQUE sessions to the NVQ (National Vocational Qualification) training they had received and suggested that the MARQUE sessions were more specific and relevant to their work, as well as being broad enough to include something of relevance to everyone.

Below I will explore which aspects of the intervention staff did and did not engage with. These are reflected in the action plans which included making time to share new learnings from MARQUE together, continuing to use Call to Mind and DICE and staff practising relaxation (see Table 11.2).

11.2.1.1.1 Call to Mind

Staff were positive about the game Call to Mind and more generally about increasing pleasant events. They were keen to build it into their practice. They valued that Call to Mind was easy to use and engaging for people with dementia and could be used both as a stimulating activity and as a strategic response when certain residents were distressed:

Manager 1: And their Call to Mind, I think, is a favourite among all the staff.

Interviewer: Is it?

Manager 1: Easy to do. You don't even need to...

Care assistant 2: And the residents tell you things like you don't even know...

I want to say, I don't know who came up with the board game, but I thought that was ingenious, like it was crystallised... It was like knowledge crystallised into a board game, and I think that was good.
(Senior carer 1)

This positive response to Call to Mind was echoed by the facilitators in their reflections. They had initially been concerned that the game would be perceived as patronising, but were surprised at how the staff had responded to the game and had used it between sessions and after the training had been delivered.

11.2.1.1.2 DICE

Staff discussed how they found the 'DICE' (Describe; Investigate; Create strategies; and Evaluate) approach to managing agitation useful:

Well, the DICE is a very helpful idea because it's covering everything in your environment, in your practice and your teamwork and whatever you are just implementing, so how we see the outcome. So we are sharing idea with you, try this one, it will help with the particular resident. (Team leader 1)

They were unclear how DICE related to their existing 'care planning' procedures and who was responsible for using the DICE approach and completing any documentation, especially since care assistants were not usually involved in care planning:

Yes, care staff normally they don't do the care plans because first of all they don't know how to do the... They didn't train for the care plan and

from the senior level staff...everyone is dealing with the care plans.
(Manager 1)

Others suggested that the documentation included in the training could be made easier to use:

Probably if you could do like a simplified template, or like, and like where you could put name, put like a trigger, and something like that, then if you just were to give it to people and they just do it and put it somewhere. (Senior carer 1)

Although they felt that DICE was well understood and popular with staff, the facilitators echoed the concerns of staff about care planning and paperwork. They suggested changes to the final manual to make DICE more accessible and easy for staff to use. They also highlighted the importance of distinguishing in the finalised manual between 'care planning' and creating a specific plan for managing agitation.

11.2.1.1.3 Focus on staff wellbeing and stress reduction

Staff appreciated the focus on their own wellbeing and responses within the training sessions; this included the emphasis on communication between team members, ways for staff to look after themselves and the inclusion of stress reduction exercises. A number of staff mentioned that this was unusual yet welcome and contributed to their overall engagement and enjoyment:

But one thing which is not mentioned on the NVQ things that you kind of consider about the staff themselves stressed. (Senior carer 2)

There was really happy moments, we have a break and then have a drink. They always look after every staff, I think. They not let anybody get bored, yes it was a happy moment for all of us, I think. (Team leader 1)

One senior carer felt uncomfortable with certain aspects of the stress reduction and with the refreshment break included in the training:

It was good because I see it was comprehensive, you're trying to help us, to look after us, or you're trying to help us look after ourselves. But I thought to myself that probably I could manage that myself. (Senior carer 1)

The facilitators thought that the focus on staff wellbeing was appreciated, in part, because this was not typically part of training and more generally, they perceived that staff were not used to their needs being considered:

Care staff appreciated being given the space to talk and to be listened to and even being given snacks and pens as they are not usually given anything. (Facilitator 1)³

11.2.1.2 How did the participants perceive the impact of the intervention?

Both the staff and facilitators described how they felt that the MARQUE intervention had impacted upon care practices in the home. The staff perspectives are described below and the facilitator views are summarised in Table 11.3.

Table 11.3: Facilitators' perceptions of the impact of the intervention on staff

Facilitators' perceptions of the impact of the intervention
1. Better relationships because of pleasant events e.g. knowing things about residents from Call to Mind, and chatting whilst putting on a resident's make up.
2. Better relationships through not pushing people to do things they don't want to e.g. coming back to get someone up a bit later if they don't agree at that moment.
3. Understanding agitation more and the DICE model helped provide reasons behind <i>why</i> the resident may be agitated resulting in less 'blame'.
4. Training allowed staff to reflect upon how important their job is as it can enhance the lives of the residents.
5. Staff were reminded of best practices and built confidence in taking time to get to know their residents and using that knowledge to inform their care practices.
6. Staff were more relaxed about trying new things e.g. giving someone time and space if they were agitated and coming back later.

11.2.1.2.1 Increased knowledge and skills in managing agitation

Staff explained that the MARQUE training addressed some gaps in their knowledge of how best to understand and respond when residents with dementia became

³ Quotations in blue are those from the MARQUE facilitators reflective logs

agitated. It built upon their existing knowledge and skills and had specifically helped them to better understand what may be causing agitation. They had noticed positive effects on the residents:

It help you, help us, you know, daily looking after the service users, the areas where they were still... Our knowledge was not... What to say? Our lack of knowledge in some of the areas as found in dementia residents. And the MARQUE project has helped us in a lot of ways in areas where we didn't know. (Senior carer 3)

Ah, yes, correct. And we done it with the practices, wherever, you know, we find a way, have to find, how to reduce the agitation as well, to find a reason why is agitated people... (Care assistant 2)

11.2.1.2.2 Improved relationships with residents

Central to their perception that the MARQUE intervention helped them to feel more equipped to manage agitation, was the sense that it enabled them to recognise and meet residents' unmet needs, and engage residents more effectively:

How to, you know, get more personal, get closer to the service user, and knowing their likes and dislikes. Like xxx said, sometime they get up and maybe they want to use the toilet, but and, you know, not knowing exactly what they want, then we say, sit down, or something like that. But it's getting to know them, talking to them. (Senior carer 3)

Staff in all the focus groups gave examples from their own and their colleagues' practice of how they had tried to improve communication with residents with dementia:

For example, if I offer them a shower, I might communicate more with them before really offering the shower, for example, because some of them would not much like to have one. So it helps me to put in my mind that I need to communicate more to them and for them to just relax first and then to come and have the shower. (Care assistant 3)

Finding new ways to respond to and communicate with residents was perceived by staff to have an impact, making residents happier and more relaxed, so it was easier to provide care:

Because we are doing stuff that xxx was saying like the singing and showing them pictures and talking about their lives, it's relaxing them and making them feel comfortable with us to do their personal care which is making them feel more relaxed, so it makes it more easier and happier for them and also us. (Care assistant 4)

11.2.1.2.3 Staff feel more confident and relaxed

Staff described feeling more relaxed and confident in their abilities to support residents with dementia. This was discussed in two of the focus groups in relation to staff feeling happier to work on the unit for people with a dementia diagnosis:

Care assistant 5: And it's the same helping with our dementia floor. We are mostly on the first floor, but when we allocated to the dementia floor now, you can relax, you are not mentally drained, you can relax because you know the techniques to use, when we had the MARQUE project.

Interviewer: Did you used to worry about going on to the dementia floor?

Care assistant 5: Yes, I never liked that place.

11.2.1.2.4 Working better as a team

Staff described how since attending the training sessions they had noticed staff were communicating better with each other, particularly in their responses when residents were distressed:

Yes, yes. It's just to do with the people interacting, you know, being a lot more helpful to each other is what I'm saying. (Activities coordinator 1)

Participants considered that staff were more willing to assist each other and were finding different ways to resolve conflict and seek support:

xxx would tell me, "xxx this, oh I need you now to do this or I need you now to..." You have to be calm, relaxed and when it's beyond you, you just have to go to your manager or your team leader to say... You don't need to just stay on your floor and keep shouting at each other and then your residents. (Care assistant 5)

11.2.1.3 *How did participants put learning into practice?*

11.2.1.3.1 Building pleasant events into routine care

One of the main ways staff were putting learning into practice was through building pleasant moments or additional social interaction into routine care. This seemed to be because of increased understanding of the importance of having time to engage residents in 'activities':

Especially the practical side of it where you spending time with service users, sometimes you don't have enough time to really do things with them. But, you know, the MARQUE project has shown us, you know, basic ways that you can interact and you can get to know them and, you know, when you spend time with them. (Senior carer 3)

Staff reported adapting how they delivered personal care to residents to make it a more enjoyable and relaxing interaction, noticing that small acts can have a powerful impact:

Like when doing medication. That time we can do something with the resident, talk to them. If you are like even walking just say hello, just like a happy event so that you can just make a laugh, make a cuddle. Just little, little things is really valued. (Team leader 1)

Care assistant 5: If you go to a resident's room and it's like, xxx, I'm coming to wash you. Stand up. No, I don't want to, go, go. Okay, and I know she likes singing. 'Stand up, stand up for Jesus' [singing]. By the time you realise, she's up.

Team leader 1: She will stand up.

Care assistant 4: Yes, yes, that's true.

Care assistant 5: And then she starts to march, yes off we go, come on, there... We sing and then dance together and then by the time you realise...She's changed her mind, washed and dressed.

Designated activity staff and direct care staff described how they had been working together more, with direct care staff getting more involved in delivering activities

rather than considering this outside of their role. This shift in practice was also observed by the care home manager:

The carers they try to sit down one-to-one with some of the residents who are isolated. I saw one who used to sit on her own and a carer actually sitting down and reading to this resident and I said, oh yes, this is only because of what she learned. (Manager 1)

Since this class, sometimes I work with people with dementia, before I would think activity was with activities staff not care [staff]. Now I think it is for every staff, before I thought only activities staff not care, now I think it is for everybody to do. (Care assistant 6)

Although this was positively described by staff after the training, the facilitators all described struggling during the training with the interactions between the activities staff and the care staff and how to shift perceptions of what pleasant events were and whose responsibility this was:

Though we did find difficulty expressing that pleasant events could be small everyday activities, rather than big planned activities ('for activity co-ordinators') – this is again cultural, more emphasis on this distinction in the manual for future training will be beneficial. (Facilitator 2)

The facilitators made specific suggestions for how this could be addressed by changing both the structure and content of the session on pleasant events (See Section 11.3).

11.2.1.3.2 Practical components were easier to implement

Some staff highlighted that it was easier for them to put more concrete components of the intervention into practice than other aspects:

The board game was readily implementable. I saw staff and getting the form in it, using it and all... The other point, I don't know if you call it Pleasure Moment, or Happy Moment, where you like, a foot massage or just talk, sitting down talking to a resident, or just giving them quality time. I saw that implemented. But there were other aspects that I didn't see implemented, like the Care Plan, and sharing the information as regards triggers. (Senior carer 1)

11.2.1.4 *What learning and change processes took place?*

11.2.1.4.1 Building on existing practices: We are already doing it

Staff felt that the MARQUE intervention built upon their existing skills and knowledge. It validated existing practices, resulting in staff feeling more valued and confident:

It reaffirms some practices that we were actually using in the past, and it makes us use these, to carry on with these practices without feeling embarrassed, that they are good. (Senior carer 1)

It also reminded staff of helpful approaches that they had forgotten; so they became more aware of what did and did not work well:

These are all things that we were doing, but it just make us more aware of doing right and wrong, and how to do it better. (Senior carer 3)

11.2.1.4.2 Learning from each other

Staff valued learning from each other, through being in training with staff at all levels, in all roles and across different units. They described benefitting from the varied and diverse experience of colleagues shared in sessions:

And what I have also realised is that we learn from each other, where people were like, oh yes, this one said this. And you will see that on the floor. Yes, because we didn't know, others are a bit more experienced on the high dependency so you can come in if you like to say, oh yes, this is what this person said, and so far it's working. (Manager 1)

Interestingly, some of the staff suggested this process meant they were perceived differently and afforded more respect from colleagues when they took a particular approach, especially if this had been promoted within the sessions:

I think that the course has put us on the same page. So like, if somebody's doing something... If somebody is using one of the techniques that we have learned from the course, that person will not be seen as being weird. (Senior carer 1)

11.2.1.4.3 Opportunity for reflection

For many staff, attending the sessions gave them the opportunity to critically reflect upon their practice in a way that they may not otherwise have done:

And also helps us to cut out practices that are not good, that we have fallen into a rut of doing. For example, sit down, sit down! We tell a resident, sit down, without really trying to know why they're getting up. So, it helps us to keep up with good practices and be happy that we're actually getting involved in those practices, and also cut out bad practices. (Senior carer 1)

The intervention sessions also had a supportive function where staff could talk together about some of the more difficult aspects of their roles:

Sometimes when a resident becomes agitated it can be very, very difficult. So is it good to have time to be able to speak about that, not in a blame way but to be able to really speak about, you know, what do we learn from that as well because there's no right answer sometimes. (Manager 3)

11.2.1.4.4 Practising between sessions

Putting into practice and trying out different approaches was integral to the learning and change processes. In part this came from the explicit 'between-session tasks'. Part of this process included the staff being motivated to act differently between sessions in order to feed back during the subsequent session; extending the reflective process beyond the training room:

It was good because it kind of make us want to do things. Like, for instance, a service user that we see every day who wanders, and like I say, sometimes you don't know the reason why. But because of the MARQUE project, then we focus on that service user so we are able to come back to deal with it and come back and give a report on how we managed that situation. (Senior carer 3)

11.2.2 Strategies to facilitate implementation

During the set-up, delivery phase and post-training support phase a range of strategies were used to support staff to put the intervention into practice; primarily

to increase attendance and to boost management and staff buy in. The strategies used and care home staff and facilitator perspectives on how these strategies were perceived and adopted are presented below in Table 11.4. Below I will also talk in more detail about the supervision and troubleshooting phase from the perspective of the facilitators.

11.2.2.1 *What strategies were used and how were they perceived?*

Table 11.4: Perception and adoption of strategies to facilitate implementation

What strategies were used to support implementation?	How were these strategies perceived and adopted by staff involved?
Meetings with management to facilitate buy in	<p>Management were cooperative and enthusiastic about the plans but lacked a total understanding of what was being asked. (Facilitator 3)</p> <p>[Management] gave support in an unconditional way, but in a way that made me think [management] wouldn't do anything particular to show the staff they support. We explained that it would be useful for the staff to know [management] was supportive as that was their biggest concern. (Facilitator 1)</p>
Flexible delivery: Repeated groups, individual catch ups, staff cover to attend	<p>Yes. I didn't really get to do it in the class, I was on holiday at that time, but when I came back they were so kind to, you know, they brought me up to date with all of the sessions. I missed about four sessions...(Senior carer 3)</p> <p>It was not that hard because we got covered. But covered mean when you get the agency, sometimes they are not quite... Yes, like your own staff is flexible, they will do whatever they're supposed to do, but when agency come they will look here, look there, you have to keep telling them what to do. So only that bit come maybe difficult. (Team leader 2)</p> <p>It helped for us to remain flexible to deliver these, yet we were keen to continually stress the importance of attending the full sessions. We had to regularly keep on top of attendance; more regular contact with management was helpful, as well as using the champions to rally people before sessions. (Facilitator 2)</p> <p>A lot going on in the home made it harder for people to attend and started late e.g. paperwork. Staff said they were not being paid to come in on their day off this affected attendance. (Facilitator 1)</p>
Champions	<p>I think the fact that we know that they are champions so that we could go to them, the staff go to them, and make a difference to say, look, they are the senior ones among us and we could go to them. It's a good idea to call somebody like the champions. (Manager 1)</p> <p>Constant nagging as well. (Care assistant 6)</p>

What strategies were used to support implementation?	How were these strategies perceived and adopted by staff involved?
	<p>Well, I feel really proud, you know because I know that this is my responsibility, I make sure the staff have a break before you go...So, it's really helpful and I think staff already, they really nicely cooperate with me. (Team leader 2)</p> <p>The put the lists on the staff room... The posters in our staff room [inaudible]. So like, the handing over room that the staff room, you cannot, oh yes, so there we have this, and they are good. (Care assistant 5)</p>
Clear, accessible and manualised	<p>This is a course that you can get people up to speed with so that they can teach... So you've got like... It's easy to train up trainers to train other people, and to pass the benefits of this course on. (Senior carer 2)</p> <p>The mark of a good teacher is to make a complicated idea simple to understand, and I think that's what the course did. (Senior carer 2)</p> <p>Yes. Like you separate it so it's easy to learn quicker as well. If you give the whole file then you feel a bit, wow, is that going all in one go, you know. (Activities coordinator 2)</p>
Practical and interactive sessions	<p>Because it was more active, participative. It was more informative, it was complete. It was for the service users and the carers, so it's like... It was just, you know... (Senior carer 3)</p> <p>It felt like we were all friends, sharing information, exchange our experiences...no boring, no nothing, you just enjoy. (Care assistant 2)</p> <p>The group discussions were very good. (Team leader 2)</p>
Between session practice tasks	<p>So everything is full packed. Outside this building they don't have time to concentrate on this training. So some of them find it is very difficult to do the task just before the next session. (Manager 2)</p> <p>If possible, if it can be done in such a way that there's less writing to do. Because a carer came to me purposefully, 'xxx, I've written something here. Is that right? Is that correct?' So people were also, the wording, you know. But this person is very good practically. They were struggling what to write down. (Manager 1)</p> <p>We were conscious throughout the training that effective culture change relied partly on staff adherence to completing the tasks in between sessions, and initially this was low. Lack of time was often the major reason, and although we tried to reinforce the message that if these ideas were successfully put into practice they could eventually save more time than they spend, it was clear that it didn't feel like that in the moment for staff. (Facilitator 2)</p>

What strategies were used to support implementation?	How were these strategies perceived and adopted by staff involved?
	The response was mixed, with one carer saying they had too many forms to fill in already and that they didn't need to share information in this way and another saying that sharing information about strategies would be helpful for the team, especially for new and bank staff. (Facilitator 4)
Action planning	<p>During our final session, when trying to put plans into place to keep things going there seemed to be resistance as to what positive changes might be possible and getting people to imagine things outside of an already restrictive system e.g. arranging time for staff relaxation sessions - which they had found helpful, but there was mass disbelief as to whether this was possible in practice. (Facilitator 2)</p> <p>Staff were not forthcoming with the plans and struggled to find ways to continue using strategies. (Facilitator 3)</p> <p>[Management] were very agreeable to the plans, but we felt that they were not committing to putting them into practice and how the plans will practically work (e.g. on what days staff could hold their MARQUE meetings, how the Call to Mind scheduling would work etc.). (Facilitator 4)</p>

11.2.2.1 *Post-training supervision and troubleshooting*

The attendance and demographic details of those who received post-training support are presented in Section 10.3.2. Although in the focus groups the staff felt the follow-up supervision period would be an opportunity for staff to revisit the training content and put this learning into practice, in reality the facilitators and I found this the most challenging part of the process. In reflective logs facilitators highlighted how this related to its relatively unstructured nature; as rather than imposing a fixed structure, with mandatory attendance and predefined content, we wanted to be flexible with the ongoing support and to reflect the specific needs of the staff (and what management and staff had agreed to).

The facilitators found the 'troubleshooting' sessions challenging as they felt that staff were too busy to talk with them or that staff felt uncomfortable talking in front of colleagues and therefore presented an artificially positive view of how they were continuing to use MARQUE. They also raised concerns about staff talking about each other and residents in public areas. Alternatively, the more structured

supervision sessions were more contained for staff and facilitators and clear boundaries were set in terms of confidentiality and what would be discussed. The main challenge of these sessions was getting people to attend. Although, as noted in Table 11.4, management were happy in principle for staff to attend these follow-up sessions, this was not always communicated with team leaders and staff themselves did not feel that they had explicit permission to take time off the floor.

Despite these challenges, the facilitators reported that staff were continuing to use Call to Mind and other pleasant events and talk about managing agitation in terms of the DICE approach and were occasionally using the DICE record forms. The facilitators made a number of specific suggestions about how to improve the impact of the post-training support for the MARQUE RCT, in addition to suggested changes to the intervention manual, which are presented below in section 11.3 and have been integrated into an implementation guide for use in the RCT outlined in Appendix 33 and section 12.5.1.

11.2.3 Quality of delivery

11.2.3.1 *How was the facilitation experienced?*

11.2.3.1.1 Validating and approachable versus firm and clear

The focus group participants talked about how the approach taken by the facilitators contributed to the learning process in section 11.2.1.3. Staff described how the facilitators were collaborative and encouraged participants to feel comfortable in sharing their experiences. This resulted in staff feeling valued and respected rather than scrutinised over their current practices:

No, they came down to our level. You know, they talk with us, they act with us. There is like... You know, people does... Yes, it was good, they laugh with us. We had our job, so... (Senior carer 3)

Care assistant 6: They'll never tell you it was terrible.

Care assistant 4: We wouldn't have liked them.

Interviewer: You wouldn't have liked them?

Care assistant 6: No, it's not even that. It's just that fact that, say if you haven't done it, right? They would prompt you and you'll be like, okay, do you know? Actually something did happen.

In their reflections, the facilitators all spoke about trying to validate the expertise of staff and create an open and relaxed atmosphere. However, this was not without its challenges. The facilitators described struggling to give staff the space to talk whilst keeping the sessions to time and covering all the content. This was made harder by the discursive and interactive nature of the training sessions. The facilitators all talked about needing to be 'firm and clear' and retaining control over the sessions, sometimes closing down conversations and moving (particularly the more dominant) participants on in the discussion. One particular challenge for the facilitators occurred when they felt that a staff member described 'bad practice' or where they were clear that a particular approach was unethical. This came up in relation to 'lying' to residents and the facilitators used their own supervision to find ways to manage this in the sessions, as well as making suggestions as to how the manual could be revised to address this point directly (See Section 11.3).

11.2.3.1.2 Facilitator's confidence increased over time

There was a clear sense in the facilitators' accounts that their confidence increased over time, particularly if they were delivering the same session more than once, and that their initial anxieties lessened as they got to know the groups:

I could have been more confident as I was worrying about not being clear or presenting well but this was not really a problem e.g. I had a spelling mistake only I probably noticed. (Facilitator 3)

I was feeling really good and amazed by how well staff were responding to training. People had done Call to Mind and really liked it. I was not prepared for how well staff responded. (Facilitator 1)

The facilitators described how supporting each other in sessions, preparing well for sessions, practising role-playing the sessions and using their own supervision to

reflect and revise their approach helped them to feel more confident and skilled. They described feeling motivated by the feedback they received from the participants and from hearing how they were using the learning in their practice.

11.2.4 Context

11.2.4.1 *What factors at political, economic, organisational, and work group level affected the implementation?*

11.2.4.1.1 Task oriented culture contributes to lack of time

In recounting difficulties in putting new learning into practice a number of staff spoke about a lack of fit with a 'task oriented culture'. This was highlighted by management and by the front-line care home staff who experienced the tensions during their shifts and by the facilitators, who noticed the impact upon staff putting MARQUE ideas into practice:

Yes because things seem, you have to be, like, task orientated don't they. So it's like things have to be done at a certain time so I suppose it just feels a bit dossy... So I suppose it's like in between when do you do it without looking like you're not doing anything? (Care assistant 1)

There is a view that you're not doing your task if you're sitting down and talking to someone as well. Which is why I think there is something about how the system supports you all to feel that that is part of your job... (Manager 3)

11.2.4.1.2 Lack of time for implementation

During both the training and post-training support periods, a focus upon tasks and efficiency seemed to result in staff struggling to find time to operationalise key components of the intervention. In relation to the between session tasks, staff could not find time to stop and reflect on what was happening whilst rushing between tasks on the floor, with no obvious time during their shifts available for them to write down their observations and thoughts:

I think our group we came into conclusion that you have to, I mean, at the end of your shift, I mean just write something because if you keep

piling, piling, you forget. So, your resident Mr. so and so and so this that... Have the time, write it down. (Care assistant 5)

Staff also described wanting to be able to use Call to Mind or spend more time doing pleasant events but finding it difficult to do so because of multiple competing demands:

So like to go around, go into their room, maybe have a little talk with them, you know, five to 10 minutes to go and do that. But if you're doing that then the bells go and then you got to come out or, you know, xxx might call you, can you help me put someone to bed or whatever. (Care assistant 2)

Although staff spoke positively about the stress reduction exercises, they had not really been using them outside of the sessions and they did not feel that there were structures or processes in place that would enable them to do so:

That's what we're saying. But obviously, we can't. All the staff can't just go off the floor. No, you can't all disappear and start meditating. There's still residents who, you know. (Care assistant 2)

At times, these difficulties resulted in the facilitators feeling overwhelmed and out of their depth, particularly when they did not feel that there was a solution to the issues being raised:

I could have been better prepared for when staff said that they felt understaffed and unsupported. Felt like was only able to discuss ways for them to work around that rather than find concrete solutions. (Facilitator 1)

11.2.4.1.3 Ongoing differences within the team

There's a big gap...We learn how to speak, communicate with each other, during the course and we would say, yes, that's a good point, yes, yes, yes. And we actually comment favourably, then when we go out, we go back to type. (Senior carer 1)

Although there is an explicit focus in the MARQUE intervention on communication within the team, a number of staff spoke about how outside of the session, there

were ongoing challenging dynamics that impacted upon their work. They explained that they tried to use the breathing exercises and communication strategies that they had learnt but that this was difficult when their colleagues were not also doing so. This was particularly so in relation to agency staff coming from outside the regular team and who had not attended the training sessions:

The agency will come in and obviously they don't know about the MARQUE project, so they will come in and see a resident's agitated, which then some of them will force the residents, in a way, to kind of get the personal care over and done with which will then make that resident agitated for the whole day. (Care assistant 4)

The facilitators all commented on there being complicated relationships within the staff team which they found difficult to manage within the training sessions and which they felt impacted upon how staff used what they had learnt between sessions:

There were complex personality dynamics within the groups, and discussions could get quite heated at times: particularly when dealing with some of the more controversial issues in care, such as staff communication difficulties and when discussing ethical care issues (e.g. how to respond when residents are upset). (Facilitator 2)

11.2.4.1.4 Management support

Both the manager and deputy manager who contributed to these interviews talked about the difficulties they had in finding time to implement MARQUE and reflected upon how this would be perceived by the staff they were managing:

So I thought that, oh my God, being [manager] if I can't do it, these people will not do anything. So I thought that I will find a separate time for that [doing between session tasks], so I did and I mentioned with the trainers also that last two sessions I couldn't do that, so I made some time for this and I have done it. (Manager 2)

Managers spoke about the importance of protecting time for specific staff to increase pleasant events so that staff felt they had permission to do so, however they also acknowledged that they had not as yet done so:

I think as a management, making sure that you just see the importance of it and just maybe give them, maybe 15 minutes, 10 minutes and to say, here you are, leave whatever you're doing. And I didn't do that. I could've done it better in the future. (Manager 1)

Although managers spoke of ways to facilitate implementation, which included suggesting that staff used their break time to do so, there was a feeling in one of the focus groups (which did not have management presence) that there was a gap between what was promised and what would actually transpire:

It's about we're not living in Utopia, like we... Because even a manager has their own way of doing things. A manager might be fully trained, well trained, but when muck hits the fan, they revert back to the way they handled things, back to type. (Senior carer 1)

11.3 Suggested changes to the intervention

The main suggestions for changes to the intervention following the initial testing came from the facilitators. The staff who attended the focus groups did not make specific suggestions for changes other than some of the participants suggesting simplifying the between session tasks and making them less writing based. The facilitators highlighted aspects of the sessions where they felt that the key focus or 'take home message' of the session was not clear. Specifically, they suggested that Session 2 on 'pleasant events' was restructured and greater emphasis placed upon how pleasant events did not need to be time and resource intensive, stand-alone activities, and that pleasant 'interactions' could be part of routine care. Facilitators also identified that during the session 'lack of time' was often given as a reason for not having done more with residents, therefore they suggested including ways to address this in the session content. Another suggestion was to make the DICE model clearer by simplifying some of the examples in the text and clarifying what is involved in the 'Create' stage of the process.

In general, the facilitators' suggestions related to the form and process of the manual with suggestions for changes to the facilitator version of the manual. This included making specific parts of the sessions more or less interactive, simplifying

and making between session tasks more concrete, checking with participants in training that they had understood tasks and making aspects of the content simpler and less repetitive. I integrated these suggestions into the finalised version of the MARQUE Manual (see Appendix 34 for a full list of the changes made).

Based upon their experiences of delivering the supervision sessions post-training the facilitators made suggestions to improve the follow-up support period. These were integrated into the implementation guide to accompany the RCT (see Appendix 33) and included:

- Adding more detail to the manual regarding what the supervision/troubleshooting period will involve and emphasising the supervision period more during training sessions.
- Meeting with managers and champions halfway through the intervention sessions to review and plan follow-up supervision/troubleshooting.
- Providing the research assistants with a written summary of a structure for the troubleshooting sessions.
- Meeting with managers / champions at end of sessions to plan follow-up supervision/troubleshooting and agree action plans.
- Facilitators either providing or supporting care home staff to collate any materials needed for action plans e.g. DICE folders, posters etc.

11.4 Summary

In this chapter, I have described how the participants and those facilitating the process perceived the intervention. These understandings of the learning and change processes and the factors that impacted upon implementation during this initial testing were used to revise the final version of the MARQUE intervention. In the next chapter, I will discuss the main findings and implications of this thesis.

Chapter 12 Discussion

In this chapter, I will summarise, integrate and interpret the main findings of this thesis. I will consider their contribution to understandings of how staff manage agitation in care homes, and how psychosocial interventions in care homes may support and improve this management. I will consider the strengths and limitations of this thesis and discuss future directions.

12.1 Main findings

12.1.1 Systematic review

In my systematic review, I synthesised qualitative and quantitative findings regarding effective components of psychosocial interventions delivered by care home staff to people with dementia. I found a lack of evidence that the effects of these interventions could be sustained after interventions stop, with no evidence of continued effects beyond six months. Interventions that showed effects up to six months later included 'reinforcing' strategies such as additional supervision. Consistent with this, staff in the qualitative studies referred to the importance of individualised support to put new learning into practice alongside group based training. Staff valued interventions that focused on getting to know, understand and better communicate with residents with dementia and that enabled them to reflect on their practice. Staff described a number of facilitators to putting interventions into practice: building interventions into routine care, seeing positive impacts on residents, having on-site mentors and champions and opportunities to share new learning within the team. Whole team engagement and management support to implement new approaches was integral to success.

12.1.2 Qualitative study findings

12.1.2.1 *Staff experiences and understandings of agitation*

Staff described caring for residents with severe agitation as part of their routine work and explained that it often left them feeling unsure how best to respond, as

well as frightened, disheartened, powerless and sometimes angry. They described trying to inhibit their own unhelpful responses. Although they experienced agitation as diverse, unpredictable and persistent, staff typically had an explanation for what they felt could be underlying causes. They explained agitation symptoms in terms of disease processes, as well as conceptualising them as relational and as expressions of unmet physical, emotional, social and environmental needs.

12.1.2.2 Staff approaches and responses to agitation

Staff described how they would try to prevent agitation from emerging and work to manage episodes of agitation once they occurred. Staff highlighted how they would try to meet the needs of individuals in their care in order to prevent residents becoming agitated. Staff described an overall approach centred on getting to know the person with dementia, which informed all aspects of their care delivery. Knowing how best to respond and what approach to take in different situations was complex and often resulted in tensions and ethical dilemmas for staff, especially when their interventions and strategies did not help. They used various techniques to de-escalate agitation. When unable to resolve an issue themselves they consulted a senior colleague or referred to external agencies, describing medication use as a last resort.

12.1.2.3 Factors influencing staff management of agitation

Staff perceived a personal inclination towards a caring role as important, with certain qualities making it easier for people to manage agitation more effectively. Communication with residents and relatives, and good relationships within teams (which enhanced care delivery and peer support) were seen as key to the effective management of agitation. At an organisational level, implicit in staff accounts was a tension between task-focused and person-centred care. Staff described a gap between the rhetoric and reality of delivering person centred care, and felt left to balance multiple competing demands. Being valued and supported by management and having opportunities for learning and development facilitated management of agitation and care delivery more generally. Negative external perceptions of care homes and sector-wide corporate practices were perceived by staff to erode morale

and motivation both directly and indirectly, impacting upon their responses to agitated residents.

12.1.3 Feasibility study and process evaluation findings

12.1.3.1 *Study recruitment and retention and intervention acceptability and feasibility*

We successfully recruited and retained staff and care home residents with dementia and delivered the intervention to eligible staff in the care home, achieving all the predetermined success criteria in terms of recruitment and retention of staff and residents with dementia to the study, and adherence to the intervention. In addition, I met with almost half of the staff on one or more occasion for clinical supervision and the intervention facilitators met with three quarters of the staff team during the supervision and troubleshooting period. These findings suggest that the study was feasible and the intervention acceptable to staff. As measured by the planned framework for the process evaluation, coverage and reach of the intervention was good and the excellent fidelity rating for therapist adherence to the manualised training sessions suggests that this aspect of the intervention was delivered as planned.

12.1.3.2 *Outcomes of the intervention*

The proportion of the main measures completed for staff and residents outcomes (as rated by staff proxy) was high, suggesting that these measures were practical and acceptable to use. I did not statistically analyse the outcome measures collected as the study was not powered to do so and it is important not to draw spurious conclusions from the results. However, the changes were in the expected direction for most of the reported outcome measures. Overall staff rated agitation as lower and resident quality of life as higher after the intervention but counterintuitively neuropsychiatric symptoms increased. This may reflect a change in how staff view and understand neuropsychiatric symptoms, noticing certain behaviours more, but since levels of agitation and neuropsychiatric symptoms were

relatively low in the participating residents initially, the change may equally reflect an increase in neuropsychiatric symptoms in one or two people.

Following the intervention, care staff reported using more emotion focused and problem solving coping strategies and fewer dysfunctional strategies, and were less emotionally exhausted, experiencing less depersonalisation and higher levels of personal accomplishment. Consistent with this, staff felt more competent and able to build relationships, manage challenges and sustain the personhood of those in their care. Just over half of staff reported that they had witnessed or perpetrated at least one abusive behaviour at least sometimes in the last three months. This was slightly lower after the intervention, while positive behaviours reported were slightly higher.

12.1.3.3 Potential mechanisms of impact of the MARQUE intervention

Staff who received the intervention who participated in post-intervention focus groups described active participation and engagement with the intervention. They appreciated the opportunities for interaction and putting ideas into practice, valuing the more practical and concrete aspects of the intervention such as Call to Mind and the DICE approach as well as the focus on their own wellbeing. Staff and facilitators felt that the intervention resulted in increased knowledge and skills in managing agitation, improved relationships with residents, increased confidence and improved team working. Intervention participants seemed to put learning into everyday practice by building in small changes, such as increased pleasant events during routine care. They found it harder to implement the more abstract intervention components such as sharing information with colleagues, and components that relied upon other people. The intervention encouraged staff to build upon existing practices and skills that they found validating and reassuring. They also valued learning from each other in a reflective space and having the opportunity to engage in active learning through practicing and trying out new skills between sessions.

A range of strategies were used to facilitate the process of intervention delivery and implementation within the care home with varying success. Facilitators felt that the supervision and troubleshooting period was the most challenging part of the intervention to deliver and that the unstructured and non-mandatory format made it less clear and tangible to care home staff. Although the barriers to putting the intervention into practice were most apparent in relation to the follow-up supervision period, throughout the intervention various contextual factors impacted upon both the delivery and uptake. These overlapped with those identified in the phase one qualitative interviews and related to the task oriented culture, lack of time and management support and ongoing conflict within the staff team.

12.2 Interpretation of findings

12.2.1 Understandings of how agitation is managed in care homes

Although the term agitation is widely used in clinical and academic settings, the term represents a 'thin description' (Geertz, 1973) and arguably does not encompass the diversity of behaviours and their underlying causes being described. My qualitative findings indicate that staff in care homes have a richer, 'thick description'; understanding behaviours labelled as agitation as multi-faceted and relational, consistent with conclusions of the MARQUE cross sectional study that agitation is not entirely explained in terms of brain pathology (Livingston et al., 2017a).

In line with the Need-driven, Dementia compromised Behaviour theory (Algase et al., 1996), staff interpreted a range of behaviours as expressions of unmet needs in those they were caring for. A potential benefit of this approach is that even if staff engage in a process of 'trial and error' and do not fully understand what is causing a particular behaviour, the process of 'sense making' encourages them to take a curious position in relation to those they are caring for. It may reinforce a sense that there are a range of behavioural responses available to them, as opposed to feeling that 'nothing can be done'. Perhaps what is absent from the staff experiences is the

opportunity to reflect systematically upon what is happening, as they are so immersed in it. This hypothesis supports the need for both structured and reflective approaches such as DICE (Kales et al., 2014). It may also explain why approaches to managing agitation that focus on communication skills (McCallion et al., 1999), structured reflection (Lichtwarck et al., 2018) and delivering individualised person-centred care (Chenoweth et al., 2009) have so far been most effective.

My qualitative findings suggest that encouraging staff to use a combination of problem solving and acceptance based coping strategies may be beneficial. The pragmatic approach adopted within the intervention to both reducing agitation directly and also to minimising the impact upon all involved, reflects this. Although not tested statistically, it was interesting to see an increase in staff use of both problem and emotion focused coping strategies, and a decrease in use of dysfunctional coping.

This concurs with epidemiological findings in family carers of people with dementia, which identified that use of more acceptance based and less dysfunctional coping strategies predicts positive outcomes for carers (Cooper et al., 2008a). The authors also found that problem and solution focussed coping strategies did not protect carers from developing symptoms of anxiety and depression one year later (Cooper et al., 2008a). This may relate to the sometimes uncontrollable and unpredictable nature of dementia and agitation, something raised by the care home staff in the qualitative study and targeted within the MARQUE intervention. It will be interesting to explore whether coping mediates paid care staff outcomes in the MARQUE RCT.

12.2.2 The relationship between personhood and agitation

In my qualitative study, interpersonal dimensions of agitation (relationships with residents and other staff) were inherent to staff accounts. Staff faced tensions in deciding how far to go along with a resident's disorientation or how to separate a person from their behaviour without undermining personhood, moving between dichotomous positions of seeing agitation as part of the person or part of the

disease. In his work on personhood and dementia, Kitwood highlighted the relational dimension of personhood as connected to both 'cared for' and 'carer' (Kitwood and Bredin, 1992). Generally, however, this has been related to how those caring for people with dementia can enhance or diminish personhood through their responses and ultimately this may result in staff being blamed or seen as the cause of problems by not being person-centred or doing a 'good enough' job.

12.2.2.1 *Acknowledging the personhood of staff*

Staff described how at times they felt powerless and frightened and this reduced their capacity to respond, although they were aware that their response could determine the outcome of an episode of agitation. These findings are consistent with existing studies where agitation in residents with dementia predicted greater distress among care staff (Zwijssen et al., 2014), which found aggressiveness, uncooperativeness and unpredictability the most difficult behaviours to manage (Brodaty et al., 2003). When 'trying not to react' in unhelpful ways, staff were balancing their own safety, the needs and safety of other residents' and those of the agitated residents.

Staff felt they were not afforded the same protection as residents and often felt blamed and under scrutiny. Ultimately, in order to promote the personhood of the residents, staff had to subjugate their own needs or had their personhoods overlooked by others (Higgs and Gilleard, 2016). This diminishing of staff personhood is likely to occur at multiple contextual levels and has been explored more fully in a secondary analysis of the qualitative interviews presented in this thesis in a paper that I have co-authored (Kadri et al., 2018).

Staff valued the focus on their own wellbeing, and ultimately having their own personhood valued in order to sustain and promote the personhood of those they are caring for. Staff appreciated having the voice of professional carers represented via the inclusion of direct quotations in the manuals and the focus on existing skills. In the context of feeling undervalued and often under critical scrutiny, this focus could have increased acceptability of the MARQUE intervention, as previous

research has reported that when staff feel their existing experience is disregarded in training, this is a barrier (Lawrence et al., 2012).

12.2.3 The impact of contextual factors on managing agitation

Maintaining a flexible and realistic approach to agitation and having a personal commitment to the role helped to prevent staff becoming overwhelmed, but was not always sustainable. The findings from my systematic review align with the qualitative findings and existing research, highlighting that good communication and interpersonal relationships within the team and with relatives enables successful management of agitation, while their absence poses significant barriers (Lawrence et al., 2016).

The impact of organisational factors upon staff wellbeing and practices in care homes is well documented. Work place dissatisfaction is associated with lack of resources, lack of management support and appreciation, negative societal attitudes and feeling unskilled (Vernooij-Dassen et al., 2009, Testad et al., 2010, Killett et al., 2013, Stanyon et al., 2016, Lawrence et al., 2016, Backhouse et al., 2016). Staffing processes, infrastructure and procedures interact in dynamic and idiosyncratic ways in different care home contexts (Killett et al., 2013) and therefore solutions to these issues need to be tailored to fit the specific context.

In my qualitative study, staff indicated that they internalised a culture of scrutiny and fear from within and outside of care homes. This sometimes prevented staff from trying new approaches to managing agitation. Staff felt that the care home sector was increasingly incompatible with an individualised approach. This fits with existing research that has found that stress in care staff is associated with psychosocial and organisational factors, particularly a sense of control, mastery and leadership, rather than the presence of agitation itself (Testad et al., 2010). This is concerning given that inappropriate treatment of people with dementia in residential and day care often occurs when staff feel unable to meet clients' needs as they wish (Sormunen et al., 2007), possibly because it results in emotional distancing in the context of more institutionalised care. This fits with our recently

published cross-sectional survey on abuse in care homes, where we found that staff reported more abusive/neglectful behaviour in homes with higher staff MBI depersonalisation scores (Cooper et al., 2018).

12.2.4 Development and delivery of MARQUE intervention

12.2.4.1 *Flexibility of delivery and fidelity to the intervention*

As noted above, we were able to engage almost the whole staff team in the intervention sessions. Being flexible in delivery, for example by offering individual catch up sessions, was beneficial and resulted in increased attendance. In the post intervention focus groups, staff described valuing this flexibility and facilitators felt it was integral to the success of the intervention. Flexibility has previously been identified as integral to successful implementation of psychosocial interventions in care homes (Lawrence et al., 2012) and to sustaining culture change more generally (Willis et al., 2016).

In developing and testing non-pharmacological interventions there is a tension between tailoring the intervention delivery to the individual context and having a manualised and therefore replicable intervention (Vernooij-Dassen and Moniz-Cook, 2014). The intervention we piloted combines a manualised approach with close attention to therapist fidelity, supervision and training with tailoring the intervention (and implementation strategies) at the level of the individual staff member and at the team and care home level, reflecting the real life care home context. The high levels of fidelity to the intervention delivery demonstrate that the manualised aspects of the intervention can be delivered as intended, however it tells us little about how the participants are engaging with the intervention and putting it into practice (Walton et al., 2017). Perhaps staff particularly valued the practical and more concrete aspects of the intervention, such as Call to Mind and DICE because these components were easier to understand and implement, not necessarily time intensive and could be built into existing practices.

12.2.4.2 *Barriers and facilitators to putting into practice*

An important objective of the MARQUE intervention is to develop an intervention which does not entirely rely upon highly trained professionals for delivery and which if clinically effective will also be cost-effective, easy to implement and scalable. Identifying at this early stage which aspects of the intervention were easiest to use, building on these and adapting those considered less tangible or useful will have potentially enhanced the intervention. Making the intervention practical, interactive and based upon staff members making small changes to their practice, potentially bypasses barriers to implementation such as not having management support or allocated time and resources, since these aspects can be delivered by individual staff members.

Certain factors were deemed to have made it harder for staff to use and continue to use the MARQUE intervention, a number of which overlapped with those identified in my systematic review, my qualitative study and other research (Colon-Emeric et al., 2016). These mainly related to a task oriented culture contributing to a lack of time, ongoing conflict within the team, lack of management support and lack of staff autonomy to make changes. I adapted the final intervention to take account of these, by giving a clearer structure to the set up and supervision period, encouraging more management buy in and by maximising the aspects of the intervention that were less dependent on these factors for success. However, ultimately, this intervention does not include explicit system wide changes or a 'comprehensive transformation strategy' (Willis et al., 2016), for example by targeting company or care home wide policy and procedures, so while the impact of these contextual factors was minimised they were not explicitly addressed at an organisational level.

12.3 Strengths and limitations

12.3.1 Qualitative study strengths and limitations

To my knowledge, this is the first qualitative study to explore how care home staff experience and respond to agitation in residents with dementia and what helps or

hinders their responses. Throughout the data collection and analytic processes I was rigorous and transparent, presenting a clear account, relevant to both clinical and research audiences (see Standards for Reporting Qualitative Research (SRQR) checklist (O'Brien et al., 2014) in Appendix 35 published with BMJ Open article (Rapaport et al., 2018)).

12.3.1.1 *Sampling strategy and context of study*

I interviewed a diverse sample of staff working in a range of care home settings in urban, suburban and semi-rural areas. Over half of those interviewed did not have English as a first language and were from black and minority ethnic groups, and I recruited staff with a range of roles and experience. Although through this sampling I accessed a breadth of viewpoints, which contributed to the richness and relevance of the analysis (Mays and Pope, 2000), we initially approached staff based upon recommendations from managers or existing relationships from an earlier phase of the MARQUE study. There is therefore probably an inherent bias in the members of staff who agreed to participate. Despite this, staff spoke both positively and negatively about their experiences of agitation and how it was managed.

Within this study, I accessed staff views on how agitation was managed rather than the views of relatives and people with dementia. Although this would have broadened the scope of the analysis, it would have been difficult to meaningfully access the perspectives of people with dementia, especially those with more severe agitation and dementia. To an extent, conducting focus groups with relatives of people with dementia who had experienced agitation living in care homes as part of our MARQUE PPI early in the research process mitigated this limitation. Relatives highlighted the centrality of relationships and communication between staff and relatives (which I subsequently built into the intervention).

12.3.1.2 *Triangulation and credibility*

I relied upon individual interviews with care home staff and did not include an observational component. Through direct observation alongside in-depth interviews, researchers can 'triangulate' data resulting in a more comprehensive

analysis (Mays and Pope, 2000). Observational approaches may be particularly useful for understanding social interactions in complex settings such as care homes (Backhouse et al., 2016). However in the present study, as is often the case in applied health research (Starks and Trinidad, 2007), we needed to produce the intervention within a relatively short time frame, so taking a more ethnographic approach was not practical.

12.3.2 Feasibility study and process evaluation strengths and limitations

MRC guidance highlights how the focus of a process evaluation varies according to when it is conducted. During an early stage it can play a role ‘in understanding the feasibility of the intervention and optimising its design and evaluation.’ (p.2) when ‘basic quantitative measures of implementation may be combined with in-depth qualitative data to provide detailed understandings of intervention functioning on a small scale’ (p.6) (Moore et al., 2015). In addition to developing and testing the intervention and demonstrating acceptability and feasibility, a strength of this phase of the study is that I have presented a detailed exploration of the processes that occurred during the intervention phase, with potential value beyond this study to inform the intervention delivery and implementation in care homes more broadly.

12.3.2.1 *Limitations to the quantitative study*

In testing the intervention in one care home, I was testing whether the intervention was deliverable as intended, how it needed to be changed, and whether it was possible to recruit and retain staff and residents at baseline and eight month follow-up so that we could conduct a full RCT. The findings are limited by recruiting a small, privately run residential home. Residents in a residential home generally have lower levels of need (as they do not require 24 hour nursing care) and staff in this context may be faced with different challenges to nursing home staff. By conducting this study in a residential home, we must remain cautious about the feasibility and acceptability of the intervention in a UK nursing home context. As I was aware of this limitation during the process of intervention development, I was mindful of

how experiences may differ in nursing homes and whether the intervention was sufficiently flexible, for example ensuring that we included examples related to residents with more severe dementia and complex needs.

A potential bias in the sample is that we relied upon the manager to provide accurate information on eligible staff. At the point of intervention delivery, we established that one eligible member of staff had been missed by the manager, despite having been working in the home for some time, highlighting the need have more stringent checking processes in place in the full RCT for example by cross checking staff lists and ensuring that all staff are accounted for.

Overall, in the study care home, the number of residents with probable dementia was lower than that reported in the MARQUE stream two study, where 86.2% of residents within participating homes had probable dementia compared to 58% in this study. Levels of agitation were also lower. In MARQUE stream two, at baseline median total CMAI scores were 41 (IQR 33, 55) and 40% of participants had clinically significant levels of agitation (Livingston et al., 2017a). In this study, the median total CMAI score was 36 (IQR 30, 39) at baseline and 12% of participants at baseline and 31% at 8 months had clinically significant levels of agitation. These differences may also reflect a reporting bias in the data collection within the study. As only three different proxy raters were involved in the study, it may be that these staff members were systematically under or over reporting agitation and with such a small sample, and therefore the overall effect of this upon the reported outcomes could be marked. This issue reflects a more general concern about relying upon proxy ratings by staff who are influenced by their own contexts and experiences (Robertson, 2017).

Overall, the sample participating in the feasibility study was small and was not designed to detect efficacy. A further limitation was that I did not include a control group and therefore the researcher collecting the baseline and follow-up data was not blinded. A randomised single blind feasibility RCT would have been a more

rigorous study design, but this was not possible within the time frame of the MARQUE programme.

12.3.2.2 *Limitations to the qualitative process evaluation*

12.3.2.2.1 Mixed membership focus groups

As I was particularly interested in the change process and intervention mechanisms of action, I chose to conduct focus groups rather than individual interviews, which provide insight into group processes and change at a team as well as an individual level (Barbour, 2007).

The focus groups included staff at all levels in the same group, including in one group, a manager and a care home director. We scheduled the focus groups in the same time slots as the intervention groups to facilitate staff attendance. Debate exists on the relative merits of conducting focus groups using pre-formed and heterogeneous groups (Freeman, 2006) and undoubtedly, the power differentials within the team will have meant that certain voices were privileged over others, particularly when many of the staff did not have English as a first language. However, participation in focus groups with mixed membership can be also empowering (Race et al., 1994). Having supervised the intervention delivery, I had some prior understanding of the group dynamics and I used my clinical skills in facilitating conversations to encourage participation and interaction and to develop trust within the focus groups. I offered all staff members the opportunity to be interviewed individually if they preferred. I conducted the focus groups prior to the supervision period in an effort to finalise the manual in time to deliver the RCT, which meant that the qualitative data did not include staff reflections on their experiences of the supervision period.

12.3.2.2.2 Lack of independent evaluation

Although my prior involvement in the project was in some ways advantageous, it was also a limitation. Ideally, rigorous process evaluation is conducted by credible, independent evaluators (Moore et al., 2015), whereas I was immersed in ensuring that the intervention was fit for purpose and invested in the overall success of

MARQUE. Although, for this reason, I did not collect the baseline and follow-up quantitative data, I did facilitate the focus groups, introducing an obvious bias into the process. I conducted the focus groups prior to the supervision period in an effort to reduce this bias, which meant that the qualitative data did not include staff reflections on their experiences of the supervision period. In being aware of my compromised position, I think I perhaps overcompensated by overly focussing on any negative experiences of the intervention. In response to this potential bias, I asked a research assistant who was new to the team and not involved in delivering the intervention to independently code the focus group transcripts and comment upon my preliminary interpretations and I engaged in a reflective process, with ongoing discussions with my supervisors during this part of the study.

12.3.3 Overall study design and process of intervention development

I drew upon the MRC framework for the development and testing of complex interventions (Craig et al., 2008) to develop and initially test the MARQUE intervention and I have used qualitative and quantitative methods and engaged in a co-production process to achieve this, taking a pragmatic approach throughout.

In co-producing the intervention I was not starting with a blank slate, but was building on an existing evidence base, in terms of what works in managing agitation and how to sustain change in care homes. I attempted at all stages in the process to balance this 'expert' knowledge and expertise with that of care home staff, a relatively marginalised group themselves, and others whose lives are affected by dementia. Since this was led by the MARQUE academic team, the co-production process was professionally dominated (Ocloo and Matthews, 2016). One way that we tried to redress this power imbalance was to build the words of the staff into the intervention, explicitly presenting their experiences alongside expert knowledge.

In drawing upon the TDM (Michie et al., 2005, French et al., 2012), I attempted to ensure that the development process was informed by specific approaches to behavioural change. This enabled me to answer questions in a systematic way, ensuring that there were specific intervention components (identified within the

qualitative study and systematic review) that mapped back onto the different theoretical domains. The TDM has been criticised for failing to focus explicitly upon specific mechanisms of behaviour change and how to choose behavioural interventions most likely to work (Michie et al., 2011). A proposed alternative that may have been useful in the present study is the COM-B Behaviour change wheel (Michie et al., 2011), which would have enabled me to link the proposed interventions more directly to the target behaviours.

12.4 Critical reflections

Undertaking this thesis has involved a number of dilemmas and tensions, heightened by completing my PhD as part of a wider programme of work, of which I was a co-applicant. Throughout this project, I have adopted different roles and positions relative to the tasks required. On the one hand, my priority was to ensure, as co-lead of the MARQUE stream three RCT, that we had a finalised and useable intervention ready for delivery. On the other hand, as a PhD student interested in developing in depth understanding of the key research areas, I wanted to take a meticulous and measured approach to developing new knowledge transferable to wider contexts. Throughout this process, I have found it useful to draw upon notions of 'methodological pragmatism' (Morgan, 2007), making decisions collaboratively and transparently, informed by what will provide the best answer to specific research questions and what approaches will be most 'workable'.

At times, it has also been challenging managing the relationships around the development and delivery of the intervention. As an experienced clinical psychologist, I was confident in training and supervising the facilitators to deliver the intervention. However, these individuals, sometimes PhD students themselves, were also my peers, resulting in blurred boundaries and complex interactions, particularly if I had any concerns around their performance, or perhaps even more, if they felt uncomfortable with any of my decisions. To manage these complexities, I used my supervisors (also my manager and colleague) as a resource and drew upon systemic approaches to consider the contexts that I was 'acting out of and into' at

any given point (Fredman et al., 2010). I moved from a 'self-reflective' to a 'relationally-reflective' (Burnham, 2005) position, weaving between different aspects of my identity as researcher, clinical psychologist, PhD student, supervisor, colleague and friend, adjusting my behaviour and communication accordingly and hopefully producing a richer and more authentic piece of research as a result.

12.5 Future directions

12.5.1 Implementation plan

One aim of the feasibility study and process evaluation of the intervention was to use the findings to inform the development of an implementation guide to accompany the final version of the intervention used in the full MARQUE RCT. This implementation guide is presented in Appendix 33 and covers the set-up period, the delivery of the training and the on-going supervision period. If the intervention is effective in the RCT, as a team, we will further refine the implementation guide and I discuss possible future routes to implementation below.

In their systematic review of implementation and dissemination in dementia care, Lourida et al (2017) used the Expert Recommendations for Implementing Change (ERIC) compilation (Waltz et al., 2015) to map existing dementia research onto nine thematic clusters made up of 73 implementation strategies. They reiterate the need for a systematic approach to implementation and highlight the increased likelihood of positive results when using multifaceted interventions targeting barriers to change and actively engaging stakeholders. Table 12.1 outlines the implementation strategies used in the initial testing phase of the intervention and retained for the full MARQUE RCT, and additional strategies to be considered for use in future implementation. In the development and feasibility testing phase of the intervention, I took a multifaceted approach to implementation, incorporating at least one strategy within each of the ERIC domains. By mapping the strategies used during these earlier stages, it has been possible to identify gaps and potential areas for future implementation.

Table 12.1: Implementation strategies used and potential future strategies

ERIC Thematic domain	ERIC Strategies adopted in MARQUE feasibility study and RCT	Potential additional ERIC strategies for future implementation
Use evaluative and iterative strategies	<ul style="list-style-type: none"> Assess for readiness and identify barriers and facilitators Purposefully re-examine the implementation Obtain and use patients/consumers and family feedback 	<ul style="list-style-type: none"> Develop and implement tools for quality monitoring Develop a formal implementation blueprint Scale up implementation gradually
Provide interactive assistance	<ul style="list-style-type: none"> Facilitation Provide clinical supervision Provide local technical assistance 	<ul style="list-style-type: none"> Centralise technical assistance
Adapt and tailor context	<ul style="list-style-type: none"> Tailor strategies Promote adaptability 	
Develop stakeholder inter-relationships	<ul style="list-style-type: none"> Identify and prepare champions Obtain formal commitments Build a coalition Inform local opinion leaders Capture and share local knowledge 	<ul style="list-style-type: none"> Organise clinician implementation team meetings Recruit, designate and train for leadership Use an implementation advisor
Train and educate stakeholders	<ul style="list-style-type: none"> Conduct ongoing training Provide ongoing consultation Develop educational materials Make training dynamic Distribute educational materials 	<ul style="list-style-type: none"> Use train the trainer strategies Conduct educational meetings Create a learning collaborative
Support clinicians	<ul style="list-style-type: none"> Remind clinicians 	<ul style="list-style-type: none"> Develop resource sharing agreements
Engage consumers	<ul style="list-style-type: none"> Involve patients/consumers and family members (in coproduction) 	<ul style="list-style-type: none"> Use mass media Involve patients/consumers
Utilise financial strategies	<ul style="list-style-type: none"> Fund and contract for the clinical innovation Make billing easier 	<ul style="list-style-type: none"> Access new funding
Change infrastructure	<ul style="list-style-type: none"> Mandate change 	<ul style="list-style-type: none"> Change record systems Create or change credentialing and/or licensure standards Change accreditation or membership requirements

ERIC= Expert Recommendations for Implementing Change

12.5.1.1 Implementation following the RCT

If the MARQUE intervention is demonstrated to be effective we will need to consider if staff within care homes can deliver the training and support the implementation of MARQUE in house, with minimal external input, by also training new staff and addressing issues of high turnover common in the sector. We could

build on our existing approach of promoting management buy in and having champions within the homes, by developing a ‘train the trainers’ model. We could upskill staff within the home to deliver the training with specialised external supervision, training and support, a model which has previously been used in the field of dementia care (Lord et al., 2017) and specifically within care home interventions (Mayrhofer et al., 2016). For this type of approach to be useful, we must also continue to address the organisational and financial barriers discussed in this thesis.

If the MARQUE intervention is clinically and cost effective, infrastructure changes, such as working to ensure that it is incorporated into professional and best practice guidelines that inform the (currently limited) professional regulation and care home certification. The intervention could become part of mandatory training within large care providers or used as a key performance indicator by commissioners. Creating additional demand by educating people with dementia and family carers on the benefits of the intervention will further contribute to ongoing implementation. Finally, a MARQUE community of practice (this could be a continuation of our existing MARQUE community of interest group), which fosters shared learning, with a coordinated yet flexible approach to implementation at a local level should be developed.

12.5.2 Future research directions

12.5.2.1 *How are changes in care delivery sustained?*

A single blind cluster RCT is in progress in twenty care homes incorporating a full clinical and cost-effectiveness evaluation. As discussed earlier, there is no evidence of psychosocial interventions in care homes having a sustained effect beyond 6 months (Jutkowitz et al., 2016, Livingston et al., 2014a). The MARQUE intervention was however, designed to maximise the potential for change in care practices and to make it fit for purpose in the UK care home sector, by incorporating intervention strategies for promoting implementation and enabling and sustaining long-term change. To demonstrate sustained changes in care practices we would need to

follow-up those care homes, staff and residents over time, but in the current MARQUE RCT, our follow-up period is only 8 months.

An important line of future research would be to establish not just whether the MARQUE intervention (if effective) has sustained effects, but also to provide an understanding of the mechanisms underpinning this change and what we can learn from this about culture change in care homes more generally. We could do this by conducting a mixed-methods study in the homes participating in the MARQUE RCT. We would quantitatively investigate whether there are any long-term benefits to staff, residents, and the care home environment and how these interact to effect change, and qualitatively explore if and how the intervention has been sustained and what impact there has been on care home, staff and management practices and processes. A limitation of my research (and the current MARQUE RCT) is the lack of direct observation of staff/resident interactions. A future study could address this by including observation based assessment such as the Quality Interactions Schedule (QUIS) (Dean et al., 1993) a structured non-participant observational measure. I am co-applicant on a submitted grant application to undertake this work (Gill Livingston is PI).

12.5.2.2 Can the intervention be adapted to other settings and populations?

In this study, I have focused on how care home staff manage and prevent agitation, since around 85% of residents with dementia will experience some symptoms of agitation (Livingston et al., 2017a). We also know that for family carers, when a relative is experiencing agitation this can be profoundly distressing and lead to feelings of hopelessness, anger and anxiety, and ultimately to the breakdown of care at home (Draper et al., 2009, Morris et al., 2015). Trials of non-pharmacological interventions to reduce agitation in people with dementia living at home have so far been unsuccessful (Livingston et al., 2014a), yet a recent qualitative study of family carers highlighted the range of strategies and personal resources that family members use in supporting relatives with dementia at home (Hoe et al., 2017). Many of these strategies overlap with the approaches described in this thesis and included in the MARQUE intervention. Future research could use the findings from

these different projects to co-produce and test an intervention designed specifically to improve care of those living with agitation at home, with the potential to improve the quality of life of people with dementia living at home, their families and to reduce care home admission.

This research has added to our understanding of how to support changes in care-delivery by staff caring for people living with dementia, and could inform future approaches in other areas of health and social care. Agitation is also common in acute hospital settings, with 75% of patients with dementia experiencing agitation (Sampson et al., 2015); however, staff in acute hospital settings are less likely to have the time and resources to build relationships with these patients in this high pressure setting. If the MARQUE intervention is effective, future research could consider how the MARQUE intervention could be adapted and streamlined for testing in an acute hospital setting. A recent systematic review identified a lack of evidence of effective approaches to paid home care delivery, particularly in caring for those living with dementia (Cooper et al., 2017a). I am deputy programme lead of The Alzheimer's Society Centre of Excellence for independence at home, a programme grant within which we will develop and test an intervention for home carers, family carers and people living with dementia to increase independence at home.

Chapter 13 Conclusions

In this PhD, I have co-produced and initially tested the MARQUE intervention, designed to reduce agitation in people living with dementia in care homes through changing care staff practices. I have considered future implementation and how to embed and sustain changes at all stages, resulting in a potentially scalable and practically useful psychosocial intervention.

Central to this thesis is the importance of engaging whole systems in both research and practice. During the co-production of the intervention, engaging stakeholders and those whose lives have been affected by dementia added to what we know from existing research and challenged our academic assumptions about what was important and would work. During the piloting of the intervention, building upon the skills and experiences of staff and using a range of strategies to engage and motivate staff at all levels was integral to maximising the reach and impact of the intervention, mitigating against some of the inevitable organisational barriers to effecting change in care homes.

In conducting in depth qualitative work, I have contributed to wider understanding of agitation experienced by those living with dementia in care homes and of how staff themselves make sense of it and respond. Conceptualising agitation in relational terms and as expression of the unmet needs of residents has utility, providing avenues for intervention via addressing these needs or adapting responses. I have also highlighted how this relates to both the personhood of those living with dementia and the staff caring for them, building on existing understandings.

I have attempted to be rigorous and methodical at all stages of the research process and ultimately, in collaboration with the MARQUE team and with clear direction from my supervisors, have delivered a feasible, replicable and acceptable intervention for testing in the MARQUE cluster RCT. The next steps largely depend on the outcome of the trial. However, together with my supervisors, I am involved

(as a co-applicant) in applying the learning acquired during this PhD to other areas of dementia care. These include: Care at home for people with dementia (NIDUS (New intervention for independence in dementia) (Alzheimer's Society funded); improving sleep for people with dementia (DREAMS (Dementia Related Manual for Sleep) START) (NIHR/HTA funded); and co-production and implementation in dementia care more broadly (Foundation laying to widen access to START) (Alzheimer's Society funded). I look forward to working on these projects and developing and leading new programmes to improve the lives of people living with dementia and those caring for them.

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BMJ Open Systematic review of the effective components of psychosocial interventions delivered by care home staff to people with dementia

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ABSTRACT

Objectives: This review aims to understand what elements of psychosocial interventions are associated with improved outcomes for people with dementia to inform implementation in care homes.

Design: A systematic review of qualitative and quantitative intervention studies was undertaken.

Eligibility criteria for included studies: We included primary research studies evaluating psychosocial interventions that trained care home staff to deliver a specific intervention or that sought to change how staff delivered care to residents with dementia and reported staff and resident qualitative or quantitative outcomes.

Methods: We searched MEDLINE, PsychINFO and EMBASE electronic databases and hand-searched references up to May 2016. Quality of included papers was rated independently by 2 authors, using operationalised checklists derived from standard criteria. We discussed discrepancies and reached consensus. We conducted a narrative synthesis of quantitative and a thematic synthesis of qualitative findings to find what was effective immediately and in sustaining change.

Results: We identified 49 papers fulfilling predetermined criteria. We found a lack of higher quality quantitative evidence that effects could be sustained after psychosocial interventions finished with no evidence that interventions continued to work after 6 months. Qualitative findings suggest that staff valued interventions focusing on getting to know, understand and connect with residents with dementia. Successful elements of interventions included interactive training, post-training support, aiming to train most staff, retaining written materials afterwards and building interventions into routine care.

Conclusions: Psychosocial interventions can improve outcomes for staff and residents with dementia in care homes; however, many trial results are limited. Synthesis of qualitative findings highlight core components of interventions that staff value and feel improve care. These findings provide useful evidence to inform the development of sustainable, effective psychosocial interventions in care homes.

Trial registration number: CRD42015017621.

Strengths and limitations of this study

- This is the first study to systematically review qualitative and quantitative studies which consider the impact of psychosocial interventions on care home staff and residents with dementia.
- By focusing on psychosocial interventions delivered either by training care staff to change their practices or interventions directly delivered by care home staff, our review informs development of sustainable interventions in 'real-world' care home settings.
- In reviewing such heterogeneous research studies, it was not possible to meta-analyse the quantitative findings.
- The qualitative papers report mainly on different interventions to those in the quantitative studies reviewed; therefore, we cannot conclude whether the intervention components staff reported as working well in qualitative studies were also associated with positive outcomes in the quantitative studies.

BACKGROUND

There are 850 000 people living with dementia in the UK and the numbers are increasing, as they are globally.¹ Around 300 000 people in the UK live in care homes, about 70% of whom have dementia.¹ Many have complex needs with high levels of neuro-psychiatric symptoms² associated with lower quality of life and higher care costs.^{3,4} Public policy calls for high quality, evidence-based psychological interventions and an 'informed and effective workforce' to support people with dementia.^{5,6} However, care home staff are often poorly trained and paid little with high staff turnover.⁷⁻⁹

Reviews considering the effectiveness of psychosocial interventions in care homes have drawn mixed conclusions, reflecting the diversity of interventions, objectives and outcomes.¹⁰⁻¹⁴ A recent systematic review of non-pharmacological management

of agitation concluded that supervised interventions which promote better communication, interaction and understanding between care home staff and people with dementia, including dementia care mapping (DCM) and person-centred care (PCC), can reduce agitation immediately and for up to 6 months afterwards.¹²

Authors of a recent review of randomised controlled trials (RCTs) of non-pharmacological interventions for agitation and aggression in dementia, which included a narrower range of study designs, reported, in contrast, that overall, neither patient-level interventions (delivered directly to residents) nor care-delivery-level interventions (targeting how or the environment in which staff deliver care) were better than usual care in managing agitation and aggression.¹⁰ They concluded that existing evidence has troubling conceptual and methodological weaknesses, and that where individual studies show significant reductions in agitation, effect sizes are unlikely to be clinically meaningful.

Overall, although some psychosocial interventions are efficacious in managing specific neuropsychiatric symptoms in care home residents with dementia,^{12–14} positive effects are not sustained^{10–12} and rely on access to highly specialist external support.¹⁵ Additionally, there is little or no evidence of efficacy of stand-alone care home staff training unless ‘reinforcing’ (eg, additional supervision or individual skills training) or ‘enabling’ (time and help to put learning into practice) strategies are incorporated.^{15–17}

To develop effective interventions for people with dementia living in care homes, we need to understand what works and how intervention effects can be sustained and embedded (ie, implementation) into practice after training. Quantitative reviews of efficacy in relation to defined outcomes can inform the former but have not until now informed the latter. Qualitative syntheses can inform implementation and translation of interventions from research into practice.¹⁸ Two existing studies have reviewed how psychosocial interventions for people with dementia in care homes have been implemented. The first (up to 2011)¹⁹ only reviewed qualitative studies, and the second (up to 2012)²⁰ reviewed the effect of the interventions on staff knowledge, attitudes and skills but not resident outcomes.

Interventions are rarely implemented in the way they were carried out in trials, and findings of overall efficacy are generally conflicting.^{10–11–15} There is thus a need to understand which intervention components work, to inform real-world implementation. We have therefore (1) reviewed the evidence in quantitative intervention studies delineating what works immediately and where there is evidence of sustained effects on outcomes for people with dementia and care staff; and (2) synthesised qualitative research exploring what intervention components were considered to have worked by care home staff and other stakeholders and to have been practicable to implement. We intend that findings will inform

the future development and implementation of sustainable psychosocial interventions.

METHODS

Search strategy

We searched MEDLINE, PsychINFO and EMBASE with no restrictions on date or language of publication on 6 June 2014 and updated the search on 20 May 2016. We used the terms ‘care home’, ‘institution’, ‘24 hour care’, ‘residential home’, ‘nursing home’, ‘assisted living residence’ or ‘long-term care’ together with ‘staff’, ‘care worker*’, ‘nursing staff’, ‘care staff’, ‘care assistant*’ or ‘paid carer*’ and ‘intervention’, ‘training’, ‘staff training’, ‘staff education’ or ‘staff training intervention*’ combined with ‘dementia’, ‘Alzheimer’ or ‘vascular dementia’. References of included papers and relevant systematic reviews were hand searched for further papers (see online supplementary appendix 1 for a full search strategy).

Inclusion criteria

We included studies that fulfilled all the following criteria:

- ▶ Primary research.
- ▶ Quantitative with a control group (either individual or cluster RCTs or pre–post test studies with control conditions) or qualitative studies.
- ▶ Evaluating psychosocial interventions without significant medical or drug care element, for example, review by pharmacists or physicians.
- ▶ *Either* interventions that trained care home staff to deliver a specific intervention *or* that sought to change how care home staff delivered care to residents with dementia.
- ▶ Reporting staff and resident outcomes.

Exclusion criteria

We excluded studies if:

- ▶ The intervention was delivered directly to older people by external health or social care professionals.
- ▶ Reporting on single-case studies and meeting abstracts.

PR read and screened titles and abstracts of studies. PR and CC independently read all retained papers. The decision to include or exclude papers was agreed by consensus.

Assessment of quality

PR, CC and AM rated the quality of papers independently, using operationalised checklists and criteria for defining higher quality studies developed by our group^{21–23} from standard quality criteria²⁴ (described in figure 1). Each quality checklist item scored 1 point; possible scores ranged from 0 to 6, with higher scores indicating better quality. We discussed discrepancies and reached consensus. For quantitative studies, we categorised papers as higher quality (ie, with a low risk of bias) if they: allocated participants to the intervention

Figure 1 Tools used to rate validity of qualitative and quantitative studies. Adapted from Mukadam *et al.*,²³ Cooper *et al.*²¹ and Lord *et al.*²²

Quality assessment tool for qualitative studies	Quality assessment tool for intervention studies
(1) Were the aims of the research clearly stated?	(1) Were participants appropriately allocated to intervention and control groups? (Was randomisation independent?)
(2) Was a clearly defined method of recruitment used and explicit inclusion/exclusion criteria described?	(2) Were patients and clinicians, as far as possible, 'masked' to treatment allocation?
(3) Was the process of data collection explained clearly? Was data collection standardised?	(3) Were all patients who entered the trial accounted for and an intention-to-treat analysis used?
(4) Did the researchers attain saturation of data?	(4) Were all participants followed up and data collected in the same way?
(5) Was the process of data analysis sufficiently rigorous, i.e. ≥2 raters, some method of resolving discrepancies?	(5) Was a power calculation carried out, based on one of our outcomes of interest?
(6) Have the findings been validated by participants?	

Criteria required for a paper to be rated higher quality are shown in bold

and control groups through independent randomisation, accounted for all participants who entered the trial and collected data and followed up participants in the same way (table 1, validity criteria 1, 3 and 4). For qualitative studies, we categorised papers as higher quality if they: used a clearly defined recruitment method, clearly stated inclusion and exclusion criteria, standardised data collection and involved two or more independent raters in data analysis (table 2, validity criteria 2, 3 and 5).

Synthesis and analysis of data

In our narrative synthesis of quantitative studies, we prioritised results from higher quality studies and findings on primary outcome measures. Results from lower quality quantitative studies are included in online supplementary table S1. As in our previous work,¹² we decided a priori to meta-analyse when there were three or more RCTs investigating sufficiently homogeneous interventions and outcomes. No intervention met these criteria. There are no commonly agreed criteria for excluding qualitative studies based on quality;^{25–28} therefore, we included all qualitative studies in our 'thematic synthesis' of qualitative findings, in line with previous similar reviews^{19–28} and accepted methods.^{26–29} PR extracted data from the qualitative papers' results sections into NVIVO 9 software and inductively coded it in an open-ended, exploratory manner. CC reviewed the data and the coding frame; differences were discussed and codes refined. We then related our descriptive themes to our question of what components of interventions were considered to have worked and to have been practical to implement.^{30–31} PR developed overarching

themes that synthesised the evidence and CC further refined emergent themes.

RESULTS

We identified 2537 unique, potentially eligible studies and included 49 relevant papers (see Prisma diagram figure 2 and online supplementary appendix 2 for the PRISMA checklist). We categorised 6 of the 27 qualitative papers and 6 of the 22 quantitative papers as higher quality. The relevant studies took place in the USA,^{32–43} Sweden,^{44–52} Australia,^{53–60} the Netherlands,^{61–67} the UK,^{68–70} Norway,^{71–74} Portugal,^{75–76} Canada,^{77–78} Ireland⁷⁹ and Germany.⁸⁰ They describe diverse interventions, including training and delivery of person-centred and relationship-focused care and DCM,^{36 37 40 43 44 52 53 55–57 59 63 66 68 72–74 78 79} training in dementia and managing difficult behaviour,^{41 42 58 60 80} communication skills and awareness training,^{32–34 38 39 62 64 69} creative and sensory interventions,^{45–47 61 65 70 71 75–77} staff supervision interventions,^{35 48–50} restraint minimisation⁵¹ and behavioural therapy interventions.⁶⁷

Findings from high-quality quantitative studies

The higher quality quantitative papers are described in table 1, and the lower quality quantitative papers are described in online supplementary table S1.

Group training interventions for care home staff with additional individual supervision

We identified one high-quality study that included individual skills training in addition to group training for

Table 1 Characteristics and quality ratings of high-quality quantitative studies

Study	Recruitment source	Group training intervention	n		Control	n		Validity criteria (see figure 1)					
			Staff	Resident		Staff	Resident	1	2	3	4	5	
McCaillon <i>et al</i> ⁶⁰	Residents with ≥ 1 problem behaviour and nursing assistants on two US nursing facilities	NA Communication Skills Programme; 5x 45 min didactic and interactive group (3–6 NAs) sessions, manual and videos; 4x 30 min individual, personalised training, practice and feedback. Individual make-up sessions offered. Monthly follow-up sessions with facilitator for 3 months. Delivered by Masters social worker	39	49	WLC crossover at 6 months (followed up at 9 months)	49	56	Y	Y	Y	Y	Y	N
Pellfolk <i>et al</i> ⁶¹	40 group-dwelling dementia units with high levels of restraint use	Restraint minimisation education. 1 person per unit attended 2 days training. 6x 30 min video lectures for all staff with units facilitating group discussion of 3 vignettes	156	149	WLC	133	139	Y	N	Y	Y	Y	Y
Cheroweth <i>et al</i> ⁵⁵ Jeon <i>et al</i> ⁶²	Staff and residents with needs-driven compromised behaviour in 15 Australian care homes using task-focused, not person-centred, care	POC—2 days of training for 2 staff/site by experienced researchers+training manuals. Trained staff supported to develop and implement resident care plans. Regular telephone contact+2 visits during intervention. DCM—2 staff at each site, trained by expert, did DCM with researchers for 6 hours/day for 2 days; developed care plans and helped staff to implement them with regular phone support	56	77	TAU	23	64	Y	Y	Y	Y	Y	Y
van de Ven <i>et al</i> ⁶³ van de Ven <i>et al</i> ⁶³	Nursing staff and residents with ≥ 1 NPS in 34 units in 11 Dutch nursing homes	Training staff to implement DCM. Managers selected 2 staff per home to train and each home had a DCM briefing day with specialists. The trained mappers then completed at least 2 DCM cycles	119	74	TAU	161	102	Y	N	Y	Y	Y	Y

CG, control group; DCM, Dementia Case Mapping; IG, intervention group; NA, nursing assistant; POC, person-centred care; TAU, treatment as usual; WLC, wait list control.

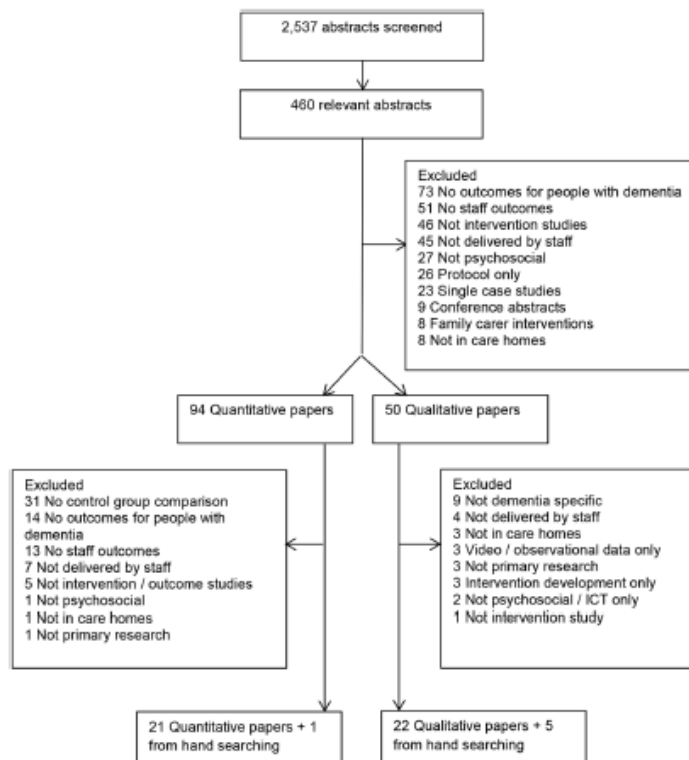
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Table 2 Characteristics and quality ratings of high-quality qualitative studies

Study	Recruitment Source	Method	N	Type of intervention	Focus of analysis/key themes	Validity criteria (see figure 1)					
						1	2	3	4	5	6
Alnes <i>et al</i> ⁷² Alnes <i>et al</i> ⁷³	Staff in 4 Norwegian dementia care units	Focus groups, semistructured interviews, analysis of recorded intervention sessions and log kept by trainer	24 staff participated in focus groups. 12 staff participated in semistructured interviews	MMC—a video-based counselling method to improve interaction skills. Staff received seven 1.5 hour weekly sessions over 2 months with an MMC trainer	Alnes <i>et al</i> —Nurses' perception of learning from MMC. 2 overall themes were staff gaining new knowledge about themselves and the residents. Alnes <i>et al</i> —Factors that impact on learning outcomes of MMC intervention. Identified: (1) Establishing a common understanding of the content and form of MMC. (2) Ensuring that staff want to participate in and have the opportunity to do so. (3) Creating an arena for discussion and interactions during and after MMC	Y	Y	Y	Y	Y	N
Figueredo <i>et al</i> ⁷⁵ Marques <i>et al</i> ⁷⁶	Day staff in 1 Portuguese long-term care home	Pilot evaluation of staff training intervention included analysis of recorded morning care and postintervention focus group	6 staff took part in training and 5 participated in the focus group	8 psychosocial-educational sessions with staff with support. Intervention included staff support, multisensory stimulation and motor stimulation. Delivered by a multidisciplinary team and included homework and handouts	Figueredo <i>et al</i> —Staff perspectives on the benefits of the programme: (1) Acquisition of new knowledge and competencies. (2) Demystification of feelings. (3) Group cohesion. (4) Self-worth feelings. (5) Positive coping strategies. Marques <i>et al</i> —The impact of motor and multisensory approach on care practices, suggestions for future programmes, and difficulties putting into practice	Y	Y	Y	Y	Y	N
Kontos <i>et al</i> ⁷⁷	Staff in 2 Canadian nursing homes	Postintervention focus groups and semistructured interviews.	14 staff participated in 2 focus groups and 10 staff were individually interviewed	12 week (2 hours each week) arts/drama informed educational intervention to improve person centred care. Used dialogue, critical reflection, role-play and dramatised vignettes	Staff perspectives on intervention. 2 main themes described: (1) Learning beyond dementia—focused on how understanding behaviour facilitated care approach to care responses were not person-centred but from success. (2) Analyzed care practices that were moderately successful and unsuccessful in multiple settings (level of difficulty in home, ward, CNA and resident levels. Presented successful studies of successful interventions and application of the	Y	Y	Y	Y	Y	N
Veraik <i>et al</i> ⁷⁷	Staff in 9 wards in Dutch nursing homes from an RCT intervention group	Semistructured interviews, questionnaire data and analysis of minutes, session reports and observations	98 CNAs were trained. 20 CNAs were interviewed including 10 most positive and 10 least positive about the intervention	Guidelines for managing depression in dementia. Included three interactive materials, three interactive team training sessions and setting up a group on each ward	Successful in multiple settings (level of difficulty in home, ward, CNA and resident levels. Presented successful studies of successful interventions and application of the	Y	Y	Y	Y	Y	N

CNS, certified nursing aides; MMC, Memory Management Counselling.

Figure 2 PRISMA diagram.



nursing assistants.³⁰ The training was designed to increase knowledge of dementia, communication and management of problem behaviours. It was tested in two US nursing homes in a crossover RCT. Resident physically aggressive behaviour in the intervention group decreased 3 months postintervention ($F=17.59$, $p<0.001$) relative to the control group, but this was not maintained at 6 months. However, verbally aggressive ($F=14.23$, $p<0.001$) and depressive symptoms ($p<0.05$) were significantly lower in the intervention group than the control group 6 months postintervention.

DCM interventions

Four papers described two high-quality RCTs^{55 56 63 66} evaluating DCM, a multicomponent, person-centred intervention. CADRES (Caring for Aged Dementia Care Resident Study)^{55 56} compared PCC and DCM with usual care in a three-arm RCT in 15 Australian care homes providing task-focused care. The DCM intervention included systematic observations of the well-being of people with dementia categorised and fed back to staff to support PCC. The mapping was completed by study experts and by trained care home staff. At the 4 month follow-up, resident agitation was lower in the

DCM (10.1, 95% CI 0.7 to 21.1; $p=0.04$) and PCC (13.6, 95% CI 3.3 to 23.9; $p=0.01$) groups compared with the intervention group. Among staff, at the 4 month follow-up on three subscales of the Maslach Burnout Inventory (MBI), emotional exhaustion was lower in the DCM group than in the PCC and control groups ($F=2.77$, $p=0.03$), but there was no significant difference in depersonalisation or personal accomplishment. In another high-quality study which tested DCM in less tightly controlled settings, with care home staff delivering more of the intervention and without recruiting task-focused homes, no significant differences were identified between the intervention and control groups on primary staff or resident outcomes.^{63 66}

Group training interventions for care home staff without additional supervision

A cluster RCT evaluated⁵¹ a restraint minimisation group training programme without additional supervision in 40 Swedish dementia units. Immediately postintervention, residents in the intervention group were restrained less than those in the control group (OR=0.35, 95% CI 0.15 to 0.83, $p=0.02$). Among staff who received the

intervention, knowledge of restraint use ($p=0.02$) and dementia ($p=0.01$) increased significantly compared with staff in the control group, but there was no difference in staff attitudes towards restraint use. Longer term outcomes were not reported.

Findings from qualitative studies

We have synthesised findings from all included qualitative papers with at least one higher quality paper contributing to each main theme, with higher quality studies contributing to more subthemes than lower quality studies. The findings from the high-quality studies are presented in table 2 and findings from lower quality qualitative papers are presented in online supplementary table S2.

What works? Beneficial components of interventions

Improving communication

Staff across diverse studies described practices that improved interaction and communication with residents with dementia.^{37 44–49 52 53 59 65 68 70–72 75 76 78 79} These included interventions that focused on: initiating 'meaningful conversation' with residents during care;^{52 53 68 75} the emotional content of interactions,^{44–48 52 68 71} touch and physical contact,^{49 52 53 71 72 78} maintaining eye contact and using simple clear instruction.^{44 47 72 76 78} In addition to improvements in their own communication, staff described positive changes in residents' responses, noticing they were more responsive, happier and more cooperative.^{45 47 52 53 79} Giving residents time and space to respond was perceived as beneficial.^{48 49 52 53 65 71 72 78} Staff observed that by taking time to understand residents' responses, residents seemed more able to make decisions and actively participate in their care. Staff who participated in singing interventions^{45–47} found themselves talking and instructing less with residents understanding and expressing themselves more effectively.

Enhanced understanding of the residents

Staff reported that interventions enhanced their understanding of the residents.^{37 44–50 52 53 57 59 61 65 67 68 70–73 75–79} They felt more able to put themselves 'in the client's shoes'⁷⁸ and empathise with people with dementia,^{48–50 52 53 57 59 68 72–75 77–79} which was intrinsically rewarding.^{48 59} Staff reflected that this extended to understanding relatives' perspectives,^{48 53 59} resulting in improved relationships between staff and relatives.^{53 59 79} Staff across a range of studies recognised the importance of getting to know the person with dementia in order to provide more individualised and 'person-centred' care.^{45 48 49 52 53 59 68 70 71 77–79} This was achieved both by engaging people with dementia in activities where they could express their individuality such as dancing, singing and sensory activity,^{45–47 70 71} and through interventions which encouraged staff through training, supervision and experiential learning to find out more about care recipients.^{48 50 53 59 68 77} Developing staff knowledge of residents facilitated their

understanding of the potential meaning of residents' behaviours, enabling them to alter their responses accordingly.^{37 44 52 53 59 68 71–73 77 79} Staff identified this as important for identifying residents' strengths and weaknesses^{48 49 53 57 59 72 75–77 79} and promoting independence when providing care.^{45–48 52 53 61 70 71 77–79}

Reflection facilitates good practice

A common process underlying improved communication and understanding is an emphasis within interventions on staff reflecting on their practices. Staff appreciated the opportunity to consider their own and residents' interactions within experiential learning,⁷⁷ interactive training,^{59 75 76} formal supervision^{48–50 71} or video feedback.^{37 41 44 46 48–50 52 71 72 75–78} This enabled them to identify patterns in their own and residents' behaviours,^{44 48 49 59 71 72} consider alternative reactions,^{44 48 49 71 72 77} and feel validated about helpful practices while recognising unhelpful practices and assumptions.^{41 59 67 76 78 79}

Barriers and facilitators: individual factors

What gets in the way?

Staff across studies described the negative impact of providing care, particularly personal care, to people with dementia on themselves and their feelings about work.^{46 49 50 52 71} When faced with resistance and verbal and physical aggression, staff described frustration and distress.^{41 46 47 49} One carer described this struggle: "I wonder how long you can do this. ... It is hard to fight every morning and only get anger back. ... What should we do, we just have to live with it, right? I hide in the laundry room to catch my breath before caring for her."⁴⁶

Staff were sometimes reluctant to engage with interventions. For some, interventions promoting emotional and physical closeness led to fears of becoming attached to residents.^{44 52 70} Staff expressed doubts about their own ability to implement interventions,^{37 44 45 49 53 61 70 73 74} either in terms of having specific skills, such as being able to sing,^{45 61} or having the confidence to take on new roles, such as approaching relatives^{37 53} or coordinating care.⁷⁴ There was initial scepticism from staff about engaging with interventions, especially if they were perceived to involve additional work, changes to existing ways of working^{45 49 53 59 65 67} or unfamiliar techniques.^{44 49 61 73} Negative responses towards interventions were more apparent when staff felt they did not accommodate the varying levels of education and experience within a team^{49 53 67 72 73} or the complex needs of those they cared for.^{52 61 67 74}

What makes it easier?

A key facilitator of staff engagement was seeing benefits for staff and residents rather than being told of potential benefits by trainers, especially when staff saw positive changes in residents.^{37 45 46 48 52 53 57 59 61 65 67 70 72 75 76 79} In numerous studies, staff observed

decreased agitation and aggressive behaviours, which they associated with the interventions.^{45 47 52 53 65 70 79} Staff identified a link between the impact of interventions on residents, and fewer difficulties providing care, a calmer and more relaxed atmosphere and improved relationships with residents and relatives.^{37 44-46 48-50 52 53 57 59 61 65 68 70 71 75-79}

Having the opportunity to reflect on and adapt practices, using active and interactive learning methods was central to a number of interventions. Staff reported that group-based activities facilitated discussion and shared learning within teams^{57 67 75} and that role-play, the use of vignettes and analysis of filmed interactions supported understanding.^{44 49 61 75 77} Access to written materials including manuals, tip-sheets and hand-outs was valued when clearly written to accommodate the educational level of the staff.^{52 57 74 75}

Barriers and facilitators: social and team factors

What gets in the way?

Lack of cooperation within teams was cited as a barrier to implementation, with staff identifying colleagues' unwillingness to help each other and poor communication as obstacles.^{45 67 76 78} Staff reported difficulties sharing new approaches with staff who had not attended training, especially those who had opted not to participate or held negative attitudes.^{44 53 59 67 73 74} Staff did not wish to be seen as telling colleagues what to do or felt that they lacked authority to do so.^{59 67 73 74} Lack of ownership of new interventions within the care team was cited as a barrier to initial implementation^{44 53 61 65 67 74 78} and maintaining positive changes after research trials.^{53 59 61} This was noted when staff felt that changes were imposed in a top-down way by managers or external professionals.^{53 67}

What makes it easier?

Participants suggested that all staff should be included in training or new interventions to promote learning and help sustain practices.^{44 52 53 59 67 73 76 78} Staff also valued the opportunity to share learning within teams.^{44 53 57 61 65 67 73-75 77} Some interventions included formal structures, such as a 'digital database' for sharing ideas,⁶¹ or structured 'consensus meetings' led by team members, while others built discussion into existing forums or had informal discussions during routine care.^{65 67 74}

Common across studies was the importance of on-site support to put skills into practice.^{53 57 61 65 67 73 75} This reinforced learning and gave staff opportunities to refine strategies and troubleshoot. Most studies included some support outside of formal training either as supervision and direct feedback on care^{37 41 44 48-50 52 61 71-76} or through on-site mentoring.^{37 53 57 59 65 67 78} Having on-site mentors trained as part of the intervention has the benefit of being sustainable postintervention but relies on committed individuals within the home who require additional support.^{37 53 59 65 67}

Barriers and facilitators: organisational factors

What gets in the way?

Lack of time was raised as a barrier across most studies in relation to finding time to attend training and supervision and put learning into practice.^{44 52 65 73 74 79}

When interventions required staff to set up additional project meetings, it was noted that these happened infrequently^{65 74} and more intensive interventions, requiring additional activities, such as detailed care plans and in-depth observation, were difficult to sustain,^{44 52 53 61 65 67 74} particularly when staff felt that research teams were unclear about the time commitment required.^{44 61} Staff identified incompatibility between their busy, pressurised shifts and interventions that required them to engage with residents at a slower pace, shifting from a task-focused to a relationship-centred approach.^{44 59 78 79} High staff turnover and low staffing ratios were also barriers. In addition to an increased workload, lack of consistency in staffing resulted in less opportunity for shared learning, less coordination within teams and less familiarity with residents.^{48 53 61 65 67 73 76 78}

Parallel change, such as organisational restructuring, new IT systems or new training initiatives were seen to hinder implementation.^{59 67 78} Although management and care home policy promoted a 'person-centred' approach, in practice staff felt that task completion remained a priority for managers and peers.^{41 44 53 59 67 70} One staff member commented: "I would rather be doing my care plans...because that is probably judged by others, whereas the project is not judged."⁵⁹ When staff felt unsupported by management, they found it difficult to prioritise new ways of working^{53 57 59 61 65 70 76} and teams were unmotivated when they felt they lacked the power to implement changes.^{67 73 74}

What makes it easier?

Staff noted that management engagement with new interventions through attending training, contributing to project meetings or arranging cover for staff participation had positive effects,^{53 65 67 73 74} but in most studies, this was not the case. Being able to build the interventions into routine care was reported as central.^{44-46 48 61 65 68 70 75 78 79} Spending time talking to residents about their interests, reminiscing, singing to them or putting on a resident's jewellery did not require additional time or resources and often made care provision more enjoyable for all.^{41 45 48 68} Sharing information via booklets left in a resident's room or in team discussions resulted in new strategies being sustained without requiring major changes to existing practices.^{48 65 68} Interventions consistent with existing approaches were valued.^{41 49 59 61 65 67 75 78 79} Benefits were reinforced when staff felt that giving more time to engage residents, rather than rushing to complete tasks, saved time overall as residents were more engaged, cooperative and less distressed.^{41 49 52 53 61 65 72 77 78}

DISCUSSION AND CONCLUSIONS

Key findings

We found a paucity of higher quality evidence that effects could be sustained after care home psychosocial interventions finished and there was no evidence that any interventions continued to work after 6 months. In one higher quality study, an individual and group programme with monthly follow-up sessions³⁹ decreased resident physical aggression after 3 months and resident depressive symptoms and verbal aggression up to 6 months later. This may relate to their inclusion of monthly top-up sessions in addition to group and individual skills training, highlighting the benefits of 'reinforcing' strategies.¹⁵ This is consistent with our qualitative findings. Staff found individualised support to put new approaches into practice and to sustain beneficial interventions. In one higher quality trial,⁵¹ training staff champions to implement a video case vignette training programme increased staff knowledge and decreased restraint use immediately; while evidence for DCM and POC was mixed, with positive findings from an Australian study^{55, 56} not replicated in a more pragmatic, real-world care home environment.^{63, 66}

The findings from the lower quality studies were consistent with our conclusions from higher quality studies. They were, however, more heterogeneous in terms of outcomes, type and intensity of interventions and study designs. Lower quality interventions offering no follow-up supervision or support demonstrated no effect on resident symptoms. Interventions which included individual skills training or supervision in addition to didactic group-based training were associated with reduced resident neuropsychiatric symptoms and improved care delivery skills among staff. In our qualitative synthesis, consistent with previous reviews,^{14, 19} we found that staff valued interventions that encouraged staff to get to know, understand and connect with residents with dementia. Interventions perceived as too intensive and complex for staff to put into practice, or as separate from rather than building on existing practices, were difficult to sustain. Staff described a number of beneficial 'enabling' practices such as having on-site mentors and opportunities to share new learning.

Implications for clinical practice

Sustaining effects of psychosocial interventions in real-world care home environments after research teams move on is challenging and rarely accomplished. Our qualitative synthesis highlighted the components and characteristics of interventions that staff considered important for achieving this. Interventions should be interactive and staff should retain materials after the groups are finished. Focusing on the benefits of the interventions for staff, residents and their relatives within training and giving staff opportunities to experience the impact of interventions by practising skills between sessions and reflecting on what works may motivate staff to continue to use and embed skills in routine care.

Interventions need to fit into day-to-day care, avoid lengthy record-keeping or intensive observations and should save more time than they take. Including management in training and holding separate sessions with management and senior staff can support implementation. Having management support to train all staff is likely to make the role of on-site mentors more achievable, increasing shared responsibility across teams.

Strengths and limitations of this review

We reviewed studies testing a broad range of interventions, using qualitative and quantitative methods. This heterogeneity meant that it was not possible to meta-analyse quantitative data. By only including quantitative studies that report outcomes for staff and residents, we have excluded high-quality RCTs that may have provided further insights into the questions being addressed. However, without considering the effects of interventions on residents and staff, it is difficult to understand how altering staff practices impacts on care home residents.

The included qualitative papers report on interventions that were largely different from those in the quantitative studies reviewed, although there was overlap in the nature of the interventions. We cannot therefore conclude whether the intervention components staff reported in qualitative studies to work well were also associated with positive outcomes in the quantitative studies. However, staff training and support interventions would only be expected to 'work' if staff or home management change practice, and managers and staff generally only adopt new ways of working if they believe they make life better for the home, the staff or the residents. Consequently, qualitative studies that ask care home staff what components of interventions improved care delivery and how, provide useful evidence in an area where many trial results have been disappointing.

Future research

Within this review, we have highlighted some of the beneficial intervention components and the potential barriers and facilitators to implementing psychosocial interventions in care homes. To fully understand what works in dementia care, studies need to report fully on the process of implementation, including full reporting on adherence and treatment fidelity, using a combination of qualitative and quantitative measures.^{81, 82} Very few of the quantitative studies gave details on attendance at sessions, how accurately staff were picking up new skills or how much staff were applying new learning or included any qualitative exploration of the process. Future RCTs in this area should consider implementation strategy from the outset and can draw on these findings to address the inherent challenges of embedding psychosocial interventions into care home settings.⁸²

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for this version to be published. PR read and screened titles and abstracts of studies and PR and CC independently read all retained papers. PR, CC and AM rated the quality of the quantitative papers and PR and CC rated the quality of the qualitative papers.

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Appendix 2 Lower quality quantitative studies

Study	Recruitment source	Group training intervention	n		Control	n		Significant differences in outcomes (Intervention group compared to control)					Validity (answers to questions 1-5)				
			staff	resident		staff	resident	Staff – immediate outcomes	Staff – longer term outcomes	Resident – immediate outcomes	Resident – longer term outcomes	1	2	3	4	5	
Borgio et al 2001; Borgio et al 2004; Borgio et al 2001	Seven Florida nursing homes	Multi component intervention: 1. 2 hour didactic training on effective communication and memory aids by Clinical Psychologist. 2. One-on-one skills training research assistants. 3. Use of memory books with residents. 4. A staff self-monitoring and supervisory feedback system. 5. Maintenance visits by project manager following intervention.	57 NAs and 23 qualified nurses	63	TAU	69	52	NAs communication skills improved PI (F(2,124) = 17.20, p = .0001) NAs used more positive statements PI (F(2,124) = 6.16, p = .004 NAs talked more PI (F(1, 64) = 5.22, p < .05)	NAs improved communication skills (F(1,27) = 12.92, p = .001) and increased use of positive statements (F(1,27) = 11.91, p = .002) were maintained at 4 month follow up	The rate of positive interactions between residents and staff increased PI (F(2, 130) = 4.81, p = .01). Residents with memory books talked more F(1, 64) = 8.96, p < .01) and perseverated less PI (F(1, 64) = 5.14, p < .05).	The increased rate of positive interactions between residents and staff was maintained at 4 month follow up (F(1,41) = 5.83, p = .02)	Y	N	N	Y	N	
Borgio et al, 2002	Residents with disturbed behaviour and staff in nine units in two US nursing homes offering 5 hours of Behavioural and communication training by a psychologist	Formal staff management behaviour supervision by trained unit supervisors.	46 Certified Nurses Assists	47	No additional supervision	39	32	At 3 month follow up staff were less likely to prompt multiple activities (F(1, 64) = 4.74, p = .05) At 6 month follow up staff announced more single activities (F(1, 56) = 6.22, p = .05), and more often delayed physical assistance following instruction (F(1,				Y	N	N	Y	N	

	Australian LTC facilities	members in 'capabilities model of dementia care'+ two staff from each intervention site trained as 'capability mentors', support and mentoring offered to staff. Training delivered by registered nurses		dent dya ds)		dent dya ds)															
Sloane et al, 2004; Hoefler et al, 2006	Nursing assistants and residents agitated during bathing in fifteen US nursing homes.	A. Person centred showering B. Person centred in bed towel bath with no rinse soap. Intervention groups crossed over at six weeks. Clinical nurse specialist or psychologist trained nursing assistants 2 days / week for 4 weeks with videotaping and live supervision.	24 (across both groups)	Group B 22	WLC	13	23	Increased use of gentleness and verbal support and in perceptions of ease in both IGS (p=0.05)*. Confidence increased in towel bath then showering group (p=0.05)*.	No long term follow up	significantly lower levels of job satisfaction than staff in the IG (F (1, 68) = 8.42, p = 0.005).	PI agitation and aggression (p=0.02)* and resident discomfort (p=0.001)* decreased and skin condition improved in both IGS (p<0.003)*. Decline in discomfort significantly greater in towel bath than showering intervention.	No long term follow up	quality of life as rated by family members on QOL-AD than residents in the IG (F (2, 92) = 3.99, p = 0.02)								
Sprangers et al, 2015	Residents with dementia and nursing aides in one Dutch Nursing home	Communication skills training + individual observation and feedback on morning care. Two training sessions provided to staff with lower baseline communication skills and one training session given to staff with higher baseline communication	24 across control and intervention group	26 across control and intervention group	TAU	N/A	N/A	Caregiver distress decreased post intervention (F (1,24)=5.20, p<0.05)	No longer term follow up			No longer term follow up									

Teriet al, 2005 (feasibility and RCT)	Day staff and residents with problem behaviours in four US assisted living facilities.	STAR, a manualised dementia-specific 2 month staff training for with two half-day group workshops and four individual sessions. Didactic and interactive. 3 meetings for managers. Delivered by clinical psychologists and then graduate students.	25	31	TAU	N/A	N/A	IG reported less impact from resident problems NPI - staff impact (Z=-2.28 p<.022), RMBPC – Staff reaction (Z=-3.47, p<0.001).	No long term follow up	Behavioural disturbance, NPI - (Z=-2.15, p=.031), RMBPC (Z =-83.85, p<.001), agitation (Z=6.75, p<.001) depression (Z=-15.99, p<.001) and anxiety (Z=-3.06, p=.002) decreased.	No long term follow up	Y	Y	Y	N	N
Wells et al, 2000	Four cognitive support units for PWD in nursing home section of US geriatric centre	5x 20-30 minute training in abilities focused morning care. Manualised, didactic and interactive. 20-30 minute reinforcement sessions fortnightly for 3 months, then monthly for 3 months.	16	20	TAU	28	20	At 6 month staff interacted with residents in more personal relevant social and flexible ways (t = -3.08, p = .005).	At 6 months resident's interactions were calmer and more positive (t = -2.07, p = .046), functioning improved (t = 2.37, p = .023) and agitation decreased (t = -2.12, p = 0.041).		Y	Y	N	Y	N	N

*T-test not shown; Bold denotes that result is on an outcome identified as primary in study; CG= control group; IG=intervention group; QOL-AD=Quality of life scale in Alzheimer's disease; QUALID=Quality of Life in Late-stage Dementia scale; PCC=Person Centred Care; RMBPC = Revised Memory and Behaviour Problems Checklist; TAU=Treatment as usual; WLC=Wait list control

** Study validity will be evaluated From Cooper et al 2014 Based on questions adapted from the Critical Appraisal Skills Programme checklist (<https://www.sph.nhs.uk/sph-files/rct%20appraisal%20tool.pdf>):

- (1) Were participants randomised to intervention and control groups?
- (2) Were patients and clinicians, as far as possible, 'masked' to treatment allocation? I have said yes if there was some attempt at blinding
- (3) Were all patients who entered the trial accounted for and an intention to treat analysis used?
- (4) Were all participants followed up and data collected in the same way?
- (5) Was a power calculation carried out based on one of our outcomes of interest?
N given for participants with data at all time points.

Appendix 3 Lower quality qualitative studies

Methodological characteristics and quality ratings of lower quality qualitative studies						
Study	Recruitment Source	Method	N	Type of intervention	Focus of analysis / Key themes	Validity*
						1 2 3 4 5 6
Brown-Wilson <i>et al.</i> (2013)	Staff in two English care homes participated in intervention. One provided follow up data.	Mixed methods practice development approach. Included questionnaires pre and post and case studies from workshops.	11 staff participated in workshops. 6 staff completed pre and 12 completed post questionnaire (2 completed both).	Facilitated workshops in relationship centred care (Senses framework).	How staff applied the Senses framework. Identified that staff felt enabled to create a sense of continuity and significance for the person with dementia.	Y N N N Y Y
Chenoweth <i>et al.</i> (2015)	Family members, care managers, nurses and carers from Australian 38 long term care facilities.	Telephone survey with relatives, semi-structured interviews and analysis of facilitator field notes and resident care plans.	Survey with 73 relatives, interviews with 29 care managers and 70 nurses and care staff.	Person Centred Care intervention delivered using a 'train the trainers' model, training 'champions' to share approach via training, supervision, care planning and handover discussion. Person centred environment intervention delivered by two experts who trained unit managers to plan and implement environmental changes.	Improvements in care practices, improvements in resident agitation and well-being and factors which enabled or impeded implementation of the interventions.	Y N Y N Y N
Cooney <i>et al.</i> (2014)	Staff, relatives and people with dementia from two public and two private Irish long term care homes.	In depth interviews.	11 residents, 5 relatives, 10 healthcare assistants, 9 nurses and 3 managers.	Reminiscence intervention – staff received structured reminiscence training and health care assistant / nurse dyads were assigned residents to complete life story and engage in four reminiscence sessions / week during 18-22 week intervention.	Core category of 'seeing me through my memories' was developed with three interrelated categories of 1. Seeing and knowing the person. 2. Reminiscence... a key. 3. Understanding and accommodating.	Y Y Y N N N
Gottell <i>et al.</i> (2012)	Staff in one Swedish special care dementia unit.	Focus groups and semi-structured interviews post intervention.	17 staff participated in intervention. 9 took part in focus groups, 2 in joint interview and 1 in individual interview.	4 week intervention of staff singing during transfer situation. Included identifying of individualised songs and training delivered by singing instructors.	Staff experiences of singing to during transfer situations. Overall theme: Reciprocally spirited movements and disposition. Four subthemes: 1. Improved mutual transfer ability; 2. Enhanced mutual verbal and nonverbal communication; 3. Caregivers' new experiences, emotions, and moods; 4. Singing can be both straightforward and challenging.	Y N N N N N
Guzman-Garcia <i>et al.</i> (2012)	Staff and people with dementia in two private English care homes.	Semi-structured interviews post intervention.	7 residents and 9 staff were interviewed.	Latin dance intervention 2x weekly 35 min sessions over 6 weeks. Led by therapist and facilitated by staff in homes.	Perceptions of the intervention and two explanatory models were developed, one for staff and one for people with dementia.	Y N Y Y N Y
Hammar <i>et al.</i> (2010a) & Hammar <i>et al.</i> (2010b)	Staff in two Swedish dementia nursing homes.	Focus groups with staff pre and post intervention.	Six care staff (3 in each home) 4 assistant nurses and 2 nurse aides.	Music intervention – Staff singing to or with people with dementia during morning care.	Hammar <i>et al.</i> (2010a) Staff perceptions of impact of intervention on residents. Pre intervention theme: Being in a different reality. Post intervention theme: Being present.	Y N Y N Y Y

Cooke <i>et al.</i> (2014)	As above	Mixed methods analysis of questionnaires and reflective diaries of facilitators.	Forty eight staff received the training with 2 facilitators /on site mentors	As above	Implementation of the CMDC. 5. Difficulty sustaining care and tensions between participants' perspectives of care.	Y	N	Y	N	N
Rosvick <i>et al.</i> (2011)	Staff in two Norwegian dementia nursing homes.	Post pilot intervention focus groups.	11 registered nurses and 12 auxiliary nurses participated in four focus groups.	Pilot implementation of the 'VIPS' practice model. Model included: Regular structured team work, supervision and training and supportive management. Staff had manual and support materials and allocated different roles within the intervention.	Five main themes: 1. Legitimacy of the model was secured when central roles were held by nurses representing the majority of the staff. 2. The model facilitated the staff's use of their knowledge of PCC. 3. Support to the persons holding the internal facilitating roles in the model was needed. 4. The authority of the leading registered nurse in the ward was crucial to support the legitimacy of the model. 5. Form of organisation seemed to be of importance in how the model was experienced.	Y	N	Y	N	Y
Soderlund <i>et al.</i> (2012)	Staff in two Swedish nursing homes in. One nursing home took part in validation intervention the other was already using method.	Semi-structured interviews.	In intervention home, 9 nurses were interviewed pre and post, 2 pre only and 3 post only. 9 nurses were interviewed in the other home.	Validation method Intervention over one year, included ten days of training with between session supervision, practical training, documentation and written test.	Compared pre and post interviews and interviews across homes. Four main themes: 1. Being attentively present in the relationship. 2. Putting oneself into the resident's world. 3. Creating a trusting atmosphere by trusting the residents and trusting one's own abilities. 4. Difficulties in using the validation method.	Y	Y	N	N	Y
Soderlund <i>et al.</i> (2014)	Staff from three wards in nursing home that received validation method	As above	12 nurses interviewed post intervention.	As above	Nurses' experiences of using the validation method. Four key themes were 1. Being under extra strain. 2. Sharing experiences. 3. Improving in confidence in care situations. 4. Feeling uncertain about continuing	Y	Y	N	N	Y
Terl <i>et al.</i> (2009)	Staff in eight assisted living facilities in three US states.	Train trainers evaluation included analysis of trainers' field notes, semi structured and questionnaires post intervention.	Three 'trainers' were trained and delivered the training in 8 sites. 40 unlicensed assistive staff and 36 leadership staff participated.	Trainers received 2 day training with follow up support. STAR delivered to staff with 1 four hour training session and 4 one hour individual sessions. Three on-site support sessions were offered to leadership.	Five main themes identified: 1. Reactions to time pressures of the job. 2. Hesitation to try new strategies. 3. Conflicts with prior training and experiences. 4. Preconceived and unhelpful notions about the "cause" of resident behaviour. 5. Lack of awareness of the impact of their own behaviours.	Y	N	N	N	N
Vatu-Guay <i>et al.</i> (2013)	Staff in 43 Canadian public	Qualitative evaluation of post	392 (94%) staff that participated in	Relationship based care training intervention included 2 days basic	Analysis presents what aspects of the intervention were most and least useful and were hardest /	Y	N	Y	N/A	Y

van Haften-van Dijk et al. (2015)	and private long term care facilities. Staff in from 21 Dutch Nursing Homes	intervention survey data. Focus groups and semi-structured interviews.	training completed the questionnaire. 12 stakeholders participated in semi-structured interviews and 35 staff participated in 5 focus groups.	training, 0.5 day coaching and 3 hr consolidation meeting. The 'Vader Method' – A living room theatre based activity to improve person centred communication. Staff 1. Observed professional actors delivering the intervention.2. Participate in a one-day training course 3. Deliver the intervention under observation and receive feedback.	easiest to integrate into care and why. Barriers and facilitators to the implementation process across existing conditions, preparation, execution and continuation phase. Organised into pre-defined theoretical framework.	Y	Y	N	Y	Y	N
Van Weert et al. (2004)	Staff in 6 Dutch nursing homes. (6/12 intervention wards in RCT).	Post intervention semi-structured interviews and follow up meeting notes analysed.	80 caregivers attended training. Interviews were with six head nurses.	Implementation of snoezelen intervention included: 4 training sessions, study group in each home, individualised care planning, in house follow up meetings over 18 months with trainers, two meetings with managers to facilitate implementation.	Analysis presents: 1. Evaluation of the training programme. 2. Process evaluation of facilitating and hindering factors. 3. Evaluation of changes in daily care at caregiver, resident and organisational level.	Y	N	Y	N	N	N

* Study validity based on questions adapted from the Critical Appraisal Skills Programme checklist (<http://www.sph.mhs.uk/sph-files/ct%20appraisal%20tool.pdf>); Adapted from Mukadam, N. et al., Int J Geriatr Psychiatry, 2011; 26: 12–20, Lord, K. et al., Int Psychogeriatrics, 2015, 27: 1301-1312.

Quality assessment tool for qualitative studies

- (1) Were the aims of the research clearly stated?
- (2) Was a clearly defined method of recruitment used and explicit inclusion/exclusion criteria described?
- (3) Was the process of data collection explained clearly? Was data collection standardised?
- (4) Did the researchers attain saturation of data?
- (5) Was the process of data analysis sufficiently rigorous, i.e. ≥2 raters, some method of resolving discrepancies?
- (6) Have the findings been validated by participants?

BMJ Open How do care home staff understand, manage and respond to agitation in people with dementia? A qualitative study

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ABSTRACT

Objectives Little is known about how care home staff understand and respond to distress in residents living with dementia labelled as agitation. The aim of this study was to describe how care home staff understand and respond to agitation and the factors that determine how it is managed.

Design We conducted a qualitative thematic analysis. **Setting** We recruited staff from six care homes in South East England including residential and nursing homes of differing sizes run by both the private and charity sector and located in urban and rural areas.

Participants We interviewed 25 care home staff using purposive sampling to include staff of either sex, differing age, ethnicity, nationality and with different roles and experience.

Results We identified four overarching themes: (1) behaviours expressing unmet need; (2) staff emotional responses to agitation; (3) understanding the individual helps and (4) constraints on staff responses. Staff struggled with the paradox of trying to connect with the personhood of residents while seeing the person as separate to and, therefore, not responsible for their behaviours. Staff often felt powerless, frightened and overwhelmed, and their responses were constrained by care home structures, processes and a culture of fear and scrutiny.

Conclusions Responding to agitation expressed by residents was not a linear process and staff faced tensions and dilemmas in deciding how to respond, especially when initial strategies were unsuccessful or when attempts to respond to residents' needs were inhibited by structural and procedural constraints in the care home. Future trials of psychosocial interventions should support staff to identify and respond to residents' unmet needs and include how staff can look after themselves.

INTRODUCTION

Over 70% of UK care home residents have dementia,¹ often with complex needs and high levels of behavioural and psychological symptoms of dementia (BPSD).² The term BPSD describes a heterogeneous range of symptoms including apathy, irritability,

Strengths and limitations of this study

- To the best of our knowledge, this is the first study to qualitatively explore how staff in care homes understand and respond to behaviours labelled as agitation in people living with dementia.
- Understanding how staff understand and manage agitation and what makes this harder or easier can inform the development of a psychosocial intervention that reflects and addresses the complexity of delivering interventions in care home settings.
- We recruited staff based on manager's recommendations or existing research team and staff relationships which may have resulted in recruitment bias.
- We conducted semistructured interviews rather than directly observing care interactions; therefore, our analysis reflects our interpretation of staff perspectives.

anxiety, depression, psychosis and agitation. As a syndrome, BPSD has been criticised as poorly defined, with authors calling for a focus on specific symptoms and targeted interventions.³ In this study, we have, therefore, focused on the most common of these symptoms, agitation.⁴ While agitation is variously defined, the term is often used to refer to a range of behaviours, including restlessness, pacing, repetitive vocalisations and verbally or physically aggressive behaviour.^{2,5} Agitation in care homes is associated with lower quality of life and higher care costs⁶⁻⁸ and is persistent and distressing.⁹

In a recent epidemiological care home study, we found that although severity of agitation was associated with severity of dementia, this was not a linear association, with 45% of those with moderate and severe dementia experiencing clinically significant levels of agitation. From this, we concluded that the agitation cannot be fully explained in terms of worsening brain pathology,⁸ reiterating the need to also conceptualise agitation in social



and psychological terms. Kitwood highlights the relational nature of personhood and outlines how negative interactions between carers and people with dementia create a 'malign social psychology' undermining personhood and resulting in unmet social and psychological needs. Conversely, interventions that address these needs and promote personhood may prevent and reduce manifestations of distress such as agitation.³⁰

Being labelled as agitated may increase the difficulties individuals with dementia face by impacting on personhood; how they are perceived, understood and responded to.^{11,12} This can have real consequences for people living with dementia in care homes, for example, by resulting in increased use of restraint^{13,14} and increased prescribing of psychotropic medications.¹⁵ Antipsychotic medication has limited effect in reducing symptoms of agitation and leads to increased morbidity and mortality in people with dementia.¹⁶ Other medications have limited efficacy and significant harmful side effects.¹⁶⁻²⁹ Evidence for non-pharmacological alternatives to manage agitation is mixed, with few interventions demonstrating effects after the intervention is completed.^{20,21}

The need-driven, dementia-compromised behaviour (NDB) theory²² proposes that behaviours in dementia, often labelled as disruptive, arise from unmet needs. Needs may be emotional (communication, comfort or contact), recreational (stimulation and enjoyable activities) and physical (pain relief, thirst, hunger or treatment of constipation or infection). Environmental limitations can prevent needs being met, when staff are unavailable, unaware or inadequately skilled in communicating and interacting with people with dementia. Care home staff often have little training and are low paid, with high staff turnover.^{23,24} Communication between staff and residents, for example, during personal care, can be dominated by instructions.²⁵

Further understanding of the relational aspects of agitation in care homes, of how staff make sense of and respond to agitation, is necessary to facilitate development of more effective and sustainable interventions. To our knowledge, this is the first qualitative study of care home staff experiences of caring for residents with dementia experiencing agitation. We aim to describe how care home staff understand and respond to agitation and the factors that determine how it is managed.

METHODS

Setting, participants and procedures

We purposively selected care homes participating in Managing Agitation and Raising QUality of Life in Dementia (MARQUE), a study involving people with dementia living in care homes⁸ interviewing staff from varied care home settings: residential and nursing, differing sizes, private and charity sector, and in urban and rural areas in Southeast England. All of the homes we approached agreed to participate. We included staff providing direct care and support to residents with

dementia, including care assistants, senior carers (who had additional responsibilities), team leaders, activities coordinators, registered nursing staff and managers. We did not interview staff in solely domestic, catering or administrative roles. We sampled purposively to ensure that we interviewed staff of either sex, differing age, ethnicity, nationality and with different roles and experience. We used a semistructured interview schedule (see online supplementary appendix 1) based on the literature, consultation with dementia family carers and research team expert opinion. Recruitment and data collection procedures are outlined in figure 1.

Patient and public involvement

People whose lives have been affected by dementia were members of the project management group and were involved in the development of the research questions for the project. To inform the development of the interview schedule, we held a focus group for family carers who had cared for a relative with agitation in a care home, discussing from their perspective, what we needed to consider in our interviews with care home staff. After completing the analysis of the data, we conducted follow-up focus groups presenting the findings and discussing how this may inform intervention development.

Data analysis

We took an inductive thematic analytical approach based on the work of Braun and Clarke.²⁶ After completing each set of interviews (in one care home), PR listened to the recordings, reflected on initial themes and revised the interview schedule to incorporate new ideas expressed by care staff, and as part of an ongoing reflective process based on both the emerging perspectives of the participants and the interviewer.²⁷ This also allowed us to check that the questions made sense to the participants, especially since over half did not speak English as a first language.

PR and one of four independent raters (OH, RT, AS and SR) systematically coded each transcript into meaningful fragments and labelled these initial codes, discrepancies were discussed and resolved.²⁸ PR, GL and CC then organised the data into preliminary themes, making connections between codes, then displaying in matrices and diagrams developing a comprehensive picture of the phenomena in question. We discussed the coding frames within the team using the constant comparison method,²⁹ identifying similarities and differences in the data and refining our account in an iterative process closely grounded in the data. We ceased interviews at thematic saturation, at the point that neither of the two researchers coding an interview identified new codes and when the authors' reflections on additional interviews resulted in no further emergent themes. PR, CC, GL and OH agreed this by consensus. We sought respondent validation by sending participants summaries of the findings, allowing them to comment on the accuracy and credibility of interpretations³⁰ (see online supplementary appendix 2). The

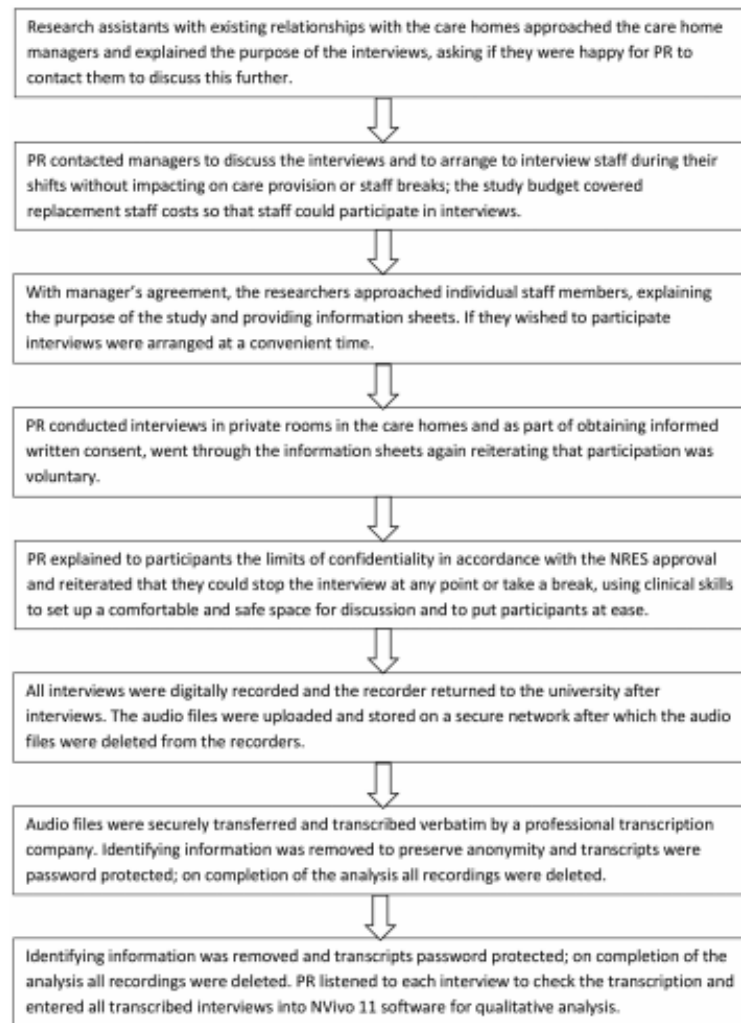


Figure 1 Outline of recruitment and data collection procedures. NRES, National Research Ethics Service; PR, Penny Rapaport.

Standards for Reporting Qualitative Research³¹ checklist is presented in online supplementary appendix 3.

RESULTS

Study participants

PR interviewed staff in six care homes in London (n=4), Kent (n=1) and Cambridge (n=1) between July 2014 and January 2015. Five homes were private and one was run

by a charity. Three were nursing homes, two residential homes and one provided residential and nursing care. [Table 1](#) summarises sociodemographic and employment characteristics of staff interviewed.

Qualitative findings

We identified four overarching themes: (1) behaviours expressing unmet need; (2) staff emotional responses to agitation; (3) understanding the individual helps and (4)



Table 1 Care staff sociodemographic and employment characteristics

Sociodemographic Category		Care staff n (%)
Gender	Female	17 (68)
	Male	8 (32)
Ethnicity	Asian or Asian British	6 (24)
	Black or black British	6 (24)
	White British	6 (24)
	White other	5 (20)
	Mixed other	2 (8)
English as first language	No	13 (52)
	Yes	11 (44)
	Not known	1 (4)
Staff role	Care assistant	9 (36)
	Senior carer	5 (20)
	Manager/deputy manager	5 (20)
	Team leader/unit manager	2 (8)
	Activities coordinator	2 (8)
	Registered general nurse	2 (8)
Shift pattern	Days	18 (72)
	Days and nights	7 (28)
Length of service	Less than 1 year	4 (16)
	1–5 years	13 (52)
	6–10 years	8 (32)
Nursing qualification	Yes	10 (40)
	No	15 (60)

constraints on staff responses. These are discussed below and presented in online supplementary appendix 4.

Behaviours expressing unmet need

Staff identified a range of behaviours as expressions of unmet emotional, physical or environmental needs. Staff experienced behaviours as persistent, unpredictable and inter-related. The behaviours most commonly described were verbal and physical aggression expressed when staff provided intimate care, such as washing, dressing or assisting a resident to the toilet.

Like when you do the personal care he just goes with you for a while and then suddenly he'll react, it's like if you are not taking care of yourself the carers can be hit or sometimes those kinds of things, he'll just smash you like that. (Team leader; Home 1)

Unmet physical need

Many staff described how residents were often unaware or unable to communicate that they were in pain or unwell.

Maybe they have pain in their legs, but they can't explain themselves. That is why I say you need patience,

because they're shouting, they don't know where the pain is. (Senior carer; Home 4)

Identifying the cause of distress involved a process of elimination and consideration of various factors such as hunger, thirst or medication. Senior staff commented that these causes may be overlooked by care staff.

Someone might be shouting out and instead of asking, are you in pain, or investigating why, you'll find a lot of, well, I'll do you a cup of tea. (Deputy manager; Home 2)

Unmet emotional need

Staff drew on knowledge of residents' past and present to understand how behaviours might arise from emotional distress. Staff conceptualised unmet emotional needs in terms of residents feeling frustrated, feeling ashamed or embarrassed during personal care and feeling insecure or abandoned. Some staff felt that physical needs were viewed as more valid or more deserving of staff responses than emotional needs, especially when working under pressure.

Unfortunately, what it comes to is you start to think to yourself, well, these people have real needs...because she wants the companionship, but, you know, we do have a hierarchy in terms of -is the person pain free, are they well hydrated, are they fed well, are they comfortable, and then maybe you can get to the social needs. (Deputy manager; Home 2)

Some staff perceived overt expressions of distress such as repeated screaming or calling out as attention seeking or intentionally demanding.

It's a bit of a game sometimes for him I think. There's a lot of play-acting getting involved. This guy probably has lot more capacity than he thinks. (Care assistant; Home 3)

Unmet environmental need

Staff described how residents may be distressed both due to a lack of interaction and under or overstimulation.

Just the whole idea of them sitting in a chair is no good. I don't like that. The brain must be stimulated, even if it is a small amount. (Care assistant; Home 3)

Like this one, who doesn't like any noise, he will stand up straightaway, like when he is having lunch, he will bang the cutlery on the table and then look at the person who is screaming. (Care assistant 2; Home 5)

Staff also believed that care home environments contributed to unmet needs.

If you walk into the lounge in a care home it isn't like your home. There isn't a sofa, there's single chairs, and who has single chairs? And something that small can make a big part on someone, especially if

someone is affectionate; they want to sit next to somebody. (Care assistant; Home 2)

A number of staff described residents feeling trapped, evoking images of imprisonment.

He finds this home that it's a prison. (Activities coordinator; Home 3)

I can open the door. I can have a walk outside. It's not for them. They are always going, either in this left corridor, or to the far end of the right one, or in the lounge, or in the dining area. That's it. Finished. (Care assistant; Home 4)

Staff emotional responses to agitation

Staff sometimes struggled to respond to residents' behaviours, especially if more than one resident was involved. They reported being unable to give space to a resident or let them express discomfort, as they wanted to minimise the impact on others.

So it can be very difficult if he shouts all night. It's not fair on them because he's disrupting somebody and they don't sleep. Alright fair enough, he's got his got his own problems but what about the other residents. (Senior carer; Home 4)

Feeling powerless and disheartened

Staff frequently described feeling powerless, especially when attempts to alleviate a resident's distress were not working, or if they could not make sense of a resident's behaviour. This was particularly so when residents displayed persistent, repetitive behaviours.

But to have someone distressed in front of you, then...someone else is getting distressed... They are looking at you to try and do something, and you can't do anything. (Deputy manager; Home 5)

At these times, staff judged themselves as not 'doing a good job' and feeling judged by others undermining their professional identity.

It can make you feel sometimes, when things aren't working, that you've failed...sometimes you do go home disarmed, because you feel that you haven't been able to do the best for that person. (Activities coordinator; Home 2)

Feeling frightened

Staff also expressed fear of being harmed. This connected to feelings of powerlessness, especially when residents hit or shouted at staff. Anticipating harm affected how staff approached and responded to residents.

They are scared. It doesn't mean they don't do it, but, you know what I mean? While you're doing things, you're not doing with all the openness and things; you do it with an 'oohf'. (Care assistant; Home 4)

Staff narrated these behaviours as 'part of the job', yet highlighted how difficult it was fearing for their own safety.

Sometimes it is quite traumatic to be slapped or to be kicked or to be scratched or...you know, it's not an easy thing to say, okay, I'll brush it off. (Deputy manager; Home 5)

Trying not to react

Although staff described resident behaviours as unintentional, they sometimes reacted in ways they regretted. They described trying not to react to aggression, the effort required to stay calm and how their immediate reactions could escalate behaviours.

It may make you react in a way that you don't want to, because you know these residents can't help their behaviours, but...you're stressed...and you may say something...you shouldn't say, or...raise your voice at a resident, which you...shouldn't do, but at that moment, you're thinking, oh, no, again. (Nurse; Home 2)

I think being calm is a big thing, and not reacting because, when you're getting smacked in the face, you know, some people's natural reaction would be to say something. (Care assistant; Home 2)

Understanding the individual helps

Staff found that having time to get to know and understand residents was critical to building trust and familiarity with residents. This helped them to understand and respond to residents' needs.

Seeing the person not the disease

Staff described what they termed a person-centred approach as getting to know the person with dementia informing their responses to distress behaviours. They talked about seeing residents as equals and imagining how they would feel in their situation. Staff drew on notions of shared humanity to describe how they maintained empathy and compassion, connecting with the personhood of individuals.

I think they should be able to come in, yes, do the personal care, but while you're doing the personal care, look at the rest of the person, not only the bit you're washing and dressing, remember that they're a human being. (Unit manager; Home 3)

However, staff also described behaviours that may be construed as socially unacceptable, like swearing or displaying aggression, as part of the dementia and separate to the person, moving between these different, arguably contradictory positions. This tension was apparent when staff tried to talk directly to residents about behaviours considered unacceptable. Seeing people with dementia as like themselves led some to feel that they might be able to control their behaviour and were, therefore, to blame for it.

We said that you have to apologise to your wife because it was not nice...swearing at her. So...maybe he realise but he say, I don't want to, I'm not going to apologise...Maybe he just doesn't remember...when he was swearing. (Care assistant; Home 5)

Connecting with previously valued identities

Knowing about a person's past and using this during care was viewed as a respectful way to calm residents.

I always like to know what did you used to do in your time. What work do you like doing, you know. All the different things really, in life. (Activities coordinator; Home 3)

Sometimes relatives facilitated this process by sharing information and explaining 'what works'. Staff often perceived behaviours as expressing distress at losing independence and spoke of supporting individuals to reconnect with what was important to them.

[It] is a way of showing your independence... So giving her the money that she can pay with, she feels that she's paid...and that...she's worthy to have that sort of thing. (Activities coordinator; Home 2)

Playing along rather than correcting

Staff struggled to know how to respond when residents were disoriented, especially when residents were unaware of the extent of their dependency. Staff at all levels talked about 'playing along' or entering their reality as better than trying to orient people.

They may not be in the here and now, but let's go back to where they are, it's very interesting when you go back to where they are...if they feel they're a teenage girl, well, okay, we talk like a teenage girl. (Care assistant; Home 2)

This was not simple and did not always have a positive effect. Staff found it hard to decide when to stop 'playing along'. They felt uncomfortable lying to residents as it could increase confusion.

While you standing arguing with someone saying, no, you're 90 and your kids are all grown up. To them they're...still at school...You wouldn't go as far as saying, oh, they've just gone to the shop. They'll be back in a minute because then that minute they could still be, well, where is she? (Deputy manager; Home 6)

Making people feel comfortable and at home

Making people feel at home involved creating a stimulating and comforting environment. Staff described trying to comfort residents, particularly more impaired residents, using music, touch and other sensory stimulation, in addition to activities led by specialist staff.

It's a 24 hours process and this is their home, they can get up when they like, as long as they eat and they

feel comfortable, that's the most important. (Senior carer; Home 5)

They talked about how touch made a big difference to residents, otherwise only touched during personal care.

I'll say to him, do you want to dance? Because he liked to dance. He'll take me really close and we'll have a little bit of a dance. (Care assistant; Home 2)

Constraints on staff responses

Procedural constraints

As noted above, getting to know the residents and delivering person-centred care and was a preferred approach, however, many acknowledged that care delivery was divided into a series of tasks, with an inherent tension between task-focused and person-focused approaches.

Changing in that [person-centred] direction is very difficult, because people start thinking, oh, if I do that, I might get told off. If I do that, then I won't be able to fill in the dishwasher by quarter past 11, or if I do this instead of that, then they're going to tell me off because I didn't take the bin, so it's all this kind of balancing act. (Deputy manager; Home 5)

Additionally, there seemed to be an implicit hierarchy of how staff should respond to residents' needs, prioritising basic needs over a need for company or interaction. Staff related this to feeling that they did not have the time to engage residents in activities, relying on activities coordinators for this.

And you might be doing an activity with someone, the guy in one of the rooms pressed the emergency... he is almost like needs one to one care so you might be rushed off to attend to him really. It really is, the activities really does demand an extra carer I think. (Care assistant; Home 3)

Structural constraints

Staff in all homes commented on financial challenges facing the sector, describing a business culture incompatible with delivering personalised care, particularly when it reduced staffing levels and therefore time. Staff also spoke about how, in a home that was part of a larger company, they felt anonymous and disconnected from the wider organisation. One staff member recalled having her glasses broken by a resident and the company refusing to pay for repair. Other staff said that minimum wage pay, antisocial shift patterns and staffing levels make it harder to maintain compassion.

Sometimes it can be challenging because if the budget doesn't meet...then the staff need to be reduced, and... The needs of the residents take second place. (Deputy manager; Home 5)

And, I think, with these big homes where there are 109, 110 beds, it's too much... It is just a conveyor belt; who's next, who's next, who's next? (Deputy

manager; Home 6)

Support and training

Staff described feeling devalued by managers and not heard or taken seriously when they raised concerns. Where they felt unappreciated by residents and relatives, appreciation by managers took on additional importance.

You don't always feel valued for the job that you're doing; it is a very difficult job. It does have an effect... on your working practise...caring for people all day and it doesn't always feel as though staff are really cared for. (Unit manager; Home 3)

In most homes staff described how they would 'keep it to ourselves', seeking support from their immediate team, assuming that managers would be unhelpful. This response was perhaps heightened by feeling that managers cannot understand their experiences as frontline carers and will not provide solutions.

Well, even if I told somebody, I don't know what they could do. What could they do? (Care assistant 2; Home 3)

Although many care staff spoke of a lack of managerial support, they (and the managers) also highlighted examples of good practice. Hands-on managers and feeling that managers had done or the job themselves left staff feeling that managers could understand their difficulties. Staff also highlighted how learning from peers and seniors through discussion and joint working enabled them to find new ways to respond.

I have had training [but] I've gone to management and they've taught me a different way to try and cope with it, I feel being there, dealing with it, doing it, is the best training. (Care assistant; Home 2)

Culture of fear and scrutiny

Staff felt that the media focused on negative aspects of care, particularly abuse and neglect. They thought media overlooked the good practice that they saw, as well as the impact, particularly of behaviours that in other contexts would be construed as abusive, from residents towards staff, eroding staff morale.

Sometimes it would be so lovely to hear a nice story about dementia, and staff, and what people do, and... You don't hear things about residents lashing out at carers. (Care assistant; Home 2)

In some cases, negative perceptions of care homes cultivated a fear of making mistakes or getting into trouble. This stifled more creative and flexible approaches to meeting residents' unmet needs. Staff felt that appearances were sometimes prioritised over minimising distress, for example, insisting a resident changed a dirty top or came out of their room.

There's the cover your back kind of fear to people... I think that translates back into the negative thing

where you don't want to try a new thing in case it hurts someone or it puts them at risk (Deputy manager; Home 2)

And they'll say, why is my mum being in bed? And, you know...obviously we tried our best and...it does annoy. We're always writing it down and just inform the Nurse so we don't get in trouble (Care assistant 2; Home 4)

DISCUSSION

Main findings

To our knowledge, this is the first qualitative study to explore how care home staff experience, understand and respond to behaviours labelled as agitation in people with dementia and what helps or hinders their responses. The findings indicate that staff in care homes understand behaviours labelled as agitation as multifaceted and relational, consistent with conclusions of the MARQUE cross-sectional study that agitation is not entirely explained in terms of brain pathology.⁸

The findings support the NDB theory with staff explaining agitation as expressions of unmet needs in residents.²² Even if staff engage in a process of trial and error and do not fully understand what is causing a particular behaviour, this process of sense making encourages them to take a curious and person-centred position in relation to those they are caring for. It may also highlight the range of behavioural responses available to them, rather than leaving staff feeling that nothing can be done; reinforcing that finding ways to address these needs by getting to know the individual can prevent or reduce agitation.¹⁰

Understanding the needs of residents was not straightforward for staff and although some staff felt that unmet physical needs could be viewed as more valid than emotional and social needs, they were also felt to be frequently overlooked. Existing research has found that pain and discomfort is underdetected in those with severe dementia in care homes and that discomfort is associated with higher levels of verbal aggression.³⁰ This is important since in the presence of behaviours perceived as aggressive, staff felt powerless and frightened, impacting on their capacity to respond to resident underlying needs. These findings are consistent with an existing study that found behaviours perceived as aggressive, uncooperative and unpredictable were felt to be most difficult to manage.³³

Staff wanted to deliver person-centred care, but struggled to do this when feeling overwhelmed, unsupported by management and unsafe or fearful. They faced tensions in deciding how far to go along with a resident's disorientation or how to separate a person from their behaviour without undermining personhood. In his work on personhood and dementia, Kitwood highlighted the relational dimension of personhood as connected to both 'cared for' and 'carer'.¹² Generally, however, this has been

related to how those caring for people with dementia can enhance or diminish personhood through their responses and ultimately this may result in staff being blamed or seen as the cause of problems by not being person centred or doing a good enough job.

The impact of structural and procedural factors on staff well-being and care practices has previously been documented qualitatively^{34–37} and quantitatively.^{24, 38} Consistent with this, staff here indicated that they internalised a culture of scrutiny and fear from within and outside of care homes. This sometimes prevented staff from trying new approaches and staff felt that the care home sector was increasingly incompatible with an individualised approach. This is concerning given that inappropriate treatment of people with dementia in residential care often occurs when staff feel unable to meet clients' needs,³⁹ possibly because it results in emotional distancing in the context of more institutionalised care. This fits with our recently published cross-sectional survey on abuse in care homes, where abusive/neglectful behaviour was more common in homes where staff experienced more burn-out and feelings of depersonalisation towards people with dementia.⁴⁰

Clinical implications

These findings have implications for the development of sustainable and practical interventions which build on approaches that staff find useful and address the practical and structural constraints discussed above. These findings reinforce the need to find ways to support staff to manage their own emotional responses and reactions when residents are agitated, as well as supporting them to reflect systematically on recognising and meeting residents' unmet needs.

Limitations

Although our sampling meant that we accessed a breadth of viewpoints, contributing to the richness of this account, we directly approached staff based on manager's recommendations or existing research team and staff relationships. There may, therefore, be an inherent recruitment bias. Staff could have felt pressured into taking part, which is why PR spent time before taking consent reiterating the voluntary nature of participation, answering any questions about the process, giving staff the opportunity to change their mind. In relying on interviews with care home staff, we present their narration of their experiences and perceptions of how they deliver care. We must be cautious not to overgeneralise our findings.

Future research

This study highlights the complex inter-relationship between notions of personhood and needs-driven behaviours labelled as agitation¹¹ building on research highlighting high skill levels required by staff expected to deliver person-centred care in care homes, and the complexity of achieving this.³⁵ Future research should explore the long-term impact of interventions designed

to reduce agitation, which incorporate this complexity, on care home culture and if and how they become embedded in care practices.

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RESEARCH ARTICLE

Relationship between speaking English as a second language and agitation in people with dementia living in care homes: Results from the MARQUE (Managing Agitation and Raising Quality of life) English national care home survey

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Objective: As not speaking English as a first language may lead to increased difficulties in communication with staff and other residents, we (1) tested our primary hypotheses that care home residents with dementia speaking English as a second language experience more agitation and overall neuropsychiatric symptoms, and (2) explored qualitatively how staff consider that residents' language, ethnicity, and culture might impact on how they manage agitation.

Methods: We interviewed staff, residents with dementia, and their family carers from 86 care homes (2014–2015) about resident's neuropsychiatric symptoms, agitation, life quality, and dementia severity. We qualitatively interviewed 25 staff.

Results: Seventy-one out of 1420 (5%) of care home residents with dementia interviewed spoke English as a second language. After controlling for dementia severity, age, and sex, and accounting for care home and staff proxy clustering, speaking English as a second language compared with as a first language was associated with significantly higher Cohen-Mansfield Agitation Inventory (adjusted difference in means 8.3, 95% confidence interval 4.1 to 12.5) and Neuropsychiatric inventory scores (4.1, 0.65 to 7.5). Staff narratives described how linguistic and culturally isolating being in a care home where no residents or staff share your culture or language could be for people with dementia, and how this sometimes caused or worsened agitation.

Conclusions: Considering a person with dementia's need to be understood when selecting a care home and developing technology resources to enable dementia-friendly translation services could be important strategies for reducing distress of people with dementia from minority ethnic groups who live in care homes.

KEYWORDS

agitation, care home, dementia

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1 | INTRODUCTION

Around 850 000 UK people live with dementia, and this is expected to be over 1 million by 2025.¹ The number of people from Black and Minority Ethnic groups (BME) with dementia in England is projected to increase 7-fold in the next 40 years.² At least two thirds of care home residents have dementia.³ People with dementia from some BME groups are less likely to move to a care home than those from the white majority population.⁴ Possible explanatory factors include expectations among family carers that services will be culturally inappropriate (in terms of language and food), and a greater sense of filial piety and obligation.⁵ Care home staff have reported challenges providing culturally appropriate care, for example appropriate diets and translation services, and in day to day communication.^{6,7} With the number of BME care home residents with dementia projected to increase due to demographic trends, it is important to consider how care homes can best provide culturally competent care.

In people with dementia, language impairment can impede functioning and effective communication, resulting in disruptive behaviour,⁸ due to unmet needs or frustration.⁹ Residents with dementia may become agitated if people use language beyond their comprehension or they are not understood when communicating.¹⁰ Language impairment may be especially challenging for people whose first language is not the local language, in whom cognitive decline can cause regression to the primary language, and loss of second language abilities.¹¹

The MARQUE (Managing Agitation and Raising Quality of life) study includes the largest ever study of care home residents with dementia, the first to compare experiences of people with dementia who do and do not speak English as a first language. As not being a native speaker may lead to difficulties communicating with staff and other residents, we tested our primary hypothesis that care home residents with dementia speaking English as a second language experienced more neuropsychiatric symptoms, including agitation than those speaking English as a first language. Our secondary hypothesis was that compared with those speaking English as a first language, care home residents with dementia speaking English as a second language had more severe dementia, because they entered care homes later in the illness due to a range of barriers to access or family structure allowing them to be supported at home. We also interviewed care home staff qualitatively to explore how they consider residents' language, ethnicity, and culture to affect how they manage agitation symptoms.

2 | METHODS

Harrow (14/LO/0034) and London (Queen's Square) (14/LO/0697) National Research Ethics Service (NRES) committees approved the quantitative and qualitative studies respectively. All staff and family carer participants gave informed consent before participating.

2.1 | Setting and sampling

We recruited care homes across England, of each provider type (voluntary, state, and private), care provision (nursing, residential), and urban/suburban and rural locations, from July 2014 to October 2015.

Key points

- The MARQUE study is the first to compare experiences of people with dementia living in care homes who speak English as a second language to those who speak English as a first language.
- People with dementia living in care homes who speak English as a second language experienced more agitation and overall neuropsychiatric symptoms than those who spoke English as a first language, after controlling for dementia severity.
- Staff narratives illustrated how linguistic and culturally isolating being in a care home where no residents or staff share their culture or language could be for people with dementia, and how this sometimes increased agitation.
- Considering a person with dementia's need to be understood when selecting a care home and developing technology resources to enable dementia-friendly translation services could be important strategies for reducing distress of people with dementia from minority ethnic groups who live in care homes.

2.2 | Procedures

We recruited homes through third sector partners, NHS trusts, Care England newsletter, and the NIHR Clinical Research Network. We divided care homes into clusters, defining clusters as units within care homes. Most units comprised 1 whole care home, but where care homes operated as distinct units with discrete staff groups (for example, residential care and nursing care units operating as distinct entities), 1 care home was considered as 2 or 3 units. If staff cross-covered between units, we defined this as 1 cluster.

We sought care home managers' agreement for their home's inclusion. In included homes, all consenting regular staff who provided hands-on care were asked to complete measures. A senior staff member identified residents with a dementia diagnosis and for others completed the Noticeable Problems Checklist¹² with care home staff to detect residents with undiagnosed probable dementia. We asked the paid carer working most closely with each resident with dementia, and their family carer if they visited at least once a month to complete proxy measures. For the qualitative interviews we purposively selected from the 86 care homes where quantitative data were collected. After initial contact with care home managers, we approached individual staff members who were involved in the day to day, "hands-on" care of participating residents to complete proxy measures. We used purposive sampling to ensure that we interviewed staff of both sexes, differing age, ethnicity, nationality, and with different roles and experience.

2.3 | Quantitative measures

Trained research assistants interviewed staff in private care home rooms. We interviewed family carers in their preferred location: the care home, their own home, or the researcher's office.

We asked managers about care home type (residential care, nursing care, or both), whether it was dementia specialist (staff had specific dementia training), and registered with regulatory authorities as providing care to people with dementia. We recorded residents' demographic information, including whether they spoke English as a second language and ethnic group; staff completed the following proxy measures:

1. The Cohen-Mansfield Agitation Inventory (CMAI) is a 29-item informant questionnaire with construct validity and reliability to measure agitation in people with dementia in care homes (32;33). Each item scores from 1 meaning "never" to 7 "several times per hour". The score sums individual items. A score of >45 is usually regarded as clinically significant agitation (34).
2. The DEMQOL proxy is a responsive, valid, and reliable interviewer-administered measure of quality of life in people with dementia (35;36).
3. Staff gave information so the researcher could rate dementia severity using the Clinical Dementia Rating (CDR) (37). This is reliable and valid (38). It is used to rate performance in Memory, Orientation, Judgment and Problem solving, Community Affairs, Home and Hobbies, and Personal Care. This information was used to classify dementia severity as very mild, mild, moderate, or severe.
4. The Neuropsychiatric Inventory (39) is a validated instrument with 12 domains of neuropsychiatric symptoms, including agitation. Each domain scores between 0 and 12 with higher scores meaning increasing severity. A summed score is calculated for total neuropsychiatric symptoms (14).

We asked relatives visiting residents at least monthly to complete the DEMQOL-proxy (36).

2.4 | Qualitative interviews

PR conducted qualitative interviews in private rooms in care homes with staff who gave written, informed consent. We developed our semi-structured interview schedule around our study aim to understand how staff managed agitation, using research literature, consultation with family carers of people with dementia, and research team expert opinion. We elicited staff perceptions using open-ended questions and revised questions iteratively, exploring issues raised. We continued interviewing until we reached theoretical saturation. Interviews were audio-recorded and transcribed verbatim.

2.5 | Analysis

We used Stata version 14 for all quantitative analyses (40). Characteristics of care homes and people with dementia are summarised using frequency (%), mean (standard deviation), or median (interquartile range) as appropriate. To investigate our hypotheses, we used random effects models to account for care home/unit clustering and clustering by paid carer, as some paid carers provided information about multiple residents in the home. We adjusted for resident's age, sex, dementia severity, and care home type (residential/nursing/both, dementia specialist, dementia registered).

We used NVivo software for qualitative data analysis and took a thematic analytic approach.⁴¹ PR and a second, independent rater (CC) systematically coded the transcripts into meaningful fragments and labelled these initial codes. Discrepancies were discussed and resolved. PR and CC then organised the data into preliminary themes. We discussed the coding frames within the team using the constant comparison method to identify similarities and differences in the data.

3 | RESULTS

3.1 | Quantitative

Eighty-six out of 114 (75.4%) of the care homes we contacted participated. Of the 28 who did not participate, 21 were nursing or mixed nursing and residential and 7 residential only. Twenty-seven declined to participate, and 1 was excluded as they were taking part in another research project. We recruited 86 care homes; 7 homes were divided into >1 cluster, totalling 18 clusters. The sample, therefore, was 97 clusters.

Seventy-one out of 1420 (5%) care home residents with dementia in our study spoke English as a second language; 37 (38%) of care home units were home to residents speaking English as a second language: 23 were home to only 1 resident, and the remainder were home to between 2 and 5 residents speaking English as a second language.

Tables 1 and 2 show the demographic, illness, and care home characteristics of residents speaking English as a first or second language, including information on missing data. As hypothesised, agitation and neuropsychiatric symptom levels were higher in those speaking English as a second language relative to those who were native speakers. After controlling for dementia severity, resident age, and sex and accounting for care home and staff proxy clustering, speaking English as a second language was associated with significantly higher CMAI (adjusted difference in means 8.3 [95% confidence interval [CI] 4.1 to 12.5] and neuropsychiatric inventory (4.1, 95% CI 0.65 to 7.5) scores compared with those who were native speakers. These results were unchanged by controlling for care home type and dementia registration or specialism (Table 2) (8.4 [95% CI 4.2 to 12.6] and 4.1 [95% CI 0.64 to 7.5], respectively). For the CMAI (standard deviation 18.3), the effect size was 0.45.

Staff rated the quality of life of people speaking English as a first and second language similarly, while there was a trend towards lower family carer proxy ratings for people speaking English as a second language (Mann Whitney *U* test $z = -1.9$, $P = 0.06$). Contrary to our hypothesis, levels of dementia severity of residents speaking English as a first or second language were very similar (Table 1).

3.2 | Qualitative

PR interviewed 25 staff in 6 care homes; London (4 homes), Kent (1 home), and Cambridge (1 home). Five of the care homes were privately run, and 1 was run by a charity. Three were nursing homes, 2 residential homes, and 1 provided residential and nursing care. Table 3 summarises staff socio-demographic and employment status.

We identified 3 main themes. These were language barriers increase resident's agitation and staff and resident's distress, difficulties in meeting residents' unmet cultural needs, and overcoming barriers—finding shared language and understanding. We illustrate these themes with quotes later.

TABLE 1 Resident demographic and illness characteristics of residents with dementia speaking English as a first or second language

		N (%) or median (IQR) in residents who did not speak English as a first language	N (%) or median (IQR) in residents who speak English as a first language
Age mean (SD)		82.7 (1.2)	85.0 (0.2)
Base population:		n = 69	n = 1327
Female sex		38 (53.5)	939 (69.6)
Base population:		n = 71	n = 1349
Ethnicity	White British/Irish	5 (7.0)	1293 (96.4)
	White other	30 (42.3)	15 (1.1)
	Asian	11 (15.5)	2 (0.2)
	Black	10 (14.1)	20 (1.5)
	Mixed/other	15 (21.1)	11 (0.8)
	Base population	n = 71	n = 1341
Dementia severity	Mild or very mild	19 (27.1)	400 (29.7)
	Moderate	22 (31.4)	444 (33.0)
	Severe	29 (41.4)	501 (37.5)
	Base population	n = 70	n = 1345
Neuropsychiatric inventory total score		14 (6,27)	9 (3,20)
Base population:		n = 69	n = 1322
Cohen-Mansfield Agitation Inventory		47 (38,61)	40 (33,54)
Base population:		n = 69	n = 1316
Staff proxy DEMQOL score		104 (95,109)	104 (95,111)
Base population:		n = 70	n = 1343
Family carer proxy DEMQOL score		96 (83,107)	102 (91,109)
Base population:		n = 49	n = 956

TABLE 2 Demographic and illness characteristics of residents speaking English as a first or second language by care home type

		N of care home units in MARQUE study	N (%) residents speaking English as second language
Care home type	Residential	12 (13%)	16 (3.0%)
	Nursing	39 (42%)	11 (5.1%)
	Both	41 (45%)	44 (6.5%)
Dementia specialist	Yes	41 (45%)	28 (4.5%)
	No	51 (55%)	43 (5.4%)
Dementia registered	Yes	81 (88%)	66 (5.1%)
	No	11 (12%)	5 (4.1%)

3.2.1 | Language barriers increase resident agitation and resident and staff distress

Several staff described how residents unable to communicate in English often became frustrated and agitated, when they could not express themselves or if they were unable to understand what was happening, for example during personal care:

Sometimes he's speaking his own language as well, which we don't understand, and he's crying, and it's difficult when we don't understand his language... you know? (Female care assistant 1, CH1)

Staff described how residents had lost their English because of the dementia and how frustrating it was when struggling to respond and reduce distress:

Because of the dementia, they tend to become like a child again, they go back to their first or their original... language. What they start saying is something that nobody understands, and that is dementia, they become

TABLE 3 Socio-demographic and employment status of staff qualitatively interviewed

Socio-demographic	Category	Care staff n (%)
Sex	Female	17 (68)
	Male	8 (32)
Ethnicity	Asian or Asian British	6 (24)
	Black or Black British	6 (24)
	White British	6 (24)
	White other	5 (20)
	Mixed other	2 (8)
English as first language	No	13 (52)
	Yes	11 (44)
	Not known	1 (4)
Staff role	Care assistant	9 (36)
	Manager/deputy manager	5 (20)
	Team leader	7 (28)
	Activities coordinator	2 (8)
	Nurse	2 (8)
Shift pattern	Days	18 (72)
	Days and nights	7 (28)
Length of service	Less than 1 year	4 (16)
	1 to 5 years	13 (52)
	6 to 10 years	8 (32)
Nursing qualification	Yes	10 (40)
	No	15 (60)

a kid, a child, and ... I go, can you just say it in English so we can know how to help you. (Male senior carer, CH1)

3.2.2 | Difficulties in meeting residents unmet cultural needs

Staff highlighted how they sometimes struggled to connect with, understand, and respond to residents' cultural needs. A care assistant described how a resident's agitation seemed to relate to an unmet spiritual need:

You know, maybe in his young age it was used to pray at this time, I don't know, and that's it, they register that in their mind. And of course, because what do we do? Do we pray with him? Sometimes, you know, I do. (Male care assistant 2, CH1)

It was sometimes unclear how well information about residents' social and cultural backgrounds was shared and used within homes:

I saw her care plan, where she worked, she was born in India, she was brought up for 35 years in Bombay, she speaks Hindi, I've never spoken to her in English, we together speak Hindi, then my manager was asking, can she speak Hindi? She was surprised. (Female senior carer, CH3)

3.2.3 | Overcoming barriers—finding shared language and understanding

Staff recounted how agitated residents became calmer and more engaged when staff fortuitously shared their language or culture, or a friend or family member visited:

...her daughter was there, ...then the menu was there, she said, I'm fed up with this food; then I asked her in the Indian language, her daughter doesn't understand because she was born here and brought up here, but her mother speaks it, then I gave her so many menu lists, ... her favourite dishes are masa dosa and pari pouri. (Female senior carer, CH3)

She tells us she knows English, but sometimes she forgets the English. She's always telling the Italian, so we don't... and she's deaf as well. Sometimes she doesn't understand what we are telling, but when [her Italian-speaking friend] comes, when she speaks in Italian, she sometimes calms down. You know, she speaks to her. (Female senior carer 2, CH2)

Finding a staff member speaking the same language could be instrumental to resolving an episode of agitation:

I just want him to calm himself down, so... and if he doesn't listen to me, There's a lady who works here, she speaks the same language as him, so it is easy for him as well to understand her, so I just call her and say, oh, can you please help? (Female care assistant 1, CH1)

Other staff explained that they would try and find creative ways to communicate, by learning a few shared words or using non-verbal approaches:

You try to talk... I mean, we ask the family the translation of the language, so we try to remember those words, language, and that's how we communicate with them. And we will rub his back and then try to calm him down. (Female care assistant, CH3)

...sometimes he points, like, you know, stomach. If you ask him, like, what's wrong with you, he will speak in his language, but he will point. (Female care assistant 1, CH1)

4 | DISCUSSION

We confirmed our primary hypothesis that care home residents with dementia speaking English as a second language experienced more agitation and neuropsychiatric symptoms than those speaking English as a first language. These differences were not because they were living in the care homes later in their illness than those speaking English as a first language, because the severity of their dementia was not greater than those who spoke English as a first language. Most of the residents speaking English as a second language had clinically significant agitation levels, and the effect size we found (0.45) suggests that the increase in agitation in this group is likely to be clinically important.

In our qualitative interviews, staff spoke of the difficulties caring for residents with dementia when they did not share a language. Where possible, they found staff or relatives with the appropriate language skills, and otherwise managed as best they could through non-verbal communication or learning a few words of the resident's language. Without a shared language, agitation was more difficult to manage and resolve. None of the staff mentioned access to professional translators, other cultural or language resources, or training they had received.

We have previously reported from the MARQUE study that agitation is associated with lower life quality.¹⁴ Family carers rated quality of life of residents speaking English as a second language lower, relative to those speaking English as a first language. For staff proxy raters, we did not find this difference. As family carers are more likely to share a language and culture with the resident compared with staff, this could indicate that staff underestimate the extent or impact of agitation where there are language or cultural barriers. We hypothesised that agitation and neuropsychiatric symptoms would be greater in people speaking English as a second language because there would be more language barriers preventing them from living well with dementia and receiving good care. Language barriers have been cited previously as a cause of reduced satisfaction with health or social care services.¹⁵

Interventions have successfully increased person-centred care in care homes, through training carers to increase the quantity and quality of their verbal communication with residents, especially around personal care (ref Bourgeois). It was clear from staff narratives that residents with dementia speaking no English, who were losing their English skills or came from minority cultural groups, were often linguistically and culturally isolated, unable to routinely communicate through a common language, unless a staff member on shift fortuitously shared their language. There is evidence that BME groups have better mental health when living in areas with higher proportions of people of the same ethnicity.¹⁶ Care homes with language or cultural specialisms are rare, but where they exist, may be less isolating and comforting for residents and their relatives. More may develop as the older English BME population increases in size. Face-to-face interpreting services are expensive and tend in our clinical experience to be reserved for appointments with health or social care professionals. Where they

are used more frequently, it is often in response to very severe agitation. Online interpreting services or other technology solutions could reduce language barriers in care homes and, together with asking families to provide staff with a few written words of basic vocabulary and training staff to understand and address unmet socio-cultural needs, may be more feasible in the current climate of austerity. Considering whether staff speak the language and planning their shifts and using local cultural as well as individual resources could improve communication for some residents.

We cannot determine causality direction: families of participants speaking English as a second language might have had a particularly high threshold for deciding care at home was untenable, and thus this group may have had high levels of agitation at care home entry. This could explain our findings as opposed to or additional to agitation arising from greater communication difficulties experienced by non-native speakers once in the care homes. We know that BME family carers are less likely to move a relative to a care home⁸ but did not find that those in the care home had more severe dementia.

MARQUE is the largest national care home survey, but our sample was not designed to be representative. We did not evaluate English language skills of residents who were non-native speakers. These probably varied. We used language rather than ethnicity as primary outcome, as fitted our hypotheses, but these are closely related (Table 1). We cannot distinguish the impact of language, ethnicity, and culture in this study.

5 | CONCLUSIONS

Care home residents with dementia who were non-native speakers experienced more agitation and neuropsychiatric symptoms than native speakers. Staff narratives described how isolating being in a care home where no residents or staff share your culture or language could be for people with dementia, and how this sometimes increased agitation. Considering a person with dementia's need to be understood when selecting a care home and developing dementia-friendly translation services could reduce distress for these residents. With numbers of BME people with dementia projected to rise, these are urgently needed.

ACKNOWLEDGEMENT

We thank the care homes, residents, family carers, and staff who took part. This study was funded by a grant from the UK Economic and Social Research Council and the National Institute of Health Research grant NIHR/ESRC ES/L001780/1. We also thank UCL Biomedical Research Centre.

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10 June 2014

Professor Gill Livingston
Professor of mental health of older people
University College London
Floor 2, Charles Bell House
63-73 Riding House Street
London
W1W 7EJ

Dear Professor Livingston

Study title: Managing Agitation and Raising QUALity of Life: Cluster RCT to decrease symptoms of agitation in people with dementia in care homes
REC reference: 14/LO/0697
Protocol number: 14/0219
IRAS project ID: 151423

Thank you for your email of 6 June 2014. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 02 June 2014

Documents received

The documents received were as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Participant consent form [RCT Care Homes]	2.0	02 June 2014
Participant information sheet (PIS) [RCT Care Homes]	2.0	02 June 2014

Approved documents

The final list of approved documentation for the study is therefore as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)	Ct currency 2013/14	29 October 2013
Interview schedules or topic guides for participants		
Non-validated questionnaire [SCIDS Form]		

Non-validated questionnaire [Cohen-Mansfield Agitation Inventory]		
Other [Letter from Funder: Award Letter]		04 November 2013
Participant consent form [Consultee Declaration Form]	1.0	31 March 2014
Participant consent form [RCT Care Staff]	1.0	31 March 2014
Participant consent form [RCT Residents]	1.0	31 March 2014
Participant consent form [RCT Care Homes]	2.0	02 June 2014
Participant consent form [RCT Relatives]	1.0	31 March 2012
Participant information sheet (PIS) [RCT Relatives]	1.0	31 March 2014
Participant information sheet (PIS) [RCT Care Staff]	1.0	31 March 2014
Participant information sheet (PIS) [RCT Consultee]	1.0	31 March 2014
Participant information sheet (PIS) [RCT Care Homes]	2.0	02 June 2014
REC Application Form		09 April 2014
Referee's report or other scientific critique report	ESRC/NIHR 1-6	
Research protocol or project proposal	1.0	31 March 2014
Summary CV for Chief Investigator (CI)	For Gill Livingston	07 April 2014
Validated questionnaire [Client Service Receipt Inventory (Care Homes)]		
Validated questionnaire [Revised_Staff_Neuropsychiatric Inventory]		
Validated questionnaire [Proxy version of the EQ-5D-5L]	2	
Validated questionnaire [Care Home Managers Measure]		
Validated questionnaire [Staff Demographics - Coping Inventory - Maslach burnout inventory]		
Validated questionnaire [NISW Checklist]		
Validated questionnaire [DEMQOL]	4	

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

14/LO/0697	Please quote this number on all correspondence
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Yours sincerely



Miss Shehnaz Ishaq
REC Manager

E-mail: nrescommittee.london-queensquare@nhs.net

Copy to: Dr Anjani Parmar,
Mrs Angela Williams, Camden & Islington/NoCLoR



University College London,
6th Floor, Maple House,
149 Tottenham Court Road,
London W1T 7NF.

Telephone: 0207 679 9467

Study to improve agitation and quality of life for people with dementia in care homes

We would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish.

Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

More than half of people with dementia living in care homes experience symptoms of agitation every month, these symptoms are associated with lower quality of life. Symptoms of agitation comprise restlessness, pacing, shouting and verbal or physical aggression. Symptoms are difficult for the person with dementia, for the family, for other residents and for the care home staff. We want to consider not only how to cope with agitation but what the difficulties might be so that we can work out how best to overcome these.

Why have I been invited?

We have approached you to take part in this study because you work in a care home and have experience of working with people with agitation and what works and what does not and what helps or hinders. We wish to speak to people from different age groups and training.

Do I have to take part?

It is up to you to decide. Please read this information sheet carefully and think about any concerns you may have. If you agree to see us or want to talk on the phone, we can discuss the study in more detail with you and answer any questions or concerns you may have. We will then ask you to sign a consent form to show you have agreed to take part and you will be given a signed copy to keep.

You are free to withdraw from the study at any time, without giving a reason. If you withdraw from the study, you can also request that we not use any of the information you may have already given us. Any stored data that can still be identified as yours will be destroyed if you wish.

What will happen to me / what will I have to do if I take part?

If you agree to participate, you will be invited to talk to a researcher in a private room in the care home and asked to sign a consent form. Any information you give us will be confidential. The researcher will ask a few questions about your age, job, ethnicity, education and where you were born. These questions



are because we want opinions from people from different backgrounds. Answering these questions will take around five minutes.

The discussion itself will last up to an hour and be tape recorded so we make sure that we do not miss anything that is said. We will ask you to think of a person with dementia (without naming them) who has been agitated and discuss the responses of people in the care home.

We will type up the discussion and send it to you. You can make comments and corrections or add things if you wish but you do not have to. We will provide a stamped addressed envelope for you to return your comments to us if you wish to. We will also ask if we can contact you in the future to ask to comment on what we have found out together from the discussions with everyone and our ideas about it.

Expenses and payments

We will provide money for the care home to cover the time taken in talking to us, so they can hire cover.

What are the possible disadvantages of taking part?

We do not foresee there being risks associated with the study. There are no right or wrong answers to the questions and you can talk about anything that you feel is relevant. It is possible that some topics discussed may be upsetting if, for example, you have looked after someone with persistent agitation. If at any time during the interview you find a topic sensitive or upsetting you can ask the interviewer to move on to another subject or leave the session altogether. If you feel upset by the interview you can speak to the researcher afterwards or ring the Admiral nurse support helpline (0845 257 9406) which is open from 11am to 8.45pm Tuesdays and Thursdays and 10am to 1pm on Saturdays.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get might help improve things for people with dementia in the future and thus also help family and paid carers who are distressed when the person they look after is agitated

Will my taking part in the study be kept confidential?

Yes. All interviews and questionnaires are confidential and anonymous so your name will not be disclosed to anyone else and neither will you be identified in any report/publication. If any person in the study tells us that they or someone else is being harmed we will ask their permission to disclose the information. We respect confidentiality but cannot keep it a secret if anyone is being seriously harmed.

Professional standards of confidentiality will be adhered to and the handling, processing, storage and destruction of data will be conducted in accordance with the Data Protection Act (1998).

Some study documents may also be looked at by authorised representatives from University College London (UCL) Research & Development Unit to check that the study is being carried out correctly. Professional standards of confidentiality will be followed by the authorised representatives.

The information you provide will only be used for the purposes for this research study and not for any other purpose.



Involvement of the General Practitioner/Family doctor (GP)

We will not need to inform your GP of your participation in this study as it will not affect your medical care in any way.

What will happen to the data collected?

All material with personal information will be kept only by researchers if in use or in a locked cabinet in UCL that can only be accessed by research staff. Transcripts of interviews will be anonymised so you cannot be identified and the information you disclose will not be discussed with anyone outside of the research team.

Transcripts and audio recordings will be kept for a period of 20 years after the study is complete, in accordance with the UCL Records Management Policy.

What if there is a problem?

If you wish to complain, or have any concerns about any aspect of the way you have been approached or treated by members of staff you may have experienced due to your participation in the research, National Health Service or UCL complaints mechanisms are available to you. Please ask your researcher if you would like more information on this.

In the unlikely event that you are harmed by taking part in this study, compensation may be available.

If you suspect that the harm is the result of the Sponsor's (University College London) or the hospital's negligence then you may be able to claim compensation. After discussing with your research please make the claim in writing to Professor Gill Livingston who is the Chief Investigator for the research and is based at Charles Bell House, 67-73 Riding House Street, London W1W 7EJ. The Chief Investigator will then pass the claim to the Sponsor's Insurers, via the Sponsor's office. You may have to bear the costs of the legal action initially, and you should consult a lawyer about this.

What will happen to the results of the research study?

We intend to publish results in relevant conference proceedings and publications and as a manual to help future carers. Please tell the researchers if you would like a copy of any publications and we would be happy to send this to you when it is published. You will not be identified in any report/publication.

Who is organising and funding the research?

The study is being organised by UCL. The study is funded by the Economic and Social Research Council and National Institute of Health Research.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given a favourable opinion by the London Queen Square Committee - National Research Ethics Service.

Contact

Please contact Hannah Savage, Trial Administrator on 020 7679 9367 for further information.

Thank you for taking the time to read this information sheet.

Appendix 8 Phase one Staff informed consent form



Charles Bell House
67-73 Riding House Street
London
W1W 7EJ

Telephone: 0207 679 9467

Managing Agitation and Raising Quality of Life: Staff interviews

Researcher(s): Prof Gill Livingston, Dr Claudia Cooper, Dr Penny Rapaport
Participant reference number for study:

Please initial in the box

	1. I confirm that I have read and understood the information sheet dated 21/03/14 (Version 1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	<input type="checkbox"/>
	2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without my legal or medical rights being affected.	<input type="checkbox"/>
	3. I agree for my interviews to be audiotaped. I understand that all material and personal information will be kept in accordance with the UCL Records Management Policy.	<input type="checkbox"/>
	4. I agree to be contacted again and asked if I would like to give an opinion about the findings and the terms use of them.	<input type="checkbox"/>
	5. I agree that I can be quoted as long as the quotes are anonymously.	<input type="checkbox"/>
	6. I understand that relevant data collected during the study, may be looked at by individuals from UCL, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to this data.	<input type="checkbox"/>
	7. I agree to take part in the above study	<input type="checkbox"/>

Name of participant (Print)	Signature of participant	Date
Name of researcher (Print)	Signature of researcher	Date

When completed: 1 copy for participant; 1 copy for researcher (IF APPLICABLE, 1 copy for medical notes)

Study to improve agitation and quality of life for people with dementia in care homes: Care worker semi-structured interview schedule

Introductions: *As you know I am a researcher from University College London and I will be conducting and recording this interview. Everything you say is confidential but I would like you to introduce yourselves for the recording so that the typist can identify you. My name is....*

Description of the research: *Thank you for agreeing to take part in this interview, I am interested in how people working in care homes think about and cope with residents with agitation; when talking about agitation we are referring to behaviours such as restlessness, pacing, shouting and verbal or physical aggression. We are asking because we know that this is something you and your colleagues manage a lot and we want to make use of your expertise. I will be asking about your experiences of working with people with agitation; about what works and what does not and what helps or hinders.*

We will use the information to help us to develop an intervention to reduce agitation in people with dementia living in care homes and we are interested in how to make the intervention something which is practical and fits with day to day work in busy care homes.

Confidentiality: *This interview is going to be audio recorded; whatever you tell me will be anonymised for the purposes of the study so you or any other individuals you mention will not be identifiable. However if you do disclose any information that you or someone else is being harmed I will ask your permission to disclose the information to my supervisor. We respect confidentiality but cannot keep it a secret if anyone is being seriously harmed.*

If at any point during the interview you feel that you need to stop or leave the room please do tell me.

Experiences of agitation:

I want you to think of a resident you know well who has been agitated. You don't need to tell me their name.

Q. *Can you tell me a bit about the person and describe their behaviour and what happened?*

- *What do you think may have caused their agitation?*
- *What do you think it means when they behave in this way?*
- *What else have you noticed in other residents when they become agitated?*

(Prompt: If there is nothing much to say about this resident ask them to think of someone else)

Managing agitation:

Q. *When you think about the person and situation you were just describing, how did you manage the situation?*

- *What was tried?*
- *What worked well?*
- *What did not work well?*
- *What did you feel able to do at the time?*
- *What did you notice other people doing?*
- *Tell me about good ways of communication with people like this?*
- *How do decisions get made about what to do?*
- *What else have you seen work well in other situations?*

- How do you think _____ would make a difference (pain control, talking, sensory stimulation, music, activities, more communication)
- What would stop them working? What would make them work?

Barriers and facilitators

Q. What makes it easier for you to manage agitation in residents?

- What is it about you?
- What is it about your role?
- What is it about the residents / their families?
- What is it about your team?
- What is it about your managers?
- What is it about your organisation / employer?
- What is it about the media e.g. TV and newspapers?

Q. What makes it harder for you to manage agitation in residents?

- What is it about you?
- What is it about your role?
- What is it about the residents / their families?
- What is it about your team?
- What is it about your managers?
- What is it about your organisation / employer?
- What is it about the media e.g. TV and newspapers?

Impact of agitation

Q. What impact does resident's agitated behaviour have upon staff?

- What effect does it have on how you feel at work?
- What effect does it have upon what you feel able to do?
- How does it affect your team?

Support

Q. When it is difficult, do staff get support?

- Do you feel you can ask for help when you need it?
- What sort of support do you find helpful? Who from?
- How do you and your colleagues support each other?
- What gets in the way of asking for support?

Training

Q. What training have you had to help you to manage when residents become agitated?

(If they can think of training):

- What was most useful?
- What was least useful?

If they cannot think of past training):

Q. What training do you think would help you to feel more able to manage agitation?

- What do you think would help you to put what you learn into practice?
- What would make it harder to put what you learn into practice?

(Prompt re self, role, team, managerial, organisational factors)

Other

Q. Before we finish, is there anything else you would like to mention that we have not already covered?

Would you be willing to give us feedback about any materials we may develop in future?

Thank you for taking part today.

What works in practice? How do care home staff understand and manage agitation in people with dementia

We are writing to you because you were interviewed by us some time ago about your experiences of caring for residents with dementia who experience agitation. We wanted to thank you again for taking part in our study and also to send you a summary of what we found out.

We interviewed 25 members of staff in six different care homes about what happens when residents become agitated, how you as staff manage and respond, and what makes it harder or easier to manage.

We have used what you and the other staff we interviewed told us about what works to develop a staff training intervention which we are currently testing in ten care homes, to see if it helps staff when residents become agitated. We have tried to address some of the things that staff told us makes it harder to manage agitation and have included some of the ideas about what can make it easier.

What agitated behaviours did staff experience?

Staff told us that they were coping with a range of agitated behaviours, the most common ones were verbal and physical aggression, like hitting or pinching (especially during personal care), screaming and getting upset, and repetitive behaviours like wandering up and down or repeating words.

Many staff members told us that these behaviours were often quite extreme, could get worse very quickly, were hard to predict and could last a long time. Staff also told us that agitation was different for different each person and 'no two residents are the same'.

How did agitation make staff feel?

Many staff said it could be difficult when residents become agitated, especially if it involves more than one resident. Staff sometimes felt frightened, especially when residents were aggressive. When nothing seemed to help, staff felt hopeless and like they did not have power to make things better. Some staff talked about how even though they tried to stay calm and not react badly, sometimes they felt angry or upset when residents were very agitated.

What did staff feel caused agitation?

Staff described how although it can sometimes feel like a 'guessing game' when trying to work out why someone is agitated, there were often a number of possible reasons for what may be triggering agitation. These included:

- Agitation as a sign of being upset
- Agitation as a sign of physical pain or discomfort
- Agitation as caused by how other people react
- Agitation as caused by the persons surroundings e.g. too hot, noisy, boring
- Agitation as caused by the dementia itself

What helps staff to prevent agitation from happening?

All the staff we spoke to said it was important to get to know the individuals in their care and build trust with the residents. There were three main things that staff said helped them to get to know residents and prevented the residents from becoming agitated. These were:

1. Seeing the person and not the disease

*Well, I think they should be able to come in, yes, do the personal care, but while you're doing the personal care, look at the rest of the person, not only the bit you're washing and dressing, remember that they're a human being, remember that they've lived a life.
(Unit manager)*

2. Connecting with previously valued identities

Well, I always like to know what did you used to do in your time. What work do you like doing, you know. All the different things, really, in life... (Activities coordinator)

3. Playing along rather than correcting

While you standing arguing with someone saying, no, you're 90 and your kids are all grown up, to them they're not. They're still at school. They need help so we just say to them... so just go in their reality with them. If they're looking for their kids, the kids are at school. They're all right. (Deputy Manager)

4. Making people feel comfortable and at home

It's a 24 hour process and this is their home, they can get up when they like, as long as they eat and they feel comfortable, that's the most important. (Senior carer)

How do staff respond when residents are agitated?

Staff described the strategies they used when residents were agitated and how they tried to be flexible and use 'trial and error':

There's no hard and fast rules, it's just really sort of trying to read the situation really. (Care assistant)

Popular strategies included:

- Distracting and reassuring residents
- Giving agitated residents space
- Walking away

When these approaches did not work, staff would ask for help from senior colleagues and would sometimes get help from specialists outside of the care home. Some staff felt medication could help but said that often it had side effects and should only be used as a last resort.

What makes it harder or easier for staff to manage when residents are agitated?

1. Having the right approach makes it easier:

Staff described that being motivated, compassionate and caring, as well as recognising that you can only do your best, made it easier to do the job. They often compared this to feeling that some staff are 'only in it for the money'.

And what else gives us hope through the day? ...I love my job, very much, and there is no explanation for that. You either have that or not. I could have done retail... I go through the day because I feel sorry for these people, simple as that. I... and I want to instinctively make it better. (Care assistant)

2. Communication is key:

Staff saw clear communication between team members as important. To respond well to agitation, staff needed to feel that they were not on their own and that colleagues would help if needed. Staff also said that building a good relationship with the families of residents was very important.

You do sometimes ... think to yourself, I don't know if I can cope with this today but then... you take five minutes, you have a chat with one of the other carers and then we sort it out. (Care assistant)

3. Task focused vs person centred care:

Staff talked about not having enough time to spend with residents because of the staffing levels or because of all of the different jobs and tasks that they were expected to do during each shift. Staff said that they liked having 'hands on' managers who were approachable and that when they did not feel supported by management they would tend to just try and sort out problems themselves. Staff found it helpful to have good quality training but also said that learning on the job and from each other was very important.

I have had training [but] I've gone to management and they've taught me a different way to try and cope with it, I feel being there, dealing with it, doing it, is the best training. (Care assistant)

4. The care home industry makes it harder:

Staff talked about how television and newspapers always seem to focus on negative aspects of care, especially abuse and neglect, ignoring the good work that they saw happening and the impact of aggression from residents towards staff. This meant that families were more worried about their relatives living in a care home and staff felt this made them more worried about making mistakes or getting into trouble at work.

Sometimes it would be so lovely to hear a nice story about dementia, and staff, and what people do, and ... you don't hear things about residents lashing out at carers. (Care assistant)

Staff in all types of home talked about some of the financial problems in care homes and how they felt that focusing on business and profit made it harder for them to meet the needs of individuals.

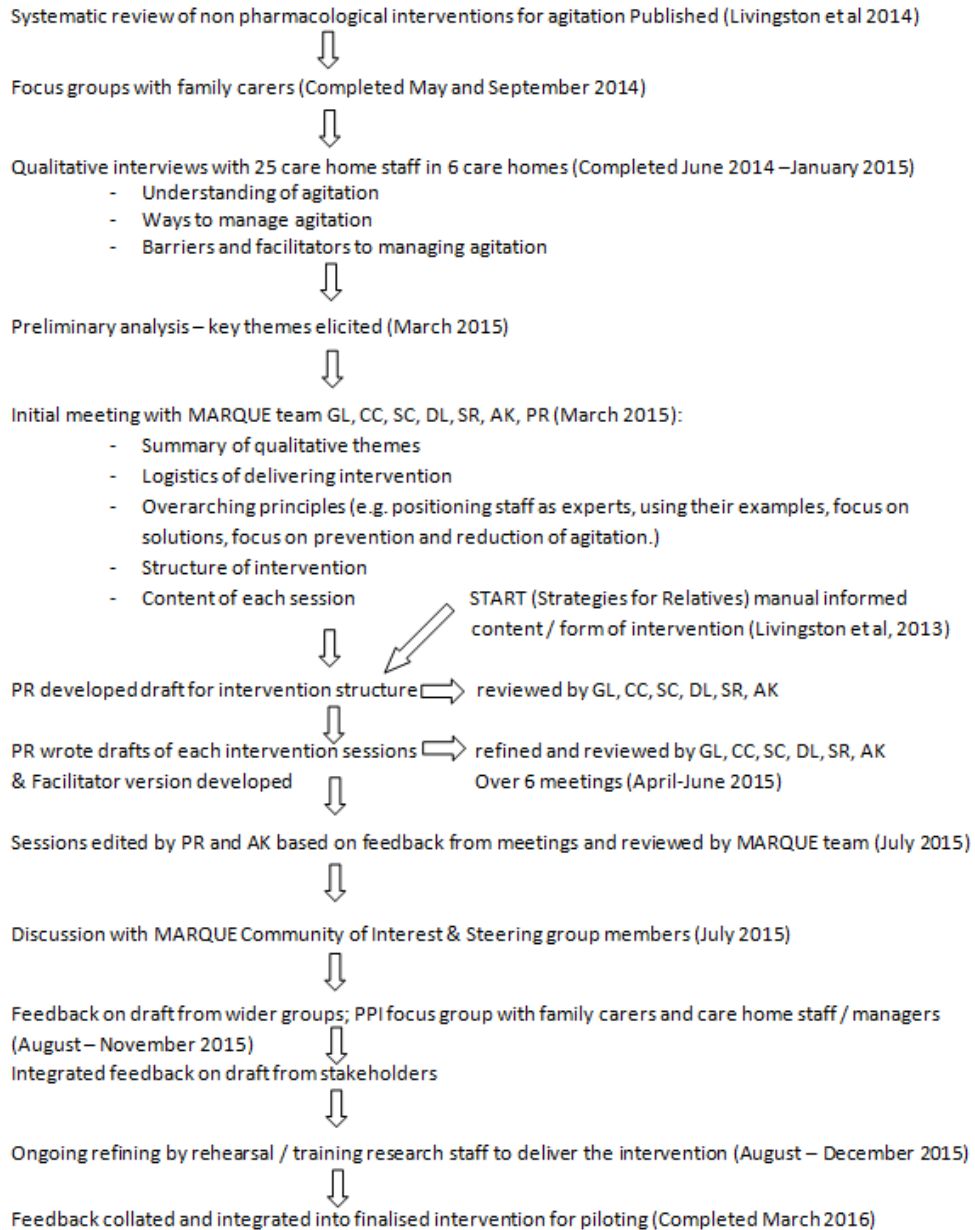
Sometimes it can be challenging because if the budget doesn't meet ... then the staff need to be reduced, and ... the needs of the residents take second place. (Deputy Manager)

We would like to thank you again for taking part. We are also in the process of writing an article based on these findings so that a wide range of health and social care professionals will be able to learn from it.

If you have any thoughts or comments on this summary we would really appreciate your feedback. We are interested in hearing if you feel there is anything missing from this summary and whether it fits well or does not fit with your own experiences. You can either email xxx or write using the enclosed stamped addressed envelope.

Appendix 11 Detailed timeline of intervention development process

MARQUE stream three Intervention development process



Data collection began January 2016 and intervention delivery began April 2016

**Study to improve agitation and quality of life for people with dementia in care homes:
Feedback on intervention manual for care home staff**

Introductions: Thank you for agreeing to take part in this interview. As you know I am a researcher from University College London and I will be conducting and recording this interview. Everything you say is confidential but I would like you to introduce yourselves for the recording so that the typist can identify you. My name is....

Description of the research: "We have developed this manual which, over the next year, we are going to be testing out in a number of care homes as part of a randomised controlled trial. The intervention will be delivered to groups of staff in care homes over six sessions, and we hope that it will help staff to prevent and cope with agitation and lead to improvement in quality of life for people with dementia. The intervention is based on what we know works from research and practice and from talking to staff and managers in care homes about how they manage agitation and what is possible.

Before we finalise the intervention, we want to get feedback from managers and staff in care homes about what we have developed, and then make further changes to the intervention manual. We are asking you because we know that you work in a care home and agitation is something you and your colleagues manage a lot and we want to make use of your expertise.

We are particularly interested in how to make the intervention something which is practical and fits with day to day work in busy care homes.

Introduce the manual: *Show them the manual and present an overall summary:*

- Staff will receive their own copy of the manual to write in and keep.
- There will be tasks to practice between sessions.
- There will be two facilitators running each group.
- The manual contains quotes from the interviews we did with care staff last year and examples which care staff described to us.
- Each session will include a combination of information giving, group discussion, practical exercises and trying out new skills.
- There will be a relaxation exercise in each session and staff will be given relaxation CD or MP3 files.
- Each session will be either one and a half to two hours long.
- We hope that this will be for all care staff excluding night staff.
- Each care home will have allocate two 'champions' who will support staff to put what they learn into practice.
- Following the training sessions there will be supervision with a clinical psychologist available.

The six sessions of the MARQUE intervention are:

- ★ Session 1: Getting to know the person with dementia

- ★ Session 2: Pleasant Events
- ★ Session 3: Improving Communication
- ★ Session 4: Understanding Agitation
- ★ Session 5: Practical Responses and Making a Plan
- ★ Session 6: What works? Using skills and strategies in the future"

Give them a few minutes to look through and make any general comments.

Q. What are your initial thoughts on the manual?

Q. What do you think about the design of the manual?

Prompts:

- How do you find the layout?
- Is it easy to read and follow, e.g. not too much text on each page / fonts / colours?
- How do you find the quotes? Prompts relevance, length
- What do you think of the pictures and images – more, less, different?
- How do you find the balance of information giving and discussion?

Go through each of the sessions one by one: (Spend a few minutes on each and talk about what each contains)

Session 1: Getting to know the person with dementia

- Overview of dementia
- What is agitation?
- What works well supporting people with dementia?
- Getting to know the person with dementia
- Introducing 'Call to Mind'
- Managing the stress that caring can bring: The signal breath

Session 2: Pleasant events

- Recap on 'getting to know the person with dementia'
- The importance of pleasant events
- What is a pleasant event?
- Creating a list of pleasant events
- Activities for people with severe dementia
- Building activities into day to day care
- Relaxation: Focused Breathing

Session 3: Improving communication

- Recap on 'Pleasant Events'
- Communicating with people with dementia
- Communicating within the team
- Communicating with relatives
- Relaxation: Guided imagery

Session 4: Understanding agitation

- Recap on Session 'Improving Communication'
- Understanding Agitation
- The *D/ICE* approach to managing agitation
- DESCRIBING agitation
- INVESTIGATING the causes of agitation
- Relaxation: Stretching

Session 5: Practical responses and making a plan

- Recap on 'Understanding Agitation'
- CREATING strategies to manage agitation
- Practical and environmental adaptations
- When to ask for help from outside agencies?
- Building strategies into a care plan
- Evaluate: Seeing what works
- Relaxation: Guided Imagery 2

Session 6: What works? Using skills and strategies in the future

- Recap on 'Practical responses and making a plan'
- Putting it all together
- What works? (going through each section)
- Keeping it going – developing an action plan

Q. What do you think about the content of the sessions? (Ask these questions in relation to each session separately).

Prompts:

- Do the topics and examples fit with what you / staff experience in you work?
- Is there anything important that you feel is missing?
- Is it pitched at the right level for a range of staff?
- Is it easy to understand?
- Do the key points stand out?

Q. What do you think about the structure of the sessions? (Ask these questions overall)

Prompts:

- Does the order of sessions make sense?
- What do you think about the length of each session?
- How do you think staff who do not have English as a first language will find the manual?
- Is there anything else we could do to make it easier to understand?
- What do you think about having relaxation and homework in each session?
- Do you think it is better to give out the manual session by session or to give out the whole thing at once?

Q. Do you have any other feedback regarding layout, design, content etc?

For managers / team leaders only:

**Q: How do you think this would work practically in a care home like yours?
What ideas have you got about the best ways to get all staff to be able to attend?
What do you do if you want groups of staff to attend training together? e.g. Holding the same session repeatedly / flexibility about timings?
Do you think staff would prefer a slightly longer session with a coffee / snack break?**

Q. Before we finish, is there anything else you would like to mention that we have not already covered?

Thank you for taking part today.

Appendix 13 Sample of MARQUE intervention used in feasibility study (Facilitator version)⁴

[Session 1: version 2]

Facilitator Version

MARQUE


Managing Agitation and Raising Quality of life in dementia

Facilitator Key

Numbers in blue boxes let you know how long each section should take.

Information in yellow boxes give instructions on how to facilitate tasks, as well as prompts for feedback and discussion.

Quotations in orange boxes are phrases you should say directly.



Session 1

General Tips for facilitating the intervention

Before you start:

- Be prepared: Arrive early with time to set up the room and liaise with managers. Make sure all materials, equipment and refreshments are available and that staff know when and where to come.
- In advance of the group, agree with your co-facilitator who will be leading on which sections and who will be time keeping, taking feedback etc.
- Try to start promptly and be clear with staff when the group will end – STICK TO TIME

You will need:

- Manuals
- A clock for the room
- Flip chart and pens
- Call to mind
- Relaxation CDs
- Additional props, e.g. twiddle-muffs
- Refreshments

General tips:

- If you feel that the examples are not relevant to the care staff, for example if there are very high levels of agitation, think with the care staff and each other of more relevant examples.
- Care staff will understand and use ideas from the manual at a different pace and will vary in their literacy levels. It is important to adapt the pace to reflect the abilities in the group, reiterating ideas more frequently if required.
- Be observant: notice which staff contribute in the group and consider ways to encourage contribution from others. Meet with your co-facilitator after each session to debrief and keep a reflective log of what worked well and challenges you faced.
- Undoubtedly problems will arise in sessions that haven't been anticipated. These should be recorded after the session to discuss during supervision.
- Balance making care staff feel listened to and understood, with keeping focused on the manual. During talking points – facilitate discussion whilst being aware of sticking to time.

Key themes:

- Care staff have a great deal of experience, it is important to value their experience and build upon their existing strategies and knowledge throughout the sessions.
- The importance of trying out tasks between sessions is highlighted in the first session. Try to reinforce the benefits of doing tasks throughout and offer encouragement when between session tasks have been completed.

Session 1

10 mins

Introduction

Introduce yourselves and each group member. Ask about their job and how long they have worked in the home. Stress that the intervention has been carefully developed in collaboration with care staff

- Welcome to the MARQUE Project.
- MARQUE is: Managing Agitation and Raising Quality of life in dementia.** It is a nationwide research project taking place in around one hundred care homes.
- We are here to talk with you about dementia, the difficult behaviours people with dementia can have, and discuss skills and strategies that can help.
- These sessions have been carefully developed, based on **what has been shown to work in care home research, and what care home staff and families have told us** is helpful and practical in managing agitation.
- We will begin by looking at ways to prevent difficult behaviours and then look at ways to respond when peoples' behaviours are harder to manage.
- You will be using some of these strategies already and not all of them will apply to you and your work, but please share your expertise with the team.

Not all difficult behaviours will change, but MARQUE should make things better.

- The sessions have been designed to fit with day-to-day work in busy care homes. We won't ask you to try things that take more time than they save.
- The best way to learn new skills is to practise them. We will practise new skills during the sessions. Additionally we also would like you to practise them in between sessions.
- There are two 'champions' who will support you and keep things going within the home.

Your MARQUE champions are:

Key Point:
Always remember: this care home is committed to MARQUE happening here.

Session 1 2


Before we begin, we want to make sure that everybody feels comfortable during the sessions. These are some of the ground rules that we have found useful in other groups.

5 mins

These are our ground rules...

- Listen to other people.
- Respect each others' points of view.
- Arrive on time and inform us or your champions if you are likely to be absent.
- Attend all the sessions – If you have to miss one, try to attend the repeat sessions being held in the home.
- Bring your manual to each session.
- Switch off your mobile phone or switch to silent.
- Contribute to the discussion and try things out in between sessions.
- Confidentiality: We will keep anything discussed confidential, unless we are concerned about a risk to you or someone else.

We are happy for you to share ideas and techniques outside of the sessions, just try not to share personal details unless necessary



Is there anything else that you would like to add?

Session 1 3

⁴ A full copy of the intervention used in initial testing and the final version of the intervention are contained in the attached CD Rom

5 mins Here is an outline of what to expect

- This manual is **yours** to keep.
- Our discussions will use **your own** experiences and examples.
- You will **put ideas and tasks into practice** during and between sessions.
- We're going to be here between and after the sessions to talk about how this is working (or not)

Each session will include...

- A new topic to discuss.
- A practical exercise for you to try out between sessions.
- A new way of reducing stress.

There will be **6** sessions lasting 2 hours each with a refreshment break in the middle.

MARQUE

Session 1: Getting to Know the Person with Dementia
 Session 2: Pleasant Events
 Session 3: Improving Communication
 Session 4: Understanding Agitation
 Session 5: Practical Responses and Making a Plan
 Session 6: What works? Using skills and strategies in the future


Session 1 4

Does anyone have any questions or comments so far?

MARQUE

Session 1 5

MARQUE Session 1:
Getting to know the person with dementia



5

5 mins Plan for today's session

Overview of dementia	p. 7
What is agitation?	p. 10
What works well for agitation?	p. 11
Getting to know the person with dementia	p. 12
Introducing 'Call to mind'	p. 13
Managing the stress that caring can bring	p. 14
Managing stress 1: The signal breath	p. 18
Summary	p. 20
Putting it into practice	p. 21

Session 1 6

20 mins Overview of dementia

Talking point: What different types of dementia are there?

- Most people living in care homes, even without a doctor's diagnosis, have dementia. The most common types are Alzheimer's disease, Vascular Dementia and Lewy Body Dementia, but there are many others.

DEMENTIA:

An umbrella term



Alzheimer's disease
Vascular dementia
Dementia with Lewy bodies

Parkinson's disease dementia
Fronto-temporal dementia

- Often, people who have dementia can hold a normal conversation but sometimes may appear confused.

Key Point: Although there is no known cure for dementia, there are ways to minimise difficulties for people with dementia and those caring for them.

Dementia continued...

- Dementia is not a normal part of ageing. It is an illness which can affect several areas of a person's life, including:



Talking point: Let's talk together about people you are working with and describe how dementia affects their day-to-day lives

Exercise:

- Ask people to give examples of people they are looking after.
- Ask the group to say which areas are being affected
- Use prepared flipchart with domains written on and fit examples to the different areas.

Key Point: Dementia can affect many different areas of people's life at the same time and it is not always obvious.

Key Point: Dementia often affects many different areas of people's lives and it is helpful to think about the specific problems an individual has.

What works well for agitation

Key Point: Getting to know the person well and understanding why they are agitated can help reduce it.

"I've noticed... in the morning when she's crying I give her a shower and she maybe feels better when she has a good, you know, shower in the morning."



Care Assistant

Q! Look at the examples of agitation you came up with on the previous page. What do you do that works some of the time?

Behaviour	What works?
Exercise: (Have the blank chart written on the flipchart in advance)	
<ul style="list-style-type: none"> • In the large group ask people to give examples of agitation from the previous exercise. (Ask them to choose three or four to focus on, not all of them) • Ask them what they do that works and what other ideas they have. • One facilitator write up on the flipchart. • Encourage people to write down possible solutions to try in the future 	

- In the first three sessions, we will focus on preventing agitation and minimising the effect that it has on everybody.
- In future sessions, we will look at ways to manage agitation.

20 mins Getting to know the person with dementia

- Getting to know the person with dementia helps you know what to do when they are agitated.

"While you're doing the personal care, look at the rest of the person, remember that they've lived a life. They may not be in the here and now, but let's go back to where they are, if they feel they're a teenage girl, well, okay."



Unit Manager

- Learning what a person with dementia was like in the past can help you to understand what they may want and need now.

"The residents, they're the same as you are. They were mums, they were going to college, they studied, they were driving, they're like us, today they are old, tomorrow I'm old."



Nurse

- A person with dementia may not be able to tell you about themselves but there may be clues in their behaviour, or their friends and family may be able to fill in gaps.

Talking point: What do you find helps you to get to know the people you are looking after?



We know that it is not always easy to get to know people with dementia, if it is difficult for them to tell you about themselves. Have a look at 'Call to mind'.

Call to mind...

Call to mind® helps you get to know residents better.

- The game is enjoyable and starts conversations.
- The questions help you discover a person's likes and dislikes, interests and opinions.
- This is for you to play with residents (not just activity coordinators).
- It may not fit for everyone but it is worth trying it out.

Let's look at how to play and try it out ourselves...

Exercise:

- Split staff into groups of four with a game for each group. Read through the instruction sheet and check that everyone has understood the rules.
- Ask people to try out the game for 10 minutes.
- Check that they have understood the rules.

Feedback:

- Ask each group to tell you something surprising or interesting that they found out that they did not know before.
- Ask each group how they found playing the game.
- Prompts: Was it easy to use? Do they think it would be useful with residents?

"Between now and next session we will be leaving two of the games with you. Please play the game with residents and complete a record form for two separate residents and bring them next week. (Show people the record form). The record form is a way of recording what you find out about people so you can remember it and share it with others. Instructions and record forms are at the back of the session.

We are now going to move on to talk about managing the stress that caring can bring"

15 mins Managing the stress that caring can bring

- The behaviours you mentioned can be frustrating and difficult to manage. It is important to remember that they are because of brain changes and are not intentional.

"It may make you react in a way that you don't want to react, because you know these residents can't help their behaviours, but then you're stressed and you may say something that you know you shouldn't say, or you may raise your voice at a resident, which you know you shouldn't do, but at that moment, you're thinking, oh, no, again."



Care Assistant

Talking point: Does this fit with how you feel at times?

Common reactions include feeling:



"These are some of the reactions that care staff told us they experience when responding to and managing agitation in residents – There may be others too."

Managing stress continued

- Stress means physical and emotional strain.
- Caring for people with dementia can be physically and emotionally draining. Over time, stress can impact on your health and well-being.
- While the challenges cannot be avoided, you can take steps to reduce the effect on you.

"It can be very stressful, there's been times where I've made my journey home and missed two stops because of what happened that day at work. Even on your day off it can remain with you."



Care Assistant

Physical effects of stress

- When a person is under stress, the body releases a stress hormone called cortisol which can make you sweaty, breathless, sick and your heart beat faster.

Talking point:

If you were feeling stressed, how would you know?
What do you notice when other people are stressed?

The importance of reducing stress

Key Point: Stress can take away your enjoyment or sense of satisfaction and make it harder to do your job.

"You get very stressed... I was never a stressed person before, I didn't even recognise it at first because I had never, ever been a stressed person."



Nurse

- We are going to use some short techniques over the coming weeks to help you reduce stress and tension.
- You may already have ways of reducing stress that work for you. We will provide you with some new skills and techniques.

"During the sessions we are going to help you to learn both how to recognise a stress and gain control over it, we are not here to say, 'When you are stressed, just relax', but to give you new tools to cope. Some of the techniques will work for some people and others for other people, the key is to find the ones that fit for you."



How stressed are you at the moment?

- It is important to take note of how stressed you feel during difficult times and identify what helps this feeling.

Q! Think about a recent stressful situation at work. Take a minute to think about it. If you want to, write it down.

Exercise:

- Ask people to do this task individually
- Check that they have understood
- Give them 3 minutes

Feedback:

- In large group, ask people to share one idea each of what helps; they do not need to tell you about the incident, just about what they find helps them to manage stress



- What did you feel?
- What did you do?
- What was helpful and what wasn't?

MARQUE Managing Stress 1:

The Signal Breath



- The Signal Breath is a simple stress reduction technique that may help when you are coping with stressful situations.

- You can use it anywhere, at any time, and it is quick.

Stress rating before exercise



5 = Terribly tense
4 = Really tense
3 = Moderately tense
2 = Slightly tense
1 = Not at all tense

- First, please rate your level of stress or tension right now, before we practise the signal breath.

Q! On a scale of 1 to 5, how would you rate your tension? _____

Signal breath: Practice session



"Now let's practise together. Sit comfortably in your chair and follow my lead..."

- Take a deep breath
- Tighten your shoulders and arms, hold it for a few seconds
- Now, let it go and say the soothing word you have chosen to yourself.
- Allow your jaw, shoulders, and arms to go loose and limp.

Now let's try it one more time.

When you practise the signal breath, it is best to do it only two or three times at once. More than that may make you feel lightheaded."



3. Now, let it go and say the soothing word you have chosen to yourself.

4. Allow your jaw, shoulders, and arms to go loose and limp.

Tension rating after exercise



5 = Terribly tense
4 = Really tense
3 = Moderately tense

Discuss as a big group:

- Did your level of tension change?
- What was this experience like for you?
- Can you think of specific times when this might have been helpful?

"Please practise at least once a day in different situations."

Q! Now, please rate your tension or stress level from 1 to 5 _____

Remember:

You can listen to these managing stress exercises any time on your CDs or by visiting: www.soundcloud.com/marque-project-relaxing

Summary

Today, we have talked about:

- Overview of dementia
- What is agitation?
- What works well to prevent or reduce agitation?
- Getting to know the person with dementia
- Introducing 'Call to mind'
- Managing the stress that caring can bring
- Managing stress 1: The signal breath

10 mins FOR NEXT WEEK: *Putting it into practice*

Key Point

It is important for you to practise what we have discussed so that it becomes a part of your everyday practice and so that you can find the best tools to suit you and your work.



The signal breath:

Try to practise this every day and to use it in stressful situations. See if it helps.



Call to mind:

Please try out the 'Call to mind' game two or three times during the week with different residents each time. Try and fill in the record forms for at least two residents and bring them with your manual next time.

MARQUE

Putting it into practice

Discuss as a big group

- When will you have an opportunity to do this?
- How can you share this with other members of staff?
- What might get in the way?
- What can your champion do to support this?

Session 1

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Call to mind... Instructions

Playing the game

Fold out the board and place the question cards and spinner on the board where indicated.

The play instructions are guidelines. The most important thing is to stimulate conversations in order to get to know a person, and for this to be an enjoyable experience for everyone. The facilitator can ask more questions if they wish, if anyone is uncomfortable or unwilling to talk about a topic, reassure them that it is OK and choose another card or move on to the next player. It is important that everyone feels safe and comfortable answering questions.

Instructions

1. The first player spins the spinner and picks up a card of the colour it stops on.
2. The player reads out the card topic and identifies a picture on the board that represents this. It will have the same colour border as the card.
3. The player answers any or all of question on the card if they wish.
4. The conversation is opened to the other players.
5. The player keeps this card as one of four colours to collect and so ends their turn.
6. If the player finds nothing to say about the card, they can pick another of the same colour.
7. Play continues with the next player doing the same.
8. If the spinner lands on the colour of a card the player already has, they can spin again until it lands on a different colour.
9. Play carries on until everyone has collected a card of each of the four colours or when the players want to stop.

Session 1

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Feedback Sheet	
Name:	Comments
PAST	Items in bold and red but moved to creating to get work on a card below.
Creating up (example)	
Plus	
Holidays	
Clowning up	
Celebrations	
Working life	
Cooking	
Other...	

This can be copied for use with Call to mind... or downloaded from the website www.call-to-mind.com

Feedback Sheet	
Name:	Comments
CREATIVE	
Puzzles + games	
Music	
Reading + knitting	
Reading	
Making + mending	
Pictures	
Other...	


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Feedback Sheet	
Name:	Comments
ACTIVE	
Dancing	
Shopping	
Football	
Religion	
Gardening	
Sport	
Keeping active	
Travel	
Other...	

This can be copied for use with Call to mind... or downloaded from the website www.call-to-mind.com

Feedback Sheet	
Name:	Comments
PRESENT	
TV + Radio	
Family + friends	
Newspapers	
Technology	
News	
Clothes	
Food	
Other...	


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[Session 2: version 2] 

MARQUE Facilitator Version

Managing **A**gitation and **R**aising **Q**uality of **L**ife
in dementia

Session 2:
Pleasant Events




Session 2 1

5 mins Plan for today's session Talk through plan

Recap on 'getting to know the person with dementia'	p. 3
The importance of pleasant events	p. 4
What is a pleasant event?	p. 5
Planning pleasant events for residents	p. 9
Including people with severe dementia	p. 10
Building activities into day-to-day care	p. 14
Managing stress 2: Focused breathing	p. 16
Summary	p. 19
Putting it into practice	p. 20


Session 2 2

[Session 3: version 2] 

MARQUE Facilitator Version

Managing **A**gitation and **R**aising **Q**uality of **L**ife
in dementia

Session 3:
Improving Communication



Session 3 1

5 mins Plan for today's session Talk through plan

Recap on 'Pleasant Events'	p. 3
Communicating with people with dementia	p. 4
How to respond when people are upset	p. 9
Communicating within the team	p. 10
Communicating with relatives	p. 16
Managing stress 3: Guided Imagery	p. 18
Summary	p. 21
Putting it into practice	p. 22


Session 3 2

[Session 4: version 2] **UCL**

MARQUE Facilitator Version

Managing **A**gitation and **R**aising **Q**uality of life **E** in dementia

Session 4:
Understanding Agitation



Session 4 1

5 mins Plan for today's session Talk through plan

Recap on 'Improving communication'	p. 3
Understanding agitation	p. 4
Ways to manage agitation: Introducing the DICE approach	p. 6
Describing agitation	p. 8
Investigating the causes of agitation	p. 9
Managing stress 4: Stretching	p. 20
Summary	p. 22
Putting it into practice	p. 23


Session 4 2

[Session 5: version 2] **UCL**

MARQUE Facilitator Version

Managing **A**gitation and **R**aising **Q**uality of life **E** in dementia

Session 5:
Practical responses and making a plan



Session 5 1

5 mins Plan for today's session Talk through plan

Recap on 'Understanding agitation'	p. 3
Creating strategies to manage agitation	p. 5
Practical and environmental changes	p. 12
When to ask for help	p. 13
Building strategies into a care plan	p. 15
Evaluate: Seeing what works	p. 18
Managing Stress 5: Guided imagery – ocean escape	p. 20
Summary	p. 23
Putting it into practice	p. 24

Session 5 2

MARQUE

Managing Agitation and Raising Quality of life in dementia

Session 6: What works? Using skills and strategies in the future



- "Look at your notes from all prior sessions before the final session so that you are able to suggest and review ideas around each of the sessions e.g. "Do you think that using this strategy helped to reduce agitation" or being able to remind people of the list of communication strategies or pleasant events". Have in mind potential action plans that could work based on the sessions with your groups so far.
- The purpose of the rest of the session is to get staff to continue to use helpful strategies in the future.
- Try to encourage staff to focus on what worked and if something was not useful, move on to the next section.
- It is important that the teams generate their own plans as much as possible and that they are as detailed, practical and usable as possible.
- Ask lots of questions to generate ideas and use managers and champions in the sessions to facilitate ownership of plans within the care home.
- Remember that there will be staff from different units / teams in the training so the plans may not apply to everyone – Encourage staff to think about how the plan would work on their units and raise with the other facilitators outside of the sessions about all the plans made across the home.
- Be flexible in this session – give time to the preliminary 'what works' discussion and then try and get at least 3 detailed plans – more if that fits with the team.

5 mins Plan for today's session

Talk through plan

Recap on 'Practical responses and making a plan'	p. 4
Putting it all together	p. 5
What works? - The DICE approach Relaxation	p. 6
What works? – Planning and trying out pleasant events	p. 7
What works? – Communicating with people with dementia	p. 8
What works? – Call to Mind	p. 9
What works? – Communicating with the team and relatives	p. 10
What works? – Relaxation	p. 11
Keeping it going – Developing an action plan	p. 12
Summary	p. 18

10 mins Recap of session five: 'Practical responses and making a plan'

We talked about:

- Creating strategies to manage agitation
- Practical and environmental adaptations
- When to ask for help?
- Building strategies into a care plan
- Evaluate: Seeing what works – rolling the DICE again
- Relaxation: Guided imagery

Q! Did you have a chance to describe and investigate, create and evaluate an episode of agitation and complete the DICE record? Did you make an individual plan for a person who was agitated?

If yes...

- How did it go?
- What went well?
- What made it easier?
- Were you able to evaluate the strategies?

If no...

- What do you think got in the way?
- Did you get the chance to think about it?
- What would make it easier in the future?


Big group discussion - encourage people to look at completed record forms

Prompts:

- What was it like using DICE to manage agitation?
- What worked best? Who did you use it on?
- How did it help you to manage agitation?
- Did people use the record form?
- If not used the approach: What could managers / champions do to help?
- Explore why some strategies might not have worked, and query whether something might have worked a little or began to help in non-obvious ways.

Please continue to use the DICE record forms and individual plans to manage episodes of agitation.

Appendix 14 Champion's guide used in feasibility study




MARQUE

Managing Agitation and Raising Quality of life in dementia

Champions Guide

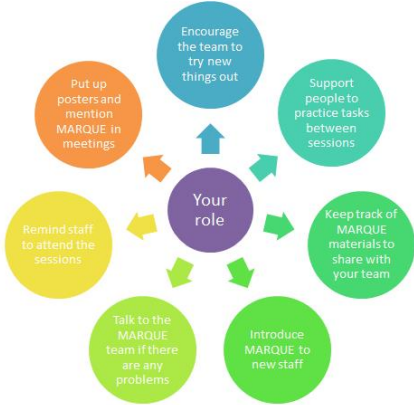
Thank you for volunteering to be a MARQUE champion. We hope that this will be a rewarding and enjoyable opportunity for you, your teams and the people with dementia that you care for.

This guide is to help you in your role as MARQUE champion.




What does being a champion involve?

- Our hope for MARQUE is that by training staff to practice and try out new skills, there will be less agitation and better quality of life for the people you care for.
- We want all staff to try out new skills and strategies between the sessions and keep what works going after we have left the home.
- As champion, we would like you to help staff to put what they learn in MARQUE sessions into practice and introduce MARQUE to new staff after the project has finished.



How will the MARQUE team support you as champion?

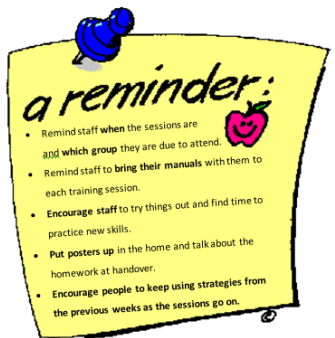
- We understand that you are very busy and we don't want you to feel that MARQUE is just adding to your workload.
- We also know that it is not always easy to ask colleagues to do things differently, especially if you are not a manager yourself.
- So we are here to **SUPPORT** you:



Everyone attending MARQUE training will receive a certificate and we will recognise your added contribution by awarding you MARQUE Champion certificates.

How can you support the MARQUE training sessions?

So that everybody gets the most out of the training we need to make sure that staff attend all of the sessions, bring what they need and practice skills in between. You can help by reminding the staff of the training in the home.



To help staff put ideas into practice you might want to make a MARQUE folder or box to keep extra record forms, copies of the manuals, relaxation CDs and 'call to mind'.

Remember to tell us if people are off sick or unable to attend...

Keep us updated!

Please tell us if any problems arise between sessions so that we can work it out together.

Session 1: Getting to know the person with dementia

- This session is our opportunity to get to know everyone and introduce MARQUE. You can help us by:
 - Making sure people know that they are due to attend.
 - Encouraging people to be ready to start on time.
 - Checking that the facilitators have everything they need (they will provide all the equipment but may need help with organising once in the home).
- We know that it can be hard to speak in a group at first, but the more we get everyone involved the better the training will be.
 - If people are very quiet in the group, perhaps you could start by offering your opinion. If you are worried about talking in front of the group, chat to the facilitators about your concerns.
- During the session we will try out a game called 'Call to Mind'. Please could you encourage the staff to practice between the sessions with residents. You can help by:
 - Putting up reminder posters.
 - Finding a sensible place to store the game.
 - Talking to unit managers to make sure they agree to staff making time to use 'Call to Mind'.
 - Reminding staff to use 'Call to Mind' when you see them at handover or in team meetings.



Session 2: Pleasant events

- This session is all about finding out what residents enjoy and building small events into day-to-day care.
- We know that often activities are led by activities coordinators and that staff find it hard to find the time sit down with residents outside of direct care.
- We want all staff to use more pleasant events during the day without it taking up too much time as we think this will make things easier for everyone.
- The activities coordinator may be in the training, but if not, why not have a chat with them outside of the training about what they are currently doing and what materials they have, for example musical instruments, arts and craft materials or massage creams.
- We will bring some examples of tools which can be used to interact with residents, like memory boxes, song books or rummage bags. If you have items like this in the home perhaps you can show the facilitators or bring them along to the session.
- **The key to this session is staff trying out new pleasant events after the session and keeping this going.** You could help with this by:
 - Reminding staff that we only want people to try things for short periods of time.
 - Checking with staff that they have what they need or talking with the managers or activity coordinators about this.
 - Putting up reminder posters.



Session 3: Improving communication

- This session is all about how improving communication can make things better for everyone and make it easier to care for people with dementia.
- The key to this session is staff noticing what they are already doing that works and doing more of it, and doing less of what doesn't.
- We want people to try out new communication strategies outside of the session with people with dementia, their relatives and with colleagues. You could help with this by:
 - Encouraging people to share useful strategies and talk about what worked outside of the sessions.
 - Putting up a poster and reminding people to have a go.
 - Asking people to write down successful strategies on record forms and in care plans if appropriate.
 - Talking with the MARQUE facilitators if any difficulties arise.



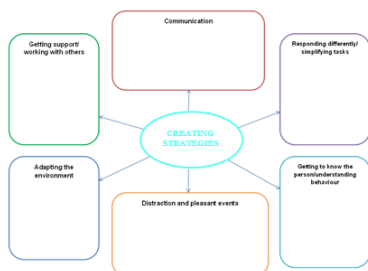
Session 4: Understanding Agitation

- In this session we introduce the DICE approach to managing agitation, focusing on describing and investigating what happens when people are agitated.
- This session will be most useful if people share examples of when residents become agitated. Have a think before the session about residents who get agitated to talk about in the session.
- After the session we will be asking people to notice, describe and investigate episodes of agitation that occur during the week. You can help with this by:
 - Putting up a poster reminding people of the task.
 - Talking in the team outside the sessions about episodes of agitation.
 - Reminding people to use the record forms and if they are stuck either showing them yourself or asking the MARQUE facilitators to help.
 - Making sure people have the record forms available.



Session 5: Practical responses and making a plan

- This session builds on the **DICE** approach focussing on **creating** strategies to manage agitation, building them into a plan, and **evaluating** what works.
- This session introduces some tools for recording what helps specifically when residents become agitated.
- As with the earlier sessions, the more ideas people have about what might help the better. You can help by:
 - Encouraging people to share useful strategies and talk about what worked within and outside of the sessions.
 - Putting up a poster and reminding people to use the **DICE** approach.
 - Asking people to write down successful strategies on record forms and in care plans if appropriate.
 - Reminding people to talk about any difficulties they have in using **DICE** both in and out of the sessions.



Session 6: What works? Using skills and strategies in the future

- This is the final session and it is all about **pulling it all together**, talking about what has worked best and **making a plan** to keep the helpful strategies and actions going.
- You may find it helpful to go over past sessions before the final one to remind yourself about what helped and what did not.
- The facilitators will bring all of the different tools and materials they have used during the sessions. Perhaps you could bring along any extra materials that you have used in the care home for MARQUE.
- The key to this session is developing action plan for keeping MARQUE going in your care home and you will have an important part to play in making this happen. You can help by:
 - Making practical suggestions within the sessions of what would work.
 - Discussing plans outside of the session with the managers to make sure they support the plans.
 - Working with the MARQUE facilitators to check you have all the materials you need after the sessions finish.
 - Working with the MARQUE facilitators to set up the supervision/ troubleshooting sessions and reminding staff to attend.

You and your team may have other ideas of how you can help keep MARQUE going in the home after the sessions. Please use the space below to write down any extra ideas:



Additional materials

- Poster template for each session
- Copies of the record forms for each session

MARQUE: Trying it out...

Getting to know the person with Dementia



Try two or three times with different residents each time.
Try and fill in the record forms for at least two residents.



Remember:
Getting to know the person well and understanding why they are agitated can help reduce it!

Also, don't forget to practise:
the Signal Breath!



Session 1: Record form

Feedback Sheet	
NAME	DATE
PAST	Comments
<p><small>Remember: Write on this sheet and not on the record form for feedback to get involved in a new activity.</small></p> <p>Cleaning up (e.g. emptying)</p> <p>Pets</p> <p>Holidays</p> <p>Getting up</p> <p>Celebrations</p> <p>Working life</p> <p>Cooking</p> <p>Other...</p>	

Feedback Sheet	
NAME	DATE
CREATIVE	Comments
<p>Puzzles + games</p> <p>Music</p> <p>Singing + knitting</p> <p>Reading</p> <p>Making + mending</p> <p>Pictures</p> <p>Other...</p>	

Feedback Sheet	
NAME	DATE
PRESENT	Comments
<p>TV + Radio</p> <p>Family & friends</p> <p>Newspapers</p> <p>Technology</p> <p>News</p> <p>Clothes</p> <p>Food</p> <p>Other...</p>	

Feedback Sheet	
NAME	DATE
ACTIVE	Comments
<p>Dancing</p> <p>Shopping</p> <p>Football</p> <p>Religion</p> <p>Gardening</p> <p>Sport</p> <p>Keeping active</p> <p>Travel</p> <p>Other...</p>	

MARQUE: Trying it out...

Pleasant Events

Try to spend at least five minutes a day trying out a new pleasant event with one or more residents.

Try not to always choose the same people and remember that planning ahead can make it easier. Add to the record form.



Remember:
Anything a person likes to do is a pleasant event!

Also, don't forget to practise the Focused Breathing!



Session 2: Record form

Day	What activity did you try?	Who did you try it with?	How did it go?
e.g. Tuesday morning	Five minute foot massage during morning care routine using scented cream.	Elizabeth and Joe	Elizabeth was humming and smiling. Joe pulled his feet away

MARQUE: Trying it out...

Improving Communication

Try to complete the communication record at 2 or 3 times.
Try to use new strategies and notice when things go well.



Remember:
Improving communication can lead to people feeling more supported and a calmer, more relaxed atmosphere in the home for everyone.

Also, don't forget to practise: Guided Imagery: Meadow and Stream



Session 3: Record form

Situation	What I said or did in the situation	What was the effect	What else could I have tried

MARQUE: Trying it out...

Understanding Agitation

Try to complete the behaviour record for three separate episodes of agitation this week.
Try to focus on **describing** and **investigating** what happened.



Remember:
There is always a cause for agitated behaviour, but the person with dementia is not doing it on purpose and can't control it.

Also, don't forget to practise: Stretching!



Session 4: Record form

Describe	Investigate...	What did you find out?
	<input type="checkbox"/> Environment? <input type="checkbox"/> Emotional / upset? <input type="checkbox"/> A reaction to others? <input type="checkbox"/> Uncomfortable /Unwell? <input type="checkbox"/> Dementia?	
	<input type="checkbox"/> Environment? <input type="checkbox"/> Emotional / upset? <input type="checkbox"/> A reaction to others? <input type="checkbox"/> Uncomfortable /Unwell? <input type="checkbox"/> Dementia?	
	<input type="checkbox"/> Environment? <input type="checkbox"/> Emotional / upset? <input type="checkbox"/> A reaction to others? <input type="checkbox"/> Uncomfortable /Unwell? <input type="checkbox"/> Dementia?	

MARQUE: Trying it out...

Practical responses and making a plan

Try to complete the **DICE** record at least once this week and use the individual plan for one resident.

Try to use new strategies and notice when things go well.

Create
Care Plan



Evaluate

Roll the **DICE**

Remember:

What works at one time may not work at another time or for someone else.

Also, don't forget to practise the Guided Imagery: Ocean Escape!



Session 5: Record form

Describe	Investigate	Create Strategies	Evaluate Did it work?
	<input type="checkbox"/> Environment? <input type="checkbox"/> Emotional / upset? <input type="checkbox"/> A reaction to others? <input type="checkbox"/> Uncomfortable/unwell? <input type="checkbox"/> Dementia?		
	<input type="checkbox"/> Environment? <input type="checkbox"/> Emotional / upset? <input type="checkbox"/> A reaction to others? <input type="checkbox"/> Uncomfortable/unwell? <input type="checkbox"/> Dementia?		

My Care Plan

1. My name is:

2. When I am getting agitated you will see me:

3. When I get agitated it is often because:

4. When I am agitated it helps to:

5. I feel better when:

6. I do not like it when:

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Contact details for the MARQUE team

Your MARQUE Facilitators are:

Name _____

 _____

 _____

The MARQUE Clinical Psychologist who will be offering supervision after the sessions is:

Name _____

 _____

 _____

Thank you very much for all your help with MARQUE. We hope that you have enjoyed the sessions.

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Research workers delivering the intervention will be psychology graduates with variable clinical experience. The MARQUE training package will consist of

- UCL generic teaching on ‘Safety’, ‘Diversity’ and ‘Good Clinical Practice’
- 6 half day sessions, which will ensure that researchers have a good knowledge and skills base around
 - Dementia and agitation within the context of dementia
 - Evidence-based approaches to managing agitation
 - Introducing MARQUE
 - Working with groups 1
 - Working with groups 2
 - Working with groups 3
- Learning the intervention (Role play and observation / feedback until ready to deliver)

Knowledge will be acquired through a combination of seminars, discussion groups, reflective learning and guided reading. Skills-based competencies will be learnt through role play, small group exercises and clinical simulation in small groups. Training will draw on the curriculum for psychological therapists devised by the Department of Health for their improving access to psychological therapies programme and the successful training program developed for the START RCT.

Session 1) Dementia and agitation

- **Dementia (seminar)**
 - definition/ prevalence /presentation
 - impact on the person (mental health through the illness course), family and carer (s)
- **Agitation in people with dementia (reading seminar, case scenarios)**
 - what do we mean by agitation
 - how is it conceptualised/ contributing factors
 - *A pair of researchers will be asked to prepare the seminar, based on refs from the MARQUE protocol including Cohen Mansfield and Algase and will receive feedback from the rest of the group*

- *Case scenarios will be used to illustrate how unmet need can result in agitation*

Session 2) Evidence-based approaches to prevention and treatment of agitation

- **Psychosocial interventions to improve quality of life (seminar)**
 - types of interventions /different stages of the illness/different settings
- **Interventions to manage agitation (reading seminar)**
 - group discussion of Livingston et al 2014 systematic review
 - discussion of Kale et al 2014 paper on DICE
 - *A second pair of researchers will be asked to prepare the reading seminar (same approach as the previous reading seminar)*
- **Pharmacological approaches to agitation and their limitations (seminar, reflection)**
 - overview/ emphasis on risks and guidelines that are in place to reduce inappropriate use
 - *group reflection on positive/negative experiences around medication based on reading Cooper et al 2012 paper*

Session 3) Introducing MARQUE

- **Overview of workstream 3 (seminar)**
 - aims and objectives
 - key components of the intervention
 - brief summary of each session
 - existing framework of care delivery/ national standards/CQC/issues around abuse (lecture)
- **Developing an intervention within a Care Home setting (reading seminar, reflection, group exercise)**
 - what have we learnt so far from Care Home staff
 - *reflection from researchers, based on qualitative work*
 - discussion of Lawrence et al 2012 paper and Teri et al 2009 paper
 - *A third pair of researchers will prepare the seminar (as above)*

- group exercise for researchers to consider solutions so far

Session 4) Working with groups 1

- **Communication skills/group work theory (seminar)**
 - verbal/ nonverbal communication
 - empathic listening
 - awareness of cultural diversity
 - encouraging a climate of mutual trust and respect
 - conflict management
 - creating a safe place to disclose information and explore
 - valuing existing knowledge & experience
 - managing power differences
- **Delivering an intervention (reflection based on session 1 of the manual)**
 - researchers will be asked to read session 1 of the manual and reflect on how it will be delivered:
 - *splitting the intervention into component parts*
 - *beginnings, endings, transitions, timings*
 - *building on existing knowledge and skills to help shape the session*

Session 5) Working with groups 2

- **Delivering session 1 of the intervention**
 - recap on key themes and structure of session 1 of the manual
 - researcher led practice of each component of the intervention
 - *carried out in pairs and prepared as part of session 4 homework*
 - *each pair will teach a different component and receive feedback from the group*
 - *Pair 1: what is dementia/ what is agitation*
 - *Pair 2: getting to know people with dementia*
 - *Pair 3: managing stress /signal breath*
- **Reflection on key issues that have arisen**

- what have researchers have learnt so far about ways to approach each component of session 1
- managing timing and co facilitation
- goal setting/ expectations when setting homework for session 2

Session 6) Working with groups 3

- **Managing group dynamics (seminar with group reflection)** (this could come before or after researchers have practised delivering the intervention ...)
- based on the transition between session 3 (communication) and session 4 (agitation) of the manual
- prior to the session researchers will be asked to think about how they will address the homework of session 3 and deliver session 4
- Key issues to be considered include:
 - containing feelings and emotions generated by the topic
 - managing a group where one person dominates or fails to engage
 - being aware of areas of potential conflict
 - risk management
 - responding to poor practice
 - managing attendance / engagement / homework tasks
 - managing different linguistic / literacy / experience levels

- **Delivering session 4 of the intervention**
- researcher led practice of session 4
 - *each pair will teach a different component of the session and receive feedback from the others*
 - *Pair 1: attendance, recap on session 3 and review of homework*
 - *Pair 2: Understanding agitation and carrying out 'D' and 'I'*
 - *Pair 3: Relaxation and setting goals around homework*



Maple House
149 Tottenham Court Road
London
W1T 7NF
Telephone: 0207 679 9367

Managing Agitation and Raising Quality of Life: Cluster RCT to improve agitation for people with dementia in care homes

We would like to invite your care home to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

More than half of people with dementia living in care homes experience symptoms of agitation every month; these symptoms are associated with lower quality of life. Symptoms of agitation comprise restlessness, pacing, shouting and verbal or physical aggression. Symptoms are difficult for the person with dementia, for the family, for other residents and for the care home staff. We have a new training package built on the evidence about how to reduce agitation and interviews with care home staff about difficulties and how to overcome them. We want to work with homes in implementing the package.

Why have I been invited?

We have approached your home to take part in this study because we are interested in whether this training works and want to try it in a range of diverse homes. It is likely that your care home has already taken part in a linked study looking at quality of life in people with dementia living in care homes.

Do I have to take part?

It is up to you to decide whether your care home takes part in the study. Please read this information sheet carefully and think about any concerns you may have. If you agree to see us or want to talk on the phone, we can discuss the study in more detail with you and answer any questions or concerns you may have. We will then ask you to sign a consent form to show you have agreed for your care home to take part and you will be given a signed copy to keep.

You are free to withdraw from the study at any time, without giving a reason. If you withdraw from the study, you can also request that we not use any of the information you may have already given us. Any stored data that can still be identified as yours will be destroyed if you wish.

What will happen to me / what will I have to do if I take part?

If you agree for the care home to participate, we will ask you to sign a consent form and ask you details about the care home, like the staff number and mix, the type of resident you look after and the number of residents. Any information you give us will be confidential. Answering these questions will take around ten minutes.



We will ask you to go through the residents (giving them numbers so we do not know them) and see if they have memory problems. We want you to approach those that do (or their family or consultee if they are not able) to ask if they will see us. If they will we would like to ask about their quality of life and whether they are agreeable for the staff to answer questions about them. We also want to ask all the staff if they consent to answering questions about the burden of care and coping with it and about the residents. We want to ask a family carer of residents about quality of life too.

Once we have interviewed all those people the homes will be randomised by a computer. Half of them will get the new training package which will consist of six sessions of a manual based training where the staff consider communication with residents. We would like to audiotape one of them to see whether the trainers are able to keep to the training package. We will also ask for two staff champions to help train new people. After the training, a psychologist will keep in touch with the staff, to help them use their new skills.

What are the possible disadvantages of taking part?

It will take up time. We will provide money for the care home to cover the time taken in talking to us, so they can hire cover. We do not foresee there being risks associated with the study.

What are the possible benefits of taking part?

We cannot promise the study will help you but the training may help and it also might help improve things for people with dementia in the future and thus also help family and paid carers who are distressed when the person they look after is agitated.

Will my home taking part in the study be kept confidential?

Yes. All interviews and questionnaires are confidential and anonymous so your name will not be disclosed to anyone else and neither will you be identified in any report/publication. If any person in the study tells us that they or someone else is being harmed we will ask their permission to disclose the information. We respect confidentiality but cannot keep it a secret if anyone is being seriously harmed.

Professional standards of confidentiality will be adhered to and the handling, processing, storage and destruction of data will be conducted in accordance with the Data Protection Act (1998).

Some study documents may also be looked at by authorised representatives from University College London (UCL) Research & Development Unit to check that the study is being carried out correctly. Professional standards of confidentiality will be followed by the authorised representatives.

The information you provide will only be used for the purposes for this research study and not for any other purpose.

What will happen to the data collected?

All material with personal information will be kept only by researchers if in use or in a locked cabinet in UCL that can only be accessed by research staff. Transcripts of interviews will be anonymised so you cannot be identified and the information you disclose will not be discussed with anyone outside of the research team.



Transcripts and audio recordings will be kept for a period of 20 years after the study is complete, in accordance with the UCL Records Management Policy.

You may be contacted about future research studies. You do not have to consent for this. By agreeing to be contacted about future studies, you will not be obliged to participate.

What if there is a problem?

If you wish to complain, or have any concerns about any aspect of the way you have been approached or treated by members of staff you may have experienced due to your participation in the research, National Health Service or UCL complaints mechanisms are available to you. Please ask your researcher if you would like more information on this.

In the unlikely event that you are harmed by taking part in this study, compensation may be available.

If you suspect that the harm is the result of the Sponsor's (University College London) or the hospital's negligence then you may be able to claim compensation. After discussing with your research please make the claim in writing to Professor Gill Livingston who is the Chief Investigator for the research and is based at Division of Psychiatry, 6th Floor Maple House, 149 Tottenham Court Road, London, W1T 7DN. The Chief Investigator will then pass the claim to the Sponsor's Insurers, via the Sponsor's office. You may have to bear the costs of the legal action initially, and you should consult a lawyer about this.

What will happen to the results of the research study?

We intend to publish results in relevant conference proceedings and publications and as a manual to help future carers. Please tell the researchers if you would like a copy of any publications and we would be happy to send this to you when it is published. You will not be identified in any report/publication.

Who is organising and funding the research?

The study is being organised by UCL. The study is funded by the Economic and Social Research Council and National Institute of Health Research.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given a favourable opinion by the Queen Square NRES Committee London.

Contact

Please contact Hannah Savage, Trial Administrator on 020 7679 9367 for further information.

Thank you for taking the time to read this information sheet.



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Participant Information Sheet
Study to improve quality of life and feelings of agitation for people with memory problems in care homes

We are asking whether you would like to take part in a research project. We want to find out whether training for staff can help the quality of life and feelings of agitation of people with memory problems who live in care homes. Before you decide whether to take part or not it is important that you understand why the research is being done and what this study will involve. Please take time to read the following information carefully and discuss it with relatives or friends if you wish.

- Part 1 tells you why the purpose of this study and what will happen to you if you take part.
- Part 2 gives you more detailed information about the conduct of this study.

Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Part 1

What is the purpose of the study?

We want to see if our new training programme for staff in how to help with agitation makes a difference to the quality of life and agitation levels of people with memory problems in the home. Some homes are going to have the training and others are not. This will be decided by a computer programme and has not yet been decided.

Why have I been invited?

Because you are a resident in a care home that is taking part in the study. Twenty care homes across England are taking part in all. We are interested in everyone whether they have these symptoms or not as we think it may prevent new symptoms emerging.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do you will be given the information sheet to keep. You are free at any point to withdraw without giving a reason.

What will happen to me if I take part?

A researcher will visit you at your care home and ask you some questions about your quality of life. The researcher will also ask the staff and your family (if they agree) about how they find you and look at your prescription chart. The researcher will then visit you again in about eight months and then ask you these questions again to see how your experiences might have changed.

What do I have to do?

We estimate it will take around 15 minutes for you to complete the questions about your quality of life on each of the two occasions. We would like to ask a family member or friend some questions about how they see your quality of life, and care home staff questions about your background, health and social care and wellbeing, as well as look at your prescription chart. You may decide that you do not want or feel able to answer questions yourself but you are happy for us to approach these people about you.

What are the possible disadvantages and risks of taking part?

We don't expect the questions to be upsetting, but if taking part brings up issues for you that you would like to talk about you can ask to speak to one of our team. You may also find it helpful to ring the Alzheimer's Society National Dementia Helpline on 0300 222 1122. The Helpline is usually open from 9am to 5pm Monday to Friday and Saturday and Sunday 10am - 4pm.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get might help us develop ways to improve the quality of life of people with memory problems living in care homes.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

Will my taking part in the study be kept confidential?

All interviews are confidential and you will not be identified in any publications. If any person in the study tells us that they or someone else is being harmed we will ask their permission to disclose the information to the care home manager or other appropriate responsible person. We respect confidentiality but cannot keep it a secret if anyone is being harmed.

Contact

Please contact the Trial Administrator on 020 7679 9367 for further information.

This completes Part 1 of the Information Sheet. If the information in Part 1 has interested you and you are considering participation, please continue to read the additional information in Part 2 before making any decision.

Part 2**What if there is a problem?**

If you have a concern about any aspect of this study, you should ask to speak with Prof Gill Livingston (principal investigator for the study) who is based at Maple House, 149 Tottenham Court Road, London W1T 7NF who will do her best to answer your questions. If you remain unhappy and wish to complain formally about any aspect of the way you have been approached or treated during the course of this study, you may contact the Research Governance Sponsor of this study, University College London. Please write to UCL Joint Research Office, 1st Floor Maple House, 149 Tottenham Court Road, London, W1T 7NF quoting study 08/0043.

In the unlikely event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against UCL but you may have to pay your legal costs.

What will happen to the results of the research study?

We intend to publish results in relevant conference proceedings and publications. Please tell the researchers if you would like a copy of any publications and we would be happy to send them to you when they are published. You will not be identified in any report/publication.

You may be contacted about future research studies. You do not have to consent for this. By agreeing to be contacted about future studies, you will not be obliged to participate.

Who is organising and funding the research?

The study is being organised by UCL. The study is funded by the Economic and Social Research Council and National Institute of Health Research.

Who has reviewed the study?

All proposals for research using human subjects are reviewed by an Ethics Committee before they can proceed. This proposal was reviewed by Queen Square NRES Committee London.

You will be given a copy of the information sheet and a signed consent form to keep. Thank you for considering taking part or taking time to read this sheet.

Contact

Please contact the Trial Administrator on 020 7679 9367 for further information.

Thank you for taking the time to read this information sheet.



Maple House
149 Tottenham Court Road
London
W1T 7NF
Telephone: 0207 679 9367

Consultee Information Sheet

Managing Agitation and Raising Quality of Life: Cluster RCT to improve agitation for people with dementia in care homes

You are being invited to act as a 'consultee' for your friend/relative because s/he is unable to make a decision for him/herself. You are being asked to advise the researcher about this person's wishes and feelings and whether they would have wished to join this research. Before you decide, it is important you understand what being a consultee means, why the research is being done and what it will involve. Please take time to read this information carefully and talk to others about the study if you wish. Ask us if anything is not clear or if you would like more information. Take time to decide whether you wish to be a consultee.

What does it mean to be a consultee?

A consultee is someone who knows a person who does not have capacity to make a decision well and is willing and able to offer an opinion on what that person's wishes would have been if they were still able to decide themselves whether to take part. You do not have to act as a consultee if you do not want to. If you decide to act as consultee, you will be asked to sign a Consultee Form. If you think that this person would not have wanted to take part, then the researchers will respect this. Please remember that you are not being asked for your personal views on the research but only what the person's wishes would have been were they being asked to take part in this research. Think about the broad aims of the research, the risks and benefits and what taking part will mean for this person. At any stage, you can advise the researcher that in your opinion the person would no longer wish to remain in the study.

Why have I been asked to be a consultee?

You may have been asked because you know the patient personally, as a friend, partner, or relative, and they would trust you to help with this decision. Or, you may be a member of the care home staff, and you have the patient's best interests in mind.

About the study

We want to see if our new training programme for staff in how to help with agitation makes a difference to the quality of life and agitation levels of people with memory problems in the home. We are interested in everyone whether they have these symptoms or not as we think it may prevent new symptoms emerging.

Half of the care home in the study will have the new training and half of them will continue usual working. We are asking your permission to collect information about how your friend/relative with memory problems is now and in eight months or so. We intend to

compare those in the care homes which have training with those in the other homes. We do not know which half this home will be in and the researcher will not know afterwards. Before you decide whether to take part it is important that you understand why the research is being done and what this study will involve. Please take time to read the following information carefully and discuss it with relatives, friends, and colleagues if you wish. Ask us if there is anything that is not clear or if you would like more information.

- Part 1 tells you why the purpose of this study and what will happen to the resident you are advising us about if they take part.
- Part 2 gives you more detailed information about the conduct of this study.

Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Part 1

What is the purpose of the study?

We want to find out whether a new training programme makes agitation and the quality of life people with memory problems who live in care homes better or not.

Why have I been asked?

Because your friend/relative lives in a care home that is taking part in the study. Twenty care homes across England are taking part in all.

Do they have to take part?

No. It is up to you to advise on whether or not your friend/relative would have wanted to take part. If they do you will be given the information sheet to keep. You are free at any point to request the person you are consultee for is withdrawn from the study without giving a reason.

What will happen to if they take part?

A researcher will ask a member of staff who knows your friend/relative well a series of questions about them including about their memory problem, whether they are distressed and agitated and ask to see their medicine chart. The researcher will also visit your friend/relative if they are able to answer at the care home and ask them some questions about their quality of life. The researcher will visit once again about eight months after all the residents have been assessed to ask them these questions again to see how their experiences might have changed.

What do they have to do?

We estimate it will take around 15 minutes for them to complete the questions about their quality of life on each of the two occasions. Not all participants will be able to answer these questions, and we will ask your advice about this. For all residents taking part, including those who cannot answer questions themselves, we would like to ask a family member or friend some questions about how they see their quality of life (this may be you if you are their carer), and care home staff questions about their background, health and social care and wellbeing.

What are the possible disadvantages and risks of taking part?

We don't expect the survey to be upsetting, but if taking part brings up issues for you or the resident that you or they would like to talk about you can ask speak to one of our team. You

may also find it helpful to ring the Alzheimer's Society National Dementia Helpline on 0300 222 1122. The Helpline is usually open from 9am to 5pm Monday to Friday and Saturday and Sunday 10am - 4pm.

What are the possible benefits of taking part?

We cannot promise the study will help your friend/relative but the information we get might help us develop ways to improve the quality of life of people with memory problems living in care homes.

What if there is a problem?

Any complaint about the way your resident has been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

Will my taking part in the study be kept confidential?

All interviews are confidential and your friend/relative will not be identified in any report/publication. If any person in the study tells us that they or someone else is being harmed we will ask their permission to disclose the information to the care home manager or other appropriate responsible person. We respect confidentiality but cannot keep it a secret if anyone is being harmed.

Contact

Please contact the Trial Administrator on 020 7679 9367 for further information.

This completes Part 1 of the Information Sheet. If the information in Part 1 has interested you and you are considering participation, please continue to read the additional information in Part 2 before making any decision.

Part 2

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak Professor Gill Livingston who is the Chief Investigator for the research and is based at Maple House, 149 Tottenham Court Road, London W1T 7NF. If you remain unhappy and wish to complain formally about any aspect of the way you or the resident you are advising us about have been approached or treated during the course of this study, you may contact the Research Governance Sponsor of this study, University College London. Please write to UCL Joint Research Office, 1st Floor Maple House, 149 Tottenham Court Road, London, W1T 7DN quoting study 08/0043.

In the unlikely event that something does go wrong and the resident you are advising us about is harmed and this is due to someone's negligence then they may have grounds for a legal action for compensation against University College London but you may have to pay your legal costs.

What will happen to the results of the research study?

We intend to publish results in relevant conference proceedings and publications. Please tell the researchers if you would like a copy of any publications and we would be happy to send them to you when they are published. The resident you are advising us about will not be identified in any report/publication.

You may be contacted about future research studies. You do not have to consent for this. By agreeing to be contacted about future studies, you will not be obliged to participate

Who is organising and funding the research?

The study is being organised by UCL. The study is funded by the Economic and Social Research Council and National Institute of Health Research.

Who has reviewed the study?

All proposals for research using human subjects are reviewed by an Ethics Committee before they can proceed. This proposal was reviewed by Queen Square NRES Committee London.

You will be given a copy of the information sheet and a signed declaration form to keep. Thank you for considering taking part or taking time to read this sheet.



Maple House
149 Tottenham Court Road
London
W1T 7NF
Telephone: 0207 679 9367

Staff Information Sheet

Managing Agitation and Raising Quality of Life: Cluster RCT to improve agitation for people with dementia in care homes

We would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish.

Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

- Part 1 tells you why the purpose of this study and what will happen if you take part.
- Part 2 gives you more detailed information about the conduct of this study.

Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Part 1

What is the purpose of the study?

More than half of people with dementia living in care homes experience symptoms of agitation every month; these symptoms are associated with lower quality of life. Symptoms of agitation include restlessness, pacing, shouting and verbal or physical aggression. Symptoms are difficult for the person with dementia, for the family, for other residents and for the care home staff. We want to see if the training programme for staff in how to help with agitation makes a difference.]

Why have I been invited?

We have approached you to take part in this study because you work in a care home which has agreed to take part in this study. A computer will randomly assign half of the care homes in the study to the new training and half of them to continue usual working. We do not yet know which half your home will be in. As part of the study we would like you to answer a series of questions about residents with memory problems you know well and also to answer questions about your coping strategies and the burden you experience in your work. We will then come back in eight months time and ask you to answer the same questions. We will compare the answers from the group of homes receiving the intervention and those who do not and see if the intervention helps the residents and also whether the staff feel more or less burdened.

Do I have to take part?

It is up to you to decide. The care home you work in has agreed to take part in this study, however you do not have to take part and answer questions about yourself. Please read this information sheet carefully and think about any concerns you may have. If you agree to see us or want to talk on the phone,



we can discuss the study in more detail with you and answer any questions or concerns you may have. We will then ask you to sign a consent form to show you have agreed to take part and you will be given a signed copy to keep.

You are free to withdraw from the study at any time, without giving a reason. If you withdraw from the study, you can also request that we do not use any of the information you may have already given us. Any stored data that can still be identified as yours will be destroyed if you wish.

What will happen to me / what will I have to do if I take part?

If you agree to participate, you will be invited to talk to a researcher in a private room in the care home and asked to sign a consent form. Any information you give us will be confidential. The researcher will ask a few questions about your age, job, ethnicity, education and where you were born. These questions are so we can describe the people who give us answers. We will also ask you about your coping strategies and burden.

We will only ask you about people with dementia whom you work closely with e.g. as key worker and who have agreed to be in the study or if they are not able to understand this, whose family or other consultee have agreed that they will be in the study. We will ask you about their age, ethnicity, education and marital status and any symptoms of agitation, memory loss, mood problems and their quality of life. We will also ask to look at their medication chart. Answering these questions will take around forty minutes.

After we have collected information about all people in the home who are in the study and talked to their families if they agree and to them if they are able, the computer will randomly decide whether your home is in the group who has the training or not. We will then return in eight months time to ask the same questions again. The researcher asking these questions will not know which group your home is in.

Expenses and payments

We will provide money for the care home to cover the time taken in talking to us, so they can hire cover.

What are the possible disadvantages of taking part?

We do not foresee there being risks associated with the study. It is possible that some topics discussed may be upsetting if, for example, you have looked after someone with persistent agitation. If at any time during the interview you find a topic sensitive or upsetting you can ask the interviewer to move on to another subject or leave the session altogether. If you feel upset by the interview you can speak to the researcher afterwards or ring the Admiral nurse support helpline (0845 257 9406) which is open from 11am to 8.45pm Tuesdays and Thursdays and 10am to 1pm on Saturdays.

What are the possible benefits of taking part?

We cannot promise the study will help but the information we get might help improve things for people with dementia in the future and thus also help family and paid carers who are distressed when the person they look after is agitated.

Will my taking part in the study be kept confidential?

Yes. All interviews and questionnaires are confidential and anonymous so your name will not be disclosed to anyone else and neither will you be identified in any report/publication. If any person in the study tells us that they or someone else is being harmed we will ask their permission to disclose the information. We respect confidentiality but cannot keep it a secret if anyone is being seriously harmed. Professional standards of confidentiality will be adhered to and the handling, processing, storage and destruction of data will be conducted in accordance with the Data Protection Act (1998).



Some study documents may also be looked at by authorised representatives from University College London (UCL) Research & Development Unit to check that the study is being carried out correctly. Professional standards of confidentiality will be followed by the authorised representatives.

The information you provide will only be used for the purposes for this research study and not for any other purpose.

What will happen to the data collected?

All material with personal information will be kept only by researchers if in use or in a locked cabinet in UCL that can only be accessed by research staff.

Part 2

What if there is a problem?

If you wish to complain, or have any concerns about any aspect of the way you have been approached or treated by members of staff you may have experienced due to your participation in the research, National Health Service or UCL complaints mechanisms are available to you. Please ask your researcher if you would like more information on this.

In the unlikely event that you are harmed by taking part in this study, compensation may be available.

If you suspect that the harm is the result of the Sponsor's (University College London) or the hospital's negligence then you may be able to claim compensation. After discussing with your researcher please make the claim in writing to Professor Gill Livingston who is the Chief Investigator for the research and is based at UCL Division of Psychiatry, 6th Floor Maple House, 149 Tottenham Court Road, London, W1T 7NF. The Chief Investigator will then pass the claim to the Sponsor's Insurers, via the Sponsor's office. You may have to bear the costs of the legal action initially, and you should consult a lawyer about this.

What will happen to the results of the research study?

We intend to publish results in relevant conference proceedings and publications and as a manual to help future carers. Please tell the researchers if you would like a copy of any publications and we would be happy to send this to you when it is published. You will not be identified in any report/publication.

You may be contacted about future research studies. You do not have to consent for this. By agreeing to be contacted about future studies, you will not be obliged to participate.

Who is organising and funding the research?

The study is being organised by UCL. The study is funded by the Economic and Social Research Council and National Institute of Health Research.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given a favourable opinion by the Queen Square NRES Committee London.

Please contact the Trial Administrator on 0207 679 9367 for further information.

Thank you for taking the time to read this information sheet.

Appendix 17 Phase three informed consent forms



Division of Psychiatry
 University College London
 6th Floor, Maple House,
 149 Tottenham Court Road,
 London W1T 7DN.

020 7679 9367

CONSENT FORM (care home) – Randomised controlled trial

Title of Project: Managing Agitation and Raising Quality of Life: Cluster RCT to improve agitation for people with dementia in care homes version randomised controlled trial

Name of Researcher(s): Professor Gill Livingston, Dr. Claudia Cooper, Dr. Penny Rapaport
 Care home reference number for study:

Care Home Number for study:

Please INITIAL in the box

1.	I confirm that I have read and understood the information sheet dated 30/09/15 (Version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	<input type="checkbox"/>
2.	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without my legal or medical rights being affected.	<input type="checkbox"/>
3.	I understand that relevant data collected during the study, may be looked at by individuals from UCL, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to this data.	<input type="checkbox"/>
4.	I understand that all material and personal information will be kept in accordance with the UCL Records Management Policy.	<input type="checkbox"/>
5.	I agree to researchers contacting me about future research and I understand that I do not have to participate if I do not wish to.	<input type="checkbox"/>
6.	I agree to take part in the above study	<input type="checkbox"/>

Care Home Name		
Name of care home manager (Print)	Signature of manager	Date
Name of researcher (Print)	Signature of researcher	Date

When completed: 1 copy for participant; 1 copy for researcher [IF APPLICABLE, 1 copy for medical notes]



University College London
6th Floor, Maple House,
149 Tottenham Court Road,
London W1T 7NF.

Tel: 020 7679 9367

CONSENT FORM (Staff) – Randomised controlled trial

Title of Project: Managing Agitation and Raising Quality of Life: Cluster RCT to improve agitation for people with dementia in care homes

Name of Researcher(s): Professor Gill Livingston, Dr Claudia Cooper and Dr Penny Rapaport

Participant reference number for study:

Care home No. Staff No.

Please INITIAL in the box

1.	I confirm that I have read and understood the information sheet dated 13.09.16 (Version 3) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	<input type="checkbox"/>
2.	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without my legal or medical rights being affected.	<input type="checkbox"/>
3.	I understand that relevant data collected during the study, may be looked at by individuals from UCL, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to this data.	<input type="checkbox"/>
4.	I understand that all material and personal information will be kept in accordance with the UCL Records Management Policy.	<input type="checkbox"/>
5.	I agree to researchers contacting me about future research and I understand that I do not have to participate if I do not wish to.	<input type="checkbox"/>
6.	I agree to take part in the above study.	<input type="checkbox"/>

I

Name of participant (Print)	Signature of participant	Date
Name of researcher (Print)	Signature of researcher	Date

When completed: 1 copy for participant; 1 copy for researcher [IF APPLICABLE, 1 copy for medical notes]



University College London
6th Floor, Maple House,
149 Tottenham Court Road,
London W1T 7NF

Tel: 020 7679 9367

CONSENT FORM (family carer) - Randomised controlled trial

Title of Project: Managing Agitation and Raising Quality of Life: Cluster RCT to improve agitation for people with dementia in care homes version randomised controlled trial

Name of Researcher(s): Professor Gill Livingston, Dr Claudia Cooper, Dr Penny Rapaport

Participant reference number for study:
Care home No. Resident No. Family Carer No.

Please INITIAL in the box

1.	I confirm that I have read and understood the information sheet dated 11.11.16 (Version 4) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	<input type="checkbox"/>
2.	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without my legal or medical rights being affected.	<input type="checkbox"/>
3.	I understand that relevant data collected during the study, may be looked at by individuals from UCL, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to this data.	<input type="checkbox"/>
4.	I understand that all material and personal information will be kept in accordance with the UCL Records Management Policy.	<input type="checkbox"/>
5.	I agree to researchers contacting me about future research and I understand that I do not have to participate if I do not wish to.	<input type="checkbox"/>
6.	I agree to take part in the above study.	<input type="checkbox"/>

Name of participant (Print)	Signature of participant	Date
Name of researcher (Print)	Signature of researcher	Date

When completed: 1 copy for participant; 1 copy for researcher [IF APPLICABLE, 1 copy for medical notes]



University College London
6th Floor, Maple House,
149 Tottenham Court Road,
London W1T 7NF

Tel: 020 7679 9367

CONSENT FORM (Resident) - Randomised controlled trial

Title of Project: Managing Agitation and Raising Quality of Life: Cluster RCT to improve agitation for people with dementia in care homes

Name of Researcher(s): Professor Gill Livingston, Dr. Claudia Cooper and Dr. Penny Rapaport

Participant reference number for study:
Care home No. Resident No.

Please INITIAL in the box

	1. I confirm that I have read and understood the information sheet dated 13.09.16 (Version 3) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	<input type="checkbox"/>
	2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without my legal or medical rights being affected.	<input type="checkbox"/>
	3. I agree to researchers interviewing care home staff and [family carer name] about me.	<input type="checkbox"/>
	4. I give permission for these individuals to have access to my drug charts.	<input type="checkbox"/>
	5. I understand that relevant data collected during the study, may be looked at by individuals from UCL or, from regulatory authorities, where it is relevant to my taking part in this research. I give permission for these individuals to have access to this data.	<input type="checkbox"/>
	6. I understand that all material and personal information will be kept in accordance with the UCL Records Management Policy.	<input type="checkbox"/>
	7. I agree to researchers contacting me about future research and I understand that I do not have to participate if I do not wish to.	<input type="checkbox"/>
	8. I agree to take part in the above study.	<input type="checkbox"/>

Name of participant (Print)	Signature of participant	Date
Name of researcher (Print)	Signature of researcher	Date

When completed: 1 copy for participant; 1 copy for researcher [IF APPLICABLE, 1 copy for medical notes]

Appendix 18 Noticeable Problems Checklist

Care home number: [] [] [] []
Resident number: [] [] [] []
Date: [] [] [] [] [] [] 2101 [] []
Researcher ID: [] [] []

Resident Eligibility Form

1. Resident ID number: CH _____

2. Does this resident have a diagnosis of dementia?

- Yes
- No

If NO, complete q2 (Noticeable problems checklist). If YES, skip to q3.

2. **Noticeable Problems checklist.** Does [name of person] have noticeable problems in:

a. **NPC 1:** Remembering recent events?

- Yes
- No

b. **NPC 2:** Working out how to do some basic every day tasks such as dressing, making tea, going to the toilet?

- Yes
- No

c. **NPC 3:** Knowing the time?

- Yes
- No

d. **NPC 4:** Knowing where he/she is?

- Yes
- No

e. **NPC5:** Correctly naming persons seen regularly?

- Yes
- No

f. **NPC 6:** Keeping in touch with a conversation?

- Yes
- No

g. **NPC Total number of 'yes' answers = _____**

3. **Is this resident eligible for this study?** *[Does the resident have a diagnosis of dementia OR a NPC score of 2 or above?]* If YES, please continue to q4.

- Yes
- No

Appendix 19 Home census

Care home Number: [] [] [] []

Date: [] [] [] [] [] [] [] [] [] [] [] []

Researcher ID: [] [] [] []

Home Census

Home details

1. Type of accommodation			
Privately managed		Council managed	
Housing association managed		Charity managed	
		Other <i>Please complete q1a</i>	
		1a. Specify other <i>Only complete if 'Other' is selected.</i>	

2. Type of care home			
Nursing		Personal care	
Nursing and Personal care			

3. Is the home dementia registered?	YES/NO
4. Is the home dementia specialist? <i>(i.e. all residents should have dementia)</i>	YES/NO
5. Is the home mental health registered?	YES/NO
6. Is the home registered for physical disabilities?	YES/NO
7. Does the care home have any other registrations?	YES/NO
7a. If yes, please specify: _____	
8. Total number of resident places in home	
9. Are there age specifications for residents of the care home?	YES/NO
9a. If yes, please select one of the following options:	<input type="checkbox"/> Over 65 years only <input type="checkbox"/> Other. Please specify: _____

Care home managers measure – Baseline v2 30.09.15

Care Quality Commission rating <i>This can be found at: www.cqc.org.uk</i>		
☆ Outstanding ● Good ● Requires improvement ● Inadequate	10. Safe	
	11. Effective	
	12. Caring	
	13. Responsive	
	14. Well-led	
	15. OVERALL	
16. Date of last CQC inspection (dd/mm/yyyy): __/__/____ Please date <i>this from the last CQC follow up, rather than the last full inspection.</i>		

17. Is the policy that all newly admitted residents with dementia are cared for in a specialist area, separate to other residents, where their physical needs do not preclude this?	YES/NO
18. Is there a special unit for residents with behavioural disturbances relating to dementia, aside from the area above?	YES/NO
19. Does the home have a specific team for dementia care?	YES/NO
20. Is it typical that, as residents needs change over time, they are moved to different locations within the home (e.g to a nursing area, closer to staff offices, to a specialist team)?	YES/NO
20a. If yes, please specify the criteria for moving: _____ _____	

Care home Number: [] [] [] []
 Date: [] [] [] [] [] [] [] [] [] [] [] []
 ResearcherID: [] [] [] []

Home statistics measured for the last 24 hours

The census period is 24 hours BEFORE the day of the interview, ending at completion of previous night shift

21. How many qualified nursing staff were rostered on during the day	0-60
22. How many care staff, other than above, were rostered on during the day	0-60
22. How many qualified nursing staff were rostered on during the night	0-60
24. How many care staff, other than above, were rostered on during the night	0-60
25. Number of staff in 24 hours period who were agency/bank	0-10
26. Number of residents present in home (ie, if in hospital, or away, do not count)	0-100
27. Number of residents with dementia present in home (ie, if in hospital, or away, do not count) <i>Amount AFTER noticeable problems checklist</i> Complete this after the interview is complete	0-100
28. Number of residents currently in hospital	0-60

Home statistics measured for the last 7 days

29. Number of permanent registered nursing staff (including those on sick/carer/compassionate/annual/maternity leave)	0-100
30. Number of permanent other care staff (including those on sick/carer/compassionate/annual/maternity leave)	1-600
31. Number of registered nursing staff from those above on sick/carer/compassionate/annual/maternity leave in the last week	0-10
32. Number of other care staff from those above on sick/carer/compassionate/annual/maternity leave in the last week	0-60

|

Appendix 20 Clinical Dementia Rating (CDR)

Care home Number: [] [] [] []
 Resident Number: [] [] [] []
 Staff number: [5] [] [] []
 Date: [] [] [] [] [2] [0] [] []
 Researcher ID: [] [] []

Clinical Dementia Rating Worksheet

This is a semi-structured interview. Please ask all of the following questions. Ask any additional questions necessary to determine the subject's CDR. Please record information from the additional questions.

MEMORY QUESTIONS

1. Does the resident have a problem with his/her memory or thinking?	YES/NO
1a. If yes, is this a consistent problem (as opposed to inconsistent)?	YES/NO
2. Can the resident recall recent events?	Always/Usually/Sometimes/never With / without prompting
3. Has there been some decline in memory whilst the resident has been with you?	YES/NO
4. Does the resident completely forget an event you would have considered significant or meaningful to them? (e.g. the celebration of a wedding anniversary or family birthday party).	Always/Usually/Sometimes/never With / without prompting
5. Does the resident forget pertinent details of the major event?	Always/Usually/Sometimes/never With / without prompting
6. Does the resident completely forget important information from the distant past (e.g., birthdate, wedding date, place of employment)?	Always/Usually/Sometimes/never With / without prompting

	None 0	Questionable 0.5	Mild 1	Moderate 2	Severe 3
Memory	No memory loss or slight inconstant forgetfulness	Consistent slight forgetfulness; partial recollection of events; "benign" forgetfulness	Moderate memory loss; more marked for recent events; defect interferes with everyday activities	Severe memory loss; only highly learned material retained; new material rapidly lost	Severe memory loss; only fragments remain

Care home Number: [] [] [] []
 Resident Number: [] [] [] []
 Staff number: [5] [] [] []
 Date: [] [] [] [] [2] [0] [] []
 Researcher ID: [] [] [] []

ORIENTATION QUESTIONS

How often does the resident know of the exact.....

1. Date of the month?	Always/Usually/Sometimes/ /never With / Without Prompting
2. Month?	Always/Usually/Sometimes//never With / Without Prompting
3. Year?	Always/Usually/Sometimes/never With / Without Prompting
4. Day of the week?	Always/Usually/Sometimes/never With / Without Prompting
5. Does the resident have difficulty with time relationships (e.g. whether it is before or after lunch)?	Always/Usually/Sometimes/ /never With / Without Prompting
6. How often can the resident find her way around indoors?	Always/Usually/Sometimes/never With / Without Prompting

	None 0	Questionable 0.5	Mild 1	Moderate 2	Severe 3
Orientation	Fully oriented	Fully oriented except for slight difficulty with time relationships	Moderate difficulty with time relationships; oriented for place at examination; may have geographical disorientation elsewhere	Severe difficulty with time relationships; usually disoriented to time, often to place	Oriented to person only

Care home Number: [] [] []
 Resident Number: [] [] []
 Staff number: [5] [] []
 Date: [] [] [] [2] [0] [] []
 Researcher ID: [] [] []

JUDGEMENT AND PROBLEM SOLVING QUESTIONS

1. Thinking about his/her ability to handle a small personal budget	Is able to manage a small personal budget. Has a personal budget but needs assistance keeping track of it. Not applicable
2. Is the resident capable of interacting in a socially appropriate way with other residents? <i>e.g. choosing who to sit next to at meal times, responding appropriately to another distressed resident.</i>	Always/Usually/Sometimes/never
3. Is the resident capable of interacting in a socially appropriate way with staff? <i>e.g. appropriate topics of conversation, appropriately asking for assistance.</i>	Always/Usually/Sometimes/never
4. Does the resident have the ability to request when they need personal appointments? <i>e.g. to see the chiropodist, have a haircut, see a dentist.</i>	Always/Usually/Sometimes/never
5. Can the resident understand situations or explanations? <i>e.g. why dinner is late, the fire alarm being tested.</i>	Always/Usually/Sometimes/never
6. Does the resident behave appropriately in social situations and interactions with other people?	Always/Usually/Sometimes/never

	None 0	Questionable 0.5	Mild 1	Moderate 2	Severe 3
Judgement and Problem Solving	Solves everyday problems and handles business and financial affairs well; judgment good in relation to past performance	Slight impairment in solving problems, similarities, and differences	Moderate difficulty in handling problems, similarities, and differences; social judgment usually maintained	Severely impaired in handling problems similarities, and differences; social judgment usually impaired	Unable to make judgments or solve problems

Care home Number: [1 1 1]
 Resident Number: [1 1 1]
 Staff number: [5 1 1]
 Date: [1 1] [1 1] [2 1 0]
 Researcher ID: [1 1]

COMMUNITY AFFAIRS QUESTIONS

1. Is the resident an active member of the home community?	Yes/No <i>Prompt for further explanation</i>
2. Is the resident able to join in activities organised in the home?	Yes/No Usually/Sometimes/Rarely/Don't know
3. Does the resident interact well with other residents at social functions/activities?	Usually/Sometimes/Rarely/Don't know
4. Does the resident interact well with staff in social at social functions/activities?	Usually/Sometimes/Rarely/Don't know
5. Is the resident able to engage in family visits both: - within the home - outside of the home	Yes/No/Not applicable
6. Does the resident use the outside areas of the home through choice? <i>e.g. the garden area</i>	Yes/No/Not applicable

	None 0	Questionable 0.5	Mild 1	Moderate 2	Severe 3
Community Affairs	Independent function at usual level in job, shopping, and volunteer and social groups	Slight Impairment in these activities	Unable to function independently at these activities although may still be engaged in some; appears normal to casual inspection	No pretence of independent function outside home; Appears well enough to be taken to functions outside a family home	No pretence of independent function outside home; Appears too ill to be taken to functions outside a family home

Care home Number: [] [] [] []
 Resident Number: [] [] [] []
 Staff number: [5] [] [] []
 Date: [] [] [] [] [2] [0] [] []
 Researcher ID: [] [] []

HOME AND HOBBIES FOR INFORMANT

<p>1. What hobbies can the resident still do well? <i>Hobbies they used to enjoy e.g. knitting, following sports, reading the daily paper, skittles.</i></p>	<p><i>Prompt for frequency</i></p>
<p>2. How engaged is the resident in the home environment? <i>e.g. does the resident take an interest in watering plants, making their own bed, helping to set or clean the table, gardening?</i></p>	<p><i>Prompt for frequency</i></p>

	None 0	Questionable 0.5	Mild 1	Moderate 2	Severe 3
Home and Hobbies	Life at home, hobbies and Intellectual interests well maintained	Life at home, hobbies and Intellectual interests slightly impaired	Mild but definite impairment of function at home; more difficult chores abandoned more complicated hobbies and interests abandoned	Only simple chores preserved; very restricted interests, poorly maintained	No significant function in home

Care home Number: [] [] [] []
 Resident Number: [] [] [] []
 Staff number: [5] [] [] []
 Date: [] [] [] [] [2] [0] [] []
 Researcher ID: [] [] []

PERSONAL CARE QUESTIONS

What is your estimate of his/her mental ability in the following areas?

1. Dressing <i>(The Dementia Scale of Blessed)</i>	Unaided	Occasionally misplaced buttons etc.	Wrong sequence, commonly forgotten items.	Unable to dress.
2. Washing, grooming.	Unaided	Needs prompting	Sometimes needs help	Always or nearly always needs help
3. Eating habits	Cleanly; proper utensils	Messily; spoon	Simple solids	Always or nearly always needs help
4. Sphincter control <i>(The Dementia Scale of Blessed)</i>	Normally complete control	Occasionally wets the bed	Frequently wets the bed	Doubly incontinent

	None 0	Questionable 0.5	Mild 1	Moderate 2	Severe 3
Personal Care	Fully capable self-care	Fully capable self-care	Needs prompting	Requires assistance in dressing, hygiene, keeping of personal effects	Requires much help with personal care; frequent incontinence

Care home Number: [] [] [] []
 Resident Number: [] [] [] []
 Staff number: [5] [] [] []
 Date: [] [] [] [] [2] [0] [] []
 Researcher ID: [] [] []

To be completed in Research office

	None 0	Questionable 0.5	Mild 1	Moderate 2	Severe 3
Memory					
Orientation					
Judgment and Problem solving					
Community affairs					
Home and Hobbies					
Personal care					

Rating	<input type="text"/>
Check this box if you want to confirm your rating with another researcher	<input type="checkbox"/>
Check this box if the rating has been confirmed by another researcher	<input type="checkbox"/>

|

Appendix 21 Cohen-Mansfield Agitation Inventory (CMAI)

Care home Number: [] [] [] []
 Resident Number: [] [] [] []
 Staff number: [5] [] [] []
 Date: [] [] [] [] [] [] [2] [0] [] []
 Researcher ID: [] [] [] []

Cohen-Mansfield Agitation Inventory:

How often have each of the behaviours below happened over the last 2 weeks?

	Never	Less than once a week	1-2 times a week	Several times a week	1-2 times a day	Several times a day	Several times an hour
1. Pacing and aimless wandering							
2. Inappropriate dressing or disrobing							
3. Spitting (including while feeding) <i>(Do not include spitting into tissue, toilet or onto ground outside)</i>							
4. Cursing or verbal aggression							
5. Constant unwarranted request for attention or help.							
6. Repetitive sentences or questions <i>(Do not include complaining)</i>							
7. Hitting (including self) <i>(Including hitting furniture)</i>							
8. Kicking							
9. Grabbing onto people or things inappropriately							
10. Pushing							

Care home Number: [] [] [] []
 Resident Number: [] [] [] []
 Staff number: [5] [] [] []
 Date: [] [] [] [] [2] [0] [] []
 Researcher ID: [] [] []

	Never	Less than once a week	1-2 times a week	Several times a week	1-2 times a day	Several times a day	Several times an hour
11. Throwing things							
12. Making strange noises							
13. Screaming							
14. Biting							
15. Scratching							
16. Trying to get to a different place							
17. Intentional falling							
18. Complaining							
19. Negativism <i>(Bad attitude, doesn't like anything, nothing is right.)</i>							
20. Eating or drinking inappropriate substances							
21. Hurting self or others							
22. Handling things inappropriately <i>(Picking up things that don't belong to them, playing with food, rummaging through drawers)</i>							
23. Hiding things							
24. Hoarding things							

Care home Number: [] [] [] []
 Resident Number: [] [] [] []
 Staff number: [5] [] [] []
 Date: [] [] [] [] [2] [10] [] []
 Researcher ID: [] [] []

	Never	Less than once a week	1-2 times a week	Several times a week	1-2 times a day	Several times a day	Several times an hour
25. Tearing things or destroying property							
26. Performing repetitive mannerisms							
27. Making verbal sexual advances							
28. Making physical sexual advances or exposing genitals							
29. General restlessness							

Care home Number: [] [] [] []
Resident Number: [] [] [] []
Staff number: [5] [] [] []
Date: [] [] [] [] [] [] [2] [1] [0] [] [] []
Researcher ID: [] [] [] []

Staff Proxy DEMQOL Proxy

Instructions: Read each of the following questions (in bold) verbatim and show the respondent the response card.

I would like to ask you about _____ (the resident's) life, as you are the person who knows him/her best. There are no right or wrong answers. Just give the answer that best describes how _____ (the resident) has felt in the last week. If possible try and give | the answer that you think _____ (the resident) would give. Don't worry if some of the questions appear not to apply to _____ (the resident). We have to ask the same questions to everybody.

Before we start we'll do a practice question: that's one that doesn't count. (Show the response card and ask the respondent to say or point to the answer).

In the last week how much has _____ (the resident) enjoyed watching television.

<input type="checkbox"/>	A lot	Quite a bit	A little	Not at all	<input type="checkbox"/>
--------------------------	-------	-------------	----------	------------	--------------------------

Follow up with a prompt question: Why is that? Or Tell me a bit more about this.

Care home Number: [] [] [] []
 Resident Number: [] [] [] []
 Staff number: [5] [] [] []
 Date: [] [] [] [] [2] [1] [] [] []
 Researcher ID: [] [] []

For all of the questions I'm going to ask you, I want you to think about the last week.

First I'm going to ask you about _____ *(the resident's) feelings*. In the last week, would you say that *(the resident)* has felt

	A lot	Quite a bit	A little	Not at all
1. cheerful?				
2. worried or anxious?				
3. frustrated?				
4. full of energy?				
5. sad?				
6. content?				
7. distressed?				
8. lively?				
9. irritable?				
10. fed-up?				
11. that he/she has things to look forward to?				

Care home Number: [] [] [] []
 Resident Number: [] [] [] []
 Staff number: [5] [] [] []
 Date: [] [] [] [] [2] [1] [0] [] [] [] []
 Researcher ID: [] [] [] []

Next, I'm going to ask you about _____ (*the resident's*) memory. In the last week how worried would you say _____ (*the resident*) has been about

	A lot	Quite a bit	A little	Not at all
12. his/her memory in general?				
13. forgetting things that happened a long time ago?				
14. forgetting things that happened recently?				
15. forgetting people's names?				
16. forgetting where he/she is?				
17. forgetting what day it is?				
18. his/her thoughts being muddled?				
19. difficulty making decisions?				
20. making him/herself understood?				

Care home Number: [] [] [] []
 Resident Number: [] [] [] []
 Staff number: [5] [] [] []
 Date: [] [] [] [] [2] [0] [] []
 Researcher ID: [] [] []

Next, I'm going to ask you about _____ (the resident's) everyday life. In the last week how worried would you say _____ (the resident) has been about

	A lot	Quite a bit	A little	Not at all
21. keeping him/herself clean (eg washing and bathing)				
22. keeping him/herself looking nice?				
23. getting what he/she wants from the shops?				
24. using money to pay for things?				
25. looking after his/her finances?				
26. things taking longer than they used to?				
27. getting in touch with people?				
28. not having enough company?				
29. not being able to help other people?				
30. not playing a useful part in things?				
31. his/her physical health?				

Care home Number: [] [] [] []
 Resident Number: [] [] [] []
 Staff number: [5] [] [] []
 Date: [] [] [] [] [2] [1] [0] [] [] []
 Researcher ID: [] [] [] []

We've already talking about lots of things: _____(the resident's) feelings,
 memory and everyday life. Thinking about all of these things in the last week, how would
 you say _____(the resident) would rate.....

	Very good	Good	Fair	Poor
32. his/her quality of life overall?				

Care home number: [] [] [] []
Resident number: [] [] [] []
Date: [] [] [] [] [] [] [] [] [] []
Researcher ID: [] [] [] []

Resident Assessment Baseline

Has the resident completed the baseline resident DEMQOL assessment?

yes
Date (dd/mm/yyyy): _____

no
If no, please give reason (tick one box only):

- Resident in hospital
- Always sleeping
- Too ill
- Cannot understand
- Cannot communicate
- Resident agitated
- Potential distress
- Other. Please specify: _____

Care home number: [] [] [] []
Resident number: [] [] [] []
Date: [] [] [] [] [] 2 [] 0 [] [] []
Researcher ID: [] [] []

Resident DEMQOL (*version 4*)

Instructions: Read each of the following questions (in bold) verbatim and show the respondent the response card.

I would like to ask you about your life. There are no right or wrong answers. Just give the answer that best describes how you have felt in the last week. Don't worry if some of the questions appear not to apply to you. We have to ask the same questions of everybody.

Before we start we'll do a practice question: that's one that doesn't count. (*Show the response card and ask the respondent to say or point to the answer.*)

In the last week how much have you enjoyed watching television?

A lot	Quite a bit	A little	Not at all
-------	-------------	----------	------------

*Follow up with a prompt question: **Why is that?** Or **Tell me a bit more about this.***

Care home number: [] [] [] []
 Resident number: [] [] [] []
 Date: [] [] [] [] 20 [] [] []
 Researcher ID: [] [] []

For all of the questions I'm going to ask you, I want you to think about the last week.

First I'm going to ask you about your feelings. In the last week, have you felt

Please tick the correct box

	A lot	Quite a bit	A little	Not at all
1. cheerful?				
2. worried or anxious?				
3. that you are enjoying life?				
4. frustrated?				
5. confident?				
6. full of energy?				
7. sad?				
8. lonely?				
9. distressed?				
10. lively?				
11. irritable?				
12. fed-up?				
13. that there are things that you wanted to do but couldn't?				

Care home number: [1 1]
 Resident number: [1 1]
 Date: [1 1 1 1 2 1 0]
 Researcher ID: [1 1]

Next, I'm going to ask you about your memory. In the last week how worried have you been about

	A lot	Quite a bit	A little	Not at all
14. forgetting things that happened recently?				
15. forgetting who people are?				
16. forgetting what day it is?				
17. your thoughts being muddled?				
18. difficulty making decisions?				
19. poor concentration?				

Care home number: [] [] [] []
 Resident number: [] [] [] []
 Date: [] [] [] [] 20 [] [] []
 Researcher ID: [] [] []

Next, I'm going to ask you about your everyday life. In the last week how worried have you been about

	A lot	Quite a bit	A little	Not at all
20. not having enough company				
21. how you get on with people close to you?				
22. getting the affection that you want?				
23. people not listening to you?				
24. making yourself understood?				
25. getting help when you need it?				
26. getting to the toilet in time?				
27. how you feel in yourself?				
28. your health overall?				

We've already talking about lots of things: your feelings, memory and everyday life. Thinking about all of these things in the last week, how would you rate.....

	Very good	Good	Fair	Poor
29. your quality of life overall?				

Care home Number: [] [] [] []
Resident Number: [] [] [] []
Staff number: [5] [] [] []
Date: [] [] [] [] [2] [0] [] []
Researcher ID: [] [] []

Neuropsychiatric Inventory

IN THE LAST FOUR WEEKS.....

1. Delusions

Does the resident have beliefs that you know are not true? For example, insisting that people are trying to harm him/her or steal from him/her. Has he/she said the family members are not who they say they are or that the house is not their home? I'm not asking about mere suspiciousness, I am interested if the resident is convinced that these things are happening to him/her.

not applicable *no (proceed to next question)* *yes (proceed to sub questions)*

[If, yes please answer A and B, using the prompt questions below]

1. *does the resident believe that he/she is in danger– that others are planning to hurt him/her?*
2. *does the resident believe that others are stealing from him/her?*
3. *does the resident believe that his/her spouse is having an affair?*
4. *does the resident believe that unwelcome guests are living in his/her house?*
5. *does the resident believe that his/her spouse or others are not who they claim to be?*
6. *does the resident believe that his/her house is not his/her home?*
7. *does the resident believe that family members plan to abandon him/her?*
8. *does the resident believe that television or magazine figures are actually present in home? (does he/she try to talk or interact with them?)*
9. *does the resident believe any other unusual things that I haven't asked about?*

A-Frequency:

- 1 **occasionally** – less than once per week
- 2 **often** – about once per week
- 3 **frequently** – several times per week but less than every day
- 4 **very frequently** – once or more per day

B-Severity:

- 1 **mild** – delusions present but seem harmless and produce little distress to resident
- 2 **moderate** – delusions are distressing and disruptive
- 3 **marked** – delusions are very disruptive and are a major source of behavioural disruption (if PRN medications are prescribed, their use signals that the delusions are of marked severity)

Care home Number: [] [] [] []
Resident Number: [] [] [] []
Staff number: [5] [] [] []
Date: [] [] [] [] [2] [0] [] []
Researcher ID: [] [] []

2. Hallucinations

Does the resident have hallucinations such as false visions or voices? Does he/she seem to see, hear or experience things that are not present? By this question we do not mean just mistaken beliefs such as stating that someone who has died is still alive, rather we are asking if the resident actually has abnormal experiences of sounds, or visions.

not applicable no (proceed to next screening question) yes

[If, yes please answer A and B, using the prompt questions below]

1. does the resident describe hearing voices or act as if he/she hears voices?
2. does the resident talk to people who are not there?
3. does the resident describe seeing things not seen by others or behave as if he/she is things not seen by others (people, animals, lights etc)?
4. does the resident report smelling odours not smelled by others?
5. does the resident describe feeling things on his/her skin or otherwise appear to be feeling things crawling or touching him/her?
6. does the resident describe tastes that are without any known cause?
7. does the resident describe any other unusual sensory experience?

A-Frequency:

- 1 occasionally – less than once per week
 2 often – about once per week
 3 frequently – several times per week but less than every day
 4 very frequently – once or more per day

B-Severity:

- 1 mild – hallucinations present but seem harmless and cause CR little distress
 2 moderate – hallucinations are distressing and are disruptive to CR
 3 marked – hallucinations are very disruptive and are a major source of behavioural disturbance. PRN medications may be required to control them

Care home Number: [1 1]
Resident Number: [1 1]
Staff number: [5 1 1]
Date: [1 1] [1 1] [2 1 0 1]
Researcher ID: [1 1]

3. Agitation/Aggression

Does the resident have periods when he/she refuses to cooperate or won't let people help him/her? Is he/she hard to handle?

not applicable no (proceed to next screening question) yes

[If, yes please answer A and B, using the prompt questions below]

1. *does the resident get upset with those trying to care for him/her or resist activities such as bathing or changing clothes?*
2. *is the resident stubborn, having to have things his/her way?*
3. *is the resident uncooperative, resistive to help from others?*
4. *does the resident have any other behaviours that make him/her hard to handle?*
5. *does the resident shout or curse angrily?*
6. *does the resident slam doors, kick furniture, throw things?*
7. *does the resident attempt to hurt or hit others?*
8. *does the resident have any other aggressive or agitated behaviours?*

A-Frequency:

- 1 occasionally – less than once per week
 2 often – about once per week
 3 frequently – several times per week but less than every day
 4 very frequently – once or more per day

B-Severity:

- 1 mild – behaviour is disruptive but can be managed with redirection or reassurance
 2 moderate – behaviours disruptive and difficult to redirect or control
 3 marked – agitation is very disruptive and difficult to redirect or control; there may be a threat of personal harm. Medications are often required

Care home Number: [] [] [] []
Resident Number: [] [] [] []
Staff number: [5] [] [] []
Date: [] [] [] [] [2] [1] [0] [] [] []
Researcher ID: [] [] [] []

4. Depression/Dysphoria

Does the resident seem sad or depressed? Does he/she say that he/she feels sad or depressed?

not applicable no (proceed to next screening question) yes

[If, yes please answer A and B, using the prompt questions below]

1. *does the resident have periods of tearfulness or sobbing that seem to indicate sadness?*
2. *does the resident say or act as if he/she is sad or in low spirits?*
3. *does the resident put him/herself down or say that he/she feels like a failure?*
4. *does the resident say that he/she is a bad person or deserves to be punished?*
5. *does the resident seem very discouraged or say that he/she has no future?*
6. *does the resident say he/she is a burden to the family or that the family would be better off without him/her?*
7. *does the resident express a wish for death or talk about killing him/herself?*
8. *does the resident show any other signs of depression or sadness?*

A-Frequency:

- 1 **occasionally** – less than once per week
 2 **often** – about once per week
 3 **frequently** – several times per week but less than every day
 4 **very frequently** – essentially continuously present

B-Severity:

- 1 **mild** – depression is present but usually responds to redirection or reassurance
 2 **moderate** – depression is distressing, depressive symptoms are spontaneously voiced by CR and difficult to alleviate
 3 **marked** – depression is very distressing and a major source of suffering for the Resident

Care home Number: [] [] [] []
Resident Number: [] [] [] []
Staff number: [5] [] [] []
Date: [] [] [] [] [2] [0] [] []
Researcher ID: [] [] []

5. Anxiety

Is the resident very nervous, worried or frightened for no apparent reason? Does he/she seem very tense or fidgety? Is the resident afraid to be apart from you?

not applicable no (proceed to next screening question) yes

[If, yes please answer A and B, using the prompt questions below]

1. *does the resident say that he/she is worried about planned events?*
2. *does the resident have periods of feeling shaky, unable to relax, or feeling excessively tense?*
3. *does the resident have periods of (or complain of) shortness of breath, gasping or sighing for no other reason than nervousness?*
4. *does the resident complain of butterflies in his/her stomach, or of racing or pounding of heart in association with nervousness? (Symptoms not explained by ill health)*
5. *does the resident avoid certain places or situations that make him/her more nervous such as riding in the car, meeting with friends, or being in crowds?*
6. *does the resident become nervous and upset when separated from you (or his/her caregiver)? (does he/she cling to you to keep from being separated?)*
7. *does the resident show any other signs of anxiety?*

A-Frequency:

- 1 occasionally – less than once per week
 2 often – about once per week
 3 frequently – several times per week but less than every day
 4 very frequently – once or more per day

B-Severity:

- 1 mild – anxiety is distressing but usually responds to redirection or reassurance
 2 moderate – anxiety is distressing, anxiety symptoms are spontaneously voiced by the resident and difficult to alleviate
 3 marked – anxiety is very distressing and a major source of suffering for the resident

Care home Number: [] [] [] []
Resident Number: [] [] [] []
Staff number: [5] [] [] []
Date: [] [] [] [] [2] [0] [] []
Researcher ID: [] [] []

6. Elation/Euphoria

Does the resident seem to be too cheerful or too happy for no reason? I don't mean the normal happiness that comes from seeing friends, receiving presents, or spending time with family members. I am asking if the resident has a persistent and abnormally good mood or finds humour where others do not.

not applicable no (proceed to next screening question) yes

[If, yes please answer A and B, using the prompt questions below]

1. *does the resident appear to feel too good or to be too happy, different from his/her usual self?*
2. *does the resident find humour and laugh at things that others do not find funny?*
3. *does the resident seem to have a childish sense of humour with a tendency to giggle or inappropriately (such as when unfortunate things happens to others)?*
4. *does the resident tell jokes or make remarks that have little humour for others but seem funny to him/her?*
5. *does he/she play childish pranks such as pinking or playing "keep away" for the fun of it?*
6. *does the resident "talk big" or claim to have more abilities or wealth than is true?*
7. *does the resident show any other signs of feeling too good or being too happy?*

A-Frequency:

- 1 occasionally – less than once per week
 2 often – about once per week
 3 frequently – several times per week but less than every day
 4 very frequently – essentially continuously present

B-Severity:

- 1 mild – elation is notable to friends and family but is not disruptive
 2 moderate – elation is notably abnormal
 3 marked – elation is very pronounced, resident is euphoric and finds nearly everything to be humorous

Care home Number: [] [] [] []
Resident Number: [] [] [] []
Staff number: [5] [] [] []
Date: [] [] [] [] [2] [0] [] []
Researcher ID: [] [] [] []

7. Apathy/Indifference

Has the resident lost interest in the world around him/her? Has he/she lost interest in doing things or lack motivation for starting new activities? Is he/she more difficult to engage in conversation or in doing chores? Is the resident apathetic or indifferent?

not applicable no (proceed to next screening question) yes

[If, yes please answer A and B, using the prompt questions below]

1. does the resident seem less spontaneous and less active than usual?
2. is the resident less likely to initiate a conversation?
3. is the resident less affectionate or lacking in emotions when compared to his/her usual self?
4. does the resident contribute less to household chores?
5. does the resident seem less interested in the activities and plans of others?
6. has the resident lost interest in friends and family members?
7. is the resident less enthusiastic about his/her usual interests?
8. does the resident show any other signs that she doesn't care about doing new things?

A-Frequency:

- 1 occasionally – less than once per week
 2 often – about once per week
 3 frequently – several times per week but less than every day
 4 very frequently – nearly always present

B-Severity:

- 1 mild – apathy is notable but produces little interference with daily routines; only mildly different from resident's usual behaviour; resident responds to suggestion engage in activities
 2 moderate – apathy is very evident; may be overcome by the caregiver with coaxing and encouragement; responds spontaneously only to powerful events such as visits from close relatives or family members
 3 marked – apathy is very evident and usually fails to respond to any encouragement or external events

Care home Number: [] [] [] []
Resident Number: [] [] [] []
Staff number: [5] [] [] []
Date: [] [] [] [] [2] [0] [] []
Researcher ID: [] [] []

8. Disinhibition

Does the resident seem to act impulsively without thinking? Does he/she do or say things that are not usually done or said in public? Does he/she do things that are embarrassing to you or others?

not applicable no (proceed to next screening question) yes

[If, yes please answer A and B, using the prompt questions below]

1. does the resident act impulsively without appearing to consider the consequences?
2. does the resident talk to total strangers as if he/she knew them?
3. does the resident say things to people that are insensitive or hurt their feelings?
4. does the resident say crude things or make sexual remarks that they would not usually have said?
5. does the resident talk openly about very personal or private matters not usually discussed in public?
6. does the resident take liberties or touch or hug others in a way that is out of character for him/her?
7. does the resident show any other signs of loss of control of his/her impulses?

A-Frequency:

- 1 occasionally – less than once per week
 2 often – about once per week
 3 frequently – several times per week but less than every day
 4 very frequently – essentially continuously present

B-Severity:

- 1 mild – disinhibition is notable but usually responds to redirection and guidance
 2 moderate – disinhibition is very evident and difficult to overcome by the caregiver
 3 marked – disinhibition usually fails to respond to any intervention by the caregiver, and is a source of embarrassment or social distress

Care home Number: [] [] [] []
Resident Number: [] [] [] []
Staff number: [5] [] [] []
Date: [] [] [] [] [2] [0] [] []
Researcher ID: [] [] [] []

9. Irritability/Lability

Does the resident get irritated and easily disturbed? Are his/her moods very changeable? Is he/she abnormally impatient? We do not mean frustration over memory loss or inability to perform usual tasks; we are interested to know if the resident has abnormal irritability, impatience, or rapid emotional changes different from his/her usual self.

not applicable no (proceed to next screening question) yes

[If, yes please answer A and B, using the prompt questions below]

1. does the resident have a bad temper, flying "off the handle" easily over little things?
2. does the resident rapidly change moods from one to another, being fine one minute and angry the next?
3. does the resident have sudden flashes of anger?
4. is the resident impatient, having trouble coping with delays or waiting for planned activities?
5. is the resident cranky and irritable?
6. is the resident argumentative and difficult to get along with?
7. does the resident show any other signs of irritability?

A-Frequency:

- 1 occasionally – less than once per week
- 2 often – about once per week
- 3 frequently – several times per week but less than every day
- 4 very frequently – essentially continuously present

B-Severity:

- 1 mild – irritability or lability is notable but usually responds to redirection and reassurance
- 2 moderate – irritability and lability are very evident and difficult to overcome by the caregiver
- 3 marked – irritability and lability are very evident, they usually fail to respond to any intervention by the caregiver, and they are a major sources of distress

Care home Number: [] [] [] []
Resident Number: [] [] [] []
Staff number: [5] [] [] []
Date: [] [] [] [] [2] [0] [] []
Researcher ID: [] [] []

10. Aberrant motor behaviour

Does the resident pace, do things over and over such as opening wardrobes or drawers, or repeatedly pick at things or wind string or threads?

not applicable no (proceed to next screening question) yes

[If, yes please answer A and B, using the prompt questions below]

1. *does the resident pace around the house without any apparent purpose?*
2. *does the resident rummage around opening and unpacking drawers or closets?*
3. *does the resident repeatedly put on and take off clothing?*
4. *does the resident have repetitive activities or "habits" that he/she performs over and over?*
5. *does the resident engage in repetitive activities such as handling buttons, picking, wrapping string, etc.?*
6. *does the resident fidget excessively, seem unable to sit still, or bounce his/her feet or tap his/her fingers a lot?*
7. *does the resident do any other activities over and over?*

A-Frequency:

- 1 occasionally – less than once per week
 2 often – about once per week
 3 frequently – several times per week but less than every day
 4 very frequently – essentially continuously present

B-Severity:

- 1 mild – abnormal motor activity is notable but produces little interference with daily routines
 2 moderate – abnormal motor activity is very evident; can be overcome by the caregiver
 3 marked – abnormal motor activity is very evident, it usually fails to respond to any intervention by the caregiver and is a major source of distress

Care home Number: [] [] [] []
Resident Number: [] [] [] []
Staff number: [5] [] [] []
Date: [] [] [] [] [2] [1] [0] [] [] []
Researcher ID: [] [] [] []

11. Sleep

Does the resident have difficulty sleeping (do not count as present if the resident simply gets up once or twice per night only to go to the bathroom and falls back asleep immediately)? Is he/she up at night? Does he/she wander at night, get dressed or disturb your sleep?

not applicable no (proceed to next screening question) yes

[If, yes please answer A and B, using the prompt questions below]

1. *does the resident have difficulty falling asleep?*
2. *does the resident get up during the night (do not count if the resident simply gets up once or twice per night only to go to the bathroom and falls back asleep immediately)?*
3. *does the resident wander, pace or get involved in inappropriate activities at night?*
4. *does the resident awaken you during the night?*
5. *does the resident awaken during the night, dress and plan to go out, thinking that it is morning and time to start the day?*
6. *does the resident awaken too early in the morning (earlier than was his/her habit)?*
7. *does the resident sleep excessively during the day?*
8. *does the resident have any other night-time behaviours that bother you that we haven't talked about?*

A-Frequency:

- 1 **occasionally** – less than once per week
- 2 **often** – about once per week
- 3 **frequently** – several times per week but less than every day
- 4 **very frequently** – once or more per day

B-Severity:

- 1 **mild** – night-time behaviours occur but they are not particularly disruptive
- 2 **moderate** – night-time behaviours occur and disturb the resident and the sleep of the caregiver; more than one type of night-time behaviour may be present
- 3 **marked** – night-time behaviours occur; several types of night-time behaviour may be present; the resident is very distressed during the night and the caregiver's sleep is markedly disturbed

Care home Number: [] [] [] []
Resident Number: [] [] [] []
Staff number: [5] [] [] []
Date: [] [] [] [] [2] [0] [] []
Researcher ID: [] [] []

12. Appetite and eating disorders

Has he/she had any change in appetite, weight, or eating habits (count as NA if the resident is incapacitated and has to be fed)? Has there been any change in type of food he/she prefers?

not applicable no (proceed to next screening question) yes

[If, yes please answer A and B, using the prompt questions below]

1. has he/she had a loss of appetite?
2. has he/she had an increase in appetite?
3. has he/she had a loss of weight?
4. has he/she gained weight?
5. has he/she had a change in eating behaviour such as putting too much food in his/her mouth at once?
6. has he/she had a change in the kind of food he/she likes such as eating too many sweets or other specific types of food?
7. has he/she developed eating behaviours such as eating exactly the same types of food each day or eating the food in exactly the same order?
8. Have there been any other changes in appetite or eating that I haven't asked about?

A-Frequency:

- 1 occasionally – less than once per week
 2 often – about once per week
 3 frequently – several times per week but less than every day
 4 very frequently – once or more per day

B-Severity:

- 1 mild – changes in appetite or eating are present but have not led to changes in weight and are not disturbing
 2 moderate – changes in appetite or eating are present and cause minor fluctuations in weight
 3 marked – obvious changes in appetite or eating are present and cause fluctuations in weight, are embarrassing, or otherwise disturb the resident

Care home Number: [] [] [] []
 Staff number: [5] [] [] []
 Date: [] [] [] [] [2] [0] [] []
 Researcher ID: [] [] []

How often have you been doing this:	1 Not at all	2 A little bit	3 A medium amount	4 A lot
15. I've been getting comfort and understanding from someone				
16. I've been giving up the attempt to cope				
17. I've been looking for something good in what is happening				
18. I've been making jokes about it				
19. I've been doing something to think about it less, such as going to the cinema, watching TV, reading, daydreaming, sleeping or shopping				
20. I've been accepting the reality of the fact that it has happened				
21. I've been expressing my negative feelings				
22. I've been trying to find comfort in my religion or spiritual beliefs				
23. I've been trying to get advice or help from other people about what to do				
24. I've been learning to live with it				
25. I've been thinking hard about what steps to take				
26. I've been blaming myself for things that happened				
27. I've been praying or meditating				
28. I've been making fun of the situation				

Appendix 25 Maslach burnout inventory (MBI)

Care home Number: [1 1 1]
 Staff number: [5 1 1 1]
 Date: [1 1] [1 1] [2 1 0] [1 1]
 Researcher ID: [1 1]

Maslach burnout inventory

These items ask *how burnt out* your job as a carer makes you feel. We want to know *how often* you've been doing what the item says.

	0 Never	1 A few times per year	2 Once a month	3 A few times per month	4 Once a week	5 A few times per week	6 Every day
1. I feel emotionally drained from my work							
2. I feel used up at the end of the workday							
3. I feel tired when I get up in the morning and have to face another day at work							
4. I can easily understand how clients feel about things							
5. I feel I treat some clients as if they were impersonal objects.							
6. Working with people all day is a real strain for me							
7. I deal very effectively with the problems of clients							
8. I feel burned out from my work							
9. I feel I am positively influencing other peoples' lives through my work							
10. I have become more callous (<i>uncaring</i>) toward people since I took this job							
11. I worry that this job is hardening me emotionally							
12. I feel very energetic							

Care home Number: [1 1]

Staff number: [5 1 1]

Date: [1 1] [1 1] [2 1 0]

Researcher ID: [1 1]

	0 Never	1 A few times per year	2 Once a month	3 A few times per month	4 Once a week	5 A few times per week	6 Every day
13. I feel frustrated by my job							
14. I feel I am working too hard on my job							
15. I don't really care what happens to some clients							
16. Working with people directly puts too much stress on me							
17. I can easily create a relaxed atmosphere with clients							
18. I feel exhilarated (<i>happy and energetic</i>) after working closely with clients							
19. I have accomplished many worthwhile things in this job							
20. I feel like I am at the end of my tether (<i>feel like I cannot take any more</i>)							
21. In my work, I deal with emotional problems very calmly							
22. I feel clients blame me for some of their problems							

Appendix 26 Sense of Competence in Dementia Care Staff (SCIDS) scale

Care home Number: [] [] [] []

Staff number: [5] [] [] []

Date: [] [] [] [] [2] [0] [] []

ResearcherID: [] [] []

Sense of competence in dementia care staff – FOLLOW UP

Working with people with dementia is complex. It takes a lot of skill and ability. Staff need to be well supported in their work. The questions below try to find out how you feel about the things you might do in your work and where you might need support.

How well do you feel you can.....

1. Understand the feelings of a person with dementia?	Not at all	A little bit	Quite a lot	Very much
2. Understand the way a person with dementia interacts with people and things around them?	Not at all	A little bit	Quite a lot	Very much
3. Engage a person with dementia in conversation?	Not at all	A little bit	Quite a lot	Very much
4. Balance the needs of the person with dementia with their relative's wishes and the service's limitations?	Not at all	A little bit	Quite a lot	Very much
5. Use information about their past (such as what they used to do and their interests), when talking to a person with dementia?	Not at all	A little bit	Quite a lot	Very much
6. Change your work to match the changing needs of a person with dementia?	Not at all	A little bit	Quite a lot	Very much
7. Keep up a positive attitude towards the people you care for?	Not at all	A little bit	Quite a lot	Very much
8. Keep up a positive attitude towards the relatives of a person with dementia?	Not at all	A little bit	Quite a lot	Very much
9. Keep yourself motivated during a working day?	Not at all	A little bit	Quite a lot	Very much
10. Play an active role in your staff team?	Not at all	A little bit	Quite a lot	Very much
11. Protect the dignity of a person with dementia in your work?	Not at all	A little bit	Quite a lot	Very much
12. Deal with personal care, such as incontinence in a person with dementia?	Not at all	A little bit	Quite a lot	Very much

Care home Number: [] [] [] []
 Staff number: [5] [] [] []
 Date: [] [] [] [] [2] [0] [] []
 ResearcherID: [] [] []

13. Deal with behaviour that challenges in a person with dementia?	Not at all	A little bit	Quite a lot	Very much
14. Decide what to do about risk (such as harm to self or others) in a person with dementia?	Not at all	A little bit	Quite a lot	Very much
15. Offer stimulation (for the mind, the senses and the body) to a person with dementia in your daily work?	Not at all	A little bit	Quite a lot	Very much
16. Offer choice to a person with dementia in everyday care (such as what to wear, or what to do)?	Not at all	A little bit	Quite a lot	Very much
17. Engage a person with dementia in creative activities during your normal working day?	Not at all	A little bit	Quite a lot	Very much

Appendix 27 Revised Modified Conflict Tactics Scale (MCTS)

Care home Number: [] [] [] []

Caring can be stressful and difficult, especially when time is short. Sometimes things work out and sometimes they don't. We are interested to know how things are.

This questionnaire is completely anonymous and you cannot be identified. In the last three months, have you been aware that you or other staff have:

	Never	Almost never	Some-times	Most of the time	All the time
1. Taken a resident out for their enjoyment					
2. Not given a resident enough time for food, or fed them too quickly					
3. Planned an activity for a resident that fits with their particular interests					
4. Isolated a resident e.g. in their room because staff are cross with them					
5. Told a resident that they will be sent away					
6. Talked to a resident nicely while giving personal care					
7. Avoided a resident who has challenging behaviour					
8. Not taken enough care when moving or handling a resident					
9. Involved a resident's family in care planning					
10. Ignored a resident while giving care or when they ask for help					
11. Spent time getting to know a resident					
12. Made a resident wait for care e.g. to go to the toilet					
13. Threatened to use physical force on a resident					
14. Enjoyed spending time with a resident, just to keep them company					
15. Shouted at, insulted or spoken harshly to a resident					
16. Hit or shaken a resident					

Appendix 28 Sample fidelity checklist used in feasibility study

Check List MARQUE session 1

Facilitator 1 Name: _____
 Facilitator 2 Name: _____
 Group number: _____
 Assessor: _____

Introduction	
All information covered	
Successfully facilitate introductions between selves and participants	
Outline and agree ground rules	
Overview of dementia	
All information covered	
Elicit how dementia impacts on work of staff	
What is agitation?	
All information covered	
Elicit specific examples of agitation that staff find difficult to manage	
What works well for agitation?	
All information covered	
Facilitate discussion on what works well, eliciting specific examples from staff	
Getting to know the person with dementia	
All information covered	
Explain and facilitate practice of 'call to mind' in session	
Successfully address questions and concerns raised by staff	
Managing the stress that caring brings	
All information covered with appropriate interaction, asking staff if these feelings describe how they felt recently	

The importance of reducing stress	
All information covered	
How stressed are you at the moment	
All information covered	
Facilitate exercise about a recent stressful experience	
The signal breath	
All information covered	
Teach signal breath	
Rate stress before and after	
Putting it into practice	
All information covered	
Summarise the session	
Remind staff to practice stress reduction technique	
Remind people to practice 'call to mind'	
Troubleshoot around 'putting it into practice' between session tasks	

Process factors (rate each facilitator separately)	Facilitator 1 1 not at all – 5 very much	Facilitator 2 1 not at all – 5 very much
Keeping the session to time		
Keeping the group focussed on the manual		
Keeping the group engaged in the session		
Managing dynamics in the group		



**Study to improve agitation and quality of life for people with dementia in care homes:
Feedback on intervention manual for care home staff**

Introductions: Thank you for agreeing to take part in this focus group. As you know I am a researcher from University College London and I will be conducting and recording this focus group. Everything you say is confidential but I would like you to introduce yourselves for the recording so that the typist can identify you. My name is....

Description of the research:

We are here today to talk to you all about the MARQUE training sessions which you have all attended over the last couple of months. Spring View is the first home where we have delivered the training and we are very keen to hear from all of you about how you found the sessions, what you liked and did not like and how you feel it has made a difference to your work.

Over the next year and a half we will be testing out the training intervention in a number of care homes as part of a randomised controlled trial and we hope that it will help staff to prevent and cope with agitation and lead to improvement in quality of life for people with dementia.

Before we finalise the intervention, we want to get feedback from staff who have taken part in the sessions as it is important that we develop an intervention which fits with the busy care home environment and which is practical and usable in your day to day care.

We are interested in hearing from everyone, whether you are a care assistant, a nurse, a manager or an activities coordinator as you will all have different points of view about the sessions.

As a quick reminder, the six sessions of MARQUE intervention were:

- ★ Session 1: Getting to know the person with dementia
- ★ Session 2: Pleasant Events
- ★ Session 3: Improving Communication
- ★ Session 4: Understanding Agitation
- ★ Session 5: Practical Responses and Making a Plan
- ★ Session 6: What works? Using skills and strategies in the future

Q. Can we start by hearing about how you found the sessions in general?

Prompts:

- What did you like best about the sessions?
- Was there anything that you did not like about the sessions?
- Is there anything important that you feel was missing/ not covered?
- Was it easy to understand?
- What were the key points that stood out for you?

Q. What did you think about the content of each sessions? (Prompt about specific sessions/content where necessary).

Prompts:

- o Which topics did you find the most helpful?
- o Which topics did you find the least helpful?
- o Is there anything that you think we should change?

Q. How did you find the manual?

Prompts:

- o How did you find the layout?
- o Was it easy to read and follow, e.g. not too much text on each page / fonts / colours?
- o How did you find the quotes?
- o What did you think of the pictures and images – more, less, different?

Q. How did you find the exercises and tasks between the sessions?

Prompts:

- o Ask about relaxation / small group discussions & homework tasks
- o What made it easier for you to do the tasks between the sessions?
- o What made it harder for you to do the tasks between the sessions?
- o Is there anything else that the facilitators could have done to help with this?

Q. How have you used what you learnt in the sessions in your work?

Prompts:

- o Which parts of the sessions have you been putting into practice?
- o What has made it harder to put what you learnt into practice?
- o What has made it easier putting what you learnt into practice?
- o How have your champions been useful in helping with this?
- o Have you noticed any changes in your interactions with the residents since taking part in MARQUE?
- o Have you noticed any changes in your interactions in the team since taking part in MARQUE?

Q. Before we finish, is there anything else you would like to mention that we have not already covered?

Next week the facilitators will be coming back to go through the action plans you made in the sessions and to troubleshoot any difficulties you have had, I will also be coming back in a couple of weeks to offer supervision and support on putting MARQUE into practice.

I look forward to seeing you all again then.

Thank you for taking part today.

Detailed summary of the sessions:

Session 1: Getting to know the person with dementia

- Overview of dementia
- What is agitation?
- What works well supporting people with dementia?
- Getting to know the person with dementia
- Introducing 'Call to Mind'
- Managing the stress that caring can bring: The signal breath

Session 2: Pleasant events

- Recap on 'getting to know the person with dementia'
- The importance of pleasant events
- What is a pleasant event?
- Creating a list of pleasant events
- Activities for people with severe dementia
- Building activities into day to day care
- Relaxation: Focus ed Breathing

Session 3: Improving communication

- Recap on 'Pleasant Events'
- Communicating with people with dementia
- Communicating within the team
- Communicating with relatives
- Relaxation: Guided imagery

Session 4: Understanding agitation

- Recap on Session 'Improving Communication'
- Understanding Agitation
- The *DICE* approach to managing agitation
- DESCRIBING agitation
- INVESTIGATING the causes of agitation
- Relaxation: Stretching

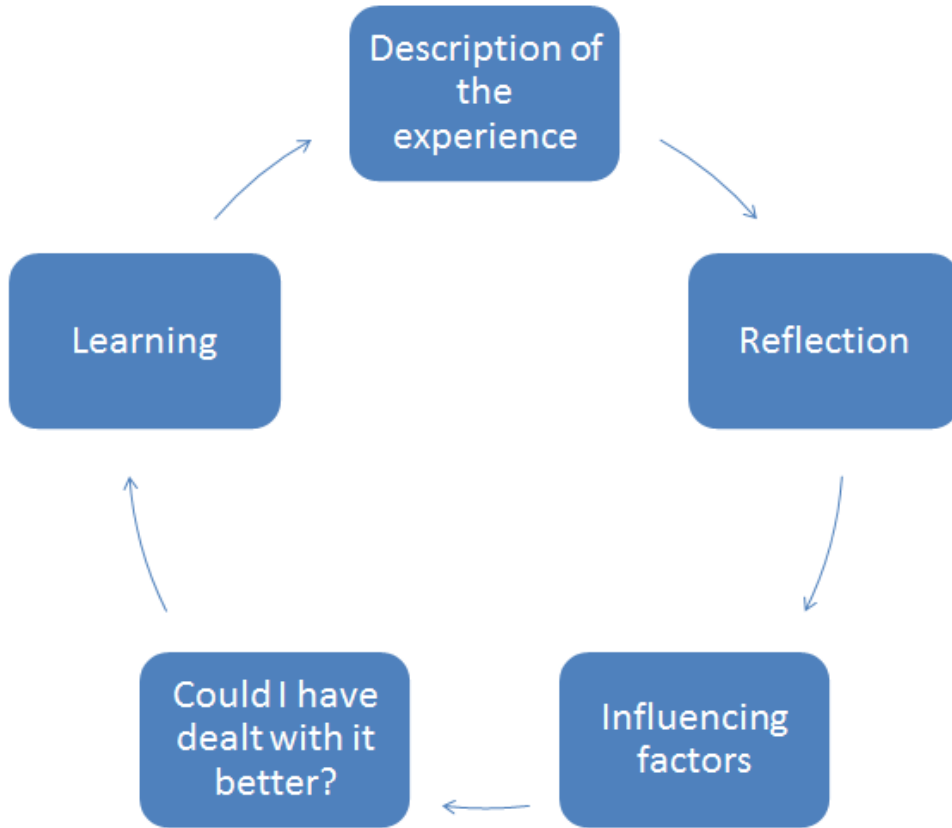
Session 5: Practical responses and making a plan

- Recap on 'Understanding Agitation'
- CREATING strategies to manage agitation
- Practical and environmental adaptations
- When to ask for help from outside agencies?
- Building strategies into a care plan
- Evaluate: Seeing what works
- Relaxation: Guided Imagery 2

Session 6: What works? Using skills and strategies in the future

- Recap on 'Practical responses and making a plan'
- Putting it all together
- What works? (going through each section)
- Keeping it going – developing an action plan

Johns's model of reflection:



Johns C (1995) Framing learning through reflection within Carper's fundamental ways of knowing in nursing. *Journal of Advanced Nursing*, 22, 2,226-234

Reflective Log (Based on Johns (1995))	
Date: Group:	RA: Session number:
Description of the experience: (What happened? Key points to consider? What did you do? What did the participants do?)	
Reflection: (What was I trying to achieve? What were the consequences? How did I feel as it was happening? What effect did I see in the participants?)	
Influencing factors: (What internal factors influenced my decision making/actions? What external factors influenced my decision making/actions?)	
Could I have dealt with it better? (What worked well? What else could I have tried? What effect might other strategies have?)	
Learning? (How do I feel now about the experience? How has the experience changed my understanding/knowledge/practice? What Action will I take as a result of the experience?)	

Table A: Number (%) of care home staff reporting that they had seen or carried out each potentially abusive behaviour at least sometimes in the last three months

MCTS abusive behaviours	Endorsing sometimes or more frequent occurrence	
	Baseline <i>n</i> (%)	8 month <i>n</i> (%)
Physical and verbal abuse		
Hit or shaken a resident	1(5)	0(0)
Threatened to use physical force on a resident	1(5)	1(6)
Shouted, insulted or spoken harshly to a resident	2(10)	0(0)
Neglect		
Made a resident wait for care	7 (33)	4(24)
Avoided a resident with challenging behaviour	7(35)	3(18)
Not given a resident enough time for food	6(29)	2(12)
Not taken enough care when moving a resident	1(5)	2(12)
Ignored a resident while giving care or when they ask for help	4(20)	3(18)
Isolated a resident	3(15)	0(0)
Told a resident they will be sent away	1(5)	0(0)
<i>Any abusive behaviour (at least sometimes)</i>	10(53)	8(47)

Table B: Number (%) of staff reporting that they had never or almost never seen or carried out each positive behaviour in the last 3 months

	Endorsing never or almost never occurring	
	Baseline <i>n</i> (%)	8 month <i>n</i> (%)
Positive behaviours		
Taken resident out for their enjoyment	7(35)	5(29)
Planned an activity that fits with their interests	5(24)	0(0)
Involved a resident's family in care planning	1(5)	0(0)
Spent time getting to know a resident	1(5)	1(6)
Enjoyed spending time with a resident just to keep them company	0(0)	0(0)
Talked to a resident nicely while giving personal care	0(0)	0(0)
<i>Any positive behaviour (never or almost never)</i>	8(42)	5(31)

Appendix 32 Action plans made in care home

UCL	UCL
<p style="text-align: center;">MARQUE – keeping it going! <u>Action Plan 1: MARQUE meetings</u></p> <p>What's the Plan? To use the supervisions from MARQUE researchers to look through the MARQUE folders and troubleshoot any issues. To maintain these meetings after the researchers stop coming in.</p> <p>Who will do this? Everyone: unit by unit.</p> <p>When and how often will this be done? When a suitable time is agreed with management. Fortnightly and then at least monthly.</p> <p>How will everyone know about it? Reminders in message board and the communication book.</p> <p>What will make this more likely to happen/how can your champions support you? Support from management and researchers. Communication within the home. Commitment to continuing with MARQUE.</p>	<p style="text-align: center;">MARQUE – keeping it going! <u>Action Plan 2: Continuing with Call to mind</u></p> <p>What's the plan? To keep using Call to mind with residents regularly.</p> <p>Who will do this? One member of activity staff with a member of care staff and a resident.</p> <p>When and how often will this be done? Two times a week: once on HDU and once downstairs.</p> <p>How will everyone know about it? Carers will be allocated and names written on the message board and activities schedule so that everyone can see.</p> <p>What will make this more likely to happen/how can your champions support you? Activities staff to organise and putting it down on the activities schedule. Discuss at MARQUE meetings.</p>

UCL	UCL
<p style="text-align: center;">MARQUE – keeping it going! <u>Action Plan 3: Using Strategies to Manage Agitation</u></p> <p>What's the plan? Use the DICE model to create strategies to manage agitation and communicate these strategies within the team. This will be done by writing record forms for agitated residents and creating care plans.</p> <p>Who will do this? All staff members will be able to fill in the forms. Researchers will bring the forms and Renu will create the folders.</p> <p>When and how often will this be done? Staff can use the DICE record forms and add to the care plan when they notice agitation and feel it would help. The DICE model will be used to talk through agitation in handovers and the MARQUE meetings.</p> <p>How will everyone know about it? Folders will be kept on each floor with a DICE record form and care plan for each resident. Mentioned at handover and MARQUE meetings.</p> <p>What will make this more likely to happen/how can your champions support you? MARQUE meetings & DICE posters (researchers will bring these).</p>	<p style="text-align: center;">MARQUE – keeping it going! <u>Action Plan 4: Keep staff relaxed</u></p> <p>What's the plan? For staff to keep taking time to relax, either in small groups or individually.</p> <p>Who will do this? Anyone!</p> <p>When and how often will this be done? Groups: when morning and afternoon staff overlap (13.30 – 15.00), between 20.00 – 21.00 or when there's a quiet time. This can be done once a week or however often carers feel they want it and can do it. Individuals: can take place during breaks, after work or any time staff feel they want to.</p> <p>How will everyone know about it? MARQUE meetings, remind each other by word of mouth.</p> <p>What will make this more likely to happen/how can your champions support you? Support from management. CDs available to use in home (in CD folder, in activities room, in MARQUE folders on floors). Champions can encourage and remind people.</p>

MARQUE – keeping it going!

Action Plan 5: Sharing information

What's the Plan?

Write down successful communication strategies and pleasant events that have worked with residents.

Who will do this?

Everyone

When and how often will this be done?

When there is time and new information is found out.

How will everyone know about it?

Discussed in MARQUE meetings

What will make this more likely to happen/how can your champions | support you?

Champions can look through folders monthly and/or in MARQUE meetings and remind other staff.

Appendix 33 Implementation guide for use in RCT

MARQUE implementation guide

Introduction:

- This is a brief guide for the facilitators of the MARQUE intervention to assist in the delivery of the intervention during the RCT.]
- This guide will cover the set up period in the home, the intervention delivery (including both the training and supervision period).

Key points:

- In advance of the set-up, facilitators will have received an in depth training in delivering the intervention and undertaken a period of self-directed learning.
- Remember, the more familiar you are with the material, the more confident you will feel about delivery. Practice in pairs so that you are used to working with your co-facilitator.
- If you have any concerns about process of intervention delivery or worries about what staff are telling you or how they are interacting, these can be raised in clinical supervision or with a senior staff member in between times.
- It is vital that care home managers and staff are engaged with the intervention. In addition to the specific structured meetings detailed below, spend time in the home getting to know staff and answering any questions or concerns that they may have. Encourage care home staff to see you as a supportive resource.
- Always remember to value the expertise and skills of the care home staff and be mindful of the multiple demands on their time.



1

Preparing to deliver MARQUE: Set up period

1. Initial introductory meeting in care home

The initial set up meeting with the care home manager will be arranged by the project manager. Encourage the manager to invite key members of staff within the home, e.g. deputy manager, activities coordinators. Ideally at least one of the facilitators will attend with project manager and team clinical psychologist.

Key tasks at initial meeting:

- Introduce the format of the intervention and key aspects of approach, including training all staff, building activities into routine care, putting plans into practice and tailoring to individual home context.
- Respond to specific concerns or questions from care home management.
- Outline responsibilities of MARQUE team and care home teams.
- Explain to the manager the rationale for wanting to train the whole team including managers and senior staff.
- Negotiate with managers how best to organise training delivery e.g. how many groups, best time / day to deliver and decide who will be responsible for organising group allocation and inform staff.
- Agree how best to maximise attendance including ways to ensure staff cover to release staff and re-numeration for staff time.
- Check list of staff eligible for training is accurate and up to date.
- Identify a room for training.
- Discuss the role of champions and identify at least one per unit.
- Outline the structure of the supervision period and make initial plan for how this should be organised in the home.
- Agree a start date for intervention delivery and arrange a follow up meeting to bring materials and speak to champions.

Key outcomes of initial meetings:

- An agreed plan for intervention delivery with clear timelines and agreed roles and responsibilities.
- Management and senior staff buy in to facilitate intervention delivery process.
- Updated list of staff and named champions.

2

MARQUE implementation guide

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- Respond to specific concerns or questions from care home management.
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- Explain to the manager the rationale for wanting to train the whole team including managers and senior staff.
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- Agree how best to maximise attendance including ways to ensure staff cover to release staff and re-numeration for staff time.
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Key outcomes of initial meetings:

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2

Mid training check in meeting:

After three sessions facilitators should arrange a meeting with the manager, the champions, senior involved staff and MARQUE clinical psychologist. This meeting is to troubleshoot any difficulties with attendance and engagement, and to plan for the supervision period. It is also an opportunity to thank management and champions for support and highlight what is working well.

Key outcomes of this meeting:

- To have addressed any concerns or questions of care home management in relation to the intervention.
- To make a clear plan for any attendance issues, outlining who has responsibility for any actions and agreed review of plan.
- To have a made preliminary plan for how supervision sessions will be organised in the home.
- To arrange meeting after final session with manager and senior staff to agree action plans.

If there are issues with attendance or staff engagement at an earlier point in the training, discuss with clinical supervisor and make an action plan e.g. speaking to manager before the scheduled mid-intervention meeting

Before and during the final training session:

- Review notes from all prior sessions before the final session so that you are able to suggest and review ideas around each of the sessions e.g. "Do you think that using this strategy helped to reduce agitation" or being able to remind people of the list of communication strategies or pleasant events".
- Have in mind potential action plans that could work based on the sessions with your groups so far.
- The purpose of the session is to get staff to continue to use helpful strategies in the future.
- Try to encourage staff to focus on what worked and if something was not useful, move on to the next section.
- It is important that the teams generate their own plans as much as possible and that they are as detailed, practical and usable as possible.
- Ask lots of questions to generate ideas and use managers and champions in the sessions to facilitate ownership of plans within the care home.
- Remember that there will be staff from different units / teams in the training so the plans may not apply to everyone – Encourage staff to think about how the plan would work on their units and liaise with the other facilitators outside of the sessions about all the plans made across the home.
- Be flexible in this session – give time to the preliminary 'what works' discussion and then try and get at least 3 detailed plans – more if that fits with the team.
- Remind staff to keep practicing the skills they have developed and describe plan for the supervision period.
- Tell staff we will be providing certificates.

After the final session:

Together with MARQUE clinical psychologist, facilitators meet with manager to agree the action plans.

5

- In advance of this meeting, combine action plans made in repeated groups to make a set of SMART action plans to share with manager.
- Discuss how these plans will be put into practice, for example if any special time or resources is needed and how staff will know that they have permission to take time to put plans into action.
- Troubleshoot potential difficulties and make notes of any further revisions to the plans, to finalise and circulate with staff.
- Finalise plans for supervision and troubleshooting sessions with care home manager and share with champions and unit managers.
- Bring staff and champions certificates to this meeting (Two copies one for staff member and one for care home notes).
- Bring some extra copies of the manual for new staff.



6

Delivering the intervention: Supervision and troubleshooting period

Following the delivery of the manualised MARQUE intervention sessions there will be an ongoing troubleshooting and supervision phase to support staff to continue to put what they have learnt in the sessions into practice. This will be for approximately three months and is a key component of the overall intervention.

During this phase facilitators will go in monthly to offer 'troubleshooting' and support putting plans into practice. The structure of this input will vary and will be co-constructed with the care home managers and staff (and will therefore be less structured than the intervention sessions).

The aim of the troubleshooting is to offer either individual or small group support to staff and will be closely related to the action plans developed during session six of the training.

Facilitators should try and be flexible when attending and build on existing relationships with staff to offer support and encouragement to continue to use MARQUE ideas in practice.

In addition to monthly troubleshooting, there will be monthly opportunities for face to face clinical supervision where more complex clinical issues can be discussed and related to MARQUE. Ideally one of the facilitators will attend with the clinical psychologist to facilitate engagement and attendance.

Below is a summary of the process for setting up / agreeing and delivering any follow up support:

Overview of the process:

- At the initial meeting with senior staff/managers the follow up support and supervision is discussed.
- In session 1 of the intervention the follow up support is mentioned in manual.
- Around session 3 or 4 a meeting is arranged with care home manager/senior staff to discuss the process so far and start to agree the form that follow up supervision will take.
- At session 6 researchers will discuss the follow up support with the training participants and discuss what would work best.
- After session 6 researchers will collate and summarise the action plans made and then arrange a meeting with manager/senior staff to discuss and finalise plans for initial troubleshooting sessions.
- In advance of the initial troubleshooting sessions any materials will be prepared and arranged by research assistants. This will include copies of action plans, certificates for staff and champions, any specific / posters / prompts and materials that have been agreed as part of the action plans e.g. tailored record forms.
- Troubleshooting sessions will begin – for each group of research assistants it is expected that all will go and spend time at the home at a set time once a month. For example this may be one pair going for a morning and one pair going for an afternoon on a different day and within this time meeting with staff on different units to maximise contact with staff.
- Following any meetings or troubleshooting sessions research assistants should complete reflective logs and keep a clear record of which staff they have had contact with and what form this contact had taken e.g. how long / individual or group / key focus.

7

Additional materials for delivery

Posters for intervention delivery

Copies of the reflective log for facilitator

8

Appendix 34 Changes to intervention post-initial testing

Summary of changes made to MARQUE manual post-pilot

- Once all the final amendments were made, the manuals for were professionally graphic designed and printed for the RCT.
- Throughout the manual, the key points were made more prominent, supporting graphics and images were more carefully tailored and the facilitator instructions were made clearer and easier to follow.
- For within session exercises and between session practice tasks facilitator instructions were streamlined, given a consistent structure and where needed additional clarification was included to simplify and aid delivery.

Session 1

Session title added to cover page.

P.2 Additional instructions were added for the facilitator at the start, these were:

- “Always check that staff have understood the exercises before beginning them.”
- “The purpose of the intervention is to support care staff to change their practice and to find their own solutions which fit with their particular work context. Therefore it is important to ask questions that encourage and guide care staff to develop their own strategies instead of offering them solutions”

P.5 Additional text – “At the end of the sessions you will get a certificate for your own records.”

P.9 In the ‘overview of dementia’ section the text was simplified and repetitions removed. A new facilitator box was added: “Key Point: There are many different types of dementia and many people in the home will not have a formal diagnosis but will display difficulties.”

P.13 The key point was moved for added impact.

P.14 The text was changed from “Getting to know the person with dementia helps you know what to do when they are agitated” to “Knowing a person with dementia well, helps you to feel closer to them and can make it easier to talk to them or comfort them if they are upset.”

P.15 Extra text was added: “*Call to Mind* – specially designed board game for those living with dementia”.

P.16 A talking point was removed and an additional facilitator box was added saying: “Encourage staff to share different reactions. Key point: Stress will affect different people in different ways.”

P.17 The section in the pilot manual on ‘the importance of reducing stress’ was removed and the key point and facilitator box were moved to the end of p.18 to avoid repetition and improve flow of the session.

P.23 'How can you share this with other members of staff?' was removed from this and subsequent putting into practice box, left in for sessions 3-5.

Session 2

Overall the structure was re-ordered and pictures changed to reiterate point that pleasant events can be small and fitted into routine care. The sections on 'building pleasant events into day-to-day care and 'including people with severe dementia' were moved to before 'planning pleasant events for residents'.

P.4 "If you did not [play call to mind], did you find yourself finding out more about residents in other ways?" was added to facilitator box on recap from last session.

P.5 "interactions" was added to "This session is about things people enjoy: pleasant events and interactions."

P.6 The section in the pilot manual called 'what is a pleasant event?' was removed and the content related to building activity into care was retained.

P.6 A talking point was added "What are you already doing which brings pleasure to the residents you look after? Think of things which don't need any extra time or planning but which do seem to make a difference."

P.6 An additional key point was added to facilitator version: "You don't need to plan big activities to make a difference to people's lives – it is about building on what is already happening."

P.7 The table of activities was separated into 'everyday care activities' and 'pleasant events'.

The following sections were removed following the pilot:

"When people are engaged in pleasant events, what changes do you notice in their mood and behaviour?" (Pilot p.5) and "Can you think of particular residents who enjoy activities that connect with their jobs or hobbies?" (Pilot p.7)

P.14 The exercise on – "Let's think together about what gets in the way of building activities into your day-to-day routine and what may make it easier" (Pilot p.14) was removed and replaced with a list of what makes it easier to plan pleasant events.

P.15 The Exercise on planning pleasant events was made more structured and focused on the pleasant events will be trying over the next week.

Session 3

P.4 "What are people already doing that brings pleasure to the residents" was added to facilitator box on recap from last session.

P.5 The quotation: "She couldn't understand what was going on, what was happening around her." (Pilot p.5) and the talking point: "Imagine that the care assistant is trying to

give this man a wash. What may he think is happening to him? How might this make him feel and behave?" were removed.

P.7 The section on 'how to talk with people with dementia' was replaced with a table of 'tips for good communication' and the facilitator box made clearer to avoid repetition.

P.9 In the exercise on 'how to respond when people are upset' further explanation was added for each example response. The key point "By validating a person's emotions and trying to meet an unmet emotional need you can make a person feel cared for and understood and get to know their needs better" was replaced with "You don't have to agree or disagree, just recognising what people may be upset about and talking with them about this or reassuring them can make people feel better."

P.10 After the talking point on 'communication problems in team', "Write these up on the flipchart to come back to on p.15" was added to a facilitator box to avoid repetition later in session.

P.17 The talking point on communicating with relatives: "How would you feel in a similar situation and what might help you feel better?" was replaced with "What works well when communicating with relatives?" a discussion in large group.

P.23 The 'putting into practice' exercise on communicating with residents was replaced with:

"Choose a resident that it can be difficult to communicate with. Try and use some new strategies to help with these difficulties or notice what works and do more of that! Look back at the communication tips (on p.7) for ideas. Write down how it goes on the communication record on p.24 at least twice this week."

P.24 the communication record was simplified and the example given made simpler. The instructions for facilitators were made more detailed.

Session 4

Throughout the intervention, in relation to DICE – 'CREATE CARE PLAN' is changed to 'CREATE [strategies] and put into a PLAN'.

P.4 "Were there other strategies, not new ones that also worked well?" was added to facilitator box in recap from last session.

P.6 The order of quotations switched around to improve flow and coherence.

P.7 In the 'Ways to manage agitation' section: "This approach builds upon the understanding and expertise that already exists in staff teams. It is helpful and easy to use." was added to the text. The diagrams on p.6 and 7 in pilot version were combined to avoid repetition and: "If a person with dementia you are caring for is agitated, then...Roll the DICE." was added to the text.

P.8 "We are going to come back to these examples later in the session." was added to the DESCRIBE exercise facilitator box.

P.10 "Ask for one or two examples from the previous exercise, which people think may connect with surroundings, to talk through." was added to the facilitator box.

P.12 A key point: “Walking up and down may be a sign or a clue that people are feeling tense or can’t relax even if they don’t seem upset.” was added.

P.17 “If a person becomes very agitated suddenly and this is unusual for them, think about consulting a GP.” was added to the text.

P.19 The record form was made clearer and easier to complete.

P.23 The practice between session exercise was changed from: “Try to complete the behaviour record for three separate episodes of agitation this week. Try to focus on describing and investigating what happened.” to “Try to describe and investigate three episodes of agitation and write them down on the behaviour record.”

Session 5

P.19 “roll the dice again” was added to the key point.

P.20 The record form was made clearer.

P.25 The putting into practice exercise was changed to: “Creating new strategies. Try to complete the DICE record on p.26 at least once this week. Focus on finding new strategies that you may not have tried before. Try to use new strategies and notice when things go well. (Remind yourself of strategies on p.12 & 13). We will use this information next week to build into DICE plans for agitated residents.”

Session 6

P.5 An exercise on completing a DICE plan for person they care for was added to the recap from the last session: “Now let’s use what you have learnt from completing the DICE record to build it into an plan for some of the people you care for ...”

P.7 “Prompts: NB – You will already have run through this in the recap of the last session so go through DICE quickly here focussing on any aspects that have not already been discussed in earlier exercise.” was added to the facilitator box.

P.8 “Stress that this is small changes to day to day care not just doing big separate activities.” was added to the facilitator box.

P.19 “Remember not to tell returning researchers that you have received this training, so we can fairly judge how much it helps.” was added to the text.

P.19 An additional facilitator box was added: “Not telling the researchers that come back whether you have had the training is a really important way of us knowing whether the training has worked as we do not want them to be affected by what you tell them... We will be back in two weeks to see how things are going and to help with any difficulties with the action plans, and there will also be support available from a clinical psychologist – Dr Penny Rapaport who will be coming each fortnight to discuss more complex issues. Remember, the best way to make a difference is to keep practicing the skills you have developed during the course and keep talking about what works in the team.”

Appendix 35 SRQR checklist

Standards for Reporting Qualitative Research (SRQR)*

<http://www.equator-network.org/reporting-guidelines/srqr/>

Page/line no(s).

Title and abstract

Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	Page 1 line 1
Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	Page 2 line 1

Introduction

Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	Page 3 lines 1-41 Page 4 lines 1-7
Purpose or research question - Purpose of the study and specific objectives or questions	Page 4 lines 4-7

Methods

Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**	Page 4 line 25
Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	Page 1 lines 9-10 Page 4 lines 25-30
Context - Setting/site and salient contextual factors; rationale**	Page 4 lines 9-23
Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	Page 4 lines 9-23 Figure 1
Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	Page 4 lines 10-11 Figure 1
Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**	Page 4 lines 9- page 5 line 2 Figure 1

Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	Page 4 lines 9- page 5 line 2 Figure 1 Supplementary appendix 1
Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	Page 5 lines 4-8 Table 1
Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	Figure 1 Page 4 lines 24 – page 5 line 2
Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	Page 4 lines 24 – page 5 line 2
Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	Page 4 lines 24 – page 5 line 2 Supplementary appendix 2

Results/findings

Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	Page 5 line 23- page 11 line 22 Supplementary appendix 4
Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	Page 5 line 23- page 11 line 22

Discussion

Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	Page 11 line 24 – page 12 line 30
Limitations - Trustworthiness and limitations of findings	Page 12 line 31-39

Other

Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	Page 14 line 17-18
Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	Page 14 line 7-16

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

Reference:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. *Academic Medicine*, Vol. 89, No. 9 / Sept 2014
DOI: 10.1097/ACM.000000000000388