Dudman, Jennifer A. (2014). Not just a simple dressing: A practitioner inquiry exploring the complexity within residential care homes and the district nursing response. (Unpublished Doctoral thesis, City University London)

CITY UNIVERSITY LONDON
EST 1894

[City Research Online](#)

Not just a simple dressing:

A practitioner inquiry exploring the complexity within residential care homes and the district nursing response

Jennifer Ann Dudman

A thesis submitted to City University in accordance with the requirements for the Degree of Doctor of Philosophy

Adult Years Division, School of Health Sciences

November 2014

DEDICATION

IN MEMORY OF MY DAD

CONTENTS

LIST OF FIGURES

LIST OF TABLES

ACKNOWLEDGEMENTS

I would like to thank a number of people without who this thesis would not have been possible. Firstly I would like to thank Professor Julienne Meyer, as without her advice, support and encouragement I never would have got here. Thanks also go to my other supervisors Dr Cheryl Holman and Professor Wendy Moyle for their comments, feedback and support.

Special mention goes to the care home staff and community nurses who participated in this study, as without them there would have been no thesis. In terms of my work colleagues thanks goes to Kathy, Linda, Jerry, Debbie, Mary and Tracey who enabled me to undertake this study and ensured that my district nursing team continued to run smoothly. I need to give special thanks to Theo, who has encouraged me throughout this process and has patiently listened to me discussing my thoughts and ideas.

I am also indebted to my family and friends who have kept me going. In particular my mum Betty, who has always encouraged me through this journey, which at times was not always easy and my sister Margaret, whose support, as well as her formatting skills, proved invaluable. Finally I would like to say a special thank-you to my husband Stuart who has always encouraged me to follow my dreams, who has believed in me and who didn't get too frustrated at my lack of IT skills.

DECLARATION

I grant powers of discretion to the University Librarian to allow this thesis to be copied in whole or in part without further reference to me. This permission covers only single copies made for study purposes, subject to normal conditions of acknowledgement.

ABSTRACT

People living in residential care homes are older, frailer and sicker than ever before. Levels of dependency and co-morbidity are increasing, with neurodegenerative diseases, and dementia in particular, having a significant impact. Previous research has reported high levels of unmet needs, including healthcare needs, amongst the resident population, yet has given a limited understanding of why staff may struggle to meet these healthcare needs.

This qualitative study used a practitioner research approach to answer the following questions. Firstly, what challenges do care staff face in meeting the healthcare needs of residents, in particular those living with dementia, and secondly, what are the challenges faced by the district nursing service in supporting care staff to meet the healthcare needs of residents. Data were initially generated from an in-depth case study involving one residential care home, specialising in the provision of dementia care. Data were collected from individual (n= 7) and group interviews (n=1) with care staff and interviews with members of the district nursing team supporting this care home (n=4), together with documentation and contextual data. The practitioner researcher used herself as a research instrument to reflect on the findings from the case study, in relation to her own knowledge and experience of working as a district nurse with care homes, focusing in particular on those aspects of the work that were familiar and those that surprised. Data were analysed using thematic data analysis (Braun and Clarke 2006). To add strength to these findings, the experiences and challenges faced by staff (n=14) from other residential care homes were also sought, as well as from community nurses (n=12), community matrons (n=4) and specialist nurses (n=2) attached to these care homes. These data were compared to the findings from the original case study and reflections of the practitioner researcher, to identify findings that resonated, as well as identifying any perceived gaps.

Findings suggested that staff could struggle to manage the healthcare needs of residents, as a result of the complexity present in today's residential care homes, complexity that was not always recognised or acknowledged, especially by those supporting care homes, including community nurses. This thesis makes a unique contribution by drawing on complexity thinking, suggesting that residential care homes are diverse, embedded systems, which are constantly adapting and are governed by simple rules, which are interpreted and applied differently by agents, according to context and individual interpretation. These are characteristics, which others, including community nurses, may be unaware of, or fail to respond to. It identifies 'simple rules' which could explain the response of community nurses to this complexity and suggests certain contextual and behavioural issues that may need to be addressed if the relationship between the two services is to improve and the healthcare needs of residents are to be better met.

ABBREVIATIONS

ALF	Assisted Living Facility
BGS	British Geriatric Society
BME	Black and Minority Ethnic Group
CANE	Camberwell Assessment of Needs in Elderly
CAS	Complex Adaptive System
CCG	Clinical Commissioning Group
CHM	Care Home Manager
CM	Community Matron
CNS	Clinical Nurse Specialist
CPN	Community Psychiatric Nurse
CQC	Care Quality Commission
CS	Care Staff
DCHM	Deputy Care Home Manager
DN	District Nurse
DNTL	District Nurse Team Leader
DOH	Department of Health
EMI	Elderly Medically Infirm
FN	Field Notes
GP	General Practitioner
HCSW	Health Care Support Worker
IV	Intravenous therapy
MDS	Minimum Data Set
NAO	National Audit Office
NHS	National Health Service
NMC	Nursing and Midwifery Council
NMS	National Minimum Standards
NVQ	National Vocational Qualification
OT	Occupational Therapist
PCN	Primary Care Nurse
PCT	Primary Care Trust
PR	Practitioner Research
PRN	As required medication
QNI	Queens Nursing Institute
RCF	Residential Care Facility
RD	Research Diary
RCN	Royal College of Nursing
REC	Research Ethics Committee
RMA	Registered Managers Award
RMN	Registered Mental Nurse
RN	Registered Nurse
SALT	Speech and Language Therapy Team
TL	Team Leader
UK	United Kingdom
USA	United States of America

CHAPTER 1: INTRODUCTION

This thesis is concerned with exploring the experiences and challenges for care staff in managing the healthcare needs of residents in residential care homes, in particular those living with dementia, as well as exploring whether the district nursing service is adequately supporting them to do this. The study was driven by a professional interest in district nursing and residential care homes, as the researcher is herself a practising district nurse, who has worked for over 16 years in the community. As well as by key policy areas which include, the need for better partnership working between health and social care services, a feature of government policy for many years (Cameron et al 2012) and the need to improve healthcare support for both care homes and people living with dementia (Heath 2007, DOH 2009, 2012).

District nurses (See Appendix 1) are the largest group of nurses working in the community, with around 13,000 qualified district nurses working across the UK today (QNI 2009). The term district nurse (DN) refers to a senior nurse who usually holds a specialist qualification and leads a team of primary care nurses and healthcare support workers, referred to collectively as community nurses (See Appendix 1). Their role is to provide skilled nursing care to any patient in the community who is temporarily or permanently housebound (Toofany 2007), including those living in residential care homes, as in the UK this type of care home is registered to provide accommodation and 'personal care' only, and there is no requirement for a registered nursing presence. They are either attached to, or work in close association with, GP practices, who provide the majority of medical support to care homes. Unfortunately due to a lack of clarity, or systematic approach in the provision of primary healthcare services, the support care homes receive is often sub-optimal (Davies and Goodman 2008, Szczepura et al 2008).

Care homes are the major provider of long-term healthcare for older people in the UK (Handley et al 2014). They are caring for those who would have previously been the responsibility of the NHS and are providing increasingly complex care (Bowman 2009, BGS 2011). In terms of residential care homes, they have become the main provider of care for people living with dementia and dementia is the strongest determinant for admission into residential care (Alzheimer's Society 2007a). Dementia is presenting a major challenge, both nationally and globally, in terms of its scale and impact. Estimates suggest that in 2013 there were 815,827 people with dementia in the UK, with numbers forecast to rise dramatically, the result of an ageing population, and predicted to reach 2 million by 2051 (Alzheimer's Society 2014a). The National Council for Palliative Care (2007) has estimated that nearly a million care home beds will be needed for this group by 2039. Yet it has only been relatively recently that dementia has started to receive attention, both nationally and globally. In 2009 the Department of Health (DOH) published the first ever National Dementia Strategy for England (DOH 2009) setting out 17 recommendations for improving dementia care services, followed in 2012 by the Prime Minister's Dementia Challenge (DOH 2012), a national programme aimed at delivering improvements, by 2015, in health and care.

A person living with dementia usually moves into a care home when their needs become either too complex, or are too expensive, to be managed in their own homes (Heath 2007). One third of people living with dementia reside in residential care (Alzheimer's Society 2007b) and up to 70% of care home residents are living with dementia, or have significant memory problems (Alzheimer's Society 2014a). The majority live in residential care homes, as historically most of their care was classified as social care (Alzheimer's Society 2004) and it has been suggested that the greater part of dementia care can be carried out effectively in such care homes (Kitwood 1997). However, given that those entering the care system today tend to have more severe forms of the disease (NAO 2007), it has resulted in large numbers of severely impaired people, often with complex health and social care needs, which can be difficult to manage, being cared for in residential care homes (Rabins et al 2006, Alzheimer's Society 2014a). Little attention has been paid in the literature to the experiences of care staff and community nurses in managing the healthcare needs of older people in residential care homes, especially those living with dementia, and is why this thesis has sought to:

- Explore the experiences and challenges faced by care staff when managing the healthcare needs of residents, in particular those living with dementia
- Explore the experiences and challenges faced by the district nursing service in supporting residential care homes to manage the healthcare needs they are faced with.

Overview of thesis

As the researcher is a practising district nurse the study used a practitioner research approach (PR) to explore the experiences of care staff and community nurses in meeting the healthcare needs of residents, especially those living with dementia, in residential care homes. As a district nurse, the researcher was particularly interested in exploring the experiences and challenges of care staff and members of the district nursing team. However, care homes are supported by a range of community nursing services, a number of which work alongside the district nursing service, e.g. community matrons. For this reason, the experiences of other such community nurses were also sought.

In PR it is important that the researcher write themselves into the account, which is why when drawing or reflecting on her own experiences, such as in Chapters 4, 6 and 7, the first person is used, whilst other chapters are written more traditionally, using the third person and referring to the practitioner researcher. An emergent study design was used. This study originally set out to explore whether the healthcare needs of residents living with dementia were being met. But on completion of the literature review the focus of the study changed, with data collected to better understand the experiences and challenges of care staff and community nurses, in meeting the healthcare needs of residents. However, given that at least 70% of residents can have some degree of cognitive impairment (CI) or dementia, their experiences of working with those living with dementia in particular were still sought.

Chapter 2 provides a contextual overview of the UK care home market. Demonstrating how this sector has changed over the years, especially in terms of residential care homes, which are now caring for residents who have high levels of health and social care needs that can be complex. It also provides a snapshot of the care home industry today, in terms of ownership, levels of dependency, co-morbidity, funding pressures, regulation and staffing issues.

Chapter 3 provides an overview of district nursing. It discusses how the role of the district nurse lacks clarity as it is constantly evolving, how the service is under researched, especially in regard to the support provided to residential care homes and describes certain challenges facing the service.

Chapter 4 provides contextual details of the local authority and NHS trust in which the study took place, together with details of the local care home sector and district nursing service, in order that the reader can judge if the findings of this study are of relevance to their own practice. The chapter also provides details of the background and previous experience of the practitioner researcher and her reasons for conducting this particular study.

Chapter 5 provides a review of the literature, which set out to gather a better understanding of the healthcare needs of residents living with dementia and to explore if these healthcare needs are being adequately met. This chapter reveals that high levels of comorbidity, dependency and healthcare needs are now common amongst residents, with many under-recognised and/or under-treated. Gaps in the literature are highlighted including a lack of research conducted either in the UK, or in residential care homes and little understanding of why healthcare needs are not being met, due to the use, by the majority of studies, of quantitative designs that are unable to explain causality, which ignore the context in which care homes operate and pay little attention to the experiences of staff.

Chapter 6 describes the methodology for the study. It explains why a practitioner research approach was used, and describes the emergent study design. The methods and techniques of data collection and analysis are described, as well as the challenges of conducting research with the care home sector and as a practitioner researcher.

Chapter 7 presents findings from a case study, involving one residential care home providing specialist dementia care. It begins by presenting contextual detail of this care home. It then goes on to describe how the researcher, using herself as a research instrument, reflected on the findings from the case study, in relation to her own knowledge and experience of working with care homes, focusing on those aspects of the work that were familiar, as well as those aspects that surprised, i.e. something that challenged either previously held assumptions, or what she would have expected to see (Tracy 2010). It reveals the complex nature of care that staff in this care homes were expected to manage on a daily basis and how as a district nurse the researcher was both surprised by, and ignorant of, much of the complexity. The original focus of the study wasn't on complexity, but during the case study the researcher became

aware of how complex the care being provided was, which led her to the literature on complexity thinking and complex adaptive systems.

Chapter 8 presents findings from other care homes in the same local authority, to explore whether the findings from the first phase were unique to that one care home. Interviews were conducted with senior staff from other care homes, with data compared to that from the original care home and reflections of the researcher, identifying findings that resonated, i.e. the findings were similar to, or differed from, the participants, or practitioners own experiences or situation (Tracy 2010), as well as identifying any perceived gaps in the findings from the case study. Findings are presented that first confirmed the complexity found in the case study, secondly that did not confirm what was found and finally new issues that were raised. A key finding in this chapter is that the complexity identified in the case study was not unique to that one care home, but was actually greater than had been first realised.

Chapter 9 presents findings exploring whether other community nurses were aware of this complexity, as well as the level of support they were providing to these care homes to manage the healthcare needs they were faced with. This chapter presents findings confirming that other nurses were also ignorant of this complexity, together with findings that did not confirm this, with evidence of community nurses ignoring this complexity, due to pressures on their service. The chapter suggests that the service they provide is not able to ensure that the healthcare needs of all residents are met, with those living with dementia at particular risk, as the service focuses on tasks and physical needs only, spends limited time in the care homes and nurses lack knowledge and skills in this field. The findings chapters are purposively descriptive (Paley and Eva 2011), to give an idea of the mechanisms and interactions occurring within the system, from which the complexity was arising. Deeper analysis and interpretation of the findings takes place in Chapter 10, when the findings are discussed in relation to complexity thinking, and in particular complex adaptive systems.

Chapter 10 discusses the key findings in relation to relevant the literature concerning residential care homes and district nursing. The level of complexity that residential care homes are dealing with and the district nursing response to this complexity, are also discussed in relation to theoretical perspectives. Drawing on complexity thinking, it argues that residential care homes are diverse, embedded systems, which are constantly adapting, governed by simple rules, which are interpreted and applied differently by agents, according to context and individual interpretation. Characteristics, which others, including community nurses, can be unaware of, or fail to respond to. It gives a possible explanation for the response of community nurses to this complexity and uses complexity thinking to offer possibilities for change. The chapter concludes by giving certain issues for consideration in regard to practice, education, policy and research and outlining the contributions that this study has made to the body of knowledge, in terms of both practical and theoretical knowledge.

This thesis suggests that district nursing support of residential care homes may need to be addressed. By raising this issue it is hoped that all those responsible for supporting care homes will take note and consider whether the type and level of service that they are providing safeguards the quality of life and care of some of the frailest, sickest and most vulnerable members of our society, namely care home residents.

CHAPTER 2: SETTING THE SCENE NATIONALLY – CARE HOMES

Introduction

This chapter provides a contextual overview of the care home sector in the UK. It shows how the development of the care home sector, with the continuing divide between health and social care provision and changes in NHS priorities has shaped the development of nursing and residential care homes into a major provider of care and support for older people. It gives a snapshot of the UK care home industry today, especially in regard to capacity, its growing status as a major provider of care for people with dementia, the health status of residents, levels of dependency, funding issues and training. Appendix 1 provides a glossary of terms used in this thesis

Development of the care home sector

Fundamental to the development of services for older people in England has been the administrative divide made between health care (originally defined within the National Health Service Act 1946) and social care (the National Assistance Act 1948). Based on the assumption that it is possible to distinguish between those who are 'sick or infirm' (people with health needs who should receive care from the NHS) and those who are 'frail and old' (people with social needs). This rather arbitrary distinction has been crucial, as those perceived to have health needs receive care that is free of charge, whilst those deemed to have social care needs are the responsibility of local authorities and are means tested and may have to pay for personal care (Glendinning and Means 2004, Dudman 2007).

The National Assistance Act gave local authorities responsibility for providing residential accommodation for those 'who by reason of age or infirmity needed care or attention' (Peace et al 1997, Means et al 2008). Those who required continuous nursing care were cared for in long-stay geriatric wards within the NHS, or in nursing homes (Godlove and Mann 1980, Davies and Seymour 2002). However, since this time there have been continual attempts to narrow the definitions and shift responsibility for the provision of care between the NHS and local authorities. In the early 1950s it was decided that residential homes could care for those who were considered to be 'infirm' but not 'sick' (Means et al, 2008). By the late 1950s the boundary was again redrawn, with those in need of 'constant care and attention' the responsibility of local authorities, whilst those needing 'constant medical and nursing attention,' were the responsibility of health authorities (Lewis 2001). In the 1960s, the definition changed yet again, with residential homes now providing care for '*people who were so incapacitated that they needed help with washing, dressing, toileting, meals and mobility'. It also covered those who had 'either temporary or continuing confusion of the mind, but who didn't need medical care'* (Means 2001).

The 1980s saw a big expansion in the care home sector, with the number of independent care homes rising by 242% between 1983 and 1986 (Netten et al, 2001), largely the result of changes to funding, with older people able to refer themselves to care homes, and costs met by social security payments (Andrews and Phillips 2000, Davies and Seymour 2002). However, it was quickly realised that this level of funding was unsustainable and the implementation in 1990 of the NHS and Community Care Act saw the introduction of a contract culture into community care provision. A primary objective of this Act was for older people to remain at home for as long as possible, supported by community services, with local authorities given responsibility to act as gatekeepers to services, including residential and nursing home places (Andrews and Phillips 2000, Jacobs and Rummery 2002). The majority of local authorities stopped investing in publicly operated care homes, with most of the provision passing to the independent and voluntary sectors (BGS 2011).

Local authorities were required to keep a tight control over their budgets which had a knock on effect on the residential care market. When local authorities took over control of purchasing care there was a corresponding fall in occupancy rates in care homes. Neither was the care home industry helped by pressure placed on local authorities to restrict fees for care home beds and to use block contracts with fixed fees attached (Means et al 2008). Whilst this placed economic constraints on both large and small providers, it was the smaller providers who suffered most and found it more difficult to survive (Holden 2002). The result has been a gradual change in the profile of the industry, with a large increase in the number of homes owned by large for-profit providers (Means et al 2008).

NHS provision has also changed significantly over the years. The introduction of the National Health Service Act saw long-term health care for the chronic sick provided by the NHS, usually in hospital settings (Glendinning and Means 2004). However, by the late 1950s the government backed the view of the Ministry of Health and many hospital doctors that the number of geriatric beds should be limited, with an emphasis on the provision of short-term acute medical care (Lewis 2001). This policy, together with the closure of large numbers of long-term care NHS beds in the 1970s, saw the role of the NHS in providing care for older people decline markedly. By 2001 the NHS was funding fewer than 10% of all nursing home places and providing just 7% of all nursing and residential places for older, chronically ill and physically disabled people (National Primary Care Research and Development Centre 2001). However, the situation appears to be changing as in 2014 23% of nursing home beds for older and physically disabled people were funded by the NHS (Laing and Buisson 2016). It should be noted that the transfer by the NHS of their responsibilities was never actually accompanied by any significant transfer of additional resources into community services (Glendinning and Means 2004). The result is that the sector is now caring for those who would have previously been the responsibility of the NHS, providing increasingly complex care, including intermediate, respite, and continuing care; and at the same time becoming one of the main providers of dementia and end-of-life care for older people (Bowman 2009, Goodman 2014).

Subsequent government policy has committed to the continued provision of more effective services outside the hospital setting and for greater integration between health and social care (Laing and Buisson 2009b). The White Paper '*Our health, Our Care, Our Say*' (DOH 2006) highlighted the need for better co-ordination of community based services for people living with long term conditions, especially frail older people (Smith et al 2009). This resulted in a continuing decline in the numbers admitted to residential care (Means et al 2008), with older people being cared for in their own homes and care home places only really provided for those with the greatest dependency, usually the oldest in society (Andrews and Phillips 2000).

More recently it was recognised, firstly by Labour and then by the Coalition Government, that the present system for providing and funding social care was not fit for purpose. People who require care, especially those who are older or disabled, are living longer and often require higher levels of care and support for longer periods of time. For these reasons care costs will continue to increase, with the current system unable to continue to sustain these costs in their current form. The White Paper '*Caring for our future*' (HM Government 2012) called for those using health and social care services to have care that was integrated, with services working together to provide care based on a person's circumstances and needs, especially those with complex needs, as in the case of older people.

The resultant 'Care Act 2014' saw the first overhaul of social care for more than 60 years. In terms of funding reforms included a lifetime cap on care costs, increasing the upper level of the means test for those entering residential care, capping hotel costs in care homes and national eligibility criteria for social care. It also recognised the importance of greater integration, for example the need to integrate housing with health and social care, with providers of social housing to be listed as one of the partners that a local authority must co-operate with when considering and planning a person's care. However, although many of the reforms are widely welcomed there is general concern that the lifetime cap will only help a small number of people. It is also suggested that the act fails to address a central issue, which is that people are given access to the correct level of support that they need (The Kings Fund 2013).

As a result of the continual changes to health and social care provision '*care homes have become the community hospitals of the future*' (Bowman 2009). Local authorities have been given responsibility for commissioning care for those with complex health and social care needs and the independent care home sector has become the major provider of long-term care for frail, older people, many of whom are extremely vulnerable and clinically unstable (BGS 2011). Residential care homes were to be 'homes', rather than nursing homes, or hospitals and it was never envisaged that they would provide 'nursing care'. However, they are now caring for people with complex health and social care needs, are relying on staff who on the whole have a social care background, with limited support from healthcare services (BGS 2011).

Negative perceptions of the care home industry

To this day the history of residential care continues to influence service provision, with policy leaving residential care marginalised and often mistrusted by those it seeks to support (Stanley and Reed 1999, Froggatt et al 2009). The origins of residential care can be traced back to the poor law and associated workhouses of the nineteenth century, where more attention was paid to the able-bodied poor, than older people, the sick or handicapped (Townsend 1962), and conditions were harsh. It was not until the early 1900s, when attitudes began to change, that the 'old and infirm' began to receive institutional care designed to meet their needs (Peace et al 1997, Davies and Seymour 2002). The 1948 National Assistance Act gave local authorities responsibility for providing residential accommodation for persons, who through age, illness or other reasons, needed care or attention. Unfortunately due to a lack of housing stock much of this care continued to be provided in the old workhouses, where conditions remained poor (Peace et al 1997, Means et al 2008).

During the latter part of the twentieth century the role and value of institutional care began to be questioned by researchers and philosophers, e.g. Goffman (1961) and Townsend (1962), with many authors painting a picture of institutions as places focused on repression and social control, rather than caring (Peace et al 1997, Stanley and Reed 1999, Means et al 2008). For example, Townsend (1962) in '*The Last Refuge'* uncovered inequalities in care provision for people with the same needs, and many admitted for social rather than physical reasons. He concluded that residential care homes were not meeting the physical, psychological and social needs of older residents, suggesting that alternative living arrangements needed to be developed. Negative perceptions of institutional care still persist to this day. Johnson et al (2012) revisited the care homes that featured in Townsend's original study. Whilst their findings presented a more positive view of residential care, they also found that the negative image of residential care still persisted. Coverage in the media is rarely positive, fostering a perception amongst the public that care is of a poor quality and that care homes can be places of abuse and neglect (Demos 2014). Many healthcare professionals hold the misguided belief that care homes are making large profits at the expense of the residents, whilst avoiding providing care and equipment they have been paid to provide (BGS 2011). As a result admittance to a care home is considered to be a negative, rather than positive option, and is often seen as the 'last resort' (Demos 2014).

Development of the care home sector for dementia care

Residential care homes have evolved into the main provider of residential care for those living with dementia (Skills for Care 2009). The closure of the large psychiatric hospitals during the 1970s and 1980s resulted in a group of older people with behavioural and/or mental health problems, including large numbers with dementia, requiring alternative accommodation. Large numbers were housed within the care home sector, often in care homes designated as homes for the 'Elderly Medically Infirm' (EMI) (Godlove and Mann 1980, Peace et al 1997). Over the years there has been a large increase in the number of care homes caring for people living with

dementia, attributed to the increasing market, but also it has been suggested, because of the possibility of the increased fees these residents offer, with care homes able to charge higher fees for this specialist category of resident (Andrews and Phillips 2000). The higher fees should be used to provide more intensive forms of care that these residents may require, such as extra staff, training, or specialised facilities. However, although these care homes may offer better trained and higher levels of staff, this is not guaranteed (All-Party Parliamentary Group in Dementia 2009, CQC 2014). Figures over the past decade show that around 37% of people living with dementia are now cared for in care homes (Laing and Buisson 2009a) and at least 80% of residents have dementia or significant memory problems (Alzheimer's Society 2013). However, as many as 40% of those living with dementia in care homes are not cared for in a dementia registered bed (NAO 2007).

Innes (2002) suggests that it is difficult to know if governments see dementia as a health or a social need and is concerned that pressures on social services may have an adverse impact on those living with dementia. The closure of the long-stay hospitals and the increase in residential care placements suggests that a condition, traditionally seen within a medical model, is now being financed through social services (Innes 2002). Service provision is focused on promoting independence and encouraging people with dementia to be cared for within the community (NICE-SCIE 2006, DOH 2009). However, community services are struggling, as evidenced by the Alzheimer's Society (2014a), who reported that cuts to services, together with uncoordinated care reforms, are leaving people without access to the support they need to live well. At some point a person living with dementia may need to move into long-term care because their needs have become too great to be managed at home, either as a result of behavioural problems, or because their carers are unable to look after them anymore (Banerjee et al 2003). With the number of people living with dementia forecast to increase dramatically over the next few decades it is unrealistic to expect that all these people will be able to be cared for in the community, suggesting that care homes are likely to remain a major care provider for this resident group for many years to come (Innes 2009, Bowman 2009).

Healthcare provision to care homes

Primary care support of the care home sector varies greatly; as there is no explicit policy setting out NHS obligations on a national or local level, in regard to care home residents (BGS 2011, Iliffe et al 2015). The transfer of long-term care from the NHS to the care home sector was not accompanied by any significant transfer of resources (Royal College of Physicians et al 2000, Steves 2009). As a consequence specialist support from multidisciplinary teams within NHS units, including access to consultants in old age medicine and psychiatry, occupational therapy, physiotherapy, speech and language therapy and others, was lost to the majority of older people living in care homes, because it was not costed into the care provided (Dudman 2007). Care homes are reliant on local arrangements for the allocation of clinical input, yet these have been found to be highly variable (Royal College of Physicians et al 2000, BGS 2011). Neither has there been any effort made to increase the levels of healthcare services to care homes,

even though residents are experiencing increasing levels of disability and dependency. A survey of Geriatric Medicine departments and primary care trusts (PCTs) across the country (Steves et al 2009) found that whilst over a half of PCTs said that they expected geriatrician involvement in admissions and on-going care assessments, only one third funded such sessions from local services and there were very few dedicated sessions for this type of work in geriatric medicine departments.

Changes in the NHS over the past fifty years have seen provision of long term care for frail older people taken away from hospitals, where a person would have been under the care of a geriatrician, and given to nursing and residential care homes, where their healthcare is the responsibility of GPs and community nurses (Bowman et al 1999). Primary responsibility for medical care of care home residents was given to GPs; however, less than 40% have had any specialist training in the health and social care needs of older people (Royal College of Physicians et al 2000). The service provided by GPs to care homes varies greatly. There appears to be no standard level of service (Jacobs et al 2001, BGS 2011) and the incentive framework for GPs fails to adequately address the needs of residents (Gordon et al 2014b). Care homes, especially nursing homes, often have to pay for GP services, in the form of retainers, with these costs often passed to the residents in their fees (Glendinning et al 2002, Balbes 2014). Care home residents reportedly have a major impact on a GP's caseload (Pell and Williams 1999, Groom et al 2000, Corroon-Sweeney et al 2009). In 1996 the British Medical Association reported that consultations in nursing and residential homes were ten times higher than the national average (Fraser 1999). However, rather than tackle this issue the response of GPs was to call for medical care of older people in care homes to be removed from their contractual care responsibilities (Turrell et al 1998, Bowman et al 1999). A call that has recently been repeated, with GP leaders voting to remove GP responsibility for care home residents and calling on the Government to introduce new contracts, to ensure that residents receive the level of healthcare support that they require, rather than the piecemeal service that is provided at present (BMA 2016). A problem compounded by the fact that many care homes are developing services, such as intermediate care, palliative care, or rehabilitation, which are beyond what was previously seen in long-term care. Such services may require even more input, as well as specialist knowledge and training, which may well not exist in the community setting (Royal College of Physicians et al 2000).

There are also '*wide variations and inequalities in accessibility to and payment for nursing, rehabilitation and other health services and equipment, both between and within care homes*' (National Primary Care Research and Development Centre 2001). Nursing support has been shown to be variable. Support by district nurses tends to be predominantly reactive, largely episodic and task orientated (Goodman et al 2003b, Evans 2007), an issue that will be discussed further in Chapter 3. Care homes can have limited access to specialist nursing support, with access varying depending on the type of nurse specialist and also the type of care home, with residential care homes having less access (O'Dea et al 2000, Goodman and Woolley 2004). Access to allied health professionals, including physiotherapists, speech and

language therapists and occupational therapists is also variable (O'Dea et al 2000, Sackley et al 2009, Gordon et al 2014b), with residents often charged for these services (National Primary Care Research and Development Centre 2001).

The need for greater collaborative working between primary care and the care home sector has at last been recognised. In England, at the end of 2009, 45% of PCTs had at least one service with a guaranteed minimum level of support for care homes (Hays et al 2012). In some areas extra services are provided such as Local Enhanced Service (LES) agreements for GPs, shared management of care between GPs and hospital geriatricians and specialist nursing support of care homes (BGS 2011). In one London borough for example, a LES for GPs enabled them to offer a more comprehensive and better organised service to care homes in their area, resulting in a noticeable improvement in service provision (Briggs and Bright 2011). However, it is up to health commissioners if they offer such services and GPs as to whether they participate (Gordon et al 2014b). The BGS report (2011) concluded that sustainably of such initiatives was also an issue, as many were temporary, receiving only short-term funding, and due to a lack of evidence, it was not possible to definitely say if one model of healthcare support was better than another. Work is beginning to address this issue. One of the work streams from the report 'Five Year Forward View' (NHS England 2014) is the setting up a number of vanguard sites, developing new models of enhanced healthcare for care homes, such as 'ward rounds', rapid access to healthcare support and the provision of education and training to care staff, which it is hoped can inform future services; whilst the 'Optimal' study (Gordon et al 2014a) aims to develop a theoretical understanding of the 'context, mechanisms and outcomes' that shape healthcare delivery models to care homes.

Care homes in the UK today

Capacity and ownership

It was estimated, as of September 2013, that there were, in the UK, 426,000 places in care homes catering for older and physically disabled people (Laing and Buisson 2014a). Over the past 30 years the balance between providers has shifted from the public to the private sector. Private for-profit providers operate 79% of the care home sector; the voluntary sector (i.e. not-for-profit) provides 13.7% of capacity and 7.4% is provided by the statutory sector, i.e. local authorities, or the NHS (Laing and Buisson 2014b). Within the for-profit sector major providers (i.e. those with 3 or more care homes) have 60% of capacity and small businesses (i.e. those with a single or pair of care homes) 40%. In terms of the not-for-profit sector the major providers control 75% of capacity (Laing and Buisson 2010). Concentration of ownership is controlled by the four largest operators: Four Seasons Healthcare, the largest provider, followed by BUPA Care Services, HC-One, formed following the collapse of Southern Cross, and Barchester Healthcare, who between them provide 15.9% of capacity (Laing and Buisson 2014a). Not-for-profit providers traditionally focus on residential care, whilst most for-profit providers concentrate on nursing homes (Laing and Buisson 2010). The independent sector dominates the provision of dedicated dementia care and is responsible for 92% of all capacity. The private sector

provides 81% and the voluntary sector 11%, with local authorities and the NHS only accounting for 8% (Laing and Buisson 2009b).

The last decade saw a significant shift from nursing to residential care home provision within the independent sector, possibly as a result of local authorities trying to reduce costs, as care homes are their largest single cost item. In recent years this trend has halted, possibly because dependency levels are becoming so high as to preclude admission into residential care (Laing and Buisson 2014a). In 2013 average occupancy rates for care homes were 88.9%, although these have increased slightly since then, with average occupancy rates as of March 2014 running at 90.4% (Laing and Buisson 2014b).

Residents in care homes

Age and health status

The proportion of older people who live in long-term care is small (4%) and age-related (Bajekal 2002). Only 3.85% of those aged between 75-84 years live in long-term care, compared to 15.92% of those aged over 85 years (Laing and Buisson 2014a). Women residents tend to be older, with an average age of 85.6 years, compared to 83.2 for men (Office of Fair Trading 2005, Laing and Buisson 2014a). People who enter residential care are likely to be female, over 80 years, suffer with one or more significant clinical conditions, have no partner, and entry is likely to have been arranged by someone else (Laing and Buisson 2014a).

Many of those who live in care homes have high levels of healthcare needs. Neurodegenerative diseases in particular have had a major impact on care homes, with over 70% of admissions due to dementia, stroke or Parkinson's disease (Bowman et al 2004). Other healthcare needs include: arthritis, cardiovascular disease, respiratory disease, deafness, depression, fractures and blindness. High levels of depression, visual and hearing loss and physical impairment have also been reported (Royal College of Physicians et al 2000).

Some degree of CI is widespread amongst residents, with estimated prevalence rates for dementia put at 55.1% in those aged 65-69 years, 61.6% in those 80-84 years and 63.9% in those aged 90-94 years (Laing and Buisson 2009a). The number of people living with dementia in long-term care is predicted to increase significantly over the next 30 years, from 224,000 in 1998 to 365,000 by 2031, an increase of 63% (Comas-Herrera et al 2003). The level of CI is higher in residents in nursing homes, although large numbers of severely impaired people are cared for in residential homes (Bebbington et al. 2001). Only about 57% of residents for whom dementia is a known cause of admission, are cared for in settings which are dedicated to dementia care provision. The remaining 43% receive care in non-specialised care homes (Laing and Buisson 2009a).

Dependency

More than 75% of care home residents are classified as severely disabled (BGS 2011). Levels of severe disability are higher for women (79%) than for men (70%), and are higher in nursing

homes (91%), than residential homes (70%) (Bajekal 2002). Across all care homes 57% of women and 48% of men need help with one or more 'self-care' tasks (Office of Fair Trading 2005). Dependency levels of residents in care homes have risen sharply over the past decades (Darton, 1998; RCN 2010) and there is now considerable overlap in the levels of dependency and health care needs of nursing and residential care home residents (Bowman et al 2004, BGS 2011). Interestingly in residential care homes staff input for people living with dementia is on average 3.5 hours/per resident/per week higher than for frail older residents, whilst in nursing homes there is no difference between the two groups (Laing and Buisson 2009a).

Funding issues

Under-funding of social care continues to be a major problem. It is claimed that government funding has been inadequate from the time of the Community Care Act, when insufficient money was transferred from the DHSS to local authorities, due to an underlying assumption that all that older people in care homes required was accommodation and physical care to cover their basic needs (SPAIN 2005). Although local authorities have received increased allocations, it remains open to debate whether these increases have been sufficient to cover the additional pressures of demand, wage costs and inflation (Dudman 2007). During the period 2010-2013 baseline fees fell by roughly 5%, as local authorities implemented zero or sub-inflation baseline fee levels (Laing and Buisson 2014a). The average increase in local authority baseline fees for 2010/11 was just 0.8%, with 63% deciding not to increase fees at all (BUPA 2011). A recent review by Laing and Buisson (2014) reports an uplift of 1.8% in fees paid by local authorities, although it is estimated that an increase of 2.0% is required for a standstill in care home margins. But as none of the ground lost in the preceding three years has been regained, care homes still face a difficult future.

The care home sector has not been helped by pressure placed on local authorities to restrict the prices they pay for care home beds, or to use block contracts with fixed fees attached regardless of the degree of care needed (Dudman 2007). Each local authority is able to set its own baseline fees and so providers face widely varying fee levels, even between nearby authorities. For example in 2010/11 the difference in maximum fees offered by two central London boroughs for the same dementia nursing care varied by around £400/week (BUPA 2011). Age UK (2011) has estimated that the average shortfall per resident is £60/week, rising to £120/week in South East England. It has also been suggested that the NHS used to pay 'premium rates' for those they funded. However, more recently it is reported that they are using the fees paid by local authorities as a benchmark, often arguing that the dependency profile of NHS continuing care patients is no different to that of local authority residents (Laing and Buisson 2016).

The fees paid by local authorities lag behind private fee rates and as a result those who pay privately continue to cross subsidise local authorities (Laing and Buisson 2014a). Those who are self-payers typically pay, on average, £50-£100 or more than the local authority, for similar services and amenities. In September 2013 average fees were £728/week for a nursing home

bed and £550/week for residential care (Laing and Buisson 2014a). If the baseline fees paid by the Local Authority do not cover the entire cost of the fees charged by the care home, it is possible for a third party, often a family member, to pay a 'top up'. Laing and Buisson (2014b) estimate that 44% of residents are private payers, 13% of residents are topping up the fees paid by local authorities, only 36% of residents are fully funded by their local authority, a decrease on previous years, and 7.2% are funded by the NHS.

There is also a disparity in the fees charged by care homes for older people when compared to other types of care homes, such as, for example, those providing care to people with mental illness or learning disabilities, especially those classed as intermediate or high dependency clients. In the case of this group the average fees paid by the local authorities are £643 for residential care for a person with mental illness and £1094 for a person with learning disabilities, although fees can rise for this latter group as high as £3000/week. It should also be noted that fees for these groups are set on a case-by-case basis, dependent upon need (Laing and Buisson 2010). Continual under-funding continues to have a marked impact on the care home sector, especially in terms of levels of investment in new homes, maintaining buildings, training staff and the ability to introduce new services (BUPA 2011).

Regulation

Attempts have been made over the past 30 years to improve standards in care homes. The Registered Homes Act (DOH 1984) gave greater powers to both Local and Health Authorities in the regulation of care homes. However, as the legislation was vaguely worded and open to interpretation it resulted in authorities applying different standards (Nazarko 2000). The need for robust regulation was initially recognised through the introduction of National Minimum Standards (NMS) (DOH 2000), followed, in 2009, by the setting up of the Care Quality Commission (CQC), who were given a remit to act as the independent regulator for all health and adult social care services in England.

All providers of care register for the type of activity they provide, for example in the case of care homes it is 'providing accommodation together with personal care or nursing care'. The NMS have been abandoned and replaced with generic essential standards, concerned with quality and safety, which apply across all health and social care sectors (Laing and Buisson 2010). Compliance against a set of 16 core standards is regularly reviewed. These core standards include for example: assessing and monitoring the quality of the service provided, the care and welfare of those who use the service, meeting nutritional needs and requirements relating to staffing levels, skills and training (CQC 2009a, 2009b, 2010). The focus of these standards is on outcomes, in terms of quality of care, and providers must be able to produce evidence that they meet these outcomes. Most providers are inspected at least once a year and all inspections are unannounced. There are three types of inspections which are: scheduled, responsive, i.e. carried out if concerns have been raised over a provider's compliance and themed, concerned with reviewing a particular type of service or a specific set of standards (www.cqc.org.uk).

Staffing/Skill Mix/training

There are roughly 425,000 people working in the residential care sector (Cavendish 2013). The workforce is predominantly female (80%) and generally older than the working population (Eborall et al 2010). 83% of the workforce is British and 17% non-British, with 26% from European (EU) and 74% from non-EU countries (Skills for Care 2011). However, this varies with setting type, with a greater reliance on migrant workers within the private sector and nursing services. It also varies by region, in London for example 51% of care workers are non-British compared to less than 5% in the North East (Skills for Care 2011).

Staff turnover in social care is typically high, with 36% of care workers in nursing homes and 33% in residential care homes having been in their current job for less than 3 years (Eborall et al 2010). A survey by the National Care Forum (2010) found that 40.8% of staff leave within 12 months and 59.6% within 2 years. Rates of turnover are reportedly higher in the private sector than in the voluntary sector and higher turnover rates have also been reported in establishments providing services for those with dementia only (Skills for Care 2009).

In 2012 the average hourly rate for care workers was £7.10. The rate for those working for local authorities was much higher (£9.61) than for those in the independent sector; £6.76 in the private sector and £7.37 in the voluntary sector. Rates of pay are often lower than for those working as 'cashiers or check out operators in the retail sector' (Dudman 2007). Skills for Care (2009) reported that care workers working only with older people with dementia have the lowest median hourly pay rates. Care workers are paid on average 91p per hour above the National Minimum Wage. Although again there are variations, with those in local authorities and the voluntary sector paid £3.42 and £1.18 respectively above the National Minimum Wage, whilst those in the private sector are only just paid above it, at 57p (Skills for Care 2013). There are also regional variations with evidence of a North/South divide. Those in the North have the lowest average pay, whilst in the South, especially in London, average pay is significantly higher, reflecting differences in living costs. If one looks at 'real term' hourly rates for care workers in the independent sector these show a decrease between 2009 and 2012. Real term pay decreased by 34p (5%) in the private sector and 64p (8%) in the voluntary sector, whilst for a care worker employed by a local authority pay decreased by around 13p (1.5%), however, these figures only apply to 2011-2012 (Skills for Care 2013).

There is little accurate data regarding ideal staffing levels or skill mix owing to a lack of guidance on staffing levels in care homes. The new core standards merely state that *'the registered person must take appropriate steps to ensure that, at all times, there are sufficient numbers of suitably qualified, skilled and experienced persons employed for the purposes of carrying on the regulated activity'* (CQC 2010). Yet as the Royal College of Nursing (RCN 2010) highlighted inadequate staffing levels are putting additional pressures on care home staff as they impact the quality of care that can be delivered and the ability of care homes to meet the needs of their residents, especially when needs are complex.

Information on training and qualifications of the social care workforce is limited (Eborall et al 2010). In terms of training it tends to be largely informal and mostly provided on-site (Skills for Care 2007, Eborall et al 2010). Induction training is the only mandatory training for social care staff. However, the amount of time given to this can vary considerably from 2 days to 2 weeks. There are also requirements for staff to undergo statutory training in first aid, moving and handling, food hygiene and health and safety (CQC 2010). Whilst generally social care employers are relatively satisfied with the skills of their employees, gaps have been identified relating to technical and practical skills, including gaps in written skills, oral communication, numeracy and management skills (Eborall et al 2010). Job specific gaps have also been identified which include recognising, understanding and managing special needs of people with specific medical conditions, case management and practical nursing skills.

The NMS for care homes set out requirements for 50% of care staff to be trained to NVQ level 2 and for all homes to demonstrate staff training and development by December 2005. However, by the end of March 2009 10-15% of care homes still had not reached these standards (Eborall et al 2010). It was noted that 67% of those working as 'care assistants' were qualified to NVQ level 2 or above, yet 7% had no qualifications. The new standards set no specific levels for training, merely stating that '*all persons employed receive appropriate training, professional development, supervision and appraisal and are also enabled 'from time to time' to obtain further qualifications appropriate to the work they perform*' (CQC 2010). With the NMS care home managers were required to possess an NVQ level 4 or equivalent in management and care and, if running a nursing home, to be a registered nurse, however, this is no longer a requirement. It was reported by the National Care Forum (2010) that 91% of managers held NVQ level 4, with 64% of organisations reporting 100% qualified managers.

The importance of care staff having appropriate knowledge and skills has been acknowledged, with Skills for Care given a major role in ensuring that all social care workers have the necessary knowledge and skills they need for their role. Common induction standards, which care staff are expected to meet, have been introduced including, understanding principles of care, communicating effectively, recognising and responding to abuse and neglect, together with knowledge sets in a variety of areas such as dementia, end of life care and nutrition. They are also involved in developing new qualifications for social care staff, with NVQ levels 2 and 3 being replaced by Health and Social Care Diplomas at levels 2 and 3, including specialist pathways in dementia and learning disabilities (Skills for Care 2010). Concerns have, however, been expressed from within the care home sector about its ability to meet set training targets as the cost of training is not reflected in care home fees (English Community Care Association 2004, Dudman and Meyer 2012).

Summary

This chapter has provided an overview of historical and current factors that have influenced provision of long-term care in England. Older people are now cared for in their own homes for

as long as possible, not entering care homes until they are really no longer able to manage at home, or the levels of care they require at home are prohibitively expensive (Bowman 2003). Levels of dependency and co-morbidity are increasing across the care home sector, with neurodegenerative diseases, and dementia in particular, having a significant impact. The needs of residents are often complex and if a good quality of life is to be achieved then adequate resources, a skilled workforce and adequate support from external services are needed (Fossey 2008). However, care homes face a number of challenges in ensuring that they receive the support required to meet the needs of the residents. The following chapter will provide an overview of the district nursing service.

CHAPTER 3: SETTING THE SCENE NATIONALLY - DISTRICT NURSING

Introduction

As the researcher is a practising district nurse, conducting a practitioner inquiry, this chapter reflects on what is known about the district nursing service. It describes the role of the service, discusses how district nursing has been under-researched, and what is currently known about the support provided by community nurses to residential care homes. Lastly it explores some of the challenges facing the service today.

The role of a district nurse

Definition of a district nurse

A district nurse is defined by the DOH (2013b) as a 'qualified nurse with a graduate level education and specialist practitioner qualification recordable with the Nursing and Midwifery Council' (NMC). Training of district nurses was originally the responsibility of The Queens Nursing Institute (QNI), who up until 1967 set the syllabus and national standards for this training, after which it was absorbed into higher education (QNI 2009). The QNI is now a registered charity that is, amongst other things, dedicated to influencing policy and campaigning for quality nursing in the home. The competencies required by a specialist nurse, including district nurses, were originally set out in a NMC document entitled 'Standards for specialist education and practice', published in 1994 (NMC 2001). In regard to district nursing these standards appear limited, comprising 6 general statements relating to their role in clinical practice and care management.

Training for district nurses was made mandatory in 1981. District nurses now undertake a year's Specialist Practitioner programme at degree level, enabling them to assess patients and carers' needs, plan appropriate services, implement and evaluate treatment programmes and manage a nursing team (Audit commission 1999, QNI 2009). It was recently acknowledged that the original NMC standards needed to be updated and enhanced, to ensure that prospective district nurses are equipped for contemporary and future practice (QNI/QNIS 2015). A new set of standards, covering four areas: clinical care, leadership and organisational management, facilitation of learning and research and development have been published, however, at present these are 'voluntary standards'. This has quickly been followed by the publication of a framework from Health Education England (HEE 2015), setting out the skills and educational requirements required by all levels of district and practice nursing services, to ensure that educational outcomes are nationally consistent. Traditionally a nurse could not be referred to as a district nurse unless they had undertaken the specialist qualification; however, as will be discussed later, this is no longer the case (Toofany 2007, QNI 2009).

Initially district nurses were employed by local voluntary organisations, funded through donations and fundraising and managed by committees. These local societies tended to be

affiliated to county nursing organisations, which in turn were often affiliated to the QNI (Sweet and Ferguson 2000, QNI 2014a). The formation of the NHS initially saw district nurses employed by local councils. However, following a reorganisation of the NHS in 1974 responsibility for community health services, including district nursing was transferred to health authorities (Toofany 2007). Today, although the majority of district nurses are still employed by NHS organisations such as acute or mental health trusts, or community foundation trusts, a number are employed by social enterprises or private companies contracted to provide NHS services (QNI 2014a). Since 2009 it has been reported that the majority of district nurses have experienced some type of reorganisation, the result of which can be repeated changes of employers, managers, titles and working practices (QNI 2014a).

Services provided

The title of district nurse has been in existence for over 150 years; however, unsurprisingly the role has changed considerably during this time. One would assume that this role would be clear and well understood, yet this is not the case, largely a result of constant changes to the service (Dickson et al 2015). In general terms a district nurse manages a caseload of patients, who are associated with either a GP practice, or geographical area. The service provides skilled nursing care to adults living in their own homes, including those in residential care homes. The role broadly comprises: holistic assessment of patients and their families, proactive and anticipatory organisation and provision of complex care in the home, population and caseload management and support and care for independence (QNI 2009, DOH 2013b, HEE 2015). The QNI (2009) reports that the main reasons for district nursing visits are for: advice and support, phlebotomy, injections, wound care, continence, diabetes care, monitoring/screening, pain control, palliative care, pressure area care, medication administration, bowel care, Peg feeding, supply of equipment, skin care, health education and general nursing care. The service is also increasingly taking over work that would previously have been provided either in hospital, or by doctors, including prescribing, IV therapy, chemotherapy and end of life care.

A national survey carried out by the Audit Commission (1999) reported that district nursing was demand led, driven by the type of referrals received and reactive in nature. As the service is not able to operate a waiting list, or refuse appropriate referrals, there is constant juggling between demands of capacity and equity, with the caseload described by some as a 'ward without walls' (Bain and Baguley 2012, QNI 2014a). Much of their work takes place within the patient's home, and as a result can be invisible (Goodman 1996, McIntosh et al 1999). This can mean differing working practices between teams and even nurses within teams, and as a result care practices and services may be inequitable (Griffiths 1996, Speed and Luker 2004). Real world factors, such as the availability of resources, can also affect service provision. For example, a study of home visits by district nurses (n=16) from 2 localities found that frequency of visits was often driven by caseload demands, rather than patient need (Griffiths and Luker 1994).

More than a 'generalist'

District nurses are often referred to as 'generalists' having, as they do, knowledge and skills across a wide variety of clinical areas and a broad range of competencies. Yet this can ignore the more 'specialist' knowledge and expertise required to deal with the complex needs of many of their patients. For example a referral could simply state 'visit to administer insulin', yet on the first visit the nurse is confronted with an older person, with multiple comorbidities, who lives alone without any help, is becoming increasingly frail and is struggling to cope, yet is reluctant to accept any support. Holistic assessment is frequently cited as central to district nursing practice (QNI 2009). The provision of care is dependent on the ability of community nurses to carry out a thorough assessment of a patient's needs and to plan care to meet these needs. In the case of people living in the community, assessment can't take place in isolation, due to the impact that personal, social and financial factors can have on an individual's health (Parkinson 2006). All community nurses will report that they carry out 'holistic' assessments, yet two small-scale studies (Bryans 1998, Worth 1999) have suggested that they tend, on the whole, to pay more attention to physical, rather than the social needs; leading one to question if their practice is truly holistic.

District nurses draw on a range of knowledge and experience when assessing and planning a patient's care: including theoretical knowledge, for example, pathology and physiology, 'knowing' the patient, personal values and previous experience (Bryans and McIntosh 1996, Bryans 1998, Hallett et al 2000). An exploratory study of what influenced the clinical decision making of 46 community nurses from four trusts revealed that central to their practice was intuition or 'know-how' knowledge (Luker and Kenrick 1992), developed by practitioners over time, through a process of reflection on what works and what doesn't. Two further studies (McIntosh1996, Bryans 1998) exploring the knowledge base of district nurses (n=30) reported that such knowledge was inherently difficult to articulate. For community nurses to develop as credible practitioners, ways need to be found to articulate and pass on this knowledge to others (Luker and Kenrick 1992). One way is through the use of practitioner-based research, as this study has done, which enables such professional knowledge and judgement to be legitimised, codified and made public (Rolfe1998, Brooker and MacPherson 1999).

Impact of referral criteria

A response to increasing demands on the service has been the use of increasingly rigid criteria to prevent the service from being overwhelmed (Audit commission 1999, Parkinson 2006). Guidance produced by the RCN (2003) recommended that district nurses should not carry out 'check' visits and that any one referred to the service should have an identified 'nursing need' requiring an intervention by a nurse. Unfortunately, this suggests that district nursing can easily be reduced to a list of nursing tasks, ignores the complex skills frequently needed to perform care in the isolation of the home environment, as well as the knowledge base underpinning district nursing practice (Griffiths 1996, McIntosh 1996, Hockey 1999). Acknowledgment is needed that district nursing practice is complex, responding as it does to the physical, emotional, social and economic needs of patients and their families, many of which are

unpredictable and constantly changing (Hockey 1999, Kennedy 2000), and that there are challenges in providing care which has to be adapted to the patient's environment (Barrett et al 2007). Inappropriate referrals remain a bone of contention. The Audit Commission (1999) suggested that one in ten of referrals were inappropriate, whilst a recent survey (QNI 2014a) found that inappropriate referrals were still being made, because the role of the district nurse was poorly understood.

District nursing is under-researched

Compared to other branches of nursing relatively little is known about district nursing practice, as historically district nursing has tended to be under researched (Goodman 1996, Luker et al 2000). There are some notable exceptions, examples include the work of Hockey (1966), Griffiths (1996), McIntosh (1996) and Speed (2003) exploring working patterns of district nurses, Bryans (1998) and Kennedy (2000) exploring the knowledge base of district nurses, Luker et al (2000) exploring provision of quality care by district nurses and Goodman et al (2003a, 2003b, 2005, 2013) exploring their role in residential care homes, yet much of this was conducted at least a decade ago. Unfortunately the knowledge base for district nursing is far less than say for example health visiting (Griffiths 1996), a consequence, it is argued, of the lack of attention often afforded to district nursing, both at a resource and policy level, together with a lack of research skills amongst practitioners (Bryar 1999b).

As a result there isn't a substantial body of knowledge for practitioners to draw on. For example a recent search using the databases BNI, CINAHL and Medline to identify literature relating to the role of the district nurse found 84 papers, yet 70% of these were editorials, discussions or descriptive in nature. Their scope was limited, with the majority focusing on the district nurses' perceived role in managing specific conditions. Interestingly, given the range of conditions the service typically manages, most focused on their role in terms of palliative care provision for those with a malignancy, with little attention paid to wider role of the district nurse. In terms of district nursing research qualitative research is favoured. Studies tend, on the whole, to be small scale, carried out within one area, and involve small numbers of participants, and although useful insights maybe provided, there are issues over wider generalisability. Little recent research involves the care home sector, suggesting that the focus is on their role in supporting older people at home, rather than in care homes. Few studies are reportedly carried out by district nurse practitioners themselves, or written as practitioner inquiries. Similar findings have been noted by Bryar (1999b), Hallett and Pateman (2000), Luker et al (2000) and Walshe and Luker (2010), who reported that research into district nursing focused on the scope of their work, specific tasks, or changes in the type of knowledge or skills used, with a dearth of literature exploring district nurses' perspectives of their work.

Role of the district nurse in residential care homes

Impact of residential homes on caseloads

In residential care homes there is no requirement for a qualified nursing presence. As a result they rely on primary care for nursing and medical support. Care homes receive support from a variety of primary care nurses; with the district nurse the most frequent visitor (Goodman et al 2003a). However, there is a dearth of literature exploring their role in supporting these care homes (Goodman et al 2003b). Residential care homes can have a significant impact on a district nursing caseload. A study of 21 district nursing teams from 7 NHS trusts across England (The Audit Commission 1999) reported that older people in care homes account for 7% of all district nurse contacts. This study also reported that the number of district nursing contacts in care homes had risen by 13% since 1992, even though the actual number of residents had not increased; a reflection of the increasing complexity of residents' needs. A census of 135 care homes in one county (Donald et al 2002) reported that district nurses were visiting 24% of residential care residents, 32% of high dependency residents, and were even found to be visiting 10% of nursing home residents, which they are not required to do as there is a nursing presence in such homes. As a result of GP attachments district nurses can have responsibility for multiple care homes (Goodman et al 2003a), and nurses from different teams may visit the same home (Donald 2002). Davies and Goodman (2008) suggest that the amount of time spent in care homes varies greatly, between 4-6 hours a week on average, although in some cases it can be as high as 27 hours a week. They may also be frequently asked to see additional residents during a visit (Goodman et al 2003a). Interestingly of the district nurses (n=89) in the study by Goodman et al (2003a) only a third wanted to develop their role in care homes, whilst a further third suggested that residents should not be their responsibility.

Role in residential homes unclear

There is no clear definition of how district nurses, or care home staff define their roles and responsibilities when an older person develops a healthcare need, with, it has been suggested, professional and organisational preoccupations dictating how care is organised, rather than residents' needs (Goodman et al 2005). A study by Goodman et al (2005) of district nurses and care home managers from two trusts, reported that the average visit to a care home lasted less than 20 minutes. Community nurses provide care for residents on an individual basis, and have no explicit on-going responsibility for a care home population (Goodman et al 2003a), only visiting a resident if there is a defined nursing need (Evans 2007). Donald et al (2002) reported that in care homes the majority of district nurse visits were for wound care, injections, or continence care, whilst Goodman et al (2005) reported three key roles: the meeting of healthcare needs that care staff are unable to manage, e.g. wound care or insulin administration, the provision of equipment, and case management; although in reality it was the first role that dominated. A study of end-of-life practice in 6 care homes in the East of England (Handley et al 2014) included the experiences of a small sample of district nurses (n=11). They reported little evidence of the residents' general health or well-being being reviewed or

discussed, it was unclear what support was offered to unqualified care staff, or relatives, and when a resident was dying support mainly involved provision of equipment and monitoring.

As there is a lack of consensus about the district nursing role in care homes, service provision can differ between teams. For example Goodman et al (2003a) found involvement of district nurses in care homes to be variable, with only half of care homes receiving support for residents with palliative care needs. Those care home managers (n=96) who received support reported that it ranged from 'need specific' support, to open access to the service, with on-going support, training and partnership working offered, although the latter was certainly not the norm. Assessment of a patient in their own home is usually an on-going process, with the nurse taking time to build up a complete picture of needs. If at the time of a first assessment there aren't any immediate needs identified, a district nurse may, given a patient's physical and psychosocial needs, maintain contact to prevent a problem becoming a crisis (Kennedy 2002). The situation appears to differ for care home residents (Goodman et al 2003a, 2003b, Evans 2007, Dobie 2010) where it has been suggested that district nurse involvement tends to be highly variable, predominantly reactive, episodic, with little evidence of wider involvement, or continuity of care and residents more likely be discharged once an episode of care is completed. A lack of continuity in terms of the nurses who visit, as well as visiting intermittently, suggests that the type of nurse-patient relationship that community nurses value could be difficult to develop.

Limited insight into working relationship

Only one study (Goodman et al 2003b, 2005) explores the working relationship that exists between care homes and district nurses in any depth. In others the focus is either on the nurses' experience (Goodman et al 2003a, Dobie 2010), or the views of nurses and care home staff have been sought as part of a wider study (Evans 2007, Goddard et al 2011, Handley et al 2014). As a result there is limited insight into the relationship, highlighting the need for further research, especially studies that seek to understand the perspective of the care staff. It is suggested that most nurses and care staff are happy with their relationship (Goodman et al 2003a Handley et al 2014). Evans (2007) reported that care staff valued being able to contact district nurses at any time and receiving prompt advice and support, although the level of support given was at the discretion of the individual district nurse. The nurses valued the support given by care staff, especially when caring for residents living with dementia, or who were dying (Dobie 2010, Handley et al 2014). Interestingly Goodman et al (2003b) found that it was the care homes placing fewest demands on the service that were viewed as providing the best care. Continuity of staff is necessary for a good relationship, but can be difficult due to high staff turnover on both sides (Goodman et al 2003a, 2014). Both Dobie (2010) and Goodman et al (2014) suggested that tools, such as clinical benchmarking, or end-of-life tools, encouraged closer working relationships, and a more proactive approach to support.

Studies also revealed an undercurrent of dissatisfaction. Community nurses suggested there was a lack of anticipatory care, with care staff not picking up issues quickly. Frustration was expressed when asked to visit for superficial wounds, or to see new patients each time they

visited the home. It was felt that there was little understanding of the services the nurses provided, as well as a lack of training for care staff (Goodman et al 2003a, 2003b, Dobie 2010, Goddard et al 2013). Care staff suggested that community nurses didn't always acknowledge the experience and knowledge they had, or the need to create a homely environment for residents. They also felt the district nursing service was pressurised, as nurses always appeared busy and visits were brief (Goodman et al 2005, Evans 2007).

Challenges facing district nursing

District nursing has been referred to as an 'invisible workforce' as the service has often felt that its contribution has gone unrecognised, with the focus of repeated governments and the media on hospital care (Cook 2006, QNI 2014a). Increasing demands have been placed on community services over the years and district nursing is no exception (Ball et al 2014). Constant reorganisations have taken place to meet the changing needs of the population and service delivery (Dickson et al 2015), and could explain why community nurses can have difficulty explicitly defining their role. A number of challenges have shaped, and continue to shape, the service, including greater integration with social care and third sector providers, skill mix, an ageing workforce and increasing numbers of specialist nurses (Austin et al 2000, Sweet and Dougall 2007, Bain and Baguley 2012).

Demand is increasing

Demand for the service is steadily rising and increasing pressures are being placed on the workforce. One in four people over the age of 75 need nursing support at home, rising to one in two for those over 85 years (QNI 2012). However, although there has been a well reported shifting of care from hospitals to the community there has been little change in terms of the numbers of nurses employed to care for these people (National Nursing Research Unit 2013). The service is stretched, as a result of workload pressures and increasing caseloads. A recent survey (Ball et al 2014) of RCN members working in the community (n=2,438) reported that the majority of district nurses (81%) were working overtime. It has also been reported that, although workloads have increased, the number of visits have decreased (Bain and Baguley 2012); a result of activity measurements which simply focus on the tasks that community nurses perform, and fail to measure the complex nature of visits. Suggesting that systems are needed which demonstrate to those purchasing and providing these services the true picture of caseloads, including the levels of dependency and care being provided by every team (RCN 2013). As well as future demand for the service, so the size of the workforce can be better determined and used efficiently to meet the needs of the changing population (QNI/NHSE 2014).

Impact of changes in social care provision

Community care reforms in the 1990s resulted in fundamental changes to the role of the district nurse (Luker et al 2000, Sweet and Dougall 2007), with responsibility for what had previously been defined as nursing work, such as washing, bathing or dressing, taken over by others, in particular the social care workforce, who may not have possessed any qualifications, e.g.

NVQs. District nurse caseloads were restricted to those who needed 'nursing' care, i.e. care provided either directly or under the supervision of a nurse (RCN 2004). As mentioned previously due to the changing definitions of what constituted health or social care it was often unclear with which service responsibility lay, especially in regard to older people, whose needs often fell in a grey area between the two. District nurses were often reluctant to hand over care of these patients, as they were concerned that the needs of this group would no longer be regularly assessed by nurses, even though this care was often performed by their auxiliaries, for whom there was no requirement to hold any formal qualifications, and so could be less qualified than the social care staff (Griffiths 1998). Such confusion continues, as evidenced by Goodman et al (2005), who suggested that district nurses were unclear of their responsibility to care home residents due to the lack of clarity regarding health and social care.

As others have taken on increasing responsibility for care provision this has had a knock on effect. As mentioned previously, community nurses will draw on their knowledge of a person when assessing and planning their care. However, an ethnographic study involving 11 district nurses (Kennedy 2004) reported that 'getting to know' or 'knowing' a patient had become increasingly difficult. Studies by Luker et al (2000), involving 62 community nurses and Speed and Luker (2004), comprising 33 district nurses, reported that 'knowing' of the patient had been replaced by 'knowing about', making assessment and care more of a challenge, because the personal knowledge that these nurses had relied upon was gradually being lost. Kennedy (2000) also suggested that when multiple agencies were involved in a person's care it could be unclear which of a patient's needs were the responsibility of the community nurse.

Skill mix

Demographic changes have seen district nursing caring for an increasingly older population, often with multiple co-morbidities and complex healthcare needs, placing increasing demands on the service (Kraszewski and Norris 2014). Yet despite these increased demands the proportion of community nursing staff has not changed greatly over the past decade (Ball et al 2014), although the makeup of the district nursing team has. Skill mix, introduced into district nursing during the 1990s as a result of a study carried out for the DOH, has seen a 40% decrease in the number of qualified district nurses (Ball et al 2014). In 2005 district nurses accounted for 20% of all NHS staff in the community, however, by 2012 only 12% of community nursing staff held a district nursing qualification (National Nursing Research Unit 2013). During the same period there was a 47% increase in the number of other nursing posts, with more than 31,000 staff nurses and 15,000 support staff estimated to be working in community nursing services (QNI 2009). This is of relevance as studies have suggested that there may be differences in care provision between grades. An observational study of 76 home visits by nurses from 21 teams (McIntosh et al 1999) found that there were considerable differences in the knowledge, level and use of skills by different grades of community nurses. For example all nurses used observation and evaluation skills, but those at higher grades (G and H) used the widest range looking, in addition, at issues such as the environment, carer support, safety, 'atmosphere' and signs of coping, or not coping. They also found that those within the same

grade could provide very different levels of care. Ball et al (2014) reported that district nurses spent longer per patient than community staff nurses.

Reduction in numbers undertaking district nurse training

Two national surveys by Hockey (1979) and The Audit Commission (1999) exploring the role of the district nurse focused on the tasks performed, rather than seeking to gather a more in-depth understanding of their work (Speed 2003). As a result it was suggested that the expertise of district nurses was underutilised and less qualified staff could provide care just as effectively. Unfortunately, this ignores the unique knowledge and experience that district nurses bring to the role, knowledge that has often been developed over many years. District nurses are more likely to have worked for longer in the community, with 44% having worked for 15 years or more, compared to only 16% of community staff nurses; whilst 37% of community staff nurses have worked in the community for less than 5 years, compared to only 9% of district nurses (Ball et al 2014).

In the past a district nurse with a team leader role was an RN with an additional post-basic qualification. However, this is no longer the case and there are fears that the district nursing service is 'being diluted by the loose use of the title and lack of recognition of the value of their specialist education' (QNI 2009). Recent guidance from The Department of Health (2013b) acknowledges that care provided in the home is unique and fundamentally different from providing care in a clinical setting. Yet there is no longer a requirement for team leaders to hold the specialist community qualification (QNI 2013). A national survey carried out on behalf of the QNI (QNI 2014a) found that 52% of employing organisations no longer required this qualification and a further 19% were planning to discontinue the requirement. Programme directors of the Specialist Practitioner course (QNI 2013) reported a decrease in district nurse training, with 21% of courses not running in 2012-13 and at least 67% of courses having 10 students of less on them.

It has been suggested (McIntosh et al 1999) that the decision to reduce the number of qualified nurses was flawed, given that the numbers of frail and increasingly complex patients was rising. If their care is to be managed effectively nurses need appropriate knowledge and skills; and less experienced community nurses may not possess all the theoretical and practical knowledge that is now required (Bryans 1998, Toofany 2007). Interestingly, the value of district nursing may finally have been recognised by workforce planners, with the number of universities providing and running the Specialist Practitioner course increasing, as are the number of new entrants, with an increase of 38% in the number of district nurses qualifying in the summer of 2014 (QNI 2014b), and a 7% increase in district training numbers planned for 2014-2015 (Ball et al 2014). Some provider organisations, who had previously promoted community staff nurses to district nurse team leader posts are now insisting that these nurses complete the Specialist Practitioner qualification in order to retain their post (QNI 2014b). However, these increases are not uniform across the country and there is an urgent need to

develop a national system to plan for the number of district nurses needed to assess and manage the care of an increasingly older and frailer population (QNI 2014b).

An ageing workforce

Nurses who are new to the community need to be given support and supervision to develop the skills and knowledge needed to work safely in the community, where they are often working in isolation, yet the RCN (2013) reports that there are not the systems in place to ensure that this always happens. This situation will only get worse given the age profile of district nursing. 72% of district nurses are aged over 40, compared to 43% in the acute sector. And 71% of those supporting district nurses are over 40 (QNI 2009, 2010). More than a third of the workforce is able to retire in the next 5 years, with roughly 25% reporting that they are planning to retire in the next 3-5 years (QNI 2014a).

Increase of specialist nurses

As generalists, community nurses have knowledge and skills across a wide range of different fields, caring for patients holistically (QNI 2009). However, the district nursing service is facing an additional challenge from the growing number of specialist nurses now visiting people at home, e.g. community matrons, Macmillan nurses, tissue viability nurses and heart failure nurses, to name but a few. By definition the focus of a specialist nurse is narrow, focusing as they tend to on a particular disease, or group of patients (Castledine 2004) and whilst there is demand for nurses who are able to address the specific health needs of certain patient populations, there is a risk of patient care becoming increasingly siloed and fragmented. Concern has been expressed that there has sometimes been a lack of integration between specialist and district nursing roles, and that such roles could even result in the deskilling of community nurses, with specialist nurses taking over what could be argued were traditional aspects of district nursing care, such as the management of long-term conditions and wound care, and may even be duplicating the role (Griffiths 1996, Austin et al 2006, QNI 2014a, RCN 2013). It should also be noted that many of these changes have been imposed upon district nursing, rather than chosen by them. As a result it can be difficult to say what district nursing is, or what its core activities are (Goodman 1996). Such changes have also not been accompanied by proportionate investment and development of the community workforce, leading to calls for improved education and development of staff, as well as recognition and clarification of the district nursing role (Kraszewski and Norris 2014).

Summary

This chapter has suggested that district nursing is facing an increasing number of challenges. There is a lack of clarity regarding their role. District nursing is often viewed in terms of the tasks performed; however, this ignores the complex skills needed to manage care in the isolation of the home environment and the knowledge base that underpins their practice. The service has faced constant change over the years, change which has tended to be imposed upon the service. Little is known about their practice, because as a service it has been under researched.

Much of the research has a narrow focus, concentrating on their role in regard to palliative care provision. Central to district nursing practice is tacit knowledge; however, few community nurses are researching their own practice. This needs to change if such 'know how' knowledge is to be revealed, with practitioner research offering a means by which this can be achieved.

Care is moving out from hospital to the community. As a result, community nurses are caring for patients who are older, frailer and sicker than ever before, many of who are living in care homes. However, this is another area of practice about which little is known. There is a lack of clarity over their role and responsibilities in regard to residential care, and little is known about the working relationship, especially from the perspective of the care staff, or what could be done to improve the relationship, highlighting the need for further research in this particular setting. All this is happening as the numbers of experienced district nurses are decreasing. District nursing is complex work, and community nurses need specialist knowledge and expertise to manage the complex care they are routinely faced with. Community nurses need to make explicit the knowledge and expertise they have to offer their patients and begin to actively engage in, and shape the direction of future services. Chapters 2 and 3 presented the national picture. The following chapter will provide the local picture, presenting a snapshot of the NHS trust and local authority in which the study was carried out.

CHAPTER 4: SETTING THE SCENE LOCALLY - CARE HOMES, DISTRICT NURSING AND THE PRACTITIONER RESEARCHER

The previous chapters provided a contextual overview of UK care homes and district nursing service. So the reader can judge the relevance of the findings to their own particular context this chapter provides additional information in relation to the local authority and NHS trust in which the study took place, together with details of the local care home sector and district nursing service, in which the practitioner researcher worked as a district nurse team leader. As a piece of practitioner research it is important for the researcher to acknowledge their own subjectivity, so that the reader can judge the potential impact of this on the findings and the researcher can demonstrate freedom from bias. With this in mind the chapter also provides details of the researcher's background and previous experience, together with details of why she chose to focus on the care home sector and the experience of caring for residents living with dementia in particular. This detail is written in the first person, which is in keeping with the research method chosen (Webb 1992). In order to maintain anonymity of participants, any information that would make either the local authority, or the NHS trust identifiable has been withheld when referencing relevant documentation.

Profile of the local authority and NHS Trust

The boundaries of the local authority in which the study took place were shared with those of the local NHS trust, in keeping with most local authorities in the area. The local authority was suburban, with good transport links, high performing schools, low crime levels, large open spaces and lower than average levels of deprivation. In 2011 the population of this local authority was estimated to be 279,000 (Office of National Statistics 2013), 22.5% were children (0-15years), 65.5% were of working age (16-64years) and 12% (33,385) were aged 65 and over. Life expectancy was higher than the national average, at 79.4 years for men and 83.0 for women.

The local authority was ethnically diverse. The 2011 census revealed that, for the first time, the number of people from Black and Minority Ethnic (BME) groups exceeded the number of white British residents. 34.5% of the population were white British, or white Irish, 41.7% were of Asian origin, mainly from India, Pakistan, Sri Lanka or Bangladesh and 9.8% were black, of Caribbean, or African origin (Office of National Statistics 2013). Older people were predominantly white (77%), with only a third of those aged 50+ from a BME background. It is estimated that there will be a significant increase in the numbers of older people, especially in certain age groups, and over the next 10 years the number of people aged 65-74 is predicted to grow by 15.7%, and those over the age of 80 by 20.4% (Public Health Team 2012). Gender differences increase significantly with age. 53% of those aged 70-74 were women, whilst in the over 90s, 73% were women. There is also projected to be an increase in ethnic diversity amongst older people, largely amongst older people of Indian origin (Public Health Team 2012).

Residents in this local authority experienced similar or better health and well-being than the average for England. However, there were considerable differences in life expectancy across the local authority, with life expectancy 7.3 years lower for men in the most deprived areas than in the least deprived areas. Limiting long-term illness rates vary with age and in 2001 49.3% of those aged 65+ reported living with a long term illness (Public Health Team 2012). If current morbidity levels continue it is suggested that increasing numbers of people will be reaching old age with disabilities, such as chronic disease, functional disabilities, or mental health issues. In terms of specific illnesses it is predicted that the numbers living with dementia are set to increase year on year, in both males and females. It is also predicted that the number of older people experiencing long-standing ill health due to heart attacks, stroke, bronchitis and emphysema will increase (Public Health Team 2008). A consequence of the growth in the number of frail older people with complex needs has been an increased demand for care packages, day care and residential care (JSNA 2012).

Commissioning and provision of healthcare and public health services has changed, as a result of the Health and Social Care Act 2012. These changes have seen a shift in the balance of power, from acute hospitals to GPs and local communities, resulting in the establishment of GP led Clinical Commissioning Groups (CCG), whose responsibility it is to commission most local health services. Together with local Health and Wellbeing boards, bringing together councillors and a range of public services, including adult social services, housing, public health, children's services, leisure, environment, community safety and GPs (JSNA 2012), with the aim of improving the health and wellbeing of local people. All 46 GP practices are part of the local CCG, whose governing body comprises elected GPs, a senior nurse, lay members, senior NHS managers and a secondary care consultant. A three year commissioning strategy plan for 2012-2015 was drawn up, which included national and local priorities, such as improving the quality and ensuring the safety of acute hospital services, primary care, community services, mental health and specialist services, working to join up health care services across general practice, community services and hospitals and reducing the need for healthcare and improving the health of the local population.

Profile of the local care home sector

Within the local authority there were, when the study began, 80 care homes. Of these 33 provided care for people aged over 65 years, 14 were nursing homes and 19 were residential care homes, equating to 1331 care home places for those aged 65 and over. Four residential care homes closed during the course of the study. During 2012, 238 older people were admitted permanently into local residential or nursing homes (Public Health England 2014). The remaining 47 care homes offered services for those with a mental health problem, or learning disability. Nine nursing homes and seven residential care homes were owned by large corporate groups, with five nursing homes and twelve residential care homes run by small businesses, owning one, or a pair of care homes. Ownership varied depending on provider type, with three quarters of these care homes (n=25) operating on a for-profit and eight

operating on a not-for-profit (n=8) basis. All nursing homes and 58% of residential homes were run for-profit, whilst in terms of not-for-profit care homes, five were run by one not-for-profit organisation, two by charities and one by the local authority, which closed during the study. No figures were collected regarding the number of residents that were self or local authority funded, however, five not-for-profit care homes had a block contract with the local authority for all their beds, but were permitted to take self-funders if the authority did not use these.

The average number of beds across care homes was 40, although there were differences depending on provider type. Nursing homes were larger on average, with 58 beds and residential care homes had, on average, 27 beds. Roughly two-thirds of nursing homes were in buildings that were purpose built, compared to residential care homes, of which roughly a half were in buildings that were converted. In terms of residents, the majority of nursing and residential care homes were providing care for 'dementia and old age not falling within any other category'. Three nursing homes were providing care for 'old age not falling within any other category', as were four residential care homes. In terms of the level of fees paid it was difficult to obtain accurate figures, as this data was not readily available. Figures obtained from the website www.bestcarehome.co.uk reported that between 2009 and 2011 average fees for a residential care home in this local authority were £494/week, with levels ranging from £450 up to £570. In comparison nursing homes in the area were charging on average £746/week, ranging from £620 up to £1200. Specific details of the residential care homes that took part in the study are provided in Chapters 7 and 8.

Profile of the local district nursing service

The district nursing service comprised a daytime and separate evening and night service. Cover was provided 20.5 hours a day, with the daytime service working between the hours of 8.30-5pm and the evening and night service working from 7pm-7am. The daytime service comprised seven district nursing teams, housed in seven health centres, aligned to one of three localities across the NHS trust. Each team was made up of one team leader (Band 7), at least one deputy team leader (Band 6) and a number of primary care nurses (Band 5) and healthcare support workers (Band 3). 73 nurses were employed in the day service, comprising 5 full-time (FT) and 1 part-time (PT) team leaders, 6 FT and 6 PT deputy team leaders, 31 FT and 11 PT primary care nurses and 7 FT and 6 PT healthcare support workers. The service was managed by a Professional Development Nurse for Leadership, and Professional Development Nurse for Clinical Practice, who reported to the Professional Head of Service/Primary Care Nursing.

This service structure was established in 2006, following a major reorganisation, driven by a number of factors, including the growth in the number of people of pension age, increased life expectancy, the complex health and social care needs of older people and a concern that the size of the UK workforce was going to decline. This reorganisation saw district nursing teams increase significantly in size, with each caseload comprising a cluster of GP surgeries, ranging from 3-9 surgeries, compared with 1-3 previously. Each team was set up to cover a practice

population of around 15,000 to 20,000, and was weighted on a number of factors, such as number of patients aged 65-74, number aged over 75, number of cancer deaths in the under 75s, number of deaths from coronary heart disease in the under 75s and predicted incidence of diabetes. It was also proposed that a number of new nursing roles would be introduced including community matron roles, advanced nursing roles to replace the district nurse qualification, and assistant practitioner roles (Band 4), a position requiring two years training, with at least one assistant practitioner based in every team, although the latter two commitments did not materialise. A central referral system was established to manage and allocate all new referrals to the service, with referral criteria produced, stating that referrals would only be accepted where a clear nursing need was identified and the patient was housebound. Those who were eligible for the service included patients requiring oncology and palliative care, wound care, risk assessment for pressure damage, continence assessments, bowel management, catheter management, those who were chronically ill, diabetic patients, those requiring specialist treatment, parenteral administration of medication and leg ulcer management.

Due to subsequent changes in the NHS and the reorganisation of community services into provider services, the district nursing service underwent a number of further changes during the course of the study. The service was initially managed by the local PCT, however, changes in Government policy required there to be a separation between commissioning and provider arms of PCTs. As a result the provider group, of which the district nursing service was part, was transferred from local PCT control, to a local foundation trust, providing services across four local authorities, resulting in a change in management structure and some tinkering to the district nursing service. In 2011 for example, the seven teams were amalgamated into three large teams, aligned to three localities, and the number of district nurse team leaders reduced from seven to three. Many of these changes occurred around the same time as austerity measures were introduced by the Coalition Government, with NHS trusts asked to save large sums of money, and the local trust required to save around £2.3 million in 2011/12 (Interim Chief Executive 2011). At the time of writing the district nursing service is facing the possibility of yet another reorganisation, as a result of the drive, by the local CCG, to join up health care services across primary care.

Profile of the practitioner researcher

In terms of my background, I qualified as a registered nurse (RN) in 1987 and spent six years initially working as a staff nurse on a number of surgical wards, and subsequently in a small private hospital, which is where I developed an interest in palliative care. I left the private hospital to develop my knowledge and skills in this area and spent the following two years working in a local hospice. It was this interest in palliative care that eventually took me into the field of district nursing. I originally planned to use the experience that I gained working as a community staff nurse, as a stepping stone into Macmillan Nursing, however, once I started working in the community I felt that I had at last found my niche and the career path that I was

looking for. A year after I started working in the community I undertook the Specialist Practitioner qualification and once qualified as a district nurse returned, as deputy team leader, to the district nursing team that I had originally joined. In 1999 I moved to the NHS trust in which I still work today, to run my own team and in 2006 was promoted to a district nurse team leader role.

My interest in palliative care has remained and for the past ten years I have also had a role as Gold Standards Framework (GSF) facilitator in the same trust, an initiative aimed at improving end of life care for all. It was whilst undertaking an MSc in Nursing in 2005 that my interest in the relationship between district nurses and care homes first began. As part of the dissertation I undertook a literature review, exploring palliative care provision in primary care, and as a result became aware of the studies by Goodman et al (1998, 2003a, 2003b), suggesting that the palliative care support offered by district nurses was of variable quality if the older person was living in a residential care home. My interest in the care home sector continued, as after completing the MSc I was given the opportunity to contribute to the literature review 'Quality of Life in Care Homes', which underpinned the *My* Home Life programme, a UK-wide initiative, sponsored by Age UK, City University and Dementia UK, which aims to improve the quality of life of people living, dying, visiting and working in care homes for older people.

During my role as GSF project manager I became interested in the field of dementia care, a result of my involvement in a multi-disciplinary project, aimed at improving end of life care for people with advanced dementia. Sitting in a number of meetings with members of the mental health team and listening to them talking about the experiences of their clients living with dementia, I realised how little I knew about this illness, as coming from a general nursing background I had, over the years, had little, if any real experience of caring for patients with dementia. A couple of patients come to mind during my time working in the hospice and I remember we had little idea how to care for patients, who were living with cancer, as well as dementia. We had little understanding of the difficulties they were facing, or how to deal with them and, as a result, we struggled to manage their needs, one of whom I can, even now, clearly remember was continually agitated and unable to settle.

It was identified that staff working in the care homes involved in this project lacked knowledge and skills in the field of palliative care and so I supported a member of the local Macmillan team to roll out a palliative care training programme, initially to these care homes, and then to staff from any care home across the local authority, a role that I am still involved with today. Providing this training gave me a better understanding of the support that care staff, especially those in the residential care homes, needed if they were to be able to support their residents to die in their place of choice. Yet, listening to some of the experiences of care staff it became clear that such support was not always available to them. I recently came across a note that I had written following a training session, in which we discussed how district nurses and care home staff needed to work together if they were to support a resident who was dying. Some care staff commented that this was not always happening and felt that they were often just left

to get on with it. An example was given of a resident who was dying, extremely distressed and agitated and continually calling out. Medication to deal with this agitation was available in the care home; however, they were unable to administer it. They described how they had spent days asking their district nurses to visit, but they didn't come, and as a result the care staff were left to try and cope as best they could. Obviously this was only one side of the story, but still it made me stop and question the support that we, as a service, were providing to these care homes and to try and ensure that those care homes who were supported by my team received the level of support that they needed.

It was whilst I was involved with this project that the opportunity to undertake a research study arose and I began this PhD, however, as I was keen not to lose my contact with practice I continued working part-time as a district nurse team leader. When designing the proposal for this PhD there were two areas of practice that I was interested in exploring further. The first was based on my observations from the palliative care training with care home staff, focusing on whether the relationship between the district nurses and residential care home staff was offering them the level of support that they really needed. Secondly, I was interested to explore, given my own lack of knowledge in this field, the experiences of other nurses in caring for a person living with dementia and whether I was alone in considering that it could present district nurses with a challenge.

During the course of the study my roles as practitioner and researcher became further blurred when, as a result of a reduction in the number of team leader positions, a new role was created for me. I was invited to share the knowledge and experience I had gained whilst undertaking this PhD with others and, as a result, began working with the community matrons for care homes, providing support and training locally for district nurses, nursing and residential care homes. For example through my research I had recognised that I lacked knowledge of dementia and so undertook a 'Training for Trainers Course' in dementia and dementia care, which I was then encouraged to roll out to district nurses and care homes across the trust. I discovered that care homes needed more healthcare skills training and so set up training in areas such as continence and catheter care and the palliative care needs of those with advanced dementia. These two roles enabled me to work as an 'insider researcher' in both settings, giving me privileged access to both care home and district nursing staff and, as a result, the opportunity to explore their practice in greater depth than someone who was seen as an 'outsider', an issue that will be explored in greater detail in Chapter 6. Since completion of the study my role has changed again and I am once more working with the district nursing service.

Summary

In order that the reader can judge if this study has relevance to their own practice this section has provided details of the local authority and NHS trust in which the study took place. It has provided a profile of the local care home sector and district nursing service, which are typical of care homes and district nursing across the UK, as described in Chapters 2 and 3. Finally it has

provided a profile of the practitioner researcher, a practising district nurse. The following chapter will explore the literature in relation to the level of unmet healthcare needs that are present amongst people living with dementia, as well as exploring what may be preventing these needs from being met

CHAPTER 5: A SYSTEMATIC REVIEW: THE CHALLENGES OF MEETING THE HEALTHCARE NEEDS OF RESIDENTS LIVING WITH DEMENTIA

Introduction

This literature review set out to gain a better understanding of the healthcare needs of residents in care homes, focusing in particular on those living with dementia, as well as exploring if there were any challenges in meeting these needs. There is an argument for focusing on the needs of those living with dementia, as an understanding of the issues as they relate to this particular group of residents, is likely to be of relevance to the wider population, given the levels of dementia and CI that are found across residential care settings. The chapter begins by outlining the aims of the review, followed by the search methods, inclusion and exclusion criteria. It then goes on to reflect on the literature overall. A number of emergent themes were identified which included: the presence of high levels of healthcare needs, these healthcare needs are often poorly managed, potential barriers preventing the meeting of healthcare needs, the experience of staff is poorly understood and little attention is paid to the context. It concludes by suggesting that there is a need to better understand why healthcare needs of residents, and in particular those living with dementia, are not being met, by exploring the experiences and views of staff involved in the day-to-day care of residents, especially in those care homes which have no on-site nursing presence, who may be facing additional challenges.

Aim of this systematic review

A systematic review, as carried out in this study, is a formal process, which brings together a raft of evidence and makes judgments about its quality, trustworthiness and relevance in order to answer a particular question (Gough 2007). This systematic review set out to answer the following question: What are the challenges to meeting the healthcare needs of residents in care homes, in particular those living with dementia?

Aim: To explore the challenges of meeting the healthcare needs of residents in care homes, in particular those living with dementia.

Objectives:

- To identify the level of healthcare need amongst this resident group
- To explore whether these needs are being met
- To examine potential barriers to the meeting of these needs

Search Methods

A review of the literature was carried out in June 2009 and updated until August 2015, based on an approach outlined by Hart (1998). To begin with the following electronic databases were searched: Medline (1996-2009), CINAHL (1981-2009), British Nursing Index (1985-2009), HMIC (1983-2009), PsycINFO (1806-2009), Social Care Online (1980-2009) and AgeInfo. Variations and combinations of the following search terms were used:

- Physical healthcare needs, healthcare needs, clinical need, assessment of healthcare need and
- Residential care homes and
- Older people, aged, geriatric, frail elderly and
- Dementia, cognitive impairment, Alzheimer's disease

As an initial search revealed a dearth of literature concerning residential care homes, especially in regard to the meeting of healthcare needs, the search was broadened to include the terms: nursing homes, care homes and long-term care. The search was also widened to include specific examples of physical healthcare problems that Goodman and Woolley (2004) suggested were prevalent amongst the general care home population; including continence, infection, pressure sores/pressure ulcers, diabetes, palliative care, pain and nutrition. Further papers were identified by searching the reference lists of identified papers, through recommendations from other researchers, by searching the master bibliography of 'Models for providing improved care in residential care homes' (Szczepura et al 2008) and by hand searching the journals Age and Ageing, Dementia and Ageing and Mental Health. Citation alerts were set up and the initial search revisited on at least three subsequent occasions, the last one in 2015, to ensure that the search was up to date.

Inclusion/exclusion criteria

Studies that used any type of research design, as well as literature reviews, were included if they were concerned with the healthcare needs of older people living with dementia and were conducted in any type of care home. Papers were also included if they were concerned with healthcare needs of older people in general within care home settings, and made specific reference to the needs of those living with dementia, or CI. Excluded were research studies concerned with the development of assessment tools or interventions and non-research based articles such as clinical reviews, overviews of practice, audits and discussion documents, as were studies carried out in care homes for older people that made no specific mention of the needs of residents living with dementia, or CI. For pragmatic reason limits were also applied which included only articles in English and those published from 1990 onwards.

Number of studies

The number of articles initially identified was 3682. The titles and abstracts were read for relevance to the topic and from the initial screening 74 articles appeared to meet the inclusion criteria. The full articles were then retrieved and assessed for eligibility, with 22 articles included from this initial screening and a further 52 articles excluded, as they were, for example, letters, editorials, or papers which were overviews of best practice. A number of articles (n= 28) were identified via other sources, including subsequent searches and citation alerts, with 50 articles included in the final review (Figure 1).

Figure 1: **Literature review process**
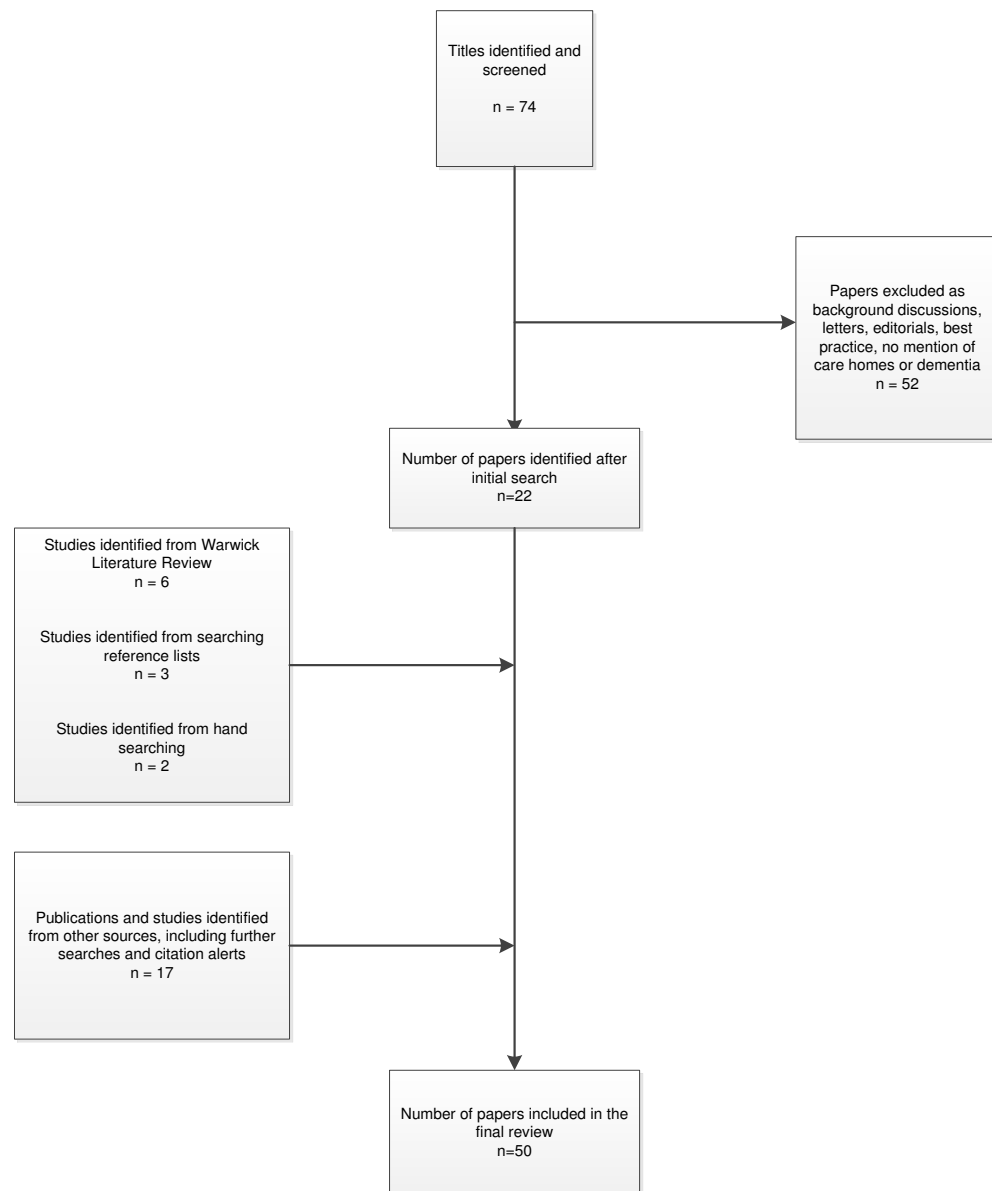
Review protocol

When analysing literature for a review such as this, it is important to be systematic, rigorous and consistent (Hart 1998), achieved by using a tool or framework that encourages one to evaluate the literature systematically (Gough 2007, Polit and Tatano Beck 2008). There are a number of frameworks available that assist in this process; in this case Polit and Tatano Beck's literature review protocol was used (2008). It was chosen as it enabled the critical appraisal of each paper, by encouraging systematic reviewing and recording of key aspects of each study, such as theoretical foundations, methodological features, findings and conclusions, together with assessment of the study's strengths and weaknesses. It also enabled the organisation of all key information onto a one-page document from which analysis of the data could begin. Details of each study were recorded on a protocol template (Appendix 2), which were then used to inform the literature review matrices (Appendices 4-7), recording key features of each study, such as

purpose of study, study design, sample size, results, conclusions and additional comments, such as strengths or weaknesses of the study. Appendix 3 contains the abbreviations used in the matrices.

Reflections on the literature overall

A dominance of quantitative studies

As can be seen from the literature review matrices (Appendices 4-7) quantitative methodologies were favoured, with 42 quantitative studies, 4 qualitative studies and 4 literature reviews included. Only 26% (n=11) of quantitative studies were carried out in the UK, 55% (n=23) in North America, including Canada, and the rest conducted in Europe (n=6) or Asia (n=2). Of the qualitative studies one was conducted in the UK (Livingston et al 2011) and the remaining three in Canada, North America and Australia (Kaasalainen et al 2007, Tilly and Fok 2008, Chang et al 2009). The majority of quantitative studies (n=29) focused specifically on healthcare needs of residents living with dementia, as did all qualitative studies and half of the literature reviews. The remaining studies and literature reviews were concerned with the healthcare needs of older people in care homes, making specific reference to the needs of those living with dementia. However, there were variations between countries, with the majority of UK studies (n=6) focusing on this latter group. The four literature reviews (Cowan et al 2003, Chalmers and Pearson 2005, Jones and Trigg 2007, Goodman et al 2009) were concerned with specific healthcare needs, pain, oral care, sight loss and end-of-life care. However, none were systematic literature reviews, suggesting that their findings may be weaker, for example Cowan et al (2003) provided no information on the number of articles identified or included.

Majority of studies carried out in care homes with on-site nursing

Over half (n=6) of UK studies were carried out across the care home sector, i.e. in both nursing and residential care homes, three in nursing homes and only two specifically in residential care homes (Mann et al 2000, Hancock et al 2006). In comparison all European (n=6) and Asian (n=2) studies and 52% of North American studies (n=13) were carried out in nursing homes. Only two US studies were carried out in personal care homes, in which there is no registered nursing presence (Quinn et al 1999, Quinn et al 2003), and although one Canadian study (Aminzadeh et al 2004) was conducted in private, unregulated residential care facilities (RCFs), these had a registered nursing presence. Another US study (Kopetz et al 2000) took place in an assisted living facility (ALF), a long-term care option that offers housing, personal support and health care, with a registered nursing presence, either 24/7, periodically, or on an on-call basis (Lewis Cleary 2004, ALNA 2009).

A further eight US studies were carried out in both nursing homes and ALFs, although it should be noted that seven of these (Reed et al 2005, Gruber-Baldini et al 2005, Sloane et al 2005, Wallace-Williams et al 2005, Williams et al 2005, Zimmerman et al 2005, Sloane et al 2008) were reporting on the findings from a national 'US dementia care study'. Involving almost 5000 residents in more than 350 residential care/assisted living facilities and nursing homes recruited

from four US states which were purposively chosen, as each varied in its regulation of ALFs, however, it is unclear whether there was a nursing presence in any of the ALFs. This suggests that there are global differences in terms of the care home market, with long-term care provision differing markedly between countries. The majority appear to have an on-site nursing presence, which is not the case in the UK; so many of the findings from the international studies may not be generalisable to the UK, although there may be lessons that can be learnt.

Limitations of methods used

Reflecting on the quantitative studies

The majority (91%) of studies used non-experimental, descriptive designs, with over two-thirds (n=27) cross sectional studies. All UK studies were non-experimental descriptive studies, as were all but two of the international studies, one a quasi-experimental study (Fuchs-Lacelle et al 2008) and one a survey (Moss et al 2002). However, a limitation of this study design is that it is unable to explain causality. As a result, although these studies were able to give an understanding of the level of unmet needs that existed, they were only able to give a limited understanding of why healthcare needs were not being met.

Samples used

Most studies used purposive or convenience samples. The majority of UK studies used convenience samples, apart from Sinclair et al (1997) who randomly selected care homes. Although most tried to increase generalisability by ensuring that care homes were representative, by either using large sample sizes, ranging from 30-157 care homes, or by selecting care homes from different geographical areas (Mozley et al 2004, Mann et al 2000, Hancock et al 2006). Resident sample size varied from 74 to 2,444, with over half of studies selecting residents randomly (Benbow et al 1997, Mann et al 2000, Macdonald and Carpenter 2003, Hancock et al 2006, Stewart et al 2014).

Most international studies also used convenience samples of care homes, apart from Aminzadeh et al (2004) and Moss et al (2002), although residents were usually selected randomly. Sample sizes varied greatly in terms of residents, from 23 (Suominen et al 2004) up to 3195 residents (Proctor and Hirdes 2001), with the median around 205 residents, and were largely dependent on where the study was conducted, with smaller samples associated with European studies. The number of care homes involved also ranged greatly, from 1 (Kopetz et al 2000, Payne et al 2002, Suominen et al 2004, Donini et al 2013) up to 643 (Mitchell et al 2004b) in any one study. Although if one removes those involved in the national dementia study (n=7), which comprised between 45-581 care homes, the median was three, suggesting that findings need to be treated with caution, due to small samples, often from one geographical area. The largest samples were associated with studies that involved secondary analysis of data collected from minimum data set (MDS) assessments, a standardised assessment tool collecting data on a wide range of health issues (Mitchell et al 2003a, 2003b, Proctor and Hirdes 2001).

Data collection methods

The majority of studies relied on data collection instruments, such as the Barthel Scale, MDS, or CANE, and/or clinical notes to measure the presence and level of needs, with some differences noted between countries. For example UK studies (n=3) used the Camberwell Assessment of Needs in Elderly (CANE) to collect data, whilst North American studies (n=10) used the Minimum Data Set (MDS). Both evaluate a resident's clinical characteristics; although CANE was developed to specifically measure needs in older people with mental illness (Worden et al 2008). All instruments have been widely used, often for many years and their validity and reliability accepted. However, they have limitations, as for example, cultural differences between countries can mean that they are not transferable, or they can focus on specific physical limitations, taking little account of the impact of psychological, emotional or social factors, such as the Barthel Scale (Gibbon 1998). As mentioned previously a number of studies relied on data collected as part of minimum data set (MDS) assessments. However, the accuracy of this data may need to be questioned, as it had often been completed by others, i.e. care home staff.

Reflecting on the qualitative studies

The four qualitative studies were all concerned with exploring the experiences of staff in providing end-of-life care for residents living with dementia. A variety of data collection methods were used, including focus groups (Kaasalainen et al 2007, Chang et al 2009) and/or interviews, either face-to-face (Livingstone et al 2011), or by telephone (Tilly and Fok 2008). Sample sizes were typically between 34-58 participants and a range of staff included, with Kaasalainen et al (2007) and Livingstone et al (2011) interviewing care and nursing staff of all grades, Chang et al (2009) interviewing nursing, medical and therapeutic staff and Tilly and Fok (2008) interviewing a variety of 'experts'. Care was taken to establish rigour in the majority of these studies through for example, member checking (Kaasalainen et al 2007, Chang et al 2009), saturation of categories (Livingstone et al 2011) and the establishing of an audit trail (Kaasalainen et al 2007, Chang et al 2009). However, there were issues with transferability, with studies carried out in small geographical areas, limited information given about participants, the use of incentives to encourage participation and it was often unclear if theoretical saturation had been reached.

It was also interesting to note that all studies were carried out by researchers from an academic and/or clinical background, such as nursing or medicine, rather than from the care home sector itself. This could explain their focus on measuring level of unmet clinical needs, rather than seeking to understand what was preventing needs from being met, and recommendations that were seen as simple to implement.

Emergent themes from the literature

Following assessment of the literature a number of broad themes emerged, which have been summarised as:

- The presence of high levels of healthcare needs
- Healthcare needs are often poorly managed

- Potential barriers preventing the meeting of healthcare needs
- The experience of staff is poorly understood
- Little attention is paid to the context

The presence of high levels of needs, including healthcare needs

High levels of co-morbidity, dependency and CI were commonly reported, even in residential care homes or ALFs, where there is an expectation that residents will be less dependent. Mann et al (2000) found high levels of morbidity amongst 309 residents in 17 residential care homes across England suggesting that these residential care homes were caring for a very disabled population. Similar findings were reported by Martin et al (2002), who found high levels of dependency in both nursing and residential care settings, although these findings need to be treated with caution as the study was only carried out across 4 care settings. A UK wide study (Mozley et al 2004) found high levels of co-morbidity, CI and depression across the care home sector, although they reported lower levels of dependency in residential care homes. More recent studies reported high prevalence of morbidity, behavioural problems and depression, with high levels of severe dementia in non-EMI homes (Stewart et al 2014); together with profound dependency and frailty in both residential and nursing homes Gordon et al (2014b); although sample sizes in both studies were small.

The international studies also reported that levels of co-morbidity and dependency were high (Quinn et al 1999, Kopetz et al 2000, Aminzadeh et al 2004, Black et al 2006, Martin-Garcia et al 2013). Aminzadeh et al (2004) found that residents in 9 RCFs had, on average, 6.3 medical conditions, with the majority presenting with 5 or more conditions. Whilst Black et al (2006) reported high levels of medical and physical comorbidity amongst residents (n=123) with advanced dementia in 3 nursing homes, including skin problems (95%), nutrition/hydration problems (85%), psychiatric/behavioural problems (85%), gastro-intestinal problems (81%) and infections (80%). High levels of healthcare needs were common, including, pain, poor oral health, sight loss, delirium, incontinence and diabetes. For example Di Giulio et al (2008) reported that 88% of residents (n=141) experienced severe symptoms such as aspiration pneumonia, urinary tract infections, pressure sores and dyspnoea in the month before they died. A number of authors (Payne et al 2002, Gruber-Baldini et al 2005, Hancock et al 2006) reported that depression was common in residents and associated with poor outcomes. In terms of malnutrition it was suggested that rates could be as high as 83% amongst those in long-term care (Reed et al 2005, Lou et al 2007).

Healthcare needs are often poorly managed

It was also apparent that many of these healthcare needs were under-recognised and/or under-treated. As can be seen in the literature review matrices the most common healthcare needs studied were pain (n=12), and end of life care (n=11), followed by nutrition (n=4), dementia (n=3), depression (n=2), sight loss (n=2), diabetes (n=2), delirium (n=1), oral health (n=1), and

mobility (n=1). Two of these, pain and end of life care, are used as illustrative examples of the poor management that was evident.

An Illustrative example: The under-treatment of pain in residents living with dementia

Pain was the most commonly researched healthcare need identified (n=12). The majority of studies (n=7) were carried out in the USA, with only one UK study identified. Although sample sizes were often small, and there are likely to be contextual differences, interestingly similar findings were reported globally. Pain is a problem for older people, with prevalence rates in the USA put at between 49-83% (Cowan et al 2003). But as this review indicated pain is also a significant problem for residents living with dementia, with one in two residents possibly in pain (Zwakhalen et al 2009). Reported rates varied between 20% (Williams et al 2005) and 63% (Black et al 2006), although the lower rate may not be a true reflection of prevalence, as it relied on proxy reporting and increased to 25-39% with self-reporting, it also used a threshold over which pain was reported, rather than recording any pain experienced.

Residents living with dementia or CI are at risk of having pain under-recognised and/or under-treated (Cowan et al 2003). In terms of assessment Ferrell et al (1995) found little evidence of any regular on-going assessment of residents' pain, whilst both Black et al (2006) and Reynolds et al (2008) reported a positive relationship between documented pain and cognitive function, suggesting that those with advanced dementia were more likely to have unrecognised pain due to communication problems. Assessment of pain improved if an appropriate tool was used, as evidenced by Fuchs-Lacelle et al (2008), who used a comparative longitudinal design, in which one group of care givers regularly assessed residents' pain (n=89) using the PACSLAC tool, compared to a second group who completed an activity log for residents in a control group (n=84). They reported that use of this tool had a positive benefit, with an increased use of as required (PRN) analgesia observed, although worryingly there appeared to be no increase in the use of regular analgesia. It was also noted that average pain scores of the independent observer were less than those of the caregivers, suggesting that staff who know a resident well are more likely to recognise when they are experiencing pain.

Residents living with dementia were also prescribed and/or administered significantly less analgesia than residents with no impairment (Ferrell et al 1995, Horgas and Tsai 1998, Williams et al 2005, Fuchs-Lacelle et al 2008, Zwakhalen et al 2009). Reynolds et al (2008), using data gathered from the MDS, set out to explore the association between CI and pain management practices, in a random sample of 551 residents, from a small sample of nursing homes (n=6) in one geographical area. They found a similar incidence of conditions that were likely to cause pain, however, worryingly those with severe CI were less likely to receive analgesia (56%) compared to those who were cognitively intact (80%), were more likely to only receive mild analgesics, and less likely to be given regular pain medication. Nygaard and Jarland (2005), using a convenience sample of 125 residents from 3 Norwegian nursing homes, examined pain management in relation to a resident's mental state. Inadequate treatment practices were again

reported, with 44% of residents considered to be in pain not receiving any treatment, and 45% of those complaining of pain receiving no treatment. Also reported by both studies, as well as by Barry et al (2015), was the tendency to use PRN analgesia in residents living with dementia, as opposed to regular scheduled medication, suggesting that staff may lack knowledge and skills in this field. Interestingly Williams et al (2005) reported that although care supervisors, predominantly nurses (n=77%), were satisfied with how pain was assessed and treated in their care home, a quarter of residents had not had their pain professionally assessed and 19% with pain were receiving no analgesia.

An Illustrative example: Inadequacies of end-of-life care for residents with advanced dementia

Good end of life care is seen as increasingly important, yet people living with dementia are receiving a poorer quality of care than those who are cognitively intact (Goodman et al 2009). 11 studies explored this issue (See Appendices 4-7), with two carried out in the UK (Livingston et al 2011, Kinley et al 2014). As in the previous section there were issues with generalisability as sample sizes were often small, little information was given about participants (Tilly and Fok 2008), or care homes were not typical, having medical staff on site (Di Giulio et al 2008). Although interestingly, given the international nature of the studies and contextual differences, similar findings were again reported.

Interviews conducted with 49 'experts' in end of life care from across the USA (Tilly and Fok 2008) highlighted key characteristics of quality end of life care, including good communication, the need for advanced decision making and good physical symptom and pain management. However, care appeared to fall short of this, as evidenced by those living with dementia receiving less pain relief, fewer medical services and decisions to forgo hospital admission not made until death was imminent (Goodman et al 2009). It was suggested that the presence of dementia was making the provision of good palliative care more difficult (Kaasalainen et al 2007, Chang et al 2009).

Problematic areas included predicting death, as evidenced by the use of non-palliative interventions (Di Giulio et al 2008). Mitchell et al (2004b) reported that staff were failing to recognise that residents living with advanced dementia had a terminal illness, as only 1.1% of such residents were given a life expectancy of less than 6 months, yet 71% died within this period. Admission to hospital was common prior to death (Mitchell et al 2004a, Moss et al 2002, Livingston et al 2011, Kinley et al 2014). In the UK study (Livingston et al 2011) this was because staff were either keen to preserve life, or were afraid of blame or litigation, whilst in an American study (Moss et al 2002) it was because residents had not completed advanced directives ruling out hospitalisation, indicating that context is important in understanding such issues. Poor symptom management and the use of aggressive treatment appeared common (Mitchell et al 2004a, 2004b, Chang et al 2009, Goodman et al 2009). Di Giulio et al (2008) exploring the last months of life of 141 residents living with advanced dementia in Italian long-term care institutions (n=7), reported the common use of life sustaining treatment in the last 48

hours such as IV therapy, tube feeding and antibiotics. Unfortunately, to the retrospective nature of the study and data collected from care records, it was not possible to understand why such care was given. Moss et al (2002) reported similar findings from a questionnaire sent to 400 randomly selected nursing homes across the USA, with care practices reported that could be considered to be inappropriate for a person dying with dementia, including residents encouraged to eat (71%), kept well hydrated (64%), the use of IV therapy (20%), tube feeding (22%) and inadequate symptom control, including pain management.

Sloane et al (2008) using data from the US dementia care study, explored the experiences and possible unmet needs of residents living with dementia dying in long term care settings, compared to those who were cognitively intact. The findings need to be treated with some caution, as data relied on after death interviews with staff and family and inadequate care may not have been reported. They found a different picture, with no differences noted in the experiences of those dying with or without dementia in regard to pain, family involvement, advanced care planning, most life prolonging interventions and hospice use; however, for those living with dementia the use of physical restraints and sedative medication was more common. They suggested that care may be moving towards a more palliative approach for those living with dementia, although that said, possible improvements in care were still identified. It should also be noted that the majority of studies in both illustrative examples were carried out in care homes, with a nursing presence, suggesting that RNs are struggling to meet the needs of these residents.

Care homes with no on-site nursing presence can struggle to manage healthcare needs

In terms of those care homes with no on-site nursing or medical support Hancock et al (2006) reported that unmet needs, including healthcare needs, were not uncommon amongst residents (n=238) in residential care homes (n=24). Unmet healthcare needs included psychological distress (48%), memory (39%), eyesight/hearing (39%), mobility (25%), continence (24%) and physical health (16%), with nearly 24% of residents also found to have undiagnosed depression. One in five residents were experiencing seven or more unmet needs. Residents with a complex profile were more likely not to have all their needs met, whilst those with more unmet needs were reported to have more challenging behaviour and staff found these residents more difficult to manage.

Again in the UK similar findings were reported by Mann et al (2000), exploring the response of staff to four specific health problems, immobility, instability, hearing loss and visual impairment, although findings may not be representative of the sector as a whole, as care homes were purposively chosen as they provided good or standard care. All four health problems were common in residents, with 72% having mobility difficulties, 67% having instability problems, 40% having hearing loss and 46% visual impairment. Recognition of depression was poor and medication was only prescribed for a small minority who needed it. Once again staff appeared to have difficulty managing residents' needs, as evidenced by the fact that the quality of their

response to the needs was variable, with only 7% of care homes rated as good and key workers failing, on occasion, to respond to, or recognise, overt signs of physical disability in residents.

As in the UK, international studies also suggested that care homes with no on-site nursing presence could struggle to manage the healthcare needs of residents (Quinn et al 1999, Quinn et al 2003). Kopetz et al (2000), comparing the clinical characteristics of residents (n=144) in one specialist dementia ALF, with those of people living with dementia (n=737) in other locations, found this ALF was supporting residents with an intermediate level of dementia and moderate care needs, with the majority of residents transferred to a nursing home after a median stay of only 10.9 months. This study was carried out in a single ALF, however, similar results were reported by Sloane et al (2005), using data from the US dementia care study, from 166 ALFs and 40 nursing homes. Significant differences in hospitalisation rates between the two sectors were found and roughly a quarter of residents were transferred annually from ALFs to nursing homes, suggesting that ALFs may be experiencing difficulty in managing residents living with dementia who have, or who develop, significant medical or nursing needs. Similar findings were also reported by Quinn et al (2003) who found that although levels of need were dependent on the severity of a resident's dementia, there was no difference in the care or support provided; suggesting that unmet health needs could result, although once again sample size and geographical area was small. Aminzadeh et al (2004) likened special care units in RCFs to unlicensed, pseudo-nursing homes, whilst Quinn et al (1999) suggested, given the level of need observed amongst residents in personal care homes, that there was a need for regular visits by RNs.

Unmet needs result in further health problems
What was also clear from the literature was that if needs were not adequately met this resulted in further episodes of ill health and a poorer quality of life. One UK study (Benbow et al 1997) reported that residents in EMI homes were significantly less likely to receive any formal diabetic care, increasing their risk of diabetic complications, however the sample size was small and the paper scant on detail. Another paper based on data from the US dementia care study (Wallace Williams et al 2005) reported that 89% of residents (n=343) had some limitation in their mobility, putting them at risk of developing pressure sores, muscle atrophy, bone loss, pneumonia, incontinence and constipation. As Chalmers and Pearson (2005) reported poor oral health in a person living with dementia affected eating ability, type of diet, weight, speech, hydration and behavioural problems. Poor sight, together with CI (Jones and Trigg 2007), could result in increased agitation, as well as an increased risk of falls. Whilst Cowan et al (2003) reported multiple problems resulting from inadequate treatment of pain, including poor mobility, sleep disturbances, increased risk of developing pressure sores, depression and decreased socialisation, appetite and memory.

Potential barriers preventing the meeting of healthcare needs
With the majority of studies using quantitative, descriptive methodologies it was difficult to gain any clear understanding of what was preventing healthcare needs from being met in care

homes. However, from the limited data that were available, certain factors appeared to be having an impact. These included:

- Issues accessing training
- Inadequate treatment
- Lack of external support

Issues accessing training

Access to training appeared to be an issue, both in terms of general training (Mozley et al 2004), as well as in regard to specific healthcare needs, such as dementia (Macdonald and Carpenter 2003), depression (Gruber-Baldini et al 2005), diabetes (Sinclair et al 1997), end of life care (Moss et al 2002, Tilly and Fok 2008, Chang et al 2009), nutrition (Reed et al 2005) and pain (Cowan et al 2003, Williams et al 2005). One UK study (Mozley et al 2004), distributed questionnaires to all members of care staff (n=1200) in 35 care homes across the country, to gather views on their experience of being an employee in that care home. The majority of staff (59%) had no job-related qualifications, 19% had various nursing qualifications and 9% had NVQ qualifications. Even basic training was not universally offered, with only 49.1% having received training in, for example, lifting and handling, or basic hygiene. Only 9.1% had been given any training in physical problems of residents and 7.8% any training in psychiatric/psychological problems, including dementia care, depression, dealing with behavioural problems and emotional care of the dying, despite high levels of CI and dependency noted across the care home population. These findings need to be treated with some caution as the response rate was poor, with large variations between care homes, from 6-84% and only 440 care staff responding (37%); also the study was carried out over 10 years ago and the situation may be different today. Training was also poor in regard to specific healthcare needs, with another UK study (Sinclair et al 1997) suggesting that inadequacies in diabetes care were the result of a lack of knowledge amongst staff, especially those in residential care homes. In terms of international studies, poor end-of-life care was attributed to a lack of knowledge and skills in regard to dementia (Moss et al 2003, Tilly and Fok 2008, Chang et al 2009)

There was some evidence to suggest that training improved care provision, with Fuchs-Lacelle et al (2008) reporting that training nursing staff in the use of PACSLAC, resulted in better management of pain, increased usage of PRN medication and reduced levels of stress and burnout amongst staff. However, other evidence suggested that access to training didn't automatically mean healthcare needs would be recognised, or well managed. A study by Macdonald and Carpenter (2003), carried out in non-EMI nursing homes in the South East, reported that training and experience in dementia care, or a RMN qualification had no effect on recognition of dementia. Although there may be issues with generalisability, as the sample size was small, with only 135 nurses interviewed from across 157 nursing homes, the sample of RMNs comprising only 6 nurses and few details provided about staff who took part. Interestingly papers from the US dementia care study reported that most staff felt adequately trained to assess and treat health problems, although, in the case of Gruber-Baldini et al (2005) over half

of residents with depression were undetected by staff, over half of residents in Reed et al (2005) had low food and fluid intake, and in the case of Williams et al (2005) 25% of residents had not been professionally assessed, 60% had not received a standardised assessment and 75% of care homes were not using any tool to assess pain.

Inadequate treatment

Another possible explanation for why healthcare needs were not met was inadequate treatment practices, although once again it was unclear why such care was given. Reynolds et al (2008) reported that documentation of pain decreased in a linear fashion, as degree of CI increased. Williams et al (2005) found that roughly 40% of residents with pain were receiving no pain medication, or any on-going treatment. Horgas and Tsai (1998) reported that residents with CI were both prescribed and administered significantly less analgesia, whilst Cowan et al (2003) reported that under-use of analgesics, especially opioids, was a major barrier to adequate pain management in older people. Inadequate treatment for a variety of other health problems was also evident. Palliative care was often suboptimal for residents living with dementia (Moss et al 2002, Mitchell et al 2004, Goodman et al 2009). Donini et al (2013) suggested that medical and nursing staff paid little attention to nutritional status. Whilst Reed et al (2005) reported that residents in ALFs were less likely to be assessed for eating and drinking difficulties, were less likely to receive treatment and were also less likely to receive help from the staff. Koch et al (2005) reported a lack of screening for visual disorders, amongst a small sample of residents (n=85) in two nursing homes. The personal and professional experiences and culture and belief systems of staff also appeared to play a part (Horgas and Tsai 1998, Cowan et al 2003), as evidenced by Voyer et al (2008) who reported that nurses were less likely to detect delirium if they regarded health in ageing as negative. Whilst the vision of many people living with dementia was deemed to be untestable (Jones and Trigg 2007), even though studies with cards used in children, found that visual acuity screening was possible in approximately 79% of residents living with dementia.

Lack of healthcare support to care homes

Little mention was made in the literature of the issue of accessing support from external healthcare professionals, possibly the result of contextual differences, with the majority of studies conducted outside the UK and in nursing homes, where there was a nursing, as well as in many, a medical presence. One longitudinal UK study (Gordon et al 2014b) reported that 48.5% of residents (n=227) had used secondary care services over a 180-day period, whilst 86.6% had used either primary or secondary care. Those using secondary care services did so intensively. A further two UK studies suggested that a lack of external healthcare support was having an impact on the management of diabetic residents. Attendance at diabetic clinics was unusual for residents, with less than half having ever attended any form of diabetic clinic and community nurses and dieticians rarely involved in the care of diabetic residents (Sinclair et al 1997). The number of residents on insulin was low, when compared to those in the community, although due to the study design it was not possible to explore why this was the case. Similar results were reported by Benbow et al (1997) who found that 63% of diabetic residents had no record of who was responsible for their care, with those in EMI care homes significantly less

likely to be receiving any formal diabetic care. Although given the small sample sizes in both studies the results should be treated with some caution. Another UK study by Kinley et al (2014), exploring the care given to 2,444 residents who had died over a 3-year period, found that support was variable. Although 20% had been visited by a palliative care nurse, support by other specialist nurses, such as heart failure nurses, was limited. They also suggested that support by healthcare professionals needed to be proactive, rather than reactive, as was common.

Issues regarding the prescribing of medication suggest that it is not only nursing and care staff who may lack the necessary knowledge and skills. As evidenced by the use of PRN, rather than regular analgesia (Horgas and Tsai 1998, Fuchs-Lacelle et al 2008, Barry et al 2015), those with CI prescribed less analgesia (Horgas and Tsai 1998), poor communication between physicians and nurses in terms of pain assessment (Fuchs-Lacelle et al 2008), a reluctance to prescribe opioids (Cowan et al 2003, Barry et al 2015) and medication not prescribed within a therapeutic range (Mann et al 2000).

The experience of staff is poorly understood

Staff providing day-to-day care to residents are in an ideal position to give insight into what prevents, or even enables them, to manage the healthcare needs of residents, yet their views were rarely sought.

Quantitative studies unable to explain why staff were failing to meet healthcare needs

As mentioned previously the use by virtually all (n=39) of descriptive study designs was able to provide a picture of the health characteristics and levels of unmet need amongst residents, but was unable to explain causality, and studies gave little indication of why needs were unmet. For example researchers identified poor assessment and treatment of pain (Ferrell et al 1995, Horgas and Tsai 1998, Reynolds 2008), but could not explain why this was, and Suominen et al (2004) and Reed et al (2005) were unable to explain the cause of the nutritional failings that they observed. In terms of end-of-life care Mitchell et al (2004), using a retrospective cohort design, compared the end of life experiences of nursing home (n=2730) and home care (n=290) recipients in Michigan, living with severe dementia, who had died within a year of admission to either service. They reported that care for both groups was sub-optimal, with the provision of oxygen therapy and transfer to hospital just prior to death, more common for nursing home residents, whilst those at home were likely to experience more pain. But were again unable to offer any insight into why there were differences between care practices, or patient experience between the two settings.

The views of care staff not sought

Too often the views of staff were not sought. Of the 45 studies identified for this review under half (n=20) involved the care staff in their study, however, their involvement was often limited to identifying training received and/or their ability to recognise a specific healthcare need (Sinclair et al 1997, Mann et al 2000, Macdonald and Carpenter 2003, Gruber-Baldini et al 2005, Reed et

al 2005, Wallace Williams et al 2005, Williams et al 2005, Voyer et al 2008, Barry et al 2015), identifying care provided (Sloane et al 2008), proxy reporting of pain (Nygaard and Jarland 2005, Leong and Nuo 2007), or involvement in the implementation of an intervention (Fuchs-Lacelle et al 2008). Only 7 studies sought the experiences and perspectives of staff in any depth (Moss et al 2002, Mozley et al 2004, Zimmerman et al 2005, Kaasalainen et al 2007, Tily and Fok 2008, Chang et al 2009, Livingston et al 2011). Four were the qualitative studies, whilst the remaining three used questionnaires, or other tools to measure staffs' experiences, such as levels of stress, job satisfaction and attitudes. Although an efficient way of collecting responses from large numbers, such tools have limitations, as the researcher is unable to probe for further detail or seek clarification and results may not be a true reflection of a respondent's thoughts or feelings. However, evidence from these few studies suggests that healthcare needs are not met for a variety of reasons and not, as suggested by many of the authors, simply the result of inadequate training.

Qualitative studies enable the 'why' to be explored

Whilst the quantitative studies provided an understanding of the levels of need and unmet need present in this resident population, they gave only a limited understanding of what was preventing these needs from being met, i.e. the 'why'. It was the qualitative studies that enabled the 'why' to be explored, although unfortunately they were only able to give a limited understanding, as there were only four studies identified and all focused on the experiences of staff in managing the end-of-life care of residents living with dementia. Livingstone et al (2011) conducted interviews with 58 staff, of all grades, from one London nursing home, caring for people from the Jewish faith. Situated as it was in a large city, caring for one religious group and with the majority of staff born outside the UK suggests that findings may not be transferrable to all settings. However, it provided some insight into the difficulties facing staff, together with an understanding of why certain care practices occurred. Most staff reported good relationships with residents, felt they were skilled in recognising when a person was dying and provided good care. Reported barriers to the provision of quality end-of-life care included issues with communication, worries over blame, a lack of emotional support and conflict between professional and personal feelings, some of which were the result of staff feeling vulnerable as they were living in a foreign country. For example, staff were reluctant to talk with residents and relatives about death and so would change the subject or use less emotive language, whilst others felt their role was to preserve life for as long as possible and were sending residents to hospital, even if this was against the wishes of the family. Although this nursing home may not be representative, what is interesting is that the other qualitative studies reported similar findings.

Interviewees from these studies (Kaasalainen et al 2007, Tily and Fok 2008, Chang et al 2009) also reportedly found end-of-life care for this particular group of residents to be challenging. Difficulties were reported in recognising when a resident was dying, managing challenging behaviour, providing symptom and pain management, assessing needs of residents due to communication problems and meeting the needs of both residents and family. A lack of

knowledge and skills in dementia was also commonly reported. For example the healthcare professionals (n=44) interviewed by Chang et al (2009) felt that many of the difficulties they encountered were due to limited knowledge in key areas including dementia, palliative care and care provision for residents living with advanced dementia. Difficulties included assessment of residents unable to communicate, symptom management, particularly in areas such as pain, dysphagia and hydration, as well as talking with family members about treatment options at end of life, including ethical issues such as withholding or suspending treatment e.g. tube feeding. Also mentioned (Kaasalainen et al 2007, Tilly and Fok 2008) were organisational and environmental factors which impacted on care provision, such as poor staffing levels, insufficient time to deliver the complex care required by both residents and their families, inadequate resourcing and access to training. Putting contextual differences aside, these four international studies were able to provide evidence of some of the challenges care staff faced in providing care to this particular group of residents.

Challenges of caring for residents with advanced dementia

Another study suggested that the nature of the work was challenging, in particular caring for residents living with dementia, especially those in advanced stages of the disease. Zimmerman et al (2005), as part of the US dementia care study, explored staffs' attitudes to dementia and work stress, as well as the satisfaction gained from working with residents who had dementia. Data were collected from 154 staff using the tools: Approaches to Dementia, Work Stress Inventory and Staff Experience of Working with Demented Residents. Stress and job satisfaction was associated with age, gender, care home type, time in role and training. Less stress and greater levels of satisfaction were reported by older workers (> 45 years), those in smaller residential care facilities (< 16 beds) and by those who had been trained to assess and treat the common problems associated with dementia; whilst higher levels of stress were reported by men, younger workers and those who had been working in a facility for between 6-24 months. More hopeful and person-centred attitudes were reported in workers with higher levels of education and in those who had been working for between 1-2 years, but not over 2 years. Higher levels of worker stress were reported in facilities with specialised dementia units, possibly a result of caring for those with more advanced forms of the disease.

As caring for a resident with advanced dementia could be a challenge, staff needed to be well prepared and well supported for this work. As evidenced by staff, who felt well trained and supported, reporting lower levels of stress and burnout, increased job satisfaction and more likely to adopt person-centred care practices (Zimmerman et al 2005). Moss et al (2002) sent a postal questionnaire to a random sample of 1429 nursing home administrators across America, although the response rate was poor with only 400 care homes (29%) replying. Training, specifically around care of dying residents living with dementia, was highlighted by 63% as poorly well-handled and training in pain control was acknowledged as poor by 29% of respondents.

The evidence suggests that if we are to better understand why the healthcare needs of residents living with dementia are not being met, that there is a need for both quantitative and qualitative methods to be used. Although quantitative studies enable the level of need or unmet need present to be measured, the complexity of the whole is being lost, or ignored. This is where qualitative studies have something to add, as they enable the 'richness and complexity' present to be more fully explored (Burns and Groves 2001).

Little attention paid to context

Evidence from some studies appeared to suggest that the context in which both staff and care homes found themselves also had an impact on care provision (Mozley et al 2004, Kaasalainen et al 2007, Tilly and Fok 2008), yet few authors paid attention to the context. For example a number of authors suggested that needs would be better met if staff were provided with training (Sinclair et al 1997, Mann et al 2000, Hancock et al 2006, Lou et al 2007, Voyer et al 2008), yet only Mozley et al (2004) acknowledged that there could be an issue accessing training, suggesting that cost and staff workloads were barriers to education. There was limited evidence of other factors that had an impact on the staffs' ability to meet healthcare needs, those mentioned included culture, beliefs, lack of support and staffing issues, but due to a lack of evidence this is an area that warrants further research.

Only one study paid any attention to context. Mozley et al (2004) gathered data from staff (n=440), from care homes across the UK, on a range of issues including background information, training, experience, pay and conditions, job satisfaction and mental health of staff. The study was carried out over 10 years ago and the figures are out of date, however, it paints a picture that is not dissimilar from that described in Chapter 2, with care homes reliant on a poorly paid workforce and working conditions that were often far from ideal, resulting in high staff turnover. Length of time in current job was related to care home type, with 45% in their present job less than two years, mean length 50 months, although it was much longer (5 years) for those in local authority homes, compared to the private or voluntary sectors. Pay and conditions of service were also related to provider type. Mean gross hourly pay was £5.16, with the most common rate £3.50/hour, 47% were paid less than £4/hour and 65% less than £5/hour. Staff in local authority homes were paid more (£5.17) than those in the private (£3.64), or voluntary sectors (£3.80). Only 22% of staff belonged to an occupational pension scheme, 12% had no paid annual leave and 34% had less than 15 days annual leave a year. There were also differences between provider type, with annual sick leave allowance lowest in the private sector and those in local authority homes most likely to be in an occupational pension scheme. 16% of respondents were found to be exhibiting symptoms of psychological distress, for which an intervention may have been appropriate, although this may not be a true reflection of the problem, as those who were distressed may have been unwilling to complete the staff questionnaire. Whilst distress was associated with having experienced a major life event (such as serious illness, divorce or marriage), or being in a lower age group (< 30), it also corresponded to a number of work-related factors including demands at work, role conflict, less

role clarity and less leader support. Job satisfaction was noted to be higher in voluntary and local authority homes and amongst older staff.

Little, if any reference was made in the international literature to context, apart from Tilly and Fok (2008) who identified the impact of healthcare funding on palliative care provision. They reported that Medicare's benefits were not sensitive to those living with advanced dementia and as a result residents did not have ready access to palliative care, and Medicaid provider payments were too low to permit providers to provide adequate palliative care; however, these issues are specific to the USA. Kaasalainen et al (2007) identified a number of system and environmental factors impacting on the ability of nurses to provide good quality palliative care, including a lack of staff, poor collaboration amongst healthcare providers, scarcity of resources and the need for consistency in staff and continuity of care. Although data were limited, it does suggest that long-term care globally may be facing similar challenges, and highlights why there is a need to better understand the impact that context may be having.

Summary

This review set out to explore the level of healthcare needs amongst residents, in particular those living with dementia, and if there were any challenges in meeting these needs. It has clearly shown that across the care home population residents living with dementia have high levels of comorbidity, dependency and healthcare needs, many of which are under-recognised and/or under-treated. But due to the over reliance on quantitative methods it has only been able to give a limited understanding of why these needs are not being met, as the views of those involved in caring for residents have not been routinely sought and the context in which care homes are operating largely ignored.

The majority of studies were conducted outside the UK, possibly as a result of the challenge of conducting research outside of a NHS setting, funding streams directed towards the NHS rather than social care, or the mistaken belief that care homes and their residents have nothing to offer (DeNDRoN 2013). Most studies used non-experimental, descriptive designs which focused on identifying the levels of dependency and/or levels of unmet needs present. However, reliance on this study design meant they were unable to explain causality, and it was largely unclear why healthcare needs were not being met. The qualitative studies were able to give a limited understanding of this 'why', as they explored the experiences of care staff. Unfortunately only one qualitative study was carried out in the UK and all focused on end-of-life care provision, although there is no reason to suppose that any challenges identified are not applicable to the meeting of other healthcare needs. Most UK and international studies also involved care homes where there was on-site nursing presence, with only two UK studies exploring the situation in residential care homes specifically.

The levels of healthcare needs under-recognised and/or under-treated in nursing homes suggest that registered nurses can find it difficult to manage all the needs of this client group. If

this is the case then there is a need to explore whether those care homes with no on-site nursing presence are facing similar or additional challenges in caring for their residents, especially as support by healthcare professionals can be limited. An understanding of context also appears to be important suggesting that further studies are needed, exploring the situation in this country in particular.

This review has demonstrated that that there is a need for more research to be conducted in this country, research that uses qualitative methods, which focuses on those care homes with no on-site nursing presence and which seeks to better understand context. As this will enable a deeper understanding of why healthcare needs are not always being met to be gathered, especially from the perspective of those involved in providing day-to-day care. These staff are ideally placed to give an in-depth understanding of the realities of caring for residents, the challenges faced in providing care, together with an indication of what help is needed to support them to meet the needs of residents, and it will only be by understanding their reality that support for both the residents and those who care for them can start to improve.

CHAPTER 6: METHODS

Introduction

This study used a Practitioner Research approach (Meyer et al 2006) to explore the challenges facing residential care homes in managing the healthcare needs of residents, in particular those living with dementia and whether the district nursing service was adequately supporting them to meet resident needs. This chapter begins with an explanation of the philosophical approach that guided this study, which influenced the choice of research method used. It goes on to give an explanation of practitioner research and the issues associated with research conducted by an 'insider'. The research questions, aims and objectives of the study are given, as are details of the participants. Details of data collection and data analysis methods are presented. The ethical issues associated with gaining informed consent and of 'insider' research undertaken by a practitioner are discussed, along with the methods used to establish the trustworthiness and transferability of the data.

Philosophical underpinnings

A paradigm is a worldview, a 'pattern of beliefs and practices that regulate inquiry within a discipline by providing the lenses, frames and processes through which the investigation is accomplished' (Weaver and Olson 2006). Research within nursing is carried out largely within four paradigms: Positivist, post-positivist, interpretive and critical social theory (Weaver and Olson 2006). For many years the positivist paradigm was the dominant one within nursing, based on the assumption that nature is ordered and there is a single reality that can be studied, defined and described through the process of careful measurement (Burns and Grove 2001). It being that this reality can be known to the researcher as long as they use and apply the correct methods to study it, values objectivity and calls for researchers to hold their personal beliefs, values and biases in check as these could risk influencing the behaviour of others (Polit and Beck 2007, Savin-Baden and Howell Major 2013). However, over the years researchers began to question the use of positivism, as causality is not able to explain what is happening in complex social situations, nor is it appropriate if one is interested in accessing data from the perspective of the first-person, focusing on the 'felt' or phenomenological experiences of participants (Edwards 2001, Appleton and King 2002). So rather than trying to objectively measure 'truth or reality' researchers began seeking ways to understand human knowledge and experience (Savin-Baden and Howell Major 2013).

Naturalistic inquiry is one example of an interpretivist approach (Gray 2009). It is based on the assumption that 'realities are wholes that cannot be understood in isolation from their contexts' (Lincoln and Guba 1985), together with the belief that there is no objective truth waiting to be discovered (Crotty 1998). Reality is not seen as a fixed entity, but rather is socially and societally embedded (Grbich 2007), a construction of the individuals taking part in the research, based on their own experiences (Savin-Baden and Howell Major 2013). Naturalistic research recognises that reality exists within a context and for this reason many constructions are

possible as different people will construct meaning in different ways, even in regard to the same phenomenon (Crotty 199, Polit and Beck 20078). If one accepts that this is the case then there is no process by which the ultimate truth can be determined, due to the multiple truths that can exist in different people's minds (Polit and Beck 2007). Thus the truth that will emerge from such a study is not an objective view, but rather a composite picture of how people think, with each person's experiences and the context in which they occur considered equally valid and incorporated into emerging theories (Appleton and King 2002).

The review of the literature in Chapter 5 indicated that the majority of studies had used positivist approaches, with their focus on identifying levels of unmet healthcare needs amongst care home residents. It also revealed that there was limited understanding of what was preventing these needs from being met, especially from the perspective of staff providing the day-to-day care. In order that a better understanding could be gained from the perspective of these staff it was recognised that adopting a research approach based on naturalistic inquiry offered the researcher the means to do just this: to explore, in detail, the experiences of care staff and district nurses who were working in and with residential care homes.

Another feature of naturalistic inquiry is that the design tends not to be pre-specified, but emerges as the research study progresses (Gray 2009). Data collection and analysis are also an interactive and iterative process, resulting in overlapping of the research design, data collection and analysis phases of a study (Brown Wilson 2007). Also of importance is the acknowledgment that interactions between researcher and participants can't be eliminated from the research study, together with the belief that knowledge is maximised when the distance between the researcher and the participants is minimised. The interpretations of those studied are often crucial to understanding a phenomenon and the subjective interactions between a researcher and participants can be a primary way to access these interpretations (Grbich 2007, Polit and Beck 2007). This is of relevance given that the researcher was conducting the study in The Trust in which she had worked as a district nurse for many years and so was already well known to many of the district nursing and care home participants.

Practitioner Research

Defining practitioner research

The aim of any research is to generate knowledge. For nursing, which is a practice based profession, it is important that nursing knowledge both be generated from, as well as used to inform nursing practice, as this will not only help practitioners better understand how to 'nurse' (Rolfe 1998, McCormack 2003), but just as importantly will enable development of the profession as a whole (Fish 1998). This is especially relevant for district nursing, which is, as previously noted, under researched. PR is often used as an umbrella term covering a variety of research activities undertaken by a range of practice based professions including health and social care; drawing on a range of methods, with small scale case studies, or ethnographic studies frequently undertaken (Campbell 2007). It has its origins in education and the work of

Stenhouse (1975), who proposed the idea of 'teachers as researchers'. He suggested that as each classroom was unique any proposed modification to practice would need to be tested, adapted and verified by each teacher in their own unique situation, with the results of this work then shared, as in the case of all research, with others (Stenhouse 1975, 1981). Its basis is the idea that practitioners learn from research, using it to inform their practice, which may not always happen with other forms of research (Campbell 2007, Gamiz and Tsegai 2014).

A variety of definitions are used in relation to PR, with the definition dependent on the profession from which it arises, or the aims of the researcher (Rolfe 2003, Meyer et al 2006), with the term even used, at times, interchangeably with that of action research. Meyer et al (2006) describe PR as *'Research that involves practitioners….actively engaged in research, regardless of whether the focus is on the practitioners' work'*. They go on to argue that no matter what type of research nurses are engaged in, whether it be large scale randomised control trials, or individual practice, such work can be considered to be PR if the practitioner is using their nursing knowledge and skills to carry out the research. As in the case of this study where the researcher used her skills and expertise as a nurse for example, to build relationships with participants and conduct interviews and her knowledge as a district nurse to inform data collection and analysis. Other definitions of PR include practitioners '*doing research into areas of their own practice'* (Reed and Proctor 1995), whilst McCormack (2003) describes it as a formal and systematic attempt by practitioners to understand their work and develop new understanding of practice. It should be noted that no matter which definition is adopted the general aims of PR are the same: to better understand practice, generate new knowledge from practice, inform policy and encourage a dialogue between practice and research (Meyer et al 2006, McCormack 2009, Noble et al 2009).

The use of self as a research instrument

The aim of this study was to explore the experiences and challenges of care staff and community nurses in managing the healthcare needs of residents living in The Trust in which the researcher worked. A Practitioner Research (PR) approach was chosen as this enabled the researcher, an experienced district nurse, to explore the experiences of others with whom she worked, and to reflect on these findings in relation to her knowledge and experience as a practitioner, with a view to adding to the body of district nursing knowledge. Using herself as a research instrument (Denzin and Lincoln 2003, Tracy 2010) she spent time in one care home which served as a case study site, familiarising herself with this setting and the role of the care staff. Using her professional knowledge and experience she was able to pay attention to, and reflect on, what she learnt from interviewing others formally, but just as importantly to what was a surprise or a shock to her. She then checked out these findings with other community nurses and care home staff, to add strength to the original findings.

Traditional research methods often call for researchers to remain detached and ignore previous knowledge, so that the research is not influenced by personal beliefs and understanding. But Reed and Proctor (1995) query the feasibility of such a stance when the researcher is an

experienced practitioner. Questioning how they can forget, or ignore the knowledge they possess. They go on to argue that as the practitioner researcher is part of the world that they are researching this brings benefits that need to be both acknowledged and respected. For example the knowledge a practitioner researcher holds can make a significant contribution to a study in terms of planning and design, as practitioners are more likely to design studies that address issues of relevance to their practice setting (Reed 1995). In this study, in order to better understand the experiences and challenges from the perspectives of both community nurses and care staff, I felt I needed an understanding of both world views, hence the decision to spend time familiarising myself with the 'world of the care home'. An understanding that proved invaluable as I realised how little I really knew about the care home sector and as a result began to question many of my previously held assumptions.

The use of self as a research instrument is of great value in PR. A researcher who is an 'outsider' is unlikely to see a setting or situation as a practitioner does; who, because of their prior knowledge and experience, is more likely to be aware of issues that may cause surprise, or challenge preconceptions (Reed and Proctor 1995). The use of self also encourages practitioner researchers to articulate knowledge and experience, which can so often be difficult to access. A strength of this study was its use of myself, an experienced district nurse, as a research instrument in both data collection and analysis (Rew et al 2003, Mulholland 2007, Tracy 2010). Being a practitioner allowed me to build up trust, rapport and credibility with participants, which was necessary if they were to be open and honest with me. Whilst when reflecting on the findings from the case study and interviews, I was able to draw on my professional knowledge to inform data analysis; highlighting those findings that were of a surprise to me as a practitioner, but which may not have been considered to be significant if I weren't a district nurse, findings that I was then able to check out with others.

'Insider' practitioner research

Practitioner researchers are usually described as being either 'insiders', conducting research with individuals who are receiving care from them, or with groups to which they belong and have a shared identity, language or common professional base (Asselin 2003); or 'outsiders', conducting research with a setting or group to which they do not belong. There are a number of benefits to being an 'insider' (Bonner and Tolhurst 2002, Blythe et al 2013). For example the researcher is in a unique position, as the knowledge they already possess can enable them to study an issue in greater depth, often as a result of an awareness of the subtleties at play, less time may be needed to fully understand a situation, and they may be more readily accepted by participants (Hewitt-Taylor 2002, Asselin 2003, Costly et al 2010). In this study entry to the organisations and/or participants was felt to be easier because of my prior knowledge of The Trust and care homes. I had an understanding of certain routines and practice and as a result was able to explore when this differed from what I, as an experienced district nurse, felt would be usual or accepted practice. Because of my credibility as a district nurse I believe that participants more readily accepted me, I was able to build relationships with them and they were

comfortable with me, and as a result they appeared willing to be more open and honest, resulting in data that was possibly richer and in greater depth.

On the other hand as an 'insider' a researcher may feel they know the culture and as a result insufficient detail is sought from participants, or routine practice missed (Asselin 2003). Whereas if they are an 'outsider' the researcher will have little understanding of the setting, or the culture and as a result will not impose their own perceptions and will seek to understand it in greater depth (Bonner and Tolhurst 2002). Reed and Proctor (1995) suggest that a researcher's position is not fixed, but can move backwards and forwards between these two positions. Reed (1995) argues that is important for a researcher to understand what position it is that they hold, so they are able to recognise when something is decontextualized and strange, or contextualised and familiar. This encourages them to see practice through fresh eyes, to acknowledge and challenge pre-existing knowledge, and consider other interpretations and conclusions, thereby adding depth to data collected. This was certainly the case in this study, as although I was an 'insider' when it came to exploring district nursing practice, when it came to understanding the care home setting I soon realised I was more of an 'outsider'. As a district nurse I frequently visit patients in care homes, for this reason I believed the setting was known to me, however, I quickly realised that it was also unknown, as I had little real understanding of how a care home functioned on a day to day basis. Being an 'outsider' was an advantage as it encouraged me to reflect, as a practitioner, on what was being uncovered, to question in greater depth what I saw, or did not understand, and to challenge any preconceptions that I had previously held.

There are however, a number of challenges associated with PR conducted by an 'insider'. The researcher can hold a number of roles at the same time, which can be confusing for participants; as a result clear boundaries are needed between roles. The researcher will have valuable insider knowledge that must be used both constructively and ethically (Reed and Proctor 1995). There is no guarantee of rapport developing with participants, who may actually be uneasy talking to a researcher who is an 'insider', or feel obliged to take part (Bonner and Tolhurst 2002, Blythe et al 2013); whilst consideration needs to be given to how anonymity can be ensured (Noble et al 2009, Costly et al 2010). Such issues need to be considered, as unlike a normal researcher the practitioner will remain in the setting once the research finishes (Reed and Proctor 1995).

Another challenge is that the researcher can hold beliefs, thoughts or assumptions, many of which they may be unaware of, but which can prevent them from being objective during data collection and/or analysis. These can affect the credibility or trustworthiness of a study and so need to be addressed by the researcher during initial planning, data collection and analysis (Bonner and Tolhurst 2002, Asselin 2003, Blythe et al 2013). Practitioner researchers are the instrument through which data are collected and analysed and as such need to build into their research ways of dealing with possible bias and influence, e.g. through reflexivity, an issue that will be discussed later in the chapter. They also need to ensure they are robust in how data are

analysed, with claims made coming from the data and not from their own creative licence, for example by actively seeking for data that disconfirms a researcher's original assumptions, as in this study (Reed and Proctor 1995, Brooker and MacPherson 1999). A number of strategies were adopted during this study to address any such bias. These included making explicit pre-held beliefs and assumptions, the keeping of a field notes and research diary, member checking and review of analysis and findings by outsiders, for example during supervision sessions (Rew et al 1993, Reed and Biott 1995, Hewitt- Taylor 2002), all of which will be discussed later in the chapter.

Bridging the theory-practice gap

Too often within nursing there is a gap between theory and practice (Rolfe 1998). Research is carried out by academics and the results fed back to practitioners to implement into practice. Associated with this is an assumption that it is easy to implement research findings into practice (McCormack 2003). However, the reality is that the implementation of research into practice can often be 'complex and messy' and too often it doesn't happen (Rolfe 1998, Jarvis 2000, McCormack 2003, Campbell et al 2004). One of the strengths of PR lies in its ability to narrow this gap (Rolfe 2003). As in any research robust and systematic research methods should be used, in particular reflective and reflexive research methodologies, and any learning set within the wider body of knowledge (Rolfe 2003, Meyer et al 2006); in doing this one can then counter any criticism that may be made. McCormack (2009) argues that research is too often judged on the quality of the methods used, rather than on the credibility of the findings. Suggesting that as long as findings are robust and there are no flaws in the way in which the research has been carried out that findings can't be dismissed simply because they are described as PR. This is important as in the past a criticism levelled at PR is that it often takes the form of stories or recollections, which contain little contextual detail, are disconnected from other accounts of practice and are not linked to relevant theory (Brooker and MacPherson 1999).

Aims of PR include generating new knowledge and influencing practice. As the practitioner researcher remains in the setting once the study is finished there is continuity between the findings and practice, which may affect change at a local level (Reed and Proctor 1995, Gamiz and Tsegai 2014). The use of robust and systematic research methods and dissemination of the research to a wider audience offers the means by which PR can inform the wider body of nursing knowledge, whilst the sharing of findings with others can encourage practitioners to think about their own practice and decide for themselves if the findings are of relevance to their own practice setting. As a result the gap between theory, research and practice can start to be bridged. However, there are no guarantees that change will occur and ultimately it may only be the practice of the researcher themselves that is influenced.

Use of a case study

Practitioner research is often written up, as in this thesis, as a case study, which enables the researcher to conduct a 'detailed and extensive study of a particular case' within its 'real life'

context (Pegram 1999, Rosenberg and Yates 2007). Different types of case studies can be used, with the type chosen dependent upon the research question (Gangeness and Yurkovich 2006). Stake (1995) identified three types of case study. Intrinsic, where a case is studied for the intrinsic interest in the case itself, instrumental, as in this study, when a particular case is chosen to gain insight or understanding into a particular issue, with the case of secondary interest, and collective, where several cases are studied to gain a better understanding of the issue or question. Case studies may consist of either single or multiple case designs (Yin 2009, Simons 2009). Whilst multiple cases are useful as they give breadth, what a single case study offers, as in the case of this study, is the ability to explore the case in much greater depth (Flyvbjerg 2006).

The selection of the 'case' is crucial and needs to be based on an explicit and defensible rationale (Gerring 2007, Payne et al 2007). If a sample population is small then it is not possible to try and randomly select the case, as it may result in a case that is substantially unrepresentative of the population (Seawright and Gerring 2008). For this reason purposive sampling is used, with cases selected for illustration purposes, or their potential to reveal new information (McDonnell et al 2000, Gagnon 2010). The independent residential care home sector dominates provision of dedicated dementia care (Laing and Buisson 2009). The care home selected as the case study typified this, being one of a number of care homes in the local authority run by a large not-for profit provider. However, it was the only care home in the area providing specialist care for those living with dementia, which is why it was chosen for the case study, as it was felt by the researcher, that it would provide greater insight into the needs of this particular group of residents.

Research question, aims and objectives

A key feature of interpretivist research is that the research design may be an emergent one. This was certainly the case in this study, with data collected from the case study, together with reflections of the practitioner researcher, informing the design of the remainder of the study. As the study design has been written up retrospectively, as well as for pragmatic reasons, the study is described as two distinct phases, which followed on sequentially. However, in reality the design of the study, together with data collection and analysis were often overlapping.

The study began with the practitioner researcher spending time in one care home, which served as the case study site. During this period the researcher, using herself as a research instrument, spent time familiarising herself with the 'world of a care home'. Data collected from this case study in the form of interviews, documentation and field notes recording reflections by the practitioner researcher, were used to inform data collection and findings for what is termed Phase 1. During what is termed Phase 2, findings from the first phase were checked out with participants from other care homes in the borough, together with members of the district nursing service. Findings were not only checked for resonance and relevance, but also for any gaps.

Figure 2 (p78), is helpful as it maps out the phases of data collection, the care homes that took part and the district nursing teams associated with each of the care homes.

This study sought to answer the following questions:
- What challenges do care staff face in meeting the healthcare needs of residents, in particular those living with dementia?
- What are the challenges for the district nursing service in supporting care staff to meet the healthcare needs of their residents, in particular those living with dementia?

The aims of this study were:
- To explore the experiences and challenges for care staff when managing the healthcare needs of residents, in particular those living with dementia
- To explore the experiences and challenges for community nurses when supporting residential care homes to manage the healthcare needs they are faced with.

The specific objectives of the study were to:
Phase 1
- To gather rich contextual detail of the residential care home chosen as the case study site
- To gain an understanding of the day-to-day running of the care home and its routines
- To explore the experiences and challenges of care home staff in managing the healthcare needs of residents, especially those living with dementia
- To explore if the service the care home received from community nurses was adequately supporting them to manage the healthcare needs they were faced with
- To reflect, as a practitioner researcher, on the findings in relation to my own experiences, knowledge and practice

Phase 2
- To explore the experiences and challenges of other staff from care homes across the borough, when managing the healthcare needs of residents
- To explore the experiences and challenges faced by community nurses in supporting care home staff to manage the healthcare needs of residents
- To explore the experiences or challenges faced by these nurses when managing healthcare needs of residents, especially those living with dementia
- To identify whether community nurses felt they had the knowledge and skills necessary to meet the healthcare needs of residents living with dementia
- To explore whether the findings generated from Phase 1 had wider resonance and relevance to other care homes and community nurses across the borough, or if there were any gaps in these findings
- To reflect, as a practitioner researcher, on the findings from Phase 2 in relation to my own experiences, knowledge and practice

Figure 2: Phases of data collection

Key
CH - Care Home
I - Interview
Team - District Nursing Team
CM – Community Matron
CNS – Clinical Nurse Specialist

Case Study Site
Period of familiarisation
Interviews (n=7)
Group Interview (n=1)
Documentation
Field notes

District Nursing Team 1

Interviews (n=4)

Reflection by practitioner researcher

Additional interviews (n=32)

Locality A

Locality B

Locality C

Specialist Nurses

CH 1
I (n=1)

CH 2
I (n=1)

CH 9
I (n=1)

CH 4
I (n=1)

CH 7
I (n=1)

CH 8
I (n=1)

CH 10
I (n=1)

CH 3
I (n=1)

CH 5
I (n=2)

CH 6
I (n=3)

CH 11
I (n=1)

Team 1
I (n=1)

Team 2
I (n=1)

Team 3
I (n=3)

Team 4
I (n=1)

Team 5
I (n=2)

Team 6
I (n=2)

Team 7
I (n=4)

CM
I (n=2)

CNS
I (n=2)

Phase 1

Phase 2

The case study site – Phase 1

In order that the reader can judge if the findings from this study have relevance to their own practice this section will provide details of the care homes and participants who took part in the study. The study took place in one NHS trust, whose boundaries correspond to those of the local authority, in which the care homes that took part were based, both described in greater detail in Chapter 4.

During Phase 1 of the study one care home was selected as a case study. When the study began there were 19 residential care homes providing care for older people in the local authority. Once ethics approval had been obtained from the South East London Research Ethics Committee (REC) all residential care homes across this local authority were approached to see whether they would consider taking part in the study. If the care home was owned by a parent organisation, this company was approached first and written permission sought prior to contacting the care home manager. A letter of introduction was then sent to all the managers of these residential care homes introducing the researcher and outlining the aims and purpose of the study. The letter was followed up by a phone call to the manager to arrange for the researcher to visit the care home to discuss in greater detail what taking part would entail. Seven care homes were visited, all having expressed an interest in becoming involved in the study. Of the remaining 12 care homes one was not interested in taking part, two were already involved in other research studies and in the case of the other nine care homes it was not possible to either contact the manager, or to visit the care home. For example, a manager would set a date for the researcher to visit and then at the last minute request that the meeting be put back a number of weeks, which was not always feasible.

At the start of this process the researcher knew little about the majority of the care homes in The Trust. For this reason she chose to visit those who expressed an interest in taking part, so that she could learn more about the differences between them all and would be in a better position to make an informed decision when selecting the case study site. The care home that was eventually selected was a 60-bedded purpose built residential care home. It was owned by a large not-for profit organisation providing a variety of services for older people including: care homes, home care, extra care and supported housing. The organisation owned five residential care homes across the local authority. This care home was purposively selected for a number of reasons. The first was that it provided specialist care for residents living with dementia. All the residents in this care home had a formal diagnosis of dementia, providing the researcher with the opportunity to gain a better understanding of the issues involved in caring for residents with this particular illness. The size of this care home provided access to a large pool of care staff whose thoughts and experiences could be explored and finally, it had received a 2 star rating (no longer in use) from the CQC which meant that the people who used the service were experiencing good quality outcomes. A more detailed picture of this care home is provided in Chapter 7.

Participants

Phase 1 – Demographics of care home participants

During Phase 1 data were collected from a number of the care staff (CS) at the case study site (see Table 1), in the form of formal interviews. A letter of introduction (Appendix 8), participant information sheet (Appendix 9) and consent form (Appendix 10) were sent to all members of care staff in the home. The researcher also attended two staff meetings to explain more about the study, what the researcher planned to do and to give the staff the opportunity to ask any questions they might have. They were then contacted during subsequent visits to the home to ascertain if they would be willing to be interviewed. Formal interviews were conducted with the care home manager, as well as two team leaders. A group interview was also conducted with one team leader and 9 other members of the care home staff.

When conducting any small-scale research participants may feel they are more easily identifiable. For this reason identifying codes have not been used in the following tables, to ensure there is no correlation between participants and their quotes, thereby protecting the identities of individuals.

Table 1: Phase 1 – Demographics of participants from the case study care home

Age	Gender	Ethnicity	Role	Qualifications	Length of time working in care home (years)	Length of time working in social care (years)
64	F	White British	Care home manager	RGN, RMA, undertaking diploma in dementia	3	25
36	F	African	Team leader	NVQ 2 and 3 NVQ infection control, NVQ communication	10	13
25	M	Asian	Team leader	NVQ 2 and 3 NVQ 2 in dementia	3	8
Not given	F	Asian	Team leader	NVQ 2 and 3 NVQ assessor	10.5	13
38	M	Asian	Care assistant	NVQ 2 and 3	2.5	6
45	F	British Indian	Care assistant	NVQ 2	1.5	6
27	F	British Indian	Care assistant	NVQ 2 and 3	7	7
22	F	British Asian	Care assistant	None	1	1
43	F	British Indian	Care assistant	RN (India)	0.5	6
29	F	African	Care assistant	NVQ 1, 2 and 3	2.5	4
29	F	Nepalese	Care assistant	RN, Undertaking NVQ 5	0.2	1.5
25	F	Asian, Indian	Care assistant	NVQ 2 and 3	2	3
58	M	British	Care assistant	NVQ 2	7	7

Participants who took part in this phase of the study are typical of the workforce found in social care, as shown in Chapter 2. The majority were female, with an average age of 39 years and

over half were born outside the UK. On the whole, participants had worked within social care for many years, with just under half having worked in the sector for between 6-8 years. However, time employed in their present care home tended to be shorter, with the majority in post for between 0.5-3 years, and is typical given the high level of staff turnover within this sector. Participants came from a range of backgrounds prior to entering social care, including education, factory work, engineering, teaching, retail and even nursing.

Phase 1 – Demographics of district nursing participants

During Phase 1 data were collected from the one district nursing team providing support to the care home which served as the case study, in the form of formal interviews. Details of these nurses are found in Table 2. The team leader was approached for permission to speak to the staff. A letter of introduction and participant information sheet (Appendix 11) were sent to all nursing staff in this team. The researcher attended a staff meeting to explain more about the study, what participating would involve and to give the staff the opportunity to ask any questions. They were then contacted a few days later to ascertain if they would be willing to be interviewed. Interviews were held with four community nurses who agreed to be involved.

Table 2: Phase 1 – Demographics of nursing staff working with the case study care home

Team	Age	Gender	Ethnicity	Title	Qualifications	Length of time in nursing (years)	Length of time in the community
1	50	F	White British	Primary Care Nurse	RN	3	2
1	40	F	White British	Health Care Support Worker	Undertaking Assistant Practitioner course	15	2
1	35	F	White British	Senior Nurse Primary Care	RN, DN	13	10
1	53	F	Irish	Primary Care Nurse	RN (Primary Care Pathway)	1.25	1.25

The nurses who took part in Phase 1 of the study are typical of the district nursing workforce, as shown in Chapter 2. All were female, with an average age of 44.5 years. Only one had worked for any significant period of time in the community and this participant held a district nursing qualification. Indicative of the skill mix that is now present in district nursing, two participants were community staff nurses and one was employed as a health care support worker. The two staff nurses were relatively newly qualified as registered nurses.

Phase 2 – Care homes involved in second phase

During Phase 2 the managers of the remaining 14 care homes in the local authority were approached for a second time, to determine if they would be interested in being involved in the second phase of the study. From the time the study commenced, until the start of Phase 2, four care homes had closed down. The researcher visited 12 of these 14 care homes to explain the purpose of the study. A participant information sheet and a copy of the consent form were then

left with either the care home manager or their deputy. They were then contacted a few days later to ascertain if they were willing to be interviewed during the second phase. The managers and/or deputies of 11 of the 14 care homes (CH) agreed to take part. Of these care homes seven were for-profit (FP), three were not for-profit (NFP) and one was owned by a voluntary organisation (V). Further details of these care homes are provided in Table 3. Although CQC categories and rating system of care homes changed during the course of the study, those in use when the study commenced are presented in Table 3. The star rating gives an indication of the quality of care provided, 3 star – excellent, 2 star – good, 1 star – adequate and 0 stars – poor.

Table 3: Phase 2 – Details of other care homes that took part

Provider Type	No of beds	Category	Inspection rating
FP	3	Dementia, old age, not falling within any other category	2 star
FP	20	Dementia, old age, not falling within any other category	2 star
NFP	40	Dementia ,old age, not falling within any other category	3 star
NFP	40	Dementia, old age, not falling within any other category	2 star
FP	15	Dementia, old age, not falling within any other category	2 star
V	18	Old age, not falling within any other category	2 star
NFP	54	Dementia, old age, not falling within any other category	1 star
FP	19	Dementia, old age, not falling within any other category	2 star
FP	41	Dementia, old age, not falling within any other category	2 star
FP	26	Dementia, old age, not falling within any other category	2 star
FP	9	Dementia, old age, not falling within any other category	2 star

The care homes involved in the second phase of the study again appear to be representative of the residential care home sector, as shown in Chapter 2. They included all provider types. The majority (n=7) were run as for-profit care homes, with three owned by small companies and run by independent managers and the remaining four managers also the proprietors of the homes. The not-for-profit care homes were all run by the same parent company, whilst the one

voluntary owned care home was run by a charitable organisation. The care homes varied in size, between 3 - 54 beds, those care homes with fewer numbers of beds were often found in premises that had been converted for the purpose, whilst the larger homes were in purpose-built premises. All apart from one were registered to provide care for older people and dementia, although the extent to which they did this varied between the care homes.

Three care homes were not involved in Phase 2 of the study. One manager was not interested in taking part, whilst the remaining two had no manager in post and so were not approached. Two of these care homes were for-profit care homes and the other, a not-for-profit home. They varied in size from 19 to 44 beds. Two were registered to provide care for older people and dementia and one to provide care for older people only.

Four care homes closed down over the course of the study (Table 4). Two of these were for-profit, one was owned by a voluntary organisation and one by the local authority (LA). It is not known why they closed but at least two care homes appeared to have been sold for housing or redevelopment purposes.

Table 4: Phase 2 – Details of care homes that closed during course of the study

Provider Type	No of beds	Category	Inspection rating
V	18	Old age, not falling within any other category	2 star
LA	43	Old age, not falling within any other category	2 star
FP	9	Dementia, old age, not falling within any other category	3 star
FP	23	Dementia, old age, not falling within any other category	3 star

Phase 2 – Demographics of care home participants

During Phase 2 data were collected from staff from the 11 care homes who agreed to take part in the second phase, in the form of formal interviews. Details of these staff are found in Table 5.

Table 5: Phase 2 – Demographics of staff from other care homes

Age	Gender	Ethnicity	Role	Qualifications	Length of time working in care home(years)	Length of time working in social care (years)
39	F	British Asian	Care home manager	RMA,NVQ 4 in Management	15	15
73	F	White British	Deputy care home manager	RMN,NVQ assessor	15	15
34	M	African	Deputy care home manager	NVQ 2 and 3	8	10
52	F	White British	Care home manager	EN, NVQ 4 Management	16	25

53	F	White British	Care home manager	RMN, RMA, NVQ 4	0.5	30
66	M	White British	Care home manager	ODA, REMT, RMA	13	30
65	M	White British	Care home manager	PhD, RMA	25	25
46	F	Indian	Care home manager	RMA, Dementia trainer	11	18
44	F	White British	Care home manager	NVQ 2, 3, 4,RMA	24	24
41	F	Black British	Deputy care home manager	NVQ 2, 3, 4,RMA	3	15
33	F	Indian	Care home manager	RN, RMA	2	10
57	F	Indian	Care home manager	EN, RN, NVQ 4 Management	22	22
53	F	White British	Team leader	NVQ 2, 3, 4,Counselling	13	13
53	F	Irish	Team leader	NVQ 2 and 3	10	20

As in the case study the majority of these staff were female. However, with the vast majority of these participants holding managerial positions within the care homes there were some differences in the remaining demographics. This time their average age was 51 years and over two thirds were born in the UK. All had worked within the social care sector for many years, which was not surprising due to their managerial positions within the industry. However, once again there was a significant level of movement between posts, with only four participants working in the same care home in which they had started their career. Yet again participants came from a range of backgrounds prior to entering the social care sector including nursing, education and accountancy.

Phase 2 – Demographics of nursing participants

During Phase 2 data were collected from other community nurses and specialist nurses from across the trust, in the form of formal interviews. Details of these staff are to be found in Table 6. District nursing teams were based in one of three localities. All seven teams were approached to ensure representation of all teams, all localities and all grades of staff. The team leader was approached for permission to speak to the staff. As in the case of the first district nursing team approached, a letter of introduction and participant information sheet were sent to all nursing staff. The researcher again attended staff meetings to explain more about the study. Any grade of nurse was invited to take part. Interviews were then held with all nursing staff who expressed an interest. A letter of introduction and participant information sheet were also sent to a number of the specialist nurses working within the trust. This information was then followed up with a phone call to ask if they were willing to be interviewed. The decision was made to include these nurses as four of them worked very closely with the care homes across the local authority, providing both support and training to all the care homes and three had also previously worked as district nurses themselves. A further two community matrons were approached as they had

recently transferred from the district nursing service, a result of the changes that had taken place within the organisation.

Table 6: Phase 2 – Demographics of community nurses who took part in Phase 2

Team	Age	Gender	Ethnicity	Title	Qualifications	Length of time in nursing (years)	Length of time in the community
5	47	F	White British	Primary Care Nurse	RN	30	11
5	56	F	Indian	Primary Care Nurse	RN	35	8
6	43	F	White British	Primary Care Nurse	RN	6	2
6	55	F	White British	Primary Care Nurse	RN	30	17
3	50	F	Chinese	District Nurse Team Leader	RN, RMN, DN, CPT	28	28
3	22	F	White British	Health Care Support Worker	NVQ 3	4	4
3	28	F	White British	Primary Care Nurse	RN	6	3
7	60	F	Indian	Primary Care Nurse	RN	30	12
7	45	F	Chinese	Senior Nurse Primary Care	RN, DN	22	19
7	50	F	White British	Primary Care Nurse	RN	3	3
7	61	F	Irish	Primary Care Nurse	EN, RN	42	20
1	44	F	White British	District Nurse Team Leader	RN, DN, PGCE	13	8
	42	F	African	Community Matron for Care Homes	RN, DN	9	7
	46	F	White British	Clinical Nurse Specialist	RN, DN	36	16
	62	F	White British	Clinical Nurse Specialist	RN, DN	40	30
	38	F	British African	Associate Community Matron	RN	20	3
4	34	M	White British	Community Matron/ Senior Nurse Primary Care	MSc, RN, DN	5	5
2	50	M	Mauritian	Community Matron/ District Nurse Team Leader	RN, DN	16	10

The nursing participants who took part in Phase 2 are again typical of the district nursing workforce. The majority were female and a little older than those who took part in Phase 1, with an average age of 50.5 years. Roughly two thirds had been qualified as RNs for over nine years, with a half of these qualified for at least 30 years. However, only a half of all nursing participants had worked in the community for over 10 years, with a half working in the community for less than 10 years. Of those who had worked in the community for less than 10 years the majority had worked there for three years or less. Nine participants held the Specialist Practitioner qualification. Of these two were team leaders (Band 7) and two were deputy team leaders (Band 6). The remaining five were either specialist nurses or community matrons. Of the remaining nursing participants ten were primary care nurses (Band 5) and two were health care support workers (Band 3).

Data collection

Phase 1 – the case study

The first phase of this study set out to explore the experiences of care staff in managing the healthcare needs of residents, in particular those living with dementia and whether they faced any challenges in managing these needs. One care home served as a case study site, from which data were collected. During a period of familiarisation the care home was visited on 17 occasions typically lasting 4-5 hours, over a period of three months, in order to deepen understanding of the context, the care provided in this care home and any challenges facing the care staff. A number of formal interviews were conducted and documentary evidence collected. As previously discussed it is important for a practitioner researcher, especially one who is an 'insider', to take into account any influence they may have on the results, or how they are interpreted (Hewitt-Taylor 2002). For this reason field notes (FN) and a research diary (RD) were also kept, recording the day-to-day progress of the study. Together with the researcher's thoughts, feelings, and reflections on what was uncovered in the case study and how this related to the researchers own preconceptions and experience of care homes. These field notes served as an additional source of data. For example the following reflection concerns district nurses insisting on a paper referral

> …..An issue raised was around referrals and the problems they have when they
> know that a DN is due to visit and something has happened to a resident….they
> are being told that the nurses are not able to do anything until they have a referral
> from a GP. I don't believe, from my experience, that this is right, as we are a
> service that is able to take referrals from anyone; people are even able to self-
> refer….They even gave an example of this happening, when a resident developed
> blisters on their legs. The problem was that it took 4 days for the whole process to
> happen, i.e. the GP to send the referral to the call centre, by which time she had
> got worse and had been admitted to hospital….RD 014, p235

Familiarisation

Becoming familiar with a 'field' is a feature of ethnographic research, but is also a useful tool in other forms of research, as it can enhance the quality of data collected during later stages of a study (Barley 2011). Prior to the start of this study any knowledge or experience the researcher had of the care home sector had been gained through her role as a district nurse, visiting care homes to provide nursing care for residents and she had never had the opportunity to, or spent any significant time in, such a setting. Schensul et al (1999) suggest four areas that a researcher needs to become familiar with during such a phase. The first is mapping of the setting, which involves the researcher familiarising themselves with the location and focusing on first impressions, which can serve as a reference point for later observations. Secondly it is important that the researcher becomes acquainted with the norms, beliefs, rules, rituals and language of the location, as this will enable them to develop a greater understanding of the setting and the rules that govern it. This is especially true if a researcher is working in a setting that they know little about. Thirdly such a period gives the researcher the opportunity to begin building relationships, which are necessary if initial and on-going access to a site is to be granted. Finally it provides an opportunity to learn how best to collect and record data, i.e. the practicalities of doing field work (Barley 2011, Barley and Bath 2014). This period of familiarisation served a number of purposes in this study. Firstly, it allowed me to familiarise myself with the organisation and to gather a better understanding of the context in which care staff were working, which is recommended when conducting research in a care home setting (Luff et al 2011); leading for example to the realisation that it would not be possible to ask staff to leave their unit to be interviewed, and that a different approach would be needed. Secondly, it offered an opportunity for establishing rapport and the building of relationships with participants so they would feel more comfortable in my presence, as well as feel that they could start to trust me. Thirdly, spending time at the care home meant that I was available to carry out interviews at times that were convenient for the staff, making the most of any opportune moments that arose.

At the commencement of data collection I was given permission by the care home manager to spend time familiarising myself with the care home. The manager introduced me to members of the staff and explained what I was doing there. A letter of introduction, together with an information sheet explaining the purpose and aims of the study and a copy of the consent form, were sent to all members of care staff. I also met with members of the care staff during the first couple of weeks to talk with them about the study. This was felt to be important as although the manager of the care home had given her approval for the care home to participate in the study, this didn't guarantee that other members of care staff would wish to participate. The care home comprised 6 separate units, each housing 10 residents. After a discussion with the care home manager I was given permission to spend time on each of the units, visiting each on at least two occasions. In my role as a district nurse the manager also gave me permission to engage with both the staff and residents, although the latter interactions were not used as sources of data.

The period of familiarisation took place over 3 months, with the care home visited on 17 occasions. This time was used to gain a better understanding of the day-to-day care provided

by care staff, the documentation used, and to build relationships with the care staff. Understanding gathered during this period informed both my thinking about care homes and also the questions used during formal interviews (n=7) and the focus group (n=1) carried out at this care home. Informed consent was given by all interviewees and it is from these interviews that data in regard to the case study site were drawn. If asked, because of my experience as a nurse, I would also provide practical support to the care staff, such as supporting residents at meal times and taking part in activities on the units. During time spent on the units I spoke with a number of the residents, as well as their family members. When this happened care was taken to explain who I was and why I was at the care home and to answer any questions or concerns that they might have had. During these periods I also observed provision of care to residents in the communal areas. But as informed consent was not sought from residents such observations have not been used as data. However, as an experienced district nurse it would be disingenuous to suggest that such experiences hadn't informed my thinking, especially in regard to the care needed by a resident living with dementia. Field notes in the form of personal reflections were recorded following each visit to the care home

The opportunity to spend a prolonged period of time in this care home proved to be invaluable, as the reality was that this was the first time I had spent any significant period of time in a care home. As I was not there in my professional capacity as a district nurse, I could not hide behind the excuse of giving physical care and instead was able to spend quality time with the care staff. It offered me the opportunity to talk with care staff away from my professional role and to hear their thoughts and experiences. It enabled me to gain a better understanding of the care they were providing, as well as the challenges the care home staff were facing, seeing it all through a new set of eyes. During this phase of the study, as a practitioner researcher, I reflected on the findings and came to realise that, as a district nurse, I was ignorant about care homes and the challenges that they and their staff were facing, reflections that subsequently influenced the direction the remainder of the study took. As evidenced by the following note reflecting on what had been learnt from the case study site

> …..What did I learn from the case study? That they are caring for people with
> multiple needs, including physical, psychological and social needs. Residents were
> often admitted with significant health problems, yet residents appeared on the
> whole to be relatively well. This could have been a result of the many healthcare
> professionals that were involved in the residents care and on whom they were
> heavily reliant. It also appeared that these healthcare professionals had little
> understanding of the care staff role, or the care they were permitted to provide, nor
> did they have any real understanding of the constraints put on them. It was also
> interesting that few of the care staff had any dealings with these healthcare
> professionals, with this role left to the team leaders…..Based on these findings I
> want to explore with others what is making it harder, or preventing care staff from
> meeting healthcare needs…..I want to find out what it is that they value from the

district nurses and the sort of relationship that they need. If some kind of nursing
input is needed what could it look like, what do they need? …..RD 018, p250-251

Field notes

Field notes were kept during the study, and were used to gather data about the context of the
care home, and to inform the researchers thinking and reflections during Phase 1. Field notes
are the 'backbone of collecting and analysing field data' (Gray 2009) and are used to give a
narrative account of what is observed in the field. These notes can be used in both analytical
and interpretive ways, to record not only what is seen during a period of observation, but also to
synthesise and try to understand any data collected (Polit and Tatano-Beck 2008). Field notes
can be both descriptive and reflective. Descriptive field notes will include descriptions of
observed events, conversations, actions, dialogue and context and should be as complete and
objective as possible (Polit and Tatano-Beck 2008). Field notes such as these were recorded
during each episode of data collection on a unit including such information as: description of the
care home and individual units, the numbers of residents, numbers of care staff, policies and
procedures and documentation used. Reflective field notes, on the other hand, are used to
document a researcher's personal experiences, reflections and progress in the field. Such field
notes were recorded separately in the research diary that was also kept. The following entry
records a reflection made about the dynamics between care staff, based on the group interview
held with a number of the care staff from the case study site and which was later checked out
during an interview with one of the team leaders

> *Something that did strike me from re-listening to the recording of the interview was*
> *that there appears to be a hierarchy within the care home itself. The more junior*
> *care staff appear to see themselves as just being there to provide the basic care*
> *and anything involving changes in a resident's health, or problems that may arise,*
> *will be reported to the team leaders, who will be the ones who then speak to the*
> *healthcare professionals. They (the care staff) don't appear to see that they have a*
> *role to play with other healthcare professionals, but appear to see themselves as*
> *there simply to do what is asked of them……RD 17, p240*

It is often not possible or appropriate to record field notes at the time. However, for reasons of
possible bias they should be recorded as soon as possible after the event and in as much rich
detail as possible so that information is not forgotten or distorted (Brodsky 2008). As I did not
feel it was appropriate to sit and write notes during my time on the units, the field notes were
written up as soon as I had left the care home, usually whilst sitting in my car, when events were
still fresh in my mind.

Reflection and the research diary

A research diary was used to systematically record the progress of the study, any issues or
difficulties encountered, together with thoughts, feelings, ideas or interpretations regarding
either the research design, or the phases of data collection or analysis (McKechnie 2008, Gray
2009). It was also used to record all reflective notes. Reflection took place at various stages of

the study, e.g. following all care home visits and interviews, during data analysis and during and after any supervisory sessions. For example, following a care home visit I would reflect on what had been seen, conversations that had taken place with care staff, personal feelings about the experience, what had been expected or unexpected, especially that which challenged my previous experiences and what were key learning points from the visit. Such reflection encouraged me to think in greater depth about what I had observed and heard. The reflective notes then enabled me to put into writing my thoughts and feelings of what had been seen, how findings possibly related to my previous knowledge and practice, and how the service might change. This process was informed by my previous experiences working as a district nurse, as well as by the literature. Supervision was an important part of the reflective process. Regular sessions were held over the course of the study, during which in-depth discussions were held with my supervisors about the study's progress, data collection, analysis of the data and conclusions being drawn. I would be regularly challenged by my supervisors to think about the data being gathered, the strength of these data, and to reflect on my interpretations of what had been found and conclusions being drawn.

Semi-structured interviews

In order to explore in greater depth the thoughts, views and experiences of the care staff, a number of interviews were conducted during Phase 1. Semi-structured interviews were used to ensure that specific topics of interest were addressed (Polit and Tatano Beck 2007). It also meant that the sequence of the topics raised could be varied in each of the interviews, in response to the answers given by each participant, as well as allowing the interview to have a more natural flow (Dearnley 2005, Casey 2006). Although an interview guide (Appendix 12) was prepared for each interview, giving an outline of the main topics to be covered and questions to be asked, it was not followed rigidly but instead was used as an aide memoire and I would move back and forwards through the questions depending on the response of the interviewee. These interviews were also guided by my thinking and reflections developed during the period of familiarisation. For example, seeking to better understand from the interviewees the importance of 'knowing' a resident, the impact of nurses rushing care provision, or a lack of continuity of nurses for the person living with dementia; issues that previously I may not have considered. After each interview I would also reflect on how the interview had gone and any issues that had been raised, with each interview influencing subsequent interviews and interview schedules

A number (n=5) of semi-structured interviews were held with the care home manager. To gather information on the day-to-day running of the care home, to explore their experience of managing the healthcare needs of the residents, as well as to feedback my thoughts and reflections on what I had seen during my time in the care home. I had, before embarking on data collection, also planned to formally interview a number of the care home staff. However, I quickly learned that when it came to conducting research in a care home setting I needed to be flexible, a finding supported by a report commissioned by the National Institute of Health Research and the School for Social Care Research (Luff et al 2011).

As a novice to this care home I had no prior knowledge of the care home environment. The layout of the home made it impossible to take members of staff away from the work environment in order to conduct interviews in private. Each unit was staffed by two carers, one of who could be called away at any time, for example to deal with a situation in another part of the care home, or visit a GP surgery, especially if they were a team leader. The reality was that in terms of interviewing care staff I had to take any opportunity that was offered to me. For example a group interview was held with 10 members of the care staff, who were attending an all-day training session at the care home. As they were there for training purposes this meant they were supernumerary. Another day I was able to interview two of the team leaders, however one of these interviews had to be cut short when the team leader was called away. During Phase 1 a number of semi-structured interviews (Appendix 13) were also carried out with members (n=4) of the district nursing team who supported this care home. These nurses comprised one deputy team leader, two primary care nurses and one healthcare support worker. These interviews followed the same course as those of the care home participants.

Documentation

Documentation was gathered to inform understanding of the care home and the care provided. In addition some documentation, e.g. policies and procedures and CQC reports were used as data for the first of the findings chapters. Factual information was gathered about the care home and its parent organisation, which was used to give a better understanding of the care home's context and history. Copies of the documentation, care plans and tools used by care staff when assessing and planning a residents' care, together with job descriptions of all members of care staff, were gathered to inform the researcher's understanding of the care staff role and the assessments and care they were providing. This understanding was further informed by their policies and procedures, which direct the care they were able to give. Finally their most recent CQC inspection reports were read, to give a better understanding of the history of the care home, as well as the quality of care they were reportedly providing.

Phase 2 – interviews with other care home staff and community nurses and checking of findings for resonance and gaps

The second phase of this study was used firstly, to explore the experiences and challenges of other care home staff in managing the healthcare needs of residents, as well as the experiences and challenges of community nurses in supporting care home staff to manage these healthcare needs. Secondly, to check whether the findings from the first phase were peculiar to that one care home, or the practitioner researcher, and if there were any gaps in the findings from the original case study.

In order to explore if the findings from the first phase were unique to that one care home, the experiences of additional care home staff were sought. Semi-structured interviews were conducted with nine care home managers, three deputy managers and two team leaders from a further 11 residential care homes across the borough. Findings from the case study and data analysis were used to direct these subsequent interviews. As previously described, an interview

guide was prepared for each interview, outlining the topics of interest to be discussed. However, it was not followed rigidly, but instead was used as an aide memoire, encouraging the interviews to take the form of a free flowing conversation. This allowed issues arising from analysis across the different data sets, i.e. the case study site, care staff, or community nurses, to be built into subsequent interviews and emergent topics to be explored in more detail, for example the specific experiences of managers who were also proprietors. After each interview I would also reflect on how the interview had gone, with each interview directing subsequent interviews:

> *…..Towards the end of the interview the manager mentioned how important the context in which care homes are operating is and the impact that this can have, especially in regard to funding of the care homes. This is something that was mentioned in the case study but appears to be having a greater impact on this care home. For this reason I will add a question to the schedule, along the lines of 'To what extent is the context in which you are operating impacting on the care you are able to provide?'…..RD 022, p260*

This second phase was also used to explore the experiences and challenges for community nurses in supporting residential care homes to manage the healthcare needs they were faced with, as well as to check out if the thoughts and observations of the researcher, from Phase 1, were unique to her, and if there were any gaps in the findings. Semi-structured interviews were conducted with a further 18 community and specialist nurses from across the trust. Interviews were conducted with two district nurse team leaders, one deputy team leader, eight primary care nurses and one healthcare support worker, with all district nursing teams, localities and grades of nurses represented. Interviews were also held with six specialist nurses, including four community matrons and two clinical nurse specialists. Once again these were free flowing, with the interviews directed by findings from the case study, as well as from the researcher's observations and themes emerging from data analysis.

The reality of conducting research in care homes

One issue that impacted on the progress of the study was the reality of carrying out research within the care home setting, which could at times prove challenging. A finding supported by a report for The National Institute of Health Research and the School for Social Care Research (Luff et al 2011), which provides help and advice to those new to the field of researching in care homes, but frustratingly was not available when the research proposal was written or the study commenced. The report gives advice that would have been of great help to me as a novice researcher. Suggesting, for example, that time and flexibility are two of the most valuable resources for a researcher, that a researcher needs to understand the hierarchies that exist within care homes, or that obtaining consent to undertake a study within a care home setting can be a time consuming process. This latter point was of particular relevance given the length of time it took to obtain full ethics approval in regard to the involvement of the care homes in this study.

I had rather naively imagined that the process would take around 3-4 months. However, the reality was very different and in fact the whole process took nearly a year, as obtaining approval to carry out research with the care homes was a slow process. For example, written permission was required from a parent organisation before a manager could be approached. Speaking to the manager could prove difficult, requiring frequent phone calls and even when an appointment had been made to visit a home this would often be changed at the last minute. This process was not helped as the point of contact for the researcher was the local NHS ethics committee, but neither they, nor the Research Governance Lead, had any knowledge of how the ethics process applied to the care home sector and so were unable to give advice or help. This was also true for any written information available, as again it focused on conducting research within the NHS. At the time the study commenced social care organisations had only recently come under the umbrella of the National Research Ethics Service, so the process was also new to the care home sector and obtaining the required signatures from the parent organisation of the case study site proved problematic and time consuming.

The report by Luff et al (2011) also suggests that a researcher has to be flexible with their time, advice that would have been of use at outset of the study, but which was something that I very quickly came to realise. Once ethics approval had finally been granted it took a further 3 months until the study could commence at the case study site. Trying to arrange an initial meeting with the manager of the care home proved difficult, as they were so busy. Meetings were arranged, but then cancelled at the last minute, due to unforeseen circumstances. For example the first day I spent in the care home I had arranged to interview the manager, however, when I arrived an unannounced inspection was taking place and so the manager was unavailable. Arranging to interview members of the care staff also proved to be difficult, due to work pressures, so in the end I had to take any opportunity offered, for example interviewing staff attending a training session.

Data analysis

Data analysed were generated from 44 interviews conducted with care home, district nursing and specialist nursing participants, together with field notes and documentation from the case study site. Data analysis is not a distinct stage of the research process, but is a reflexive activity informing data collection, writing and further data collection (Tesch 1990, Coffey and Atkinson 1996, Gibbs 2007). Thematic data analysis was used, identifying, analysing and reporting patterns in data, based on an approach outlined by Braun and Clarke (2006). Their approach incorporates six stages: familiarisation with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes and producing the report. Although the stages are described in this thesis as separate happenings, analysis is not a linear process and there was continual movement back and forwards between the different stages.

Familiarisation with the data

In total 44 interviews were conducted during the course of the study. After each interview notes were made in the research diary reflecting, for example, on how it was felt the interview had gone, any issues that had arisen during the course of the interview and whether the interview schedule needed to be revised. The first stage of analysis involved listening to, transcribing and reading each of the interviews. I would initially listen to the digital recording, in order to get a feeling of the interview as a whole, and then transcribe verbatim each interview. This was a useful process as it allowed me to more fully immerse myself in the interview and to develop a more thorough understanding of what had been said and how (Braun and Clarke 2006, Polit and Tatano Beck 2008). The next stage was to read each of the interviews in their entirety. This reading was important as it gave an initial sense of the issues which were arising from the data, an understanding of fragments of data in context and it also encouraged me to be alert for any unexpected responses (Miles and Huberman 1994, de Wet and Erasmus 2005). Transcripts were also checked back against the original recordings for accuracy. Once the interviews had been transcribed they, together with the field notes, were entered into NVivo (version 9), a qualitative data analysis computer software package, ready for the next stage of the process.

Generating initial codes

In thematic analysis themes within the data are identified either inductively or deductively. An inductive approach, as in the case of this study, means that themes are strongly linked to the data themselves, are not driven by any theoretical interest on the part of the researcher and a pre-existing coding framework is not used (Braun and Clarke 2006). The second phase of analysis involved the production of initial codes from the data. The purpose of coding is to enable data to be 'segregated, grouped, regrouped, and relinked in order to consolidate meaning and explanation' (Saldaña 2009). Initially each interview was read and re-read, with codes written next to words, lines, or sections on each transcript (Appendix 14). This process was then repeated using the NVivo software. The emergent coding framework derived inductively from the data, was informed by the research questions and my professional knowledge and experience.

Data from the case study site were analysed initially, with the transcripts of the interviews and the field notes read, re-read and coded. Analysis of these data then directed subsequent data collection. The initial coding was fairly simple, using coding methods outlined by Saldaña (2009), including attribute, structural, descriptive and in-vivo coding. Attribute coding was used for notating basic descriptive information, such as participant demographics collected at the start of each interview. Structural coding, a question based code used to label or index data, was used when coding answers given in response to specific research questions, for example 'Have you got an example that you could give of your experience of providing care to a person with dementia?' or 'What is your experience of working with care home staff?' Descriptive coding, the most common coding method, was used to summarise the basic topic of a passage of data, informed partly by the research questions. In-vivo coding, the use of a word or short phrase used by the participants themselves, was also used. For example, the word 'safe' was

used frequently by the community nurses in relation to residents, whilst a number of the care staff used the phrase 'just a carer'. As coding is not a one off exercise transcripts were revisited upon a number of occasions throughout the study.

Searching for themes

Once all data were coded and collated the next stage was to begin to reorganise and reanalyse this data, looking for broader themes and collating all relevant data extracts within these themes (Braun and Clarke 2006). This process was again driven, in part, by the research questions and areas of interest. It took place initially within, and then subsequently across, the different data sets, comparing and contrasting the data from Phase 2, with that from the original case study and reflections of the practitioner researcher. Initially extracts of data were coded in NVivo as separate tree nodes. But once a number of interviews had been coded it became apparent that recurring themes were emerging. As a result nodes that had something in common were regrouped together (Appendix 15); e.g. a tree node called 'risk', brought together codes such as 'care given because of risk', 'a safe environment', '24-hour care' and 'to cover themselves'; whilst another entitled difficulties working with nurses included codes such as: 'not a priority', 'poor communication' and 'critical'.

New codes were also added as additional themes began to emerge, and by drawing on my professional knowledge and experience, to identify findings that I would have expected, as well as findings that were a surprise, in that they challenged my assumptions, or were not what I had expected. This resulted in a number of data display models being drawn in NVivo such as: 'complexity of the issues facing care staff', 'complexity of caring for residents living with dementia' and 'factors impacting on the meeting of healthcare needs of residents'. The use of visual displays proved useful, as it provided a clearer picture of the data overall and a better understanding of the relationships between codes and themes (Miles and Huberman 1994, Braun and Clarke 2006). A word that I kept using when reflecting on the data was 'complex', which I felt described the array of different factors and challenges that the care staff were expected to deal with, and which suggested that they were not providing simple or straightforward care. As a result of this I began to explore the literature, discussed in greater detail in Chapter 10, on complexity thinking and in particular complex adaptive systems. This literature made a clear distinction between a system that was complicated and one that was complex, as well as outlining characteristics of complex systems, informing the later stages of data analysis.

Reviewing themes

This stage involved refinement of the themes identified in the previous stage and involved reviewing all coded data and checking that it formed a coherent pattern. If not, the theme was reworked, or a new theme created. Finally these themes were checked in relation to the data set as a whole. It is during this phase that the researcher develops a clearer idea of the different themes, how they relate to each other, together with the overall story that is to be told (Braun and Clarke 2006). In this case my growing awareness, as a district nurse, of the complexity

present in these care homes, evidenced by the care homes demonstrating certain characteristics of complex systems, together with the response of the community nurses to this complexity. A number of themes were refined during this phase, with the reworking of themes such as: 'pressure from all sides', 'they are sick, not healthy and 'what makes care difficult for nurses'.

Defining and naming themes

This stage involved identifying the 'essence' of what each theme was about, determining what aspect of the data each theme captured, as well as the story that each theme was telling (Braun and Clarke 2006). The overall themes devised during this phase included 'understanding the complexity in care homes', 'struggling to cope' and 'ignorance of, or ignoring complexity', which it was felt would give the reader a sense of what each theme was about. The final stage of data analysis would be the production of a written report.

Ethical issues arising from practitioner research

Ethical approval for the study was granted by the South East London REC (Ref 10/H0807/7 Appendix 16) to interview community nurses and members of care staff from a small number of care homes regarding their experience of managing the healthcare needs of residents, as well as to observe interactions between the two. However, due to the emergent design of the study, once data had been collected from the case study site the main REC and local NHS ethics committee were contacted and a minor amendment agreed by both committees, permitting the researcher to approach and interview further participants from all other care homes across the local authority.

Informed consent

Central to any research is freely given informed consent, with people making a decision to take part based on comprehensive and accurate information about the study (Atkinson and Hammersley 2007). Gaining informed consent in a care home setting, such as the case study site, involves a continual process of information provision and renegotiation (Madjar and Higgins 1996, Luff et al 2011). When carrying out research in a care home it has been suggested that the researcher acts as a moral agent, adapting their approaches and actions to the needs of those in the setting, rather than merely adhering to prescribed protocols (Madjar and Higgins 1996). As a practising nurse the researcher is also bound by her professional code of conduct (NMC 2015). Such moral, ethical and professional codes will guide a researcher's judgment about what is and is not acceptable behaviour and ensure that participants are not exploited (Atkinson and Hammersley 2007). Meetings were held with all those approached to take part in the study, when the purpose of the study was explained, questions and concerns addressed, and information sheets and consent forms provided. Prior to any formal interview the purpose of the research was again explained and interviewees were again given participant information sheets, together with information about consent and opting out of the study. Written consent was then gathered from all interviewees.

Although the care home manager had granted access to the care home there was no guarantee that other members of care staff would wish to participate in the study. Taking part in any research can be stressful and cause anxiety, especially if the researcher is felt to be evaluating one's work (Atkinson and Hammersley 2007). In order that any concerns could be addressed, time was spent meeting informally with care staff, both on the units and at team meetings, providing verbal information about the purpose and aims of the study, answering any questions they might have and building relationships with them so they might feel more at ease with the researcher. Information sheets and consent forms were given to all members of care staff at the case study site. Brown Wilson (2007) suggests a number of strategies to achieve on-going consent in a setting such as a care home, in this study these included:

- Permission given by the directors of parent organisations for the researcher to contact their care homes
- Verbal consent given by the care home manager when inviting the researcher into the care home
- Written consent given by any participant prior to being interviewed using a digital recorder
- Permission sought from all participants for the use of their interview transcripts

The manager of the case study care home gave consent for initial and on-going access to the site, introducing me to members of her staff and explaining why I was there. Time was spent familiarising myself with the care home, making observations about the day to day running and layout of the care home, gathering information about the roles of different members of staff, an understanding of the sort of care they provided to residents and documentation used. When carrying out research in a natural setting the researcher has no control over who enters the field of study. As a result it may not always be possible to ensure that all participants are fully informed, that they freely consent to be involved and gaining written consent can be difficult (Atkinson and Hammersley 2007, Gray 2014).

One of the aims of the study was to explore the experiences of care staff in managing the healthcare needs of residents. At the case study site the focus of the study was on familiarising myself with the context, informing my understanding and exploring the experiences of the care staff. As a result a decision was made not to include the experiences of the residents in the study and consent was not sought from them. However, this raises certain ethical issues. During this period of familiarisation time was spent talking with various members of care staff who were working on the different units, in order to build relationships with them. As a nurse, governed by a code of professional conduct and working in the local area, the manager granted formal permission to interact with the residents, as well as to talk with the care staff about the residents and the care that they required. As much of the time at this care home was spent either at the carer's desk in the units, or in the lounge of the unit, I also routinely came into contact with residents. In order that residents were aware of what I was doing there whenever I met, or spoke with a resident I would take care to introduce myself to them, telling them who I was and

why I was there. I would try to put them at their ease by chatting with them, for example, asking about their family or their lives before they moved into the care home. Given that the residents all had some degree of CI this had to be an on-going process, and I would always introduce myself to residents and explain why I was there. These interactions have not been used as data. When talking with any resident I was always mindful of any non-verbal signs, such as agitation or facial expressions, that could suggest that they were distressed my presence and if any such signs had been noted I would have removed myself from their presence. I remained in the public areas of the care home and never entered a resident's room, unless invited by the resident. When this did happen on a couple of occasions it was because the resident wished to show me where they lived, or some personal possession. When meeting any family members, I would again always explain what I was doing on the unit, reiterating that I was there to gather an understanding of day-to-day care in the home and the role of the care staff.

As time was spent in the public areas of the care home, and I was interacting with the residents, I did record in the field notes the sort of care that was being provided by the care staff, but these notes have not been used as data. Information shared by residents during conversations with them has also not been used as data. However, I have to acknowledge that these interactions did inform my thinking as a practitioner, especially in regard to caring for residents living with dementia. For example I gained an understanding of the importance of 'knowing' a person who has dementia and the benefits of such knowledge in managing healthcare needs more effectively, i.e. in being able to pick up small changes in their behaviour that could suggest that they were not well. Any data concerning residents and particular healthcare needs were gathered from interviews with care staff, who spoke in general terms about the healthcare needs of residents who they had, or were caring for, and their experiences of trying to manage these needs. However, talking about residents and their healthcare needs, interacting with them and observing the care they received, without the residents consent could raise concerns over confidentiality and intrusion, and on reflection runs the risk of breaching their right to privacy. Although verbal permission was given by the manager to interact with the residents and great care was taken not to use data pertaining to specific residents and what had been observed, on reflection, in order to counteract any such criticism, the researcher would, in the future, approach this issue in a different way, seeking to gain formal written consent from either the residents or their nominated consultee.

Addressing any power imbalance

Working as an 'insider' researcher can raise a number of ethical issues. However, given the depth and richness of data that may not have been accessible any other way, I felt that working as an 'insider' was justifiable. Participants may feel they are expected to take part (Noble et al 2009), which is why reassurance was given to all those who participated, during either phase of the study, that they were under no obligation to take part and that they were free to withdraw from the study at any time and for any reason if they so wished. Unequal power relationships can be another potential problem (Hewitt-Taylor 2002). In terms of power, I was aware that because I was a district nurse, members of the care staff may not have felt comfortable talking

with me and so every effort was made to try to address any imbalance of power by getting to know them and putting them at their ease, not writing any field notes in front of them and wearing appropriate clothing to blend in with the staff. Another way was by drawing on their knowledge and experience of caring for a person living with dementia. I knew very little about this aspect of care and was aware that many of the staff had a greater understanding of the subject than I did. This was something I would explain to them and would ask for their thoughts and experiences on the subject. I would acknowledge that I felt they knew much more about the subject than me and for this reason I was there to learn from them. They appeared to appreciate this honesty and willingly described the issues that they faced regularly and the difficulties and challenges that caring for their residents could bring. The same was true for the district nursing participants, as I was one of the district nurse team leaders. For this reason I sought to make clear that my role when interviewing them was as a researcher. Any interviews conducted were done outside of my normal working days, I would not be in uniform, would ensure that I fitted around their work demands and all interviews were conducted in an environment in which they felt comfortable.

Anonymity

As an 'insider' it may be difficult to guarantee complete anonymity as participants will know where the study has taken place (Gray 2009). As part of the consent process participants were reassured that any information given would be treated as confidential. In order to maintain anonymity letters and numbers, rather than names, have been assigned to all the care homes, district nursing teams and participants who took part. Some of the demographics of the care homes mean that it may be possible to work out which care home they refer to. For this reason every effort has been made to ensure that participants cannot be linked to a particular care home or district nursing team, by not using their assigned codes in the methods chapter. For the same reason, when giving details of the local authority, or NHS trust in which the study was carried out, or when referencing documentation relating to either the trust or local authority, such as annual reports, any information that would make either of them identifiable has been withheld.

Lastly the researcher can bring their own personal beliefs and values to the study, especially if they have worked in the field for some time (Noble et al 2009). The field notes and research diary were used to record personal beliefs and values and these, together with regular supervision sessions, were used to try to ensure that any bias was identified and dealt with as needed (Noble et al 2009).

Trustworthiness: Ensuring quality of the data

Researchers have to persuade the reader that their findings are worth paying attention to (Lincoln and Guba 1985). Researchers using an interpretivist approach seek to do this by establishing trustworthiness, rather than the criteria of validity and reliability commonly associated with positivist research. Researchers seek to establish the trustworthiness of the

data (Lincoln and Guba 1985) in a number of ways which include: credibility, the value and believability of the findings, transferability, whether the findings can be transferred to a similar context or situation, dependability, how reliable the data are and confirmability, the neutrality and accuracy of the data (Lincoln and Guba 1985, Houghton et al 2013).

Adherence to good methodology

One way to achieve trustworthiness is through a rigid adherence to good methodology. For example, the use of clear sampling methods, multiple sources of data, rigorous analysis, theoretical support for the chosen methodology and explicit attention to rigor through for example a clear audit trail (Bryar 1999b, Bergen and While 2000, Rosenberg and Yates 2007, McGloin 2008, Anthony and Jack 2009). This chapter has sought to give a detailed description of how and why the case study site was selected, details of how participants were selected, together with details of data collection and analysis methods. The research diary, together with memos recorded in NVivo, were used to keep a detailed account of the progress of the study, together with analysis and interpretation of the data, in order to establish a clear audit trail. For example whilst writing up the research diary after each interview I would reflect on how I had presented myself, which was necessary given that I was a novice researcher. Reflecting on the interviews I highlighted a number of mistakes that I was making which included: asking yes or no questions, asking questions that at times rambled or were too complicated, or asking leading questions. I also noticed that I used the word 'we' on occasion when referring to an issue affecting district nurses, especially if the interviewee was a nurse I had worked with previously. Doing this encouraged me to reflect on my skills and to try, in subsequent interviews, to address such issues.

Other ways in which the researcher has sought to establish trustworthiness include triangulation, with data and information collected from multiple sources, including observation, field notes, interviews, documentation and findings of the case study checked for resonance and relevance with others, with the aim of corroborating the same fact or phenomenon (Yin 2009, McGloin 2008). Peer debriefing was another method used. Regular supervision sessions were held with a number of supervisors throughout the course of the study, with possible interpretations of data explored, findings and analysis challenged and possible biases discussed (Lincoln and Guba 1985, Lietz et al 2006). Another way is through the provision of 'rich contextual detail' of the study setting. Providing sufficient detail of both the context and participants involved in a study is necessary, in order that a reader can compare the study and its findings to the situation in which they work, or have knowledge about. The reader will then be in a position to decide whether or not the study is applicable to their particular situation (Stringer and Genat 2004, Rosenberg and Yates 2007).

Member checking

Trustworthiness can also be established through the cross checking of findings. Member checking (Lincoln and Guba 1985) involves the feedback of data, analysis, interpretations, or conclusions to participants in a study (Cohen and Crabtree 2006). It can take a number of

forms, for example it may be continuous, or a one off event and can be done both formally and informally (Cohen and Crabtree 2006, Doyle 2014). Informal member checking can take place during the normal course of observation and conversation, whilst formal member checking involves providing participants with transcripts of interviews for verification of their accuracy and editing if they so wish (Carlson 2010). It is a valuable tool as it provides participants with the opportunity to correct any errors, provide additional information and to challenge what they may perceive to be the wrong interpretation of what was said. However, there are drawbacks associated with it. Checking with participants can lead to confusion as they may, in the interim, have changed their mind about an issue, or they may have had new experiences since the original interview (Cohen and Crabtree 2006). They could also disagree with the interpretation, yet who is to say they are right, as they may have forgotten what they said.

Formal and informal member checking was used during the course of the study. In terms of informal checking the researcher would often check out, with staff at the case study site and interviewees, observations, reflections and interpretations that she had made. As demonstrated in the following field note

> …..X was saying how different it was in this care home compared to a nursing home where they had previously worked…..This discussion once again lead on to the skills that I felt the carers in this care home were demonstrating, caring for these highly dependent residents. We also discussed that I was now aware of and understood the importance of knowing the residents. How you have to spend time with them just learning about their behaviour, which I now understand is especially important with residents who are very often unable to tell you if they have a problem, or are unwell…..FN 015, p146-147

Formal member checking was also used. Initial reflections from the field notes and interpretations from data analysis were fedback to the manager of the care home to get their thoughts and feelings. These reflections were also used to adapt the interview questions in both Phase 1 and 2. Transcripts of interviews were sent to all those who had taken part, to verify whether participants felt it was an accurate reflection of the interview and if they wished to amend it in any way. For pragmatic reasons, which included the pressures of work for both the care and nursing staff, it was felt that it would not be appropriate or possible to personally share each transcript and findings, as had been done with the manager of the case study site. Instead the transcript was sent, together with a letter of explanation, to all those interviewed. The letter explained why they had been sent the transcript and that they were free to amend it if they so wished. The letter also explained that if the transcript was not returned within 6 weeks the researcher would assume they were happy with the contents. A stamped addressed envelope was included to encourage participants to provide feedback if they wished. A number of transcripts were returned, however, no one requested any changes be made.

Reflexivity

Finally reflexivity was used to establish credibility. Reflexivity differs from reflection, which involves looking back on what has taken place. Reflexivity, on the other hand, encourages the researcher to consider their position and influence during a study (Savin-Baden and Howell Major 2013). The credibility of a study can be put at risk because of the past experiences, beliefs, expectations and emotions of a researcher, which can prevent them from achieving the detachment needed when collecting and analysing data (Asselin 2003). Reflexivity, defined as the 'active acknowledgement by the researcher that their actions and decisions will inevitably impact on the meaning and the context of the experience under investigation' (Lietz et al 2006) enable such issues to be addressed. Field notes were recorded throughout the study and included personal memos, reflections on the researcher's reaction to people and events, reflections on data that were of a surprise, reflections on her relationship with participants and reasons for decisions and interpretation made. As an 'insider' researcher such reflexivity was especially important, as she needed to consider and also make clear, how her position as a district nurse was influencing the reality of what she was recording (Gagnon 2010). It is also important that a researcher's beliefs and values are made explicit in the written account, so that readers are able to judge for themselves if they have been addressed (Meyer 2000), which is what the researcher has sought to do in the findings chapters.

The reflective field notes recorded the researcher's personal and professional background and experiences, expectations that she held which had been influenced by the literature and previous experience of working with the care home sector, as well as issues or observations that were of a surprise or a shock to her as a practitioner. These field notes were used as a data source. For example, in Chapter 7, the practitioner researcher has reflected on areas of care and practice that took her by surprise, challenging a number of preconceptions that she held. The following is an example of such a reflection

> …..What I have observed at the case study site is very different from what I had been expecting. I have spent over 19 years working as a district nurse and have visited a wide range of care homes during this time. Yet the reality is that I have spent very little time in any of them, due to the type of care that we as a service tend to provide, which is task focused care and concentrates on the meeting of physical needs. Such a focus is evidenced by the title of my original proposal in which my intention had been to concentrate on the meeting of 'physical healthcare needs'. What I am beginning to realise is that I have very little idea of what life in a care home is really like. I have been surprised by the reported level of dependency of the residents and how much their needs could apparently fluctuate during the course of even a day. I have also had to acknowledge how little I know about caring for a person with dementia……The knowledge that I am gaining is making me question the care that we, as district nurses, are providing to these particular residents. Caring for residents who have dementia requires time, as they can't or shouldn't be rushed. You also need to build a relationship with them, something

that we are unlikely to do, given the pressures that we as a service are often under…..RD29, p275-276

Transferability

A frequent criticism of case studies is that it is difficult to generalise from them, either because the sample is not representative of the population as a whole, or because the sample is small, for example, a single case (Pegram 1999). The problem is that case studies are often analysed using criteria appropriate to the quantitative paradigm, referring to issues such as validity and reliability (Bryar 1999a, Zucker 2001, McGloin 2008). Simons (2009) suggests that the researcher is under no obligation to generalise from a case study however, they do have to demonstrate how, and in what way, the findings are transferable to other contexts and can be used by others. Ways to achieve this include the use of multiple case studies to identify common issues and interconnecting themes, or the provision of rich description and sufficient detail so that the reader can decide it the findings are applicable to their own context, or enable them to recognise similarities and differences to their own experiences.

Yin (2009) and Sharp (1998) however, argue that it is possible to generalise from case studies, even from a single case, and is done by generalising to theoretical propositions, rather than by generalising to populations, i.e. empirical generalisation; as well as by 'making a case' (Sharp 1998). Theoretical generalisation does not depend on upon representativeness for validity. But rather relies on the researcher identifying some general principals concerning the case, which can be explained by existing models, theories or concepts. Whilst in terms of 'making a case' (Sharp 1998) the researcher has to provide sufficient detail, so the reader can decide if their situation has anything in common with that of the sample.

The researcher has reasonable confidence that the findings of this study are transferable to other settings as firstly she has sought to provide a rich description of the study setting, together with contextual details of all care homes and participants, so readers can decide on the usefulness and applicability of the findings to their own practice setting. Secondly, in Chapter 10, she has sought to relate the findings to complexity thinking, to give a better understanding of why the healthcare needs of residents may not always be met and certain contextual and behavioural issues that may need to be considered if this is going to happen. Interestingly Sharp (1998) suggests that empirical generalisation commonly refers to the findings of a case being typical of the population from which it has been drawn. If this is true then it could be argued that there is also an element of empirical generalisation, as the findings from the case study and reflections of the practitioner researcher, resonated with, and were relevant to, other care homes and district nurses when feedback to them.

Summary

This chapter explained the rationale for adopting a practitioner research approach, together with the advantages and disadvantages associated with 'insider' research. Furthermore it outlined

the aims and objectives of the two phases of the study, has provided rich detail of the case study site and participants and outlined how access to participants was obtained. The chapter detailed the data collection methods used and the challenges of conducting research with the care home sector. Details have been provided of the process used to analyse the data, as well as the ethical issues of research that was conducted by an 'insider'. An explanation was given of how the researcher sought to ensure the quality of the data, by establishing trustworthiness through the use of a variety of methods, including reflexivity.

INTRODUCTION TO THE FINDINGS

Residential care homes have changed. Levels of dependency, co-morbidity and healthcare need are increasing amongst residents and are often on a par with those found in nursing homes. Residents are cared for by staff who, on the whole, have received training focused on the management of social care needs, the expectation being that nursing needs will be met by the district nursing service. A review of the literature suggested that residents across the care home sector, especially those living with dementia, have healthcare needs which are under-recognised and/or under-treated. It also highlighted that there is limited understanding of why these needs are not being met, as the views of those involved in caring for residents have not been sought, and the context in which care homes are operating largely ignored. It concluded that there was a need for more qualitative research to be conducted, gathering the experiences of those providing day-to-day care for residents, to enable a better understanding of the issues and challenges they face in meeting the healthcare needs of residents.

This study set out to explore the experiences and challenges of care staff in managing the healthcare needs of residents in residential care homes, in particular those living with dementia, as well as exploring the experiences and challenges for the district nursing service in supporting care staff to manage these healthcare needs. The findings were generated over two phases, described in more detail in Chapter 6. Phase one comprised a case study of one care home. The aim of which was to explore the experiences of care staff from one care home in managing the healthcare needs of residents living with dementia and whether they faced any challenges managing these needs. The researcher spent time familiarising herself with the care home and building relationships with the care staff. Data were collected from various sources, which included interviews with the care home manager, other care home staff and members of the district nursing team supporting the care home, together with documentation and contextual data regarding the care home. Using herself as a research instrument the practitioner researcher reflected on these findings in relation to her own knowledge and experience of working with care homes, focusing on those findings that resonated, as well as those aspects that surprised.

The second phase of the study was used firstly, to explore whether the findings from the first phase were unique to that one care home, with further data collected from care home staff across the borough and compared to that from the original care home and reflections of the researcher, identifying findings that resonated, and any gaps in the findings from the original case study. The researcher again used herself as a research instrument, to note, in particular, findings that were a surprise, or a shock. Secondly, it was used to explore the experiences and challenges faced by other community nurses when supporting residential care homes to manage the healthcare needs they were faced with. As well as to check out whether the issues that had surprised the researcher in Phase 1 were unique to her, or whether they resonated with other nurses.

The findings are set out across three chapters. Paley and Eva (2011) argue that if one wishes to refer to a system as being complex, that a 'complexity explanation' should be offered, an explanation that describes the mechanisms and interactions occurring within the system, from which the complexity arises. For this reason the findings chapters are purposively descriptive, in order to demonstrate the complex nature of these care homes and how community nurses were responding to this complexity. Deeper analysis and interpretation of the findings then takes place in Chapter 10, when the findings are discussed in relation to complexity thinking, and in particular complex adaptive systems.

Chapter 7 addresses the initial aim of the study which was to explore the experiences and challenges of care staff in managing healthcare needs of residents, in particular those living with dementia. Findings in this chapter are based on data gathered from the case study site. A criticism levelled at case studies is a lack of generalisability to the wider population. In order to address this issue the researcher has sought to describe the case study in rich, contextual detail, thereby giving readers the opportunity to decide if the findings presented here are of relevance to their own practice. Confirmability is another way in which the researcher has endeavoured to establish the trustworthiness of the findings, by demonstrating, through the use of an audit trail and her reflexive field notes and research diary, the neutrality and accuracy of the data. The opportunity to spend a prolonged period of time at the case study care home proved to be an invaluable experience. An advantage of PR is that when studying the complexity of a situation an 'insider' researcher may have knowledge of the complex issues they see, enabling them to unravel and better understand intricacies and complications that may be present. The period of familiarisation enabled the researcher to deepen understanding of the context, build relationships with care staff, and inform her thinking about the management of residents' healthcare needs; whilst data from the interviews offered an understanding of the care provided by care staff, together with any challenges faced. Using herself as a research instrument the researcher reflected on the findings from the case study, identifying those issues that were a surprise or a shock to her, in that they challenged previously held assumptions. This chapter presents descriptive findings which demonstrate how, by using herself as a research instrument, the practitioner researcher became increasingly aware of the complexity involved in meeting the healthcare needs of residents, especially those living with dementia (Figure 3, p113); complexity which the researcher, as a practitioner, had been largely unaware or, and was surprised by.

During Phase 2 the researcher set out to explore whether the findings from the original care home, and reflections of the researcher, were unique to that one care home and if they resonated with others, or if there were any gaps in the findings from the original case study. To make clear when findings did, or did not, resonate with those from the first phase, a framework has been used to demonstrate when findings from Phase 1 were confirmed, unconfirmed, or when new findings were uncovered (Table 7, p132 and Table 8, p156). Chapter 8 presents data gathered from interviews carried out with care home staff during this second phase. The findings suggest that the complexity noted at the case study was not unique and in fact was

even greater than had first been realised. Whilst Chapter 9 presents data gathered from interviews conducted with community and specialist nurses during Phases 1 and 2 of the study; exploring their experiences of working with residential care homes, and in addition, whether the issues that had surprised the researcher in Phase 1 were unique to her, or whether they resonated with other nurses. These findings suggest that, like the researcher, many of the nursing participants were ignorant of much of the complexity present, however, another response was to ignore it. The findings also suggest that the service currently provided by the district nursing service was not able to ensure that all needs of residents would be met, with residents living with dementia at particular risk.

As mentioned previously, the descriptive findings in these three chapters are analysed in greater depth in Chapter 10, where they are discussed in relation to complexity thinking and in particular, the literature relating to complex adaptive systems. In this final chapter it will be suggested that residential care homes demonstrate many of the characteristics of complex adaptive systems, due to the diverse and embedded nature of the residents and staff, the care they are providing and the nature of their relationships with other services, including the district nursing service. It will suggest that certain barriers may be preventing the healthcare needs of residents from being fully met, and that the service provided by community nurses is guided by certain rules, offering a possible explanation for the response of these nurses to the complexity that is present. It will also argue that previous attempts to address primary care support of care homes have largely been unsuccessful and that using complexity thinking may offer possibilities for change.

CHAPTER 7: FINDINGS FROM THE CASE STUDY: UNDERSTANDING THE COMPLEXITY IN CARE HOMES

Introduction

This chapter draws on data from the case study, which set out to explore the experiences and challenges of care staff in managing the healthcare needs of residents, in particular, those living with dementia, and whether the district nursing service was adequately supporting them to manage the healthcare needs they were faced with. Data were collected to deepen understanding of the context, the care provided in this care home and any challenges facing the care staff. These data included: five interviews (I) conducted with the care home manager (CHM), together with two interviews (I) with team leaders (TL) and a group interview (GI) with 10 care home staff. Documentation (D) was also gathered, including policies, procedures, factual information about the care home and CQC inspection reports.

In PR bias on the part of the researcher may put the credibility of a study at risk (Blythe et al 2013). The researcher may assume that they know the culture, failing to probe for deeper meaning, or overlooking important pieces of data. One way to overcome such bias is through the use of reflexivity. Reflexive field notes (FN), together with a research diary (RD) were kept by the researcher throughout the course of the study and were used as an additional data source. As a district nurse with many years of experience, the researcher used herself as a research instrument, reflecting on the findings from the case study, in relation to her own knowledge and experience of working with care homes, focusing on aspects of practice that were familiar, as well as those that surprised.

As with any case study there are issues with transferability. For this reason rich contextual detail is provided in order that readers can judge if this single case study is of relevance to their own practice. This chapter begins by painting a picture of the case study site, drawing on observations of the care home made during the period of familiarisation, interviews with the staff and relevant documentation. It then goes on to report on relevant data from the interviews conducted with the care staff, together with data from the reflexive field notes and research diary.

Case study site

The care home that served as the case study site was housed in a building that was relatively new and which was purpose built. It was one of 30 care homes owned by a not-for-profit organisation providing care for older people across the country. In the local authority in which this study took place, described in detail in Chapter 4, five residential care homes were run by this organisation. This care home provided specialist care for people living with dementia.

The building

The care home was laid out across two floors and comprised six individual units, each caring for up to 10 residents. One entered the building into a central atrium extending over both floors. It was a warm, bright, inviting space, due largely to its large glass ceiling. This atrium served as a central lounge, used by both residents and visitors and was filled with sofas, armchairs and lots of memorabilia. A number of rooms lead off the two floors of the atrium. These included: a reminiscence room, hairdressers and a 'pub', complete with bar. There was also a quiet lounge, the manager's office, a general office housing the bursar, together with the team leader who was on duty for that shift, a staff room, a medical room and the main kitchen. A large garden encircled much of the care home and was accessed from many of the ground floor rooms. The garden was fenced off, giving residents freedom to walk out there as they wished. However, the doors to this outside space were alarmed, to alert staff if a resident was to go out unnoticed.

The units

There were three units on each floor, all leading off the atrium. Outside each unit were pictures of the permanent care staff for that unit. Each unit appeared to function as an individual 'home'. The door to each unit was opened via a keypad. However, these doors were often left open so that residents could walk around the home as they wished and certain residents were often to be found sitting in the central atrium. The layout of each unit was identical and comprised a central corridor off which lay the bedrooms. Each resident had their own bedroom. Outside each was a picture box holding photos and visual reminders for the resident. All the rooms were individually furnished, each had a profiling bed, unless the family had requested otherwise and all had en-suite facilities comprising a toilet and wet room. There was also a separate bathroom on the unit with a specialised bath, together with a sluice room and communal toilets. At the end of each unit was a lounge with numerous armchairs, a large television, music system and activity items including books, magazines and puzzles.

There was a further seating area for the residents adjacent to the carer's station, where all information concerning the residents was kept. The corridors had recently been redecorated and along the walls were numerous paintings, as well as photographs of activities and day trips, including residents past and present. Each unit had its own dining room, which included a small kitchen area with fridge, microwave, tea making facilities and toaster. Breakfast was prepared here, with the remaining meals prepared in the main kitchen and sent up on a trolley. As the care home was part of a non-profit making organisation, profits were ploughed back into the care homes. The previous year the manager had been given £80,000 to spend on capital improvements, which had included refurbishment of the main kitchen, new carpets, curtains and furniture in all the rooms, provision of profiling beds for all rooms, as well as refurbishment of the reminiscence room.

Activity

Activity was regarded as an important part of the resident's day and took place both on and off the units. Informal activities such as exercise, singing or playing games were organised and led

by the staff on the units. Formalised activities such as dances, parties and demonstrations would take place in the central atrium. These were organised and run by the activity co-ordinator, who also spent much of the day working with residents on the individual units. The care home was heavily involved with pet therapy and there were a large number of animals at the home including: rabbits, guinea pigs, cats, chickens and birds.

Staff

When the study commenced the manager had been in post for three years. She had worked for the company for a number of years and had been brought in to improve the care home. She had a wealth of previous experience, working first as a registered nurse and then as a manager in the care home sector for over 25 years. She was supported by 100 care staff, of whom 60 were permanent staff and 40 were employed on the bank, working as needed. There was an administrator/bursar who supported the manager in the day-to-day running of the home, as well as domestic and laundry staff, a chef, kitchen staff, a maintenance person and the activity coordinator. A number of the permanent care staff had worked in this care home for many years. This was particularly true of the team leaders and one had been there since it opened over 10 years previously. The professional backgrounds of care staff were varied and included education, retail, office work, teaching and factory work. Interestingly, a number of the care staff were RNs, mainly from overseas. Although this data was not formally gathered, the majority appeared to have come from the Philippines.

Qualifications and training

In terms of qualifications, 97% of the care staff had either an NVQ level 2 or 3 qualification in social care. All team leaders held an NVQ level 3, which was a prerequisite for this role and some were studying for an NVQ level 4. Mandatory training for care staff included: protection of vulnerable adults, health and safety, fire safety, moving and handling, infection control, a one day first aid course and control of substances hazardous to health. These were all undertaken annually. Other training available to the staff included a one day and four day dementia awareness course, mental capacity act training, food hygiene, food nutrition, training in use of the malnutrition universal screening tool, dietary needs, medicine administration, safeguarding adults, care planning, managing challenging behaviour and person centred care. Care staff also had access to additional training provided by the local NHS trust, local authority and voluntary organisations such as the Alzheimer's Society.

Staffing levels

In terms of staffing levels there were always at least 13 care staff on a morning and afternoon shift and 6 on a night shift. This comprised two carers on each of the units morning and afternoon, together with a team leader in the office each shift, who would act as a floater if needed anywhere in the care home. There was one carer on each unit overnight, including one who was a team leader. There were no formalised staff/resident ratios; instead these were based on dependency levels and skill mix. So for example, if there was a new member of staff

they would initially be supernumerary, with the floater making up the numbers. The dependency levels were reviewed monthly as part of the residents' monthly reviews. Permanent members of care staff were assigned to one unit to ensure continuity for both the residents and their family, but would move between units if needed. They acted as a key worker for up to three residents on their unit and in this role were responsible for the monthly reviewing of the residents' care plans and monitoring care provision.

Residents

The care home was home to 60 residents, all of whom had a diagnosis of dementia. This number did fluctuate, with 6 residents either already in, or admitted to, hospital during the period of familiarisation. The profile of these residents appears typical of the residents living in residential care homes today, as shown in Chapter 2. The residents were mainly women. In terms of age, residents were reportedly getting older, with the majority admitted in their 80s or 90s. High levels of healthcare needs and dependency were reportedly present, an issue that will be discussed later in the chapter. Although ethnicity of the residents did not reflect the wider population of the local authority, as nearly all residents were white British.

Inspections

The quality of the care was continually monitored and regular inspections were conducted by their parent organisation and the local authority, in addition to those carried out by the CQC. The parent company required monthly quality audits, together with a large quality audit every six months. There was also regular auditing of the residents' care plans, the mealtime experience and medication, as well as health and safety assessments. The parent company also conducted a yearly unannounced quality audit. The pharmacy supplying the home conducted a medication audit every six months. As the home had a contract with the local authority, they carried out regular monitoring, together with a yearly inspection.

Regular inspections were also carried out by the CQC. An unannounced inspection had been carried out in 2008 prior to the study commencing, when the care home had been awarded a 'good' or two star rating. The next unannounced inspection had taken place in 2011, following a change to the grading and inspection process. At this time the care home was found to be fully compliant on all five outcomes on which they were assessed. The inspection report from 2008 commented that, following the appointment of the present manager, the management of the care home had greatly improved. It was noted that staff members were now working as a team and that training was being implemented. It also went on to report that 'the residents were receiving personal and healthcare support using a person centred approach' and as a result 'the residents' dignity, rights, independence and respect were maintained at all times'.

Having described the case study site the next section will describe the level of complexity that this care home and their staff were reportedly facing. It will also describe how, as a practitioner researcher, my eyes were opened and I had to acknowledge that, as a district nurse, I had little real idea of the challenges, or the complexity that care staff were routinely dealing with.

Level of complexity at the case study site

As previously described, interviews conducted with the manager and members of the care staff, together with documentation and reflexive field notes provide the data for this chapter. Prior to undertaking this study my knowledge of care homes had developed through my limited involvement with care homes as a district nurse and from what I had read in the literature. This limited knowledge contributed to a number of surprises that I experienced on analysing the data, often a result of assumptions, or preconceptions that I held, being challenged. A number of issues were of particular surprise (Figure 3) and are summarised as:

- Level of need and degree of complexity present
- The added complexity that dementia brings
- Level of healthcare skills needed by care staff
- Level of healthcare support needed by residents
- Dissatisfaction with the care home/district nursing relationship
- Funding pressures

Level of need and degree of complexity

The reflexive field notes recorded a growing realisation on my part, of the degree of complexity reported in the residents, in terms of both their healthcare needs and the level of care required to ensure these needs were met. Working in district nursing for over 19 years I recognised that the residents in residential care homes had changed greatly over the years and had become more dependent. However, I began to realise that as a district nurse I had not given these changes much thought and I certainly had not considered the impact of such changes on the care homes themselves. As the following field note recorded:

> .....What is beginning to dawn on me is the level of need and the degree of complexity that is present amongst many of the residents that these staff are caring for. I was aware from previous experience that they are looking after increasingly ill residents, but I really hadn't thought about what this meant in practice. And I certainly hadn't fully appreciated the level of needs that are present, until I was able to spend this time in the care home. Because of this opportunity I am realising that they are looking after people with truly complex needs. Yes, a number of them are mobile and able to feed themselves, but actually all reportedly need support in some form or another and some need assistance to meet all their care needs. And it certainly isn't limited to only physical needs; the care staff are being asked to provide complex psychological and social support too…..FN 080, p317

Co-morbidity and complex needs were apparently common amongst the residents. Whilst all of the residents had a diagnosis of dementia, many also reportedly had multiple long-term conditions and health problems, adding to their healthcare needs. Conditions included: Parkinson's disease, cancer, stroke, arthritis, hypertension, heart disease, diabetes, bladder and urinary problems, depression and general frailty.

Figure 3: Reflections from the case study site

Hierarchy diagram:

The level of complexity at case study site

Branches:
- Level of need and degree of complexity
- The added complexity that dementia brings
  - Importance of 'knowing' the person
  - Difficulty providing care
- Level of healthcare skills needed by care staff
  - Dealing with complex healthcare needs
  - Benefits from access to healthcare training
  - A hidden workforce
- Level of healthcare support needed by residents
  - Accessibility of healthcare support is good
  - Accessibility of GP support problematic
  - Benefit of specialist support
- Dissatisfaction with the care home/district nurse relationship
  - Reluctant to criticise
  - Dissatisfaction with the service received
  - Ignorance of district nurse role
  - The service offered needs to change
- Funding pressures
- Ignorance - reflections of a practitioner researcher

A result of such co-morbidity was that the care staff appeared to be providing care that didn't differ much from the type of nursing care carried out on hospital wards when I worked there. A sentiment echoed by the manager who stated '*there is a very, very fine line between nursing and residential'* care (CHM, I, 5). For example care staff were reported to be carrying out nutritional, risk and continence assessments, and in order to manage the healthcare needs they were faced with were receiving training in regard to tissue viability, recording of baseline observations, mouth and eye care, management of constipation and end-of-life care.

High levels of dependency were perceived to be present and needs could constantly change. It was reported that residents required support in terms of their mobility, with some immobile, wheelchair bound and requiring hoisting, necessitating the presence of two carers when providing any care. Over half of residents were supplied with continence pads, suggesting some degree of incontinence, many reportedly required regular toileting, and a small number were catheterised, something that in the past would have necessitated transfer to a nursing home. In terms of nutrition the manager reported that as residents were admitted later in their disease process malnutrition, weight loss and pressure sores were not uncommon at time of admission. Residents often required input from dieticians and/or the speech and language (SALT) team due to nutritional problems, or swallowing difficulties. Many residents reportedly required support with fluid and food intake. Even when no physical assistance was needed there was still a need to monitor their nutritional intake and to prompt residents to eat and drink. Increasing levels of need and dependency could be the result of the care home caring for residents for as long as they could because the care home was their 'home', and the manager would only seek to have them transferred to a nursing home as a last resort if their needs simply became too great for them to manage:

> *…..but when it is something acute….or anything like that then we can't. End of life we manage, but then that is supported with the palliative care team and that is brilliant because it is lovely for the residents to die here, because it is their home. But then when you have got somebody acutely ill, they are not weight bearing, they are rigid, they need more allegedly more nursing input then we can't keep them here, if it is identified…..P23 CHM, I, (3)*

The added complexity that dementia brings

Coming from a general nursing background I have, over the years, had very little experience of working with people living with dementia. The opportunity to spend time in a care home specialising in dementia care gave me greater insight into the care needs of this group of residents, the challenges facing care staff when caring for them and the extent to which dementia was adding to the complexity that was present. These challenges are summarised as:

- Importance of 'knowing' the person
- Difficulty providing care

Importance of 'knowing' the person

Meeting the care needs of residents living with dementia appeared to be a challenge, with many residents reportedly losing the ability to communicate verbally. In the early stages of the disease residents were able to tell care staff if there was a problem, but as the disease progressed communication would reportedly become more of an issue. Understanding what a resident is trying to say was dependent on the person working with that resident having a good understanding of them as a person. The care staff described this as 'knowing' their residents. They spoke of being able to read and understand a resident's non-verbal cues and behaviour and as a result could respond appropriately to what they saw. All of the care staff who I spoke to and interviewed described the importance of having such knowledge, especially when it came to managing the healthcare needs of that person. Often there would be no obvious signs that a resident was unwell, just a slight change in behaviour, which could suggest that something was wrong. It was these signs that care staff were able to pick up on, as they knew their residents so well and they would monitor them more closely. As a practitioner I began to appreciate the importance of having such in-depth knowledge of the person living with dementia. Also, more importantly, I began to question whether as community nurses we ever possessed such knowledge, or if it was even possible given the nature of the service we often provide:

> …..you really have to make the effort to talk to these residents. This is something that I have never really done in the past especially in one of the homes that I visit, where many residents have dementia but often we are just in and out. So how, if we don't spend time with them and we don't know them, can we really know or understand if there is anything more that is wrong with them? It really makes you question how we are approaching the residents who do have any cognitive impairment. I remember a chap in one care home who had cancer who we used to visit each month to keep an eye on. I would go in and sit by him and try to talk, but I found it very difficult and so was glad to go after about five minutes. But how much was I really getting from him? There needs to be a realisation that there is more to meeting a person's needs than concentrating solely on their physical problems…FN 003, p14

Yet I was not alone in failing to appreciate the benefit of such in-depth knowledge. One team leader expressed frustration that healthcare professionals did not recognise the importance of such knowledge and care staff would, on occasion, have to try and convince these professionals that the resident was unwell, or there was a problem.

It was also reportedly getting harder for care staff to get to know the residents. This was attributed to a number of factors. Firstly, government policy aimed at keeping people in their own homes for as long as possible meant residents were not admitted until much later in their disease process, often with limited verbal communication skills. An ageing population had resulted in many more admitted who had outlived family and friends, so little background information was available, as was the case for those admitted for respite care. As a result it

could now take care staff weeks to get to 'know' and understand the resident, as the manager explained:

> *..…it is like a tree, you have got the base and you know who they are, what age they are, yes you have got to care for them, you have got their diagnosis and everything else but then you have got to branch that out, open it up…..and sometimes you know it, sometimes it doesn't happen and they might pass away for some reason or another before getting all the actual details. So yes it is hard for us…..P23 CHM, I, (5)*

Difficulty providing care

I was also able to gather some insight into the difficulties and challenges facing the care staff when providing care to residents. As mentioned previously care staff were reportedly dealing with a wide range of complex care needs, especially amongst those residents with advanced dementia, as this participant explained:

> *…..it is the way they change drastically every day. Because they are ageing from day-to-day, you are used to her having one particular way of doing things and then the next day you are coming back, seeing her changing into another way of life. So it does take you time to understand the new nature of like the way she talks, the way she answers…… and before she could understand but the level of her dementia is going higher, she can't really communicate her needs……and for you to get exactly what you need to do for her to feel comfortable and happy. You have to be more patient and try to study her and look at her means of communication, to get her settled and give her….like it is really difficult to get exactly what is wrong because she can no longer communicate her needs to you….it is really hard….P44 FG, CS*

Providing care was said to be demanding, with care staff dealing with residents who required support with all activities of daily living, yet who could refuse care, for example personal care, or to eat or drink. Needs were often not the same two days running. As a result care staff had to be flexible and continually adapt their care practices, adding yet another layer of complexity to their working day. As a person's dementia progressed increasing support was also needed from a wide range of healthcare professionals to enable care staff to meet their changing needs.

Level of healthcare skills needed by care staff

I was surprised by the level of knowledge and skills, including healthcare skills, which many of the care staff in this home possessed, being far greater than I had anticipated. Summarised as:

- Dealing with complex healthcare needs
- Benefit from access to healthcare training
- A hidden workforce

Dealing with complex healthcare needs

The high levels of healthcare needs present meant that care staff were providing care that would, in the past, have been considered to be the responsibility of a qualified nurse. For example: carrying out simple dressings, changing catheter bags, checking blood glucose levels and carrying out urinalysis, although it should be noted that much of this work was only carried out by the team leaders. Care staff were reported to be caring for residents who could have swallowing difficulties, including some who required risk feeding, which carried with it the risk of choking or aspiration. They were also increasingly involved in the provision of palliative care, a result of residential care homes being encouraged to continue to care for residents as they approached the end of their lives. In addition they were also performing an assessment and monitoring role. With team leaders recording baseline observations and carrying out incontinence assessments and all care staff involved in maintaining fluid and food charts, weight charts, recording Waterlow Scores monitoring risk of pressure sore development and monitoring risk, including falls risk, moving and handling risk and nutritional risk.

However, the care staff were not simply meeting physical needs. They also spoke of dealing with complex emotional and psychological needs present amongst many of the residents. Participants reported dealing with residents whose levels of confusion and mood could, as a result of their dementia, fluctuate markedly throughout the day. Or whose behaviour could suddenly change, especially if faced with an unfamiliar environment or carer, becoming agitated, or even on occasion reportedly aggressive towards staff, as well as other residents.

Care staff also had to deal with the demands and needs of family and friends of the residents, dealing with relatives who could at times be unrealistic, hostile, aggressive or even on occasion abusive. As in this example given by the manager:

> *….. A daughter is asking for the GP to come and see her father who has a bruise on his hand. He used to be a boxer so if he don't like it he says come on then and puts his fists up. The other night he knocked the TV off the side when he was getting up to go to the toilet, he may have stumbled and caught it and knocked it on the floor. But when the daughter was told what had happened she wasn't having that and didn't believe them……She comes in and starts swearing at the staff……People often seem so hostile these days. They are bullies some people but they upset the other families at the same time. The staff are also on edge all the time, even the GP. It is hard for the other relatives as they say it is hard enough to bring their family member in here without having to listen to someone being so rude…..P23 CHM, I, (1)*

All of which gives an indication of the level of skills required by a member of care staff and the demands that can be placed on them.

Benefit from access to healthcare training

It appeared that the care staff were able to manage many of the healthcare needs they were faced with as a result of the healthcare training they had received from staff from across The Trust. This training was varied and included: end-of-life care, recording of observations such as BP and pulse, blood glucose monitoring, management of diabetes, management of continence, management of constipation, basic wound care and pressure area care/management. However, even when care staff had received healthcare training, managing such needs could still prove to be a challenge, with care staff lacking, at times, the confidence to deal with the healthcare needs they were faced with, and highlighting the importance of care staff being well supported by healthcare professionals:

> …..care like is everyday learning…you have been taught how to do this care today. Tomorrow because this situation is changing you have to update your skills and knowledge to meet the new standard of care that the person needs…..But when the changes is there and the training is not there to meet that need we tend to think as if we are doing the right thing with our own knowledge but sometimes it is not really right, we will think we are doing the right thing but we are not…… P44, GI, CS

A hidden workforce

It appeared that I was not alone in underestimating the knowledge and skills of care staff, as frustration was expressed by a few of those interviewed that care staff were not seen as professionals in their own right. As this participant explained:

> ….. they do work somewhere else as well. So they have different skills on a different side. So not all the people know this carer, they think he is only a carer but somewhere else he works as other things….The caring job, maybe he is just a carer, but beside that maybe he has other skills, who knows…..P39, GI, CS

It was suggested by some care staff that the skills and knowledge they possessed were often ignored by healthcare professionals, especially the knowledge and experience they had in caring for people living with dementia. This appeared to be especially frustrating for a couple of the team leaders, who had undertaken additional training, yet commented that all too often they were seen as '*just a carer*'. Such frustration could be understood when one looked at the qualifications held by the participants. The manager was an RN, held the Registered Managers Award (RMA) and was in the process of undertaking a diploma in dementia care. The two team leaders interviewed both held NVQ level 3 qualifications. One also had NVQs in communication and infection control, whilst the other had an NVQ in dementia care. In terms of the care staff who took part in the group interview, the team leader had an NVQ level 3 and was also an NVQ assessor. Of the remaining staff two held nursing qualifications, four held NVQ level 3 and two NVQ level 2 qualifications and only one had no qualifications of any kind.

I had to question further my assumption that the workforce in a residential care home would be largely unskilled, when during my time in this care home I became aware that there was in fact a hidden workforce of RNs working as members of the care staff. Three of the participants who were interviewed were qualified nurses and according to the care home manager there were between 15-20 nurses working in the care home. This was not something that I had expected to come across. The majority had trained abroad, predominantly in the Philippines, and most were working as carers whilst undertaking the Overseas Nursing Programme:

> ……And the biggest thing is it is their eyes and their opinions and their knowledge………when you have got a staff team it is so important to have people that have different skills and for me what has been brilliant for me on my bank is the bank Filipino staff. That have come over to this country and do an NVQ 3, but however, they have been a qualified, probably a senior nurse back home…..So they are brilliant to have here because of their knowledge, they are first class…..But I think for care homes, especially where we get residents with such complex needs it is so great to have somebody on that is…on the ball is the word. And that has awareness….are more use to talking to other professionals and also they will stand their ground…..when you see somebody else actually challenging that has given…..given them an added bonus to challenge. So that does help…..well train my staff up…....P23 CHM, I, (4)

The protocol covering residential care homes does not permit a nurse to work as a nurse practitioner in the care home and any nursing care needed can only be provided under the direction of a district nurse. Yet it would seem naïve to assume that these nurses are not using their knowledge and skills in one way or another. In fact this account given by the manager demonstrates that these particular staff members had indeed brought with them additional skills which were benefiting other care staff, as well as the care home itself and were in fact highly valued by the manager, given the complex needs her care staff were faced with on a daily basis.

Level of healthcare support needed to manage residents

As a result of the complex needs present amongst residents in this care home it became apparent that to manage their needs effectively required access to an extensive support network of healthcare professionals. This support is summarised as:

- Accessibility of healthcare support is good
- Accessibility of GP support is problematic
- Benefit from specialist support

Accessibility of healthcare support is good

From my background reading I was under the impression that the care home could be receiving limited healthcare support. However, during my time at the case study site I was surprised to discover the level of support that the care home was easily able to access. They were

supported by a wide range of healthcare professionals, many of whom were accessed on a regular basis. Those visiting included: a community matron, dieticians, physiotherapists, occupational therapists (OTs), speech and language therapists, a community psychiatric nurse (CPN), a Macmillan nurse, diabetic nurse specialists, chiropodists, dentists and opticians. Given the high levels of needs present, some residents were receiving input from multiple healthcare professionals:

> …..we put a case to the GP…we have tried moving and handling and we have proved to them that this is what is needed now, if we need further input from the specialist in that field then they do a referral and that goes to the domiciliary and the physios come out. We also have the same with speech therapists, the SALT team. It all has to be done by a referral from the GP…...We have got a lady at the moment…..she has the SALT team, speech and language is involved, physios and the dietician…....P23 CHM, I, (2)

In terms of district nursing support they were served by one district nursing team. At the time of the study this team was visiting residents at least twice weekly, although this could fluctuate greatly depending on the needs of the residents and in the past daily visits were not unusual. The working relationship the care home had with these nurses will be discussed in more detail later in the chapter.

Accessibility of GP support is problematic

The care home was also served by three local GP surgeries. However, the relationship they had with all three surgeries appeared to be strained at times:

> …..we call them out on Monday for a couple of residents, maybe they come in Tuesday morning and it is reported to me maybe overnight this person wasn't well and we know that it can't wait, so you have to call them out and it is like you called us yesterday and now you are calling us out today again….P24 TL, I

Given my own experiences as a district nurse of working with certain surgeries, I was not really surprised to find that accessing support could prove difficult on occasion. Although it was of concern how difficult they could find it, with issues reported such as reluctance on the part of GPs to visit residents in the care home, failing to turn up when a visit had been promised and staff being questioned as to whether visits were actually necessary. This particularly angered the manager, as did the surgery that had asked the community matron to visit every week to assess the residents, as they felt the home was requesting too many visits, which the manager suggested left the care staff 'feeling humiliated'. The manager also reported that it was becoming harder to register residents with local surgeries as there was reluctance on the part of the GPs to take on increasing numbers of new residents.

Benefit from specialist support

Due to the particular healthcare needs of the residents, the care home was able to access additional support from the local dementia resource centre. The care home also had a close relationship with the community mental health team. Whereas previously when a resident was admitted the CPN would stop visiting, this had changed and they would now continue to visit that person, providing the care staff with additional support. However, what appeared to be of particular benefit was the access the residents had to specialist support, in the form of two hospital consultants:

> *…..So you have got continuity from when they have been in hospital, they have come in here, so then it is just like having, being shadowed……families are also now coming to meet with them. We had one last week and it was very, very good, because out of it 2 residents have been referred back to the psychiatrists because they feel the medication isn't correct. Because we have done all the underlying….infection nothing…so then obviously there is medication that is causing it. So it is like an audit trail and the main thing out of all of it is that person is still here. So he is not being pulled from pillar to post. Because if you take somebody out of this environment you are not going to see the true picture…that is also the value because when they are out there they panic…..They get the continuity and it is a thorough check up………..But also the consultant psychogeriatrician is here once a month and that is so important because no one here is on any medications to dope them, no anti-psychotics nothing because it is about managing behaviours…..P23 CHM, I, (4)*

One consultant was a geriatrician and the other an old age psychiatrist and each were visiting on a monthly basis to review any residents who there were concerns about. As the above account demonstrates there were obvious advantages to this support, which had resulted in a proactive approach to care. Residents were regularly reviewed within their own environment and care staff who knew the resident well were also encouraged to attend these meetings, resulting, the manager believed, in a reduction in hospital admissions.

Dissatisfaction with the care home/district nursing relationship

It was suggested by participants that, on the whole, the relationship they had with the community nurses was a positive one. However, it became apparent during interviews and analysis of data, that there was, in fact, an undercurrent of dissatisfaction with the service they were receiving, summarised as:

- Reluctant to criticise
- Dissatisfaction with the service
- Ignorance of the district nurse role
- The service offered needs to change

Reluctant to criticise

Data from the interviews with care staff suggested that they had good relationship with the community nurses. With the manager in particular using phrases such as '*I have got some good nurses*', '*they are all nice girls*' and '*I have got great admiration for her*'. When questioned about their experience of working with the service the experience was reported on the whole as being a favourable one. Although interestingly the care staff in the group interview said that they had little interaction with the community nurses, leaving the team leaders to communicate with them. There appeared to be reluctance on the part of care staff to criticise the service, as the following field note recorded:

> *…..This interview was interesting, but it was only afterwards that they were more*
> *critical of the service. Expressing concerns about what would happen for example*
> *as a result of all the cuts that were happening to the district nursing service, as time*
> *was already a significant factor and they were aware that the nurses were already*
> *so busy and they have so many people that they need to visit…..FN 17, p158*

Their reluctance could, in part, have been a result of the researcher being a district nurse herself. Although, as the above account demonstrates, whilst this participant stated during the interview that '*I can't complain about the service*', interestingly once the interview had finished they were more willing to express negative views of the service the care home received. This was equally true of other participants who would give the impression of being satisfied with the relationship and/or service; however, when prompted further, would often reveal issues they had with the service and/or the attitude of the nurses. For example the manager made mention of the fact that on occasion nurses could be critical of both the care home and the care given, questioning why care had not been given. She also cited the example of one nurse who would come in and say '*this is not good enough*' leaving the care staff reportedly feeling unsupported.

Dissatisfaction with the service

Dissatisfaction was expressed by the participants in regard to a number of issues, summarised as:

- Community nurses ignorant of care staff role
- No time to spend
- Nurses have little understanding of dementia

Community nurses ignorant of care staff role

One issue that appeared to be causing conflict was community nurses expecting care staff to provide care that went beyond their remit. All participants were very clear about the 'nursing' care they were permitted to provide. Yet friction could arise as a result of community nurses assuming that care staff were able to provide certain care, as this team leader explained:

> *…..they do expect us to do more, which we aren't allowed, we can't go over that….*
> *there are some things that you need a district nurse to come in and do and they*
> *come in and they say but you can do this and we say no, I am not a district nurse. I*

might put the wrong dressing on and then it will escalate, become a big thing…..but
you are the district nurse, you know the difference between the dressings and all
that…..so we have to get you guys to come and do it…..P24, TL, I

I was surprised to discover that the care home had a policy entitled 'Nursing Care Procedures' clearly outlining the 'nursing' care that they, as a residential care home, were able to give, as this was something that I had never been aware of before. It set out a number of what were termed 'minor nursing tasks/procedures' that a district nurse could pass over to the care staff such as: blood glucose monitoring, renewal of a topical dressing as part of on-going wound care, instilling of eye drops/ear drops, administration of Insulin via syringe/pen and taking and recording of baseline observations.

This guidance was equally explicit about the responsibilities of the nurse when handing over such care, something that, once again, I, as a district nurse, had never been aware of before. It recommended that care staff be given appropriate training from the professional devolving responsibility and that their practice be assessed to decide whether they were competent to undertake the task. There was a requirement for a care plan giving detailed care instructions to be drawn up and reviewed regularly and finally, the professional was to be available for support and advice at all times. However, with the community nurses assuming that the care staff could provide any care asked of them, it could suggest that the nurses associated with this care home were also unaware of the existence of this guidance.

It is understandable that nurses may be confused about the carers' role as what became apparent from the group interview, was that the role of care staff is not clearly defined and may vary between care homes. Interviewees who worked on the bank mentioned that the type of care they were able to provide was dependent on the particular care home. For example, one member of care staff spoke of being permitted to dispense medication in another care home, yet in this care home it was only team leaders who were able to perform this role.

No time to spend
In terms of dissatisfaction with the support received from the district nursing service there were a number of issues raised by the manager. These often came as a surprise to me as a district nurse, because they challenged the service that I, as a district nurse, would have expected to be given. The first was the perception by the manager that, since the introduction of a new referral process, gaining access to the district nursing service was harder than it had been in the past. I was surprised to discover that some community nurses were reportedly refusing to see a new resident until a written referral had been received by the service, even though they were visiting other residents at the time. I was equally surprised to learn that some district nurses were reportedly reluctant to visit the care home on a daily basis, as this field note reflected:

….One issue seems to be that if the district nurses are not happy to visit every day
to dress a wound then this has some influence on the resident being moved on. I
find this strange as my team has cared for a number of residents in care homes

123

who have required daily dressings but having them moved has never been an
issue for us and we go in as a team as often as we need to…..FN 004, p20

On occasion community nurses had, according to the manager, expressed the view that a resident should be transferred to a nursing home if they needed daily visits from the service. She was concerned as her staff were quick to pick up on comments such as these, believing that the resident should be moved if the nurse said so. Yet what I was growing increasingly aware of was the ethos of the care home, which was that it was that person's home and as such, a resident would only be moved as a last resort, when the manager felt that they, as a care home, were no longer able to meet that resident's needs. Such issues, it was suggested, were arising due to pressures on the district nursing service, which resulted in the nurses having limited time to spend in the care home:

…..I don't know if it is me, but I just think that it seems a lot of their time is being
withdrawn and it is just rush, rush, rush. So when they come in here they have got
an amount, I mean this is assumption, or observation, but I just think that they get
so many a day and they haven't got the time to actually spend…..P23, CHM, I, (3)

I found it sad that as a result of these pressures, the care home manager appeared willing to accept that residents were less important than patients out in the community and to accept, without question, that they would be prioritised over their residents. A situation not helped by the community nurses themselves. I was talking with the manager when one district nurse almost immediately upon entering the care home told them how busy she was that day. Afterwards I reflected with the manager the impact that such a comment could have. It may have been said with little thought given. Alternatively it may have been that nurse's way of preventing any further problems being passed on to her. Whatever the reason though the result could be the same, with staff in the care home reluctant to ask for additional help or support from the 'busy' nurses.

I was also interested to learn that the manager had found it difficult at times to access pressure relieving equipment through the service, with nurses apparently questioning why, as a residential care home, they weren't purchasing such equipment themselves. The manager explained that, because they only provide personal care, the level of fees paid do not cover the purchasing of such equipment. She also commented that they were not expected, or permitted, by the CQC to provide this type of equipment. Comments such as this suggested that community nurses had little idea of the policies, or guidelines, governing residential care homes. A sentiment the manager agreed with, believing that nurses were generally ignorant of care homes and their ethos of care.

Nurses have little understanding of dementia
It was also suggested by a number of the participants that the service provided by the community nurses was failing at times to take into account the particular needs of residents living with dementia. As the following comments demonstrate:

…..I just think that if you take that little bit more time you could still get it done quicker. But I think when you are task focused I just find that quite harsh. Because these residents living with dementia do need the time given…..P23, CHM, I, (5)

….P41: I don't always think they are always very sympathetic towards the dementia residents

P40: And they say like they come in to do a dressing and stuff and they are asking them questions and you are standing there saying well they can't really communicate and they still you know…..oh can they answer that question and you are saying no their dementia is like this stage and they can't…..P40 and P41, GI, CS

It was suggested that certain care practices were not conducive to a resident living with dementia. These included not getting to know the residents, not helped by a lack of continuity in terms of nurses who visited the care home, expecting residents to fully comply with any care provided, which was not helped by nurses trying to rush care provision. District nursing practice was not perceived to be person-centred and lastly, there was felt to be a lack of understanding of dementia itself.

Ignorance of the community nurse role

I was surprised and also concerned to discover how little the care staff and even the manager knew about the role of a community nurse, or the service itself. As this suggested that the care home would not be in a position to get the most from the service:

…..As district nurses I know their role is just to give injections, do dressings and….they do communicate with the doctors as well when they come in…..P24, TL, I

…..because we sort of do everything, they would normally come and do the things, the basic things like dressings that we can't do…..P25, TL, I

I was disappointed, although not entirely surprised to discover that the majority of participants viewed the service as one that simply met 'tasks'. Most commonly mentioned were wound care, pressure area management, catheter care and insulin administration. Provision of support by community nurses was rarely mentioned. In terms of palliative care provision, a significant part of the community nurses' role in the community, it was interestingly the Macmillan team that the manager would approach first, as they were perceived to be easier to access. Of concern, as a district nurse, was the opinion expressed by one team leader that nurses were there simply to pick up what care staff were unable to do. This not only suggests little understanding of the district nursing service, but more importantly, little awareness of what it could offer the care home, or their residents.

Care staff were accessing much of the support they needed from the community matron for care homes, rather than the community nurses:

> …..Yes it does help when we try to get into the, you know the local GPs we find it difficult. It is like we keep calling them out, you know, so if anything since she came on board if anything we go through her and then she will then come in, do some assessment and then take the results to the GP, the GP knows that we are not just calling them out unnecessarily and then they take it up from there….P24, TL, I

The above account was one of a number revealing how this community matron was seen as a valuable resource, because she was a nurse to whom they had direct and easy access. What they appeared to value was a nurse who they could contact at any time to ask for advice or help and who could support them in dealing with other healthcare professionals. Although, as with the community nurses, the relationship with the community matron was not always straightforward and there had been conflict on occasions, in particular when the manager felt that her authority in the care home was being usurped.

The service offered needs to change

Interestingly, the manager, who had over 25 years' experience of working in the sector, had no recollection of ever being asked about the type of support, or assistance from the district nursing service that would be of help to her or her staff.

> …..I think if they had a bit of a meeting with us on a regular basis it would help and it would also tell us where we are and where they are and what things we could make easier for them and what things they could make easier for us. I think that is all to do with communication and working as a team I suppose……but like I say if they would come and do it in a person-centred approach it would be much more appreciated and if they would always give us a bit of extra information sometimes. Just instead of coming and doing the dressing and just go off. If we are there, if they show us a bit like, I mean I am not saying they don't but if they give us extra information, what things we can do and what things we can't do I think that would help both of us……P25, TL, I

As the above account demonstrates, when given the opportunity participants had a clear idea of what they would like to see offered and the type of relationship they would like to have. One suggestion made was for community nurses to have more time to spend in the care home. The manager and team leader both expressed a desire to hold regular meetings with the community nurses, as this would provide them with an opportunity to discuss any issues or concerns they had regarding any of their residents. As they both described it '*to work together as a team*'. This, it was felt, would prevent problems being missed, would encourage a more person-centred approach to be adopted and would result in the nurses getting to know the residents better. It was felt that continuity of nurses would be of help and it was also suggested that nurses should

receive more training in dementia care, as there was a feeling amongst participants that nurses, in general, lacked knowledge about dementia and the needs of people living with this condition.

Funding pressures

Finally, following the interviews with the manager I realised that I had little real appreciation of the financial pressures facing care homes, which appeared to be adding to the challenges they faced. I had little awareness of the level of fees a residential care home received, or what these fees actually covered and it came as a surprise to discover that this care home was receiving only £568/week from the local authority. This is not as high as one might expect given the services they were expected to provide from these fees, which included: staffing costs associated with the provision of 24-hour care, accommodation, heating, lighting, meals, laundry, as well as other facilities, including the funding of training. Even more surprising was that they had only received a minimal increase in funding each year, as they were tied into a block contract with the local authority for 30 years. Whilst this contract meant that the cost of any empty bed was met by the local authority, the down side was that any additional expenditure such as extra staffing then had to be borne by the care home:

> *….. you do look at the most important thing staffing because you might have to have one that needs one to one and you do have to charge more, you can't absorb it. In the past where I was before you could go back to the local authority and say this person needs more and they would pay it, but because here it is under the contract we can't do that, we can't charge extra, because they do pay for your voids, if you have got a bed empty they still pay for that. But also as soon as they know you have an empty bed they fill it, or you can put respite in it, but what I do is if I have an empty bed and I have someone who is private they allow me to bring that one in which does help my income, I can give that little bit more back to my staff. I can give more training…..and I can put it into activities for the residents, training for my staff. We also charge the hairdresser 10% of what they earn because she uses my electric, we do all the washing, we make £24/week from that but it is money that goes in the pot that I can actually, and residents gain from. Yesterday we had an owl display which cost about £70 for 2 hours…..P23 CHM, I, (1)*

The above account gives an indication of the financial pressures faced by the manager and could explain why she was annoyed that there was a widely held belief that care homes were well funded. This certainly did not appear to be the case. In fact it was shocking to learn that there had been no increase at all in the level of fees paid by the local authority that year, at a time when all other costs were rising significantly. An additional drain that I had been unaware of was the cost of training, with the care home expected to fund all training, apart from NVQs, as well as fund cover for staff attending training. This had resulted in the manager actively seeking out additional funding sources.

Ignorance – Reflections of a practitioner researcher

The period of familiarisation, together with analysis of the data from the interviews gave me the opportunity as a practitioner researcher to reflect on and question what I really knew about the challenges facing a care home and their staff; providing me with a better understanding of the complex nature of the care needed by residents, as well as the challenges faced by care staff on a daily basis. What gradually dawned on me was that, as a district nurse, I held a rather simplistic view of care homes and I was actually ignorant of what could be considered to be the level of complexity faced by a residential care home and their staff:

> ….When I entered the care home I had assumed from reading the literature that there would be lots of obvious identifiable healthcare problems. Rather naïvely I thought that all that would be needed would be for district nurses to get a little more involved, problems would then be picked up and dealt with and that would be all their problems sorted. That was so simplistic and actually not what was needed….The residents had good support from the GP and also the hospital consultants and were regularly monitored. But there were still some practical issues and staff needed guidance on care, or had not picked up on small issues. What they don't need is someone who comes in and does things to the residents and then leaves, but someone who will help them to monitor residents, monitor them in ways that they are unable to do. A role that is proactive, not waiting to be called in when the problem has arisen, but who monitors and works with the staff to pick up on problems…..RD 039, p324

From the case study I gained a greater appreciation of the demands that care staff were reported to be facing. The population in the care home had changed greatly as a result of government policy, discussed previously in Chapter 2. Care staff were reportedly managing high levels of co-morbidity, dependency and needs, including complex physical, psychological, emotional and social needs. Care provision was made harder as a result of needs that could constantly change, as well as unrealistic demands or pressure placed on staff by family, friends, or healthcare professionals, who often had little understanding, or appreciation of their role. To manage such needs required increasing levels of knowledge and skills, especially around the management of healthcare needs. Staff were given access to a wide range of training opportunities however, the provision of training had financial implications for the care home manager and there was no guarantee that even after training staff would have the confidence to deal with healthcare needs. Funding pressures also appeared to be placing further demands on this care home. I had assumed that the care staff would largely be unqualified or unskilled however, in this care home that certainly was not the case. Many staff had developed extensive knowledge and skills, having worked in the sector for years. In addition RNs were found to be working as members of the care staff. Although national policy prevented them from providing nursing care, their knowledge and skills were still being used to the benefit of residents. Ready

access to healthcare support was needed to manage the levels of needs, but was not always available.

It also became apparent that the service offered by community nurses did not appear able to meet all the needs of the residents, or care staff, as a result of pressures on this service and that there were issues in regard to the relationship between the two services, issues that were not always voiced. Guidelines were clear about what 'nursing' care could be undertaken by care staff, yet community nurses appeared unaware of this guidance, resulting in unrealistic demands placed, at times, on the care staff. I was surprised to discover that the district nursing team was sending in healthcare support workers (HCSWs), who are of a similar grade to the care staff, to provide some of the nursing support as this was something that I as a district nurse would not personally do. What also surprised me was the lack of understanding by either service of each other's role and/or responsibilities. Suggesting that the care homes may not be in a position to seek the support needed to manage their residents and the district nursing service may not offer the level of support needed:

> ….I used my time in the first care home to get a better idea of what happens in a care home. Although I was a novice researcher the reality was that I was also a novice when it came to care homes. I had always seen them through the eyes of a nurse. Not understanding what was happening to them, how they were being forced to change, being quick to criticise when problems occurred, questioning why they hadn't picked something up. Spending time in this care home has opened my eyes and given me a better understanding of their side of the story, the level of complexity that they are dealing with and because of this I have to be more supportive of them, to find out and offer them the type of support that they actually need, not what I think they might need…..RD 036, p312

Of particular benefit to me as a district nurse was the understanding gathered of the needs of residents living with dementia. I had little previous experience of working with patients living with dementia and as the field notes reflected at times I felt '*out of my depth*', '*uncomfortable*', or found it '*difficult*' when talking with residents. Through this experience I believe I gained a greater understanding of the importance of looking at the whole person, not concentrating solely on physical problems. I also gained an understanding of the level of support that is needed from a range of healthcare professionals, as well as changes that could be made to district nursing practice, which could improve care provision for this group of residents. This opportunity also gave me the knowledge to question if the service community nurses were providing to the care homes and these residents in particular was fit for purpose. Such a reflection was recorded in the following field note reflecting on a situation with a patient living with dementia who my district nursing team had been visiting at home and who had suddenly been admitted to hospital:

> …..When talking to the daughter I felt guilty that we had let this lady down in some way and would need to learn from this experience…. This is all new to us and we

have a lot to learn, but it shows how we all need to work together and to support the family who may not have the necessary skills either……I am beginning to appreciate how complicated it can be caring for a person with dementia and how mental and physical problems are so closely intertwined, that they can't actually be separated and we need to be thinking about trying to care for both. But do any of us have all the skills, or do we all need to be thinking about how to work better together…….looking at the whole picture…..FN 012, p111-112

Summary

This chapter has presented findings from the case study giving an idea of the day-to-day care needed by residents and the demands facing care staff in managing this care, which often appeared to be complex in nature. It has also revealed how as a district nurse I was both surprised by and ignorant of what could be considered to be the level of complexity faced by a residential care home and their staff. Many of these findings are not new. High levels of co-morbidity, need and dependency have been reported over the years and it is known that dementia is having a significant impact on all types of care homes. Healthcare support is known to be patchy when it comes to supporting care homes and care home staff can face an uphill battle to access the support that they require. But what this case study has shown is that if a care home is able to access a wide range of healthcare support, including specialist support and care staff have access to both health and social training, then it is possible for residents to be well supported and cared for. However, to ensure that care staff are well trained requires sufficient resources and the level of funding care homes receive remains an issue. It also revealed that RNs are to be found in these care homes, working as care staff, yet bringing with them additional knowledge and skills that benefit both the residents and the care home itself.

What this chapter has also shown is the benefits of using self as a research instrument. Analysing the data both as a practitioner and a researcher led me to question the findings as a practitioner and what I had previously taken for granted, and to realise that as a district nurse I was largely ignorant of the complexity that was present. I also began to question the support the district nursing service was providing to the care home, which did not appear at times to be sufficient and could even be considered to be 'not fit for purpose'. This was especially true for those residents living with dementia, who need the support of a district nursing service that offers more than the meeting of tasks, as quickly as possible. This chapter also highlighted that care home staff had never been asked about the type of support that would benefit their service, or what this support could look like. However, the findings in this case study could simply be unique to this one care home. The next chapter will explore the situation in other care homes, within the same local authority. To explore the challenges and experiences of other care staff and whether the complexity noted by the researcher and the challenges facing this one care home were unique, if they resonated with the experiences other care home staff and if there were any gaps.

CHAPTER 8: FINDINGS FROM OTHER CARE HOMES: STRUGGLING TO COPE

Introduction

This chapter also reports on relevant data exploring the experiences and challenges of care staff in managing the healthcare needs of residents and whether the district nursing service was adequately supporting them to manage any healthcare needs they were faced with. The findings in the previous chapter were based on evidence from a single case study. A weakness of any case study is transferability of the findings. In this study, in order to add strength to the findings from the case study, the experiences of additional care homes and their staff were sought, with findings compared and contrasted to those from the case study site and reflections of the researcher. To explore whether the findings from the original care home were peculiar to that one care home, or if they resonated with other care home staff and whether there were any gaps. Interviews were conducted with nine care home managers, three deputy managers (DCHM) and two team leaders from a further 11 residential care homes across the local authority.

Findings from the case study were used to direct these subsequent interviews. As previously described, an interview guide was prepared for each interview. However, it was not followed rigidly, but instead was used as an aide memoire. This encouraged the interviews to take the form of a free flowing conversation and, where relevant, allow emergent topics to be explored in more detail, e.g. the experiences of managers who were also proprietors. To add strength to the findings from the case study this chapter will begin by presenting findings that resonated, confirming much of the complexity found in the original care home. Another way in which to add strength to the findings, as well as to demonstrate that the researcher is free from bias, is to look for data that challenges their assumptions, or previous findings. For this reason the chapter will then present data that did not confirm what had previously been found, and finally it will present data highlighting a number of new issues raised by participants, which the researcher had not observed, or been aware of, at the case study site. To make it clear how the findings from this chapter relate to the previous one, where applicable the same headings and sub-headings from Chapter 6 have been used. The findings are also presented diagrammatically in Table 7.

Confirmed findings - 'Sick, not healthy'

This section presents data of findings that were confirmed, summarised, as previously, as:
- Level of need and degree of complexity present
- The added complexity that dementia brings
- Level of healthcare skills needed by care staff
- Level of healthcare support needed by residents
- Dissatisfied with the care home/district nursing relationship
- Funding pressures

Table 7: Reflections from other care homes

Themes from case study	Sub themes	Confirmed Findings	Unconfirmed Findings	New Findings
Level of need and degree of complexity present		✓		
Added complexity that dementia adds	Importance of 'knowing' the person	✓		
	Difficulty providing care	✓		Struggle with respite care
Levels of healthcare skills needed by care staff	Dealing with complex healthcare needs	✓		
	Benefit from access to healthcare training		✓	Accessing training an issue
	A hidden workforce	✓		
Level of healthcare support needed to manage residents	Accessibility of healthcare support is good		✓	Difficulty accessing medical information
	Accessibility of GP support problematic	✓		
	Benefit of specialist support		✓	
Dissatisfied with the care home/district nursing relationship	Reluctant to criticise	✓		
	Dissatisfied with the service received	✓		Not working in partnership
	Ignorant of the DN role	✓		
	Service offered needs to change	✓		
Funding pressures		✓		Impact of vacancies Unable to fund improvements

Level of need and degree of complexity present - 'Bordering on nursing'

One finding that resonated was the degree of complexity present amongst todays' residents. Many agreed that the population had changed significantly:

> .….you are looking after a completely different group of people; you are looking after people who are sick, not healthy anymore. Either they have mobility issues, major ones, or they have mental health problems, or they have.....if you wish you can have everything in one person. Doubly incontinent, he is diabetic.....high blood pressure, high cholesterol. How are you meant to deal with all this.....? P32, CHM, I

> .….we are now having a lot of people being diagnosed with different types of cancer. We are also having people with high blood pressure that is very common in here, also people with some kind of thyroid impairment, thyroid function impairment…….. We have also got people who have got kidney problems, they are also appearing quite often and also now we have also got a big number of people who are diabetic….P35, DCHM, I

In the past residents reportedly would typically have been in their late 70s, able-bodied, needing little, if any support with care needs, often able to go out and about and admitted largely for social reasons. This was no longer the case, a result if was suggested of government policy, encouraging care to be provided at home for as long as possible, resulting in a typical resident, who was much frailer and older than ever before. Residents were often admitted as they were no longer able to manage at home, often as a result of a fall, or a safeguarding concern. As a result increasing numbers were reported to be in a poor state of health on admission, often due to self-neglect and suffering from malnutrition, weight loss, pressure damage and sores and requiring high levels of support from the care staff. As one manager phrased it '*they need 24-hour care*', whilst another suggested that the care now needed in residential care homes was '*bordering on nursing*'.

High levels of health problems and multiple co-morbidities were again not uncommon, with participants reportedly caring for residents suffering from diabetes, arthritis, heart disease, respiratory problems, sensory deficits, stroke, cancers, as well as supporting terminally ill residents to remain in the care home to die. Some were even providing care for those with mental health issues, including bipolar and personality disorders. As a result, high levels of physical and psychological healthcare needs were reported to be present across much of this care home population.

The added complexity that dementia brings

Another finding that resonated with participants was the impact that dementia was having, summarised, as previously, as:

- High prevalence of dementia
- Importance of knowing the person – it is getting harder
- Difficulty providing care – it can be demanding

High prevalence of dementia

The case study care home specialised in dementia care however, this was not typical of the 11 care homes in Phase 2. When this study commenced 10 of these care homes were registered to provide care for older people and dementia and one to provide care only for older people. Of the 10 care homes providing services for those living with dementia and/or older people, two had small dementia units within the larger home, caring for between 10-14 residents living with dementia. Whilst in the remaining homes residents living with dementia were cared for alongside other residents:

> *P27: If I give you general terms, if we were full up, normally it seems to be that one third are functionally ill and just elderly and just confused, or agitated, or whatever and the rest of them are with dementia*

> *Interviewer: But you seem to be suggesting that the others have got some problems…*

> *P27: Well the others may be elderly confused without a diagnosis, yes…..P27, DCHM, I*

Although none were specialising solely in the provision of dementia care, there were reportedly high levels of dementia to be found across the resident population, with nearly all those who took part estimating that well over 50% of their residents were living with dementia. Even the care home that was registered to provide care for older people only, reported that at least two residents had been diagnosed with dementia. Most participants were unable to give accurate figures as many residents had never been given a formal diagnosis, a situation which in itself is not unusual. One manager explained that she was reluctant for residents to be given a diagnosis of dementia as it could '*put them at risk and affect their life here',* with residents being transferred, because the care home did not provide specialist dementia care.

Importance of knowing the person – it is getting harder

All agreed that the need to 'know' their residents was important if good care was to be provided. Yet once again it was suggested by a few participants that their ability to do this was being hampered, as a result of people being cared for at home for as long as possible and only admitted at a much later stage of their disease process:

> *…..I have had people in here who came in just because of a little forgetfulness and the years they have been with us they have gradually slumped in. We have been able to adjust to them and they have been able to trust us all the way through. We are now getting people in the, because of the social, pressure from social services, that are in the advanced stages of Alzheimer's and therefore they cannot understand us and it takes us longer to get to, into their psyche…..P31 CHM, I*

It was suggested that care had been easier to provide in the past, as the person was typically admitted at an earlier stage of the disease process, and the care staff had been able to really get to know the resident well and '*grow with them'.*

Difficulty providing care – it can be demanding

Caring for a person living with dementia could be demanding, especially for those care homes not offering specialist care, who were more likely to report difficulty managing certain behaviour. Care staff could find it difficult to cope when a resident was perceived to be 'challenging', aggressive, verbally abusive, extremely distressed, agitated, or continually calling out for help. Other challenges included non-compliance, in particular difficulty administering medication and personal care, *never knowing what will happen next'* and family or friends showing little understanding of the difficulties regularly faced in providing care:

> *…..as I said the families they need a lot of work as well…….They don't really understand we have got people coming in and taking the residents out… the family….expects everything to be on time on Sundays when they arrive, not*

thinking about the residents side….we can get her ready a hundred times…..she can take the clothes off, there is incontinence, all this can happen in the moment, you can put a hundred kind of shoes on, they will take them off. I mean we…….talk to them, try to get it back on, but the family comes and they are not wearing this which is what they expect them to wear. Practically it is quite hard…..P28, DCHM, I

Certain challenges could be in part attributed to an apparent lack of understanding on the part of care staff about the disease, as the following account demonstrates

P30: And so the staff couldn't understand…… this lady's dementia was…a lot of her confusion was due to the UTI…

Interviewer: Whereas they were just thinking it was the dementia?

P30: Yes, absolutely and it was acceptable for this lady to do this because oh she has got dementia ……..and it was sad for the lady as well because. What her family said is that if she is in pain she rocks and she was always rocking…. because she must have always been in pain. She is not now. They have got her on the right medication and they are doing the right investigations which are needed and for the staff to see that difference in this lady because of the UTIs being dealt with appropriately. Because there is a change in this lady's behaviour, where she is actually talking…..P30, CHM, I

Level of healthcare skills needed by care staff

Managing high levels of healthcare needs was a finding that resonated with all of these interviewees. Summarised, as before, as:

- Dealing with complex healthcare needs
- A hidden workforce – not 'just a carer'

Dealing with complex healthcare needs

The presence of high levels of healthcare needs was again said to be common. Care staff were reportedly supporting residents with all activities of daily living, providing simple wound care, and managing urinary catheters. The provision of palliative care in this setting was not uncommon, including advance care planning. They were reported to be increasingly caring for residents who were dying, a result of residential care homes able to provide care for residents whose condition had changed significantly, which in the past would have necessitated transfer to a nursing home. Once again care provision was not simply focused on the meeting of physical needs and care staff were said to be routinely dealing with psychological, behavioural, social and emotional needs of residents, together with the emotional needs of family and friends:

…..when we get an admission in we are always honest with people. When they are bringing in their loved one I tell them you have brought in your mum…..you are aware that she has dementia, it could get worse, it could stabilise....but it won't get any better which is true. And then I can tell them what we can do. And I also have been encouraging staff that if there is any changes just get on the phone immediately and tell the family because they have to be more involved. They have to really understand, they have to see their mother or father changing and then they will, they will sort of like come to terms with, when they come next time, and they don't recognise them…..P35, DCHM, I

A hidden workforce – not 'just a carer'

Once again qualified staff, including RNs, were employed in these care homes. Participants who took part in this phase were either qualified healthcare professionals or had worked in social care for many years. Of the nine managers who took part four held a nursing qualification, one was a paramedic, seven held a RMA, four had an NVQ qualification at level 4 and one a PhD. In terms of the deputy managers, one held a nursing qualification, another both a RMA and an NVQ level 4 and the remaining one held an NVQ level 3. One of the team leaders had an NVQ level 4, together with a counselling qualification, whilst the final one had an NVQ level 3:

…..this morning I have got on a midwife and a physiotherapist and one of them is a nurse, qualified in their own countries. I am a nurse…..……..there is also another nurse on the team who is trained in her own country, not here in England….oh we have got another nurse as well that I forgot about. This girl is a, she has got a degree in nursing in her own country……P27, DCHM, I

But it was not only amongst the managerial positions that RNs were to be found. As the above quote demonstrates there was a significant nursing presence reported amongst the care staff. Qualified professionals were reportedly working in all but one of these care homes, either as managers, or as members of staff. However, it was unclear if any held specialist qualifications in care of older people. 10 care homes reported having at least one member of staff who held either a nursing qualification, or was a healthcare professional and many reported having significant numbers on their staff. In only one care home was there no qualified nursing presence. Once again the vast majority of these healthcare professionals had trained abroad and were not able to work in a professional capacity in this country.

The presence of qualified staff was again felt by many to bring a number of perceived benefits, which include problems picked up earlier, hospital admissions prevented and care staff who were better at problem solving and who were able to lead by example, resulting in other members of care staff picking up skills and gaining in confidence:

…..and I see a resident and I have been away for 3 days, why hasn't nobody followed up the dietician, you know sometimes I am pulling my hair out thinking….I know we have all got different brains but we have all got a brain haven't we. So

what is the difference between my brain, I would love to cut some of their brains up
you know and then put it back in and say what makes your, you so different to me
that you can't see what I see. Why do you have to wait for me to come back and
then say why has no one chased up the dietician for this lady when I know that she
is still losing weight…..? P29, CHM, I

Interestingly it was reported that a number of homes were actively seeking to employ nurses, either as managers or care staff, in order to improve service provision in response to the perceived complexity present amongst many of the residents. The presence of this hidden workforce leads one to question how well healthcare needs would be met if qualified staff were not working in these care homes.

…..But when they see us probably they feel we know nothing, or you get that
feeling that you know nothing. But what they have to understand is that there are
so many skills among the care staff we have here and they would be surprised if
they took the time to talk. Because......there are so many people with backgrounds,
from medical backgrounds…..P35, DCHM, I

It was once again suggested that the knowledge and experience of care staff was often overlooked, or even ignored. Care staff were equally frustrated by healthcare staff who had little idea of the skills that they possessed and who never bothered to ask about their background, or experience. Some managers spoke of care staff feeling that they were '*looked down on*' or seen as '*just a carer*' by many healthcare professionals, including nurses. As a result, it was suggested, care staff could lack the confidence to speak up, or question those who they saw as in a position of authority, such as GPs for example.

Level of healthcare support needed to manage residents

Difficulty accessing support from GPs was another issue that resonated.

Accessibility of GP support problematic

Seven of the care homes were supported by one GP surgery, whilst the remaining four homes relied on multiple surgeries, up to 5 in one case. This was not dependent on the size of the care home, as three of the larger care homes with 40+ residents used only one surgery:

…..But sometimes the closer one is where the difficulty is. They don't really have
time to come and they want us to come there. But we tell them people with
dementia, people being frail, they are not really in good health, it is very difficult to
get them to the surgery…….They don't think about the weather, they don't think
about how physically good they are. I mean….someone with dementia who is not
feeling well, it gets worse…..P28, DCHM, I

> *…..I have problems with my GP here…….he is….not very helpful, not very*
> *forthcoming. I think he would rather jump inside a….tank of sharks than come over*
> *to the building…..P30, CHM, I*

In the previous chapter the care home had reported difficulty accessing support and as the above quotes demonstrate they were not unique. Roughly a third of the care homes in this phase reported difficulties similar to those experienced by the original care home. Difficulties included an unwillingness to visit the care home, an expectation by some surgeries that residents would be taken to the surgery, something that was not always feasible or appropriate, as well as a lack of willingness on the part of certain surgeries to engage at all with the care home.

Dissatisfied with the care home/district nursing relationship

Although participants spoke of having a good relationship with the community nurses, there was again evidence of underlying tensions, summarised, as before, as:

- Reluctant to criticise
- Dissatisfied with the service received – evidence of underlying tensions
- Ignorance of the district nurse role
- The service offered needs to change – to work in partnership

Reluctant to criticise

The majority of these participants again spoke of having a positive relationship with the community nurses who visited their care homes. With phrases such as '*we have a good working relationship*', '*they are like just like a family*', '*I can't fault the nurses*' and '*they are extremely good*' used. Support that was valued included nurses who were easily accessible, could simply be contacted for advice, who were willing to work with the care home as a 'team' and who would give guidance to care staff in respect of on-going care needs. Practical support was equally valued and included nurses providing equipment without question, as well as training to the care staff, something that a number of managers commented community nurses were no longer able to do.

> *..….We are also lucky with the district nurses, you know we get, as I said I*
> *mentioned pressure relief, we get a good service, a good relationship, they even*
> *help the carers, they give them training in bandaging and dressings and moving*
> *people, so I think this home myself is a very fortunate home in that respect….P27,*
> *DCHM, I*

As in the previous chapter many participants appeared reluctant to offer any criticism of the nurses, which may well have been, in part, a result of the researcher being a district nurse. Comments were made such as: '*I can't complain about it*', '*you know district nurses are always accessible. I am not just saying that because you are a nurse*', or '*how can I put this without, because our district nurses are really, really nice*'. They also appeared reluctant to criticise the

service as they perceived district nursing to be under increasing pressure, as will be discussed in more detail later.

Dissatisfied with the service received – further evidence of underlying tensions

There was again evidence pointing to the existence of underlying tensions between the two services. When criticism was made of either community nurses, or the service they offered, it centred on the following issues:

- Community nurses ignorant of care staff role - Quick to criticise
- No time to spend - 'In and out'
- Nurses have little understanding of dementia

Community nurses ignorant of care staff role - Quick to criticise

It was suggested by a small number of participants that community nurses could be critical, as well as judgmental, in their dealings with care homes and their staff. Community nurses could reportedly be quick to criticise when problems arose, especially in regard to the development of pressure sores without, it was felt, taking into account that care homes were caring for increasingly frail residents, many of whom were nearing the end of their lives. Nor did they appear to appreciate the difficulties care homes faced when caring for this type of resident, including the need to be able to access timely support and/or advice:

> *….I have had a very bad experience 2 years ago where a district nurse came in, the client had a red spot, I rang them immediately, told them to come in and by the time, that happened on Friday and they didn't come in until Monday and obviously the skin had broken, it had become grade 2, grade 3 and was reported as a, to safeguarding and the whole can of worms....and I was quite annoyed…..once that referral was made I was investigated and that particular nurse didn't even turn up for one of the meetings…..P37, CHM, I*

The attitude of some nurses appeared inconsistent. Community nurses could reportedly be critical when called in to deal with what the nurse may perceive to be a 'minor dressing', yet would, on another occasion, criticise if care staff dressed such a wound. Such perceived criticism left care staff unclear of what they should be doing and as a result care staff could be reluctant to ask for advice or support in the future. There was, once again, a reported lack of understanding of the role and skill set of care staff, which had resulted in community nurses on occasion questioning why care had not been provided, or why problems had arisen. They could also have unrealistic expectations as to the type of care that care staff could provide and were reportedly unhappy when care staff refused to take on care provision that fell outside their remit. Although, it should be mentioned, that this criticism went beyond the community nurses and other healthcare professionals, such as physiotherapists or GPs, would also reportedly expect them to take on care that went beyond their knowledge and skill set:

> *…..I do find it difficult when the district nurses are asking my care staff to take off the dressing and wash their leg and I have a slight concern there about what they*

are allowed to do or not allowed to do as we discussed before…..they expect the
staff to do it but I don't think they were ever shown how to do it and when they went
to do it and they see blood coming through for example they are not supposed to
do it…..P36, CHM, I

No time to spend - 'In and out'

Accessing the district nursing service was again perceived to be more difficult. In the past when there was a concern over a resident, participants had valued being able to speak to the nurse informally when they were visiting and the nurse agreeing to review that resident immediately. But this was no longer happening and the care homes were now being asked to complete a referral form requesting a visit:

.….If the district nurse has got the clients on their books and they are already
coming in to see them then they will see them, but if you ask the….some of the
nurses when they come in will have a look and go yes we will do it, but get a
referral….but there will be another one that won't it, it will be get a referral…..P48,
TL, I

As the above example demonstrates, some nurses would agree to visit a resident before the referral had been received, but this was not always the case and once again the need for a written referral had resulted on occasion with nurses reportedly refusing to see a resident until the completed referral had been received, even though they were in the care home at the time. This was one reason why accessing specialist nurses such as the community matron or Macmillan Nurses was perceived by participants to be easier, as reportedly they were able to simply phone these services when help or support was needed.

Most participants spoke of a district nursing service which they saw to be under increasing pressure:

…..I think the district nurses now they are really having to work hard aren't they.
You would know better than I but I think they are really being cut. They are cutting
everything aren't they at the moment and I think this is wrong. How can they really
spend time with their patients if they are on the go…..P27, DCHM, I

A frequent criticism made was that community nurses always appeared in such a hurry, were continually rushing and did not have sufficient time to spend in the care homes. As one manager described it they just '*want to be in and out quickly'.* As their time was felt to be limited this had resulted in a small number of participants, as in the case study site, appearing to accept that the primary focus of the district nursing service was the patients living in the community. A couple of care homes had even reportedly tried to help by agreeing, if the nurses were stretched, to redress wounds that would normally be the responsibility of district nursing, or ensuring that everything was ready for them when they arrived.

Although care staff appreciated that community nurses were under pressure, it was suggested that this was not reciprocated. Some participants felt that community nurses did not always appreciate the demands care staff were faced with, with some nurses reportedly expecting care staff to stop what they were doing to attend to them. On occasion this had resulted in nurses reportedly unwilling to wait for care staff to finish what they were involved with and leaving the care home without visiting the patient.

Nurses have little understanding of dementia

There was general agreement that many healthcare professionals, including nurses, lacked knowledge and skills in caring for people living with dementia. However, it should be noted that when discussing this issue participants appeared to be talking about nurses in general and were not singling out community nurses in particular. It was suggested by a few interviewees that healthcare professionals, including nurses, often appeared unsure how to either approach, or talk to a person living with dementia. Others mentioned a lack of understanding of the disease itself and the impact it may have on the individual. Whilst one interviewee, based on personal experience, went as far as to say that she was '*disgusted with the care of dementia clients*', suggesting that healthcare professionals are *'ignorant', 'very uncaring'* and '*lacking in compassion'*. The need for healthcare staff to be given dementia training was an issue raised by some.

Ignorance of the district nurse role

Once again there appeared to be little understanding of the support that could be offered by community nurses to help care staff manage a resident's healthcare needs:

> ..…The role of the district nurse is to do things which we are unable to do probably on the nursing side of it. Things like if a catheter is blocked they can come and unblock it. Or if a dressing needs to be changed they come and change it and also to advise us sometimes because we ask and say this person do they need pressure relief equipment or something like that......that is the main role of a district nurse and insulin of course, they give the insulin….P35, DCHM, I

As previously care was felt to be task focused; with most participants suggesting that district nursing mainly provides wound care, pressure area management, insulin administration or catheter management. Less frequently mentioned was the provision of palliative care, including the setting up of syringe drivers and only a couple of those interviewed mentioned that these nurses provided advice. Participants appeared to have little knowledge about the district nursing service as a whole. Managers and care staff were often unsure of when and why district nurses could be asked to visit, the range of services and support offered, or even practical information about the service. Such lack of understanding is of concern as it suggests that residents may not have access to all the support available to them. Equally if care homes are unsure of either who or when to call, this could result in them trying to manage without the support that is available.

As in the previous chapter, much of the support needed was again being accessed through the community matron and as in the case study it was a role that was valued by a number of participants. In particular, the training that these nurses had provided, which had reportedly up-skilled many of the care staff and the liaison role offered, which had supported care home staff when working with difficult GPs and other healthcare professionals.

The service offered needs to change – 'work in partnership'

Care home managers have had little say in the type of service they would like to receive. As was the case in the previous chapter, the majority of participants were surprised to be asked what support they would like and one even commented *'you are the first person to ask me that'*. It would appear that they have simply made do with the service that was provided to them and have had no input in shaping nursing support available to them. Whilst some participants did struggle to put into words the support they would benefit from, others had clear ideas:

> *…..I just think they need to understand they are going into homes, homes are busy too and they have a day-to-day routine and they have tasks to do…….it is not all about eating, drinking, feeding and toileting, it is the social skills. So once that is done it tends to be more the social time and then they come in and just want it done straight away. They also have to understand if the staff is explaining look we have got a problem, can we do this, they need to….adjust themselves. And also not to put the burden of their work on top of the staff…..P26, CHM, I*

> *…..it would be nice and I would appreciate it if me and the district nurse team, my staff and the district nurse team to sit together and what is expected of me and what I am expecting from them so we can maintain a good relationship, one that we won't have any misunderstanding…....Rather than me thinking about oh that person is no good and she is thinking oh my home is not good. So I would rather sit and talk to them and that would make everything smoother and run the homes properly….. I just want them to understand what carers can do and what can't they do and what is expected from the carers in a residential home and what is not…..P36, CHM, I*

Many wanted a service that offered better partnership working, as a common theme was to hold regular meetings with the community nurses. These meetings were seen as a way to '*bounce ideas off each other*', to raise concerns regarding any of the residents in the home, not just those on the district nurses' caseload, to discuss areas of practice that could be improved, to receive feedback and finally to give nurses the opportunity to become more interested and involved in the care home. The provision of healthcare training by community nurses was another suggestion commonly made. There were, it was felt, benefits to community nurses providing training, as it could be done on an ad-hoc basis, provided at the time it was needed, as well as being responsive to the needs of both current residents and care staff. Other suggestions included community nurses having more time to spend in care homes so they were

not continually rushing, having a better understanding of the needs of residents living with dementia, and a clearer understanding of the role, responsibilities and issues facing care staff. If community nurses were able to work with care homes in ways such as this, it was suggested that it would not only provide the care homes with a greater level of support than they were getting at present, but it might also enable a closer working relationship to develop.

Funding pressures – 'It is getting harder'

Another finding that resonated with the majority of these participants was the impact that funding pressures were having on their care home. The situation appeared to be even worse amongst these care homes, with a number reportedly finding it hard to survive financially, as a result of the levels of funding they were receiving. This was especially true for the small 'family' run care homes. The managers of some of the smaller care homes were the proprietors too and were finding the present climate particularly hard to cope with. They used phrases such as '*it is getting harder'* and '*the smaller homes are struggling'*. Although managers of some of the larger care homes also spoke of being under pressure, using phrases such as '*it is ugly out there at the* moment' and '*it is a lot of pressure':*

> *….. when a client passes away and we don't have another client then it becomes very difficult because we are not competitive like the bigger homes. You know that is when it really becomes quite detrimental....as I say our last patient passed away in December last year, so we are 14 months now with just 2 patients and we don't know how long we can carry on with just 2 you know…..P33, CHM, I*

> *…..I was approached last year by another local authority to say look I have got a placement I need the person placed as an emergency, I said fine no problem, but we can't pay you till our new budget comes in. I said excuse me I can't tell my staff I can't pay you because they can't….. A private family came in and they said oh the money is all tied up, I said okay I could take the client and the client might die next month and you might do a runner and I am left with a big bill, I said no, no, no, no you have got to have some security in regards that, I am running a business….P37, CHM, I*

Those care homes who were struggling were doing so for a number of reasons. Firstly, they had seen no significant rise in the levels of fees paid by local authorities over the past few years. This appeared to be a widespread issue, as care homes who were taking residents from across the region reported similar problems. Some care homes even reported having had their fees decreased, or requests from local authorities to postpone payments. Secondly, the care home in the case study had a block contract with the local authority, as did four other care homes run by the same parent company. This contract had benefits for these care homes, with the fees paid even when beds were not occupied. However, it appeared that these block contracts were having a knock on effect for other local care homes, with the local authority refusing to countenance sending someone to a care home, other than to one with whom they had this

contract. One manager explained that the fees they received to provide care for a person living with dementia only equated to £3.27/hour and as they so eloquently put it *'you couldn't get a baby sitter for that money'*.

Unconfirmed findings - Inequity present

The previous section suggested that findings from these participants confirmed much of the complexity that had been observed in the original care home and adding strength to the original findings. Another way in which to add strength to findings, as well as to demonstrate that the researcher is free from bias, is to look for data that challenges their assumptions, or previous findings. For this reason this section presents those findings that did not confirm what had been found in the case study, summarised as:

- Level of healthcare support needed to manage residents
- Level of healthcare skills needed by care staff

Level of healthcare support needed to manage residents

Difficulties in accessing support from GPs had resonated with many participants. But difficulties were not confined to GPs and it was apparent that access to healthcare support was not uniform across The Trust.

Access to specialist support not equitable

Not all care homes had good access to healthcare support, with evidence pointing to inequities between care homes. Residents in the case study had access to specialist support, receiving regular visits from a geriatrician and old age psychiatrist. However, this level of support was not uniformly available to all other care homes across the borough. A second care home had been receiving regular visits from this geriatrician, but visits had suddenly stopped; whilst in the case of the remaining care homes they only had access to this geriatrician if a referral was made and then it would only be as a one-off visit.

Access to healthcare support variable

For some care homes not having access to specialist support was mitigated by the increased level of support they received from their GP:

> *…..He comes out if we call and he holds a surgery in here every fortnight….. we just fax over a list of all the people that he needs to see, that we have concerns about, or they are complaining of some aliment or something. He will see them there. Sometimes he is guided by us. If we spot something you know and we relay it to him….P31, CHM, I*

> *…..Our GP comes in once a week anyway so if there is any change in their mental state, we monitor it as well as the GP because she comes in every week so she can see…..P49, TL, I*

Six care homes reported having a very good relationship with their GP and were receiving regular visits from them. It should be noted that these care homes were all, on the whole, served by a single GP surgery. Three were visited weekly by the GP, who would hold a small surgery in the care home and the remaining three received a regular visit every 2-3 weeks, to review residents with whom there were problems. These regular visits were felt to be of benefit to both residents and also care staff, who spoke of feeling well supported.

In the case study, regular support was accessed from a wide variety of healthcare professionals. However, usage of healthcare professionals appeared to vary between care homes in Phase 2. Whilst all spoke of using GPs, community nurses, dentists and chiropodists regularly, use of other healthcare professionals such as CPNs, dieticians and the SALT team was mentioned less frequently. However, this may have been a result of the different client groups in the care homes, i.e. a dementia specific home vs. care homes for dementia and/or older people. Inequality was also noted when it came to accessing allied healthcare professionals, such as dieticians, or the SALT team. Certain care homes reported accessing support directly from these services, whilst others were only able to access them through their GP, who would act as a gatekeeper, deciding if the referral was necessary and often slowing down the process significantly:

> *…..You have to do that through the GP. You can't do it yourself and then if I go through the GP then he has to decide…….and you have to chase the GP. You have to wait. Some of the GPs are not proactive, it takes a while……P26, CHM, I*

> *…..If I call out any services…..they say but no you are…in X. I say no 50 yards I will be in X and I say why do I have to geographically explain to you where I am? I pay my taxes, I pay council tax……I don't get support from you….P37, CHM, I*

For a care home situated on the border of two trusts, as the above account demonstrates, accessing healthcare services could prove even more problematic, with professionals from the various local authorities continually questioning and even arguing over who should be visiting.

Whilst the manager in the case study had not reported any particular difficulties accessing support from allied healthcare professionals, a number of participants in the second phase did report issues accessing the support they needed. Difficulties included: long delays in response times for certain services such as the Parkinson's Nurse Specialist, the need to continually chase up professionals, such as in the case of regular social work reviews and difficulty accessing follow up visits from some services, e.g. OTs. Suggesting that residents in these care homes do not have access to the same level of medical and healthcare support and/or backup that had been so highly valued by the manager in the original care home.

Level of healthcare skills needed by care staff

A second finding that was not confirmed was the accessibility that care staff had to healthcare training, which had been found in the original care home.

Benefit from access to healthcare training

The strength of this finding needs to be questioned, as it was an issue that was raised by only one care home in this phase. What was mentioned briefly in the previous chapter, but which became more apparent from one particular interview, was the apparent differences that existed in regard to the skill set of care staff, especially in terms of healthcare skills, with differences dependent, it appeared, on the care home in which care staff were working. For example, in the case study team leaders had received training in the recording of pulse and BP and were carrying out baseline observations. Yet this training did not appear to be widespread, as the following account demonstrates:

> *…..we normally take the temperature reading….when I came here we were not doing …the blood sugars……but we spoke to the doctors and he said we can do that….we had training on the pulse as well, that is what we do. Not even blood pressure, we don't do it here. Because we have to give the accurate reading like in emergencies when we call for an ambulance and you know that you have to make sure you are accurate giving them the necessary readings. Some doctors won't come when you call them, say if you give the blood pressure reading they think oh this is fine, it is normal and they won't, they will tend to stay away…..P28, DCHM, I*

In this care home the staff were only recording temperature and pulse and were not permitted to record the BP, as a way of ensuring that the GP would visit if they had a concern. Staff were however, reportedly measuring blood glucose levels and had even administered insulin, which is certainly not common practice in my experience.

New findings - Struggling to cope

In this final section data will be presented identifying a number of new issues raised by participants in this second phase, of which the researcher had been unaware following the case study. These are summarised as:
- Difficulty accessing information
- Struggling with respite care
- Accessing training
- District nurses not working in partnership
- Need for a nursing presence
- Financial pressures

Difficulty accessing information

An issue not previously raised, but mentioned by the majority of these participants, was the difficulty faced in accessing information concerning a resident's medical history. Participants

were aware of the importance of having access to up to date medical information, yet appeared to have difficulty accessing information required:

> *CHM 37…..I did have a bit of a barney with one of the GPs practice managers and she was saying oh but we can't do this. I said excuse me, I mean we are actually the centre point for the client……If we are giving holistic care which means you are one of the professionals, your input is important as much as mine is and I need to know, if I don't know how am I going to care for the person…..P37, CHM, I*

Hospital discharge information was felt to be of a poor quality and lacked sufficient detail. As a result care homes were often relying on assessments carried out by social workers. However, it was suggested by some that these were not always up to date and, on occasion, important information regarding a resident's medical history had not been passed on. Of surprise was the difficulty some participants reported in accessing information from GP surgeries and in particular from GP surgeries that were outside the borough, with surgeries often reluctant to provide them with a resident's medical history, or other relevant information. Of concern was the practice reported by a few care homes of relying on family to provide them with information concerning a resident's medical history, as this relies on the family member having up to date knowledge, which may not always be the case. A lack of relevant medical information can have implications and a couple of participants reported examples of treatment omissions that had resulted from a lack of information. For example, the condition of a resident had deteriorated, requiring hospital admission, as the care home had been unaware that they had a history of diabetes.

Struggling with respite care

A small number of participants were facing additional demands when people living with dementia were admitted for short-term respite care:

> *…..I think it is our respites we struggle with the most……and they are only here for a week so we don't know them. So we have to rely on families but by then it is too late because they have put a safeguarding because you have neglected my mother and they have developed an infection while they have been in your care……. That is why we have stopped bringing in respites for one week only and hopefully in the fortnight you have got to know somebody a little better and their behaviour……P29, CHM, I*

Some care homes were admitting increasing numbers for respite care as a way to increase income. Yet with these residents came additional challenges which included: staff struggling to manage episodes of challenging behaviour and residents who were unable to settle as a result of care staff not knowing that resident well. Accessing medical support for these residents could prove difficult with the resident's own GP reluctant to provide the care home with information concerning their medical history, or practical support, especially if they were based in a different NHS trust. Yet the care home's own GP could be equally reluctant to register these residents on

a temporary basis. Such difficulties had even resulted in safeguarding reports raised against care homes on occasion.

Accessing training

Accessibility to training appeared to be an issue for a number of participants. The cost of training was having an impact on many of the care homes and could explain why courses run by staff from the local trust were so well received, as these were free to the care homes. In the case study, training had brought additional costs incurred as a result of funding replacement staff. However, this was not standard practice and care staff were not always paid to attend training, with many expected to undertake training on their days off. The cost of training resulted in much of it being undertaken in-house and given by the mangers themselves, especially in the smaller, privately owned care homes

A number of other factors were also having a significant impact. The language and literary skills of some care staff were a concern for some. This was especially problematic when complex ideas and skills were being taught, as care staff were not always able to grasp the concepts being discussed. Poor language skills were even preventing care staff accessing training opportunities, with a few managers reluctant to send those care staff with a poor command of the language on any training. For some care homes, especially the smaller ones, where training took place was an issue, with the small care homes finding it harder to release staff to attend training if it were off site. The length of training sessions was also of importance, with one manager suggesting that training delivered in short bursts, up to half a day, was of greater benefit to care staff than one day sessions or longer:

> …..if I knew I had staff here who can't speak English I wouldn't be sending them to training because it is a waste of their time, it is a waste of your time and that is no good to anyone. But I have seen in the bigger homes because you need to have some sort of training if the inspector comes they just send them and that is that is wrong…you are using funds to provide that training and it should be because you think you are going to use that training not just so you have got a piece of paper in your folder to say that you have done it but you don't actually understand a thing….P33, CHM, I

High staff turnover did not appear to be helping, especially amongst the more junior care staff, who some reported, often found the work difficult, leaving the job after a relatively short period of time. This had reportedly resulted in care staff who were not developing the experience and confidence they needed to care for the increasingly complex residents they were faced with. Frequent turnover of staff and the complexity of what needed to be taught also meant that training could not simply be offered as one off sessions, needing instead to be on-going, putting yet more demands on the care homes in terms of time and cost:

> *CHM29: …..the senior structure has changed and I have got 3 new team leaders in. Whereas I keep referring back to the old, where it was older people, that started out as carers and worked their way up…the new team leaders now are sort of in jobs a year, two years and then they are getting promoted and they haven't got that long line of work experience behind them*
>
> *Interviewer: So they are lacking in that confidence to make the decisions?*
>
> *CHM29: Yes and so they put calls out all the time….P29, CHM, I*

Not working in partnership

An issue that had not been raised by staff at the case study site was a failure on the part of community nurses to provide feedback to them. However, in Phase 2 there was evidence of communication between district nurses and care staff that was reportedly poor, or at times, even non-existent. Frustration with nurses who failed to communicate with care staff was evident on the part of some participants. Nurses would reportedly visit the home, provide treatment and then simply leave, without ever talking to a member of care staff. It was then left to the care staff to try and get information, or feedback. Poor communication between the services had left two participants feeling particularly frustrated and annoyed. Both reported community nurses coming into their care home and trying to dictate the care that they, as a care home, should be providing, without any apparent appreciation of the ethos of the care home, especially around managing risk:

> *…..a good number of nurses they are always in and out, you know they come in, they don't talk to you, they ask you for, where is madam So and So, then they ask you for the notes, where are they kept, where is the medical room. Then they disappear and they do whatever they have to do and then they go off and you are forever running after them, what is the, what have you done, what should we do, what do you expect, to find information, you know they just come in go…..P35, DCHM, I*

When a couple of managers had encountered an issue with the nurses, what was interesting was the way in which they had handled the situation. One had chosen to write to the manager of the district nursing service rather than talk to the nurses first. The reason given was that they saw too many nurses and so weren't able to talk with all of them. Another manager asked the researcher to intervene with an issue she had regarding care staff being asked to provide care for which they had not been trained, yet again did not appear to have either raised, or attempted to tackle the issue with the nurses in question.

Need for a nursing presence

Some participants went as far as to suggest that there was a need by for a qualified nursing presence in today's residential care homes. Although it should be noted that this suggestion tended, on the whole, to be made by those participants who were themselves RNs. It was even

reported that some care homes were actively seeking to employ nurses, either as managers or care staff, in order to improve service provision in response to the increasing complexity present amongst many of the residents:

> *…..because they use their skills don't they and they recognise, they recognise things that may be the untrained eye wouldn't recognise, I think that brings quality to the home and I do feel actually that residential homes should have somebody with a nursing background, at least one person, there should at least one…..I think it would bring better quality care to the residents because they would identify things, just simple things like you know somebody has got conjunctivitis, it is different from having just a sore eye and you need to get it treated and even talking to other professionals it makes a difference…P27, DCHM, I*

The presence of nurses was believed to be beneficial, as it reportedly improved the quality of care offered to residents, with problems picked up sooner, residents able to receive clinical care from someone who they were familiar with and care staff who were better equipped to manage and work with other healthcare professionals. Although, as one manager suggested, any nurse working in a care home setting would need more than simply an acute healthcare background. She felt that they would also need either a background and/or training in social care, as they would have to understand, as well as be able to meet, not only health, but social needs too.

Financial pressures

Although financial pressures had been noted to be having an impact on the original care home, the picture painted by most managers in the second phase was far bleaker than in the case study. With most of these care homes finding the climate at the time extremely hard and some struggling to even stay afloat. The pressures faced are summarised as:

- Impact of vacancies
- Unable to fund improvements

Impact of vacancies

As mentioned earlier, many care homes had concerns over the levels of funding received, not helped by high levels of vacancies that were reported by participants. A result, it was suggested, of government policy encouraging people to remain in the community for longer, together with the financial constraints facing local authorities. This was not an issue that had been noted in the case study and in fact that care home actually had a waiting list at the time the study took place:

> *…..And you can imagine if I am losing, I have 7 empty beds, multiplied by £500 minimum, I am losing £3000 a week.....If I….have 7 empty beds.......how can I survive? I am trying to maintain my good staff, I don't want to lose them, don't want to lose them. So on the rota I have to keep giving them shifts otherwise they will leave…..P32, CHM, I*

The above accounts demonstrate the pressures that vacancies were having on some care homes. Whilst the number of vacancies appeared to fluctuate over the course of the study, what was noticeable was that of the 11 care homes in Phase 2, at the time of interview only one reported being full, all the others had vacancies to fill, ranging from 1-14 vacancies. Although these vacancies usually amounted to no more than one or two unoccupied beds, the financial impact this appeared to have on the care homes and in particular on the smaller homes was great and some were losing significant amounts of money each week. A couple of the managers spoke of the knock on effect this had on staffing levels and appeared both frustrated and concerned, questioning the sustainability of their care home. Another two manager/proprietors were considering their future, finding it harder to compete with the larger homes and concerned, given the level of losses they were sustaining, how long they would be able to carry on for.

Restraints on local authority spending had resulted in people being inappropriately referred to, or even placed in, the care homes. A few participants spoke of social workers trying to place people in residential homes based on cost not need, as well as pressure applied from hospitals to take residents back quickly, even when healthcare needs had changed significantly. However, this problem was not helped by care homes putting themselves under pressure to accept residents due to the high number of vacancies they were experiencing. This could result in them not being able to meet the resident's needs leading to safeguarding alerts being raised and reluctance on the part of the local authority to place further residents in their care:

> …..X gives me pressure; I have got the borough giving me pressure. So we are going out and thinking yeah we can meet that person's needs but when they come in….did we make a big mistake, were we under pressure to bring this person in, so we did because we knew we would get a week's rent and it would get someone off your head…..P29, CHM, I

Unable to fund improvements
The reason why insufficient funding was such an issue for the managers, especially those who were manager/proprietors, was that all this was happening at a time when other costs were rising, often significantly:

> …..I have got plans, which I could show you for a garden room in here,……..which I would dearly love to have because it would provide me with more space and more facilities to provide a better service for people with Alzheimer's, a more adventurous site, a more diverse site. But I am restricted because the finances are not there to put in the infrastructure to put that in……P31, CHM, I

Many of the care homes reported facing difficult times, but the managers of those care homes seeking to make a profit were facing additional pressures and were increasingly being asked to run their businesses for less money. This had a knock on effect with them struggling to give staff pay rises, pay for any external training provision, provide services such as specialist equipment, or even to fund capital improvements within the care home.

Reflections of a practitioner researcher

As a practitioner researcher I reflected, as I did during the case study, on data from Phase 2. Reflecting on those findings that confirmed what I had previously learnt of the complexity that existed in residential care homes and the service provided by community nurses, as well as those findings that were new to me and made me question further the level of complexity and the support that community nurses were offering to these care homes.

Given the high levels of healthcare needs that were present in the case study I was not really surprised to find similar levels amongst the care homes in the second phase. I was surprised to find such high levels of dementia reported in this second group of care homes, as many were not offering specialist care, which meant that staff, in some care homes, could struggle at times to manage these residents. But what I began to question was that if, as was suggested, many nurses did not have much knowledge or experience in dementia care and neither did some care staff, were these residents at even greater risk of not having their needs adequately met?

What surprised me was the way in which the skill set of care staff could apparently differ between care homes, possibly explaining, in part, why some healthcare professionals were expecting care staff to take on care that they were in fact unable to provide. In the case study, the care home had access to a high level of healthcare support to manage their residents. However, this level of support appeared to have been unusual and there was inequity in terms of both medical and healthcare support available to these care homes. Many care homes were also experiencing difficulty accessing information regarding a resident's medical history, which was concerning.

As a district nurse I had been unaware of the true impact of the present economic climate, the immense pressures that many care homes were facing and how these were, in turn, impacting on the care and services they were able to provide:

> ….I had little real idea of the pressures facing these care homes before this interview….The manager was chatting generally about what is happening in the home. They now have 14 empty beds which are just not being filled. The manager mentioned that there are a large number of homes in a very small area, all competing for the same business. This is made even harder with people managed at home for as long as possible. They are worried what is going to happen to the home and if it will survive. The parent company wants to put in a 10 bedded dementia unit, but this would require extensive refurbishment, plus additional staffing for an additional £50/week, so it may not be cost effective for the company. It appears that there is pressure coming from all sides and it doesn't seem to let up…..RD 024, p262-263

I was not surprised by the reluctance, on the part of these participants, to overtly criticise either the nurses, or the service, as this was something that I had experienced on more than one

occasion, when working as a district nurse with care home staff. Nor was I surprised that nurses were always reportedly in a hurry, as over the years the pressures on the service have continually been increasing. But what did once again surprise and concern me was how little was known about the district nursing service, either the service itself, or the support the service was able to offer. I was surprised by the reported attitude of some community nurses, who appeared unwilling to communicate with care staff, were quick on occasion to criticise or pass judgement and were failing to appreciate the pressures that care staff were facing. Although I can understand how this might happen, a result of the seemingly endless pressures facing the service, that can at times make one feel as if you are drowning and can result in one trying to limit, when possible, any added pressure on your time. I was also saddened that the care homes and community nurses didn't always appear able, or willing to talk to each other, or to work through any problems. As the following note reflects:

> *…..The thing that strikes me time and time again is how on the whole there are issues on both sides about the support and care that is being given yet no one ever appears to have spoken to each other, or tried to resolve their issues. Why is this, why haven't they asked to be shown for example how to wash a leg, why don't they all try to resolve issues. Instead they just seem to put their heads down and soldier on…..RD 063, p194*

Summary

This chapter has revealed that the complexity identified in the case study was not unique to that one care home, but instead typified the experience of care homes across the local authority. Much of the complexity was similar to that in the case study, with high levels of complex health and social care needs across all the care homes and dementia adding to the complexity present. The skill set of care staff varied between care homes and a number of barriers were identified preventing care staff from accessing the training that they needed for their role. As in the original care home there were a large numbers of qualified nurses, or healthcare professionals working as care staff, bringing with them experience and skills that benefited the residents as well as other care staff. The relationship the care homes had with the community nurses was complicated and yet again the service offered by the nurses was not fully meeting the needs of these care homes.

However, what this chapter also revealed was that the complexity that existed in care homes was actually greater than first realised. Certain care homes were facing an uncertain future, having to contend with insufficient funding, high levels of vacancies and ever increasing costs. Some were even questioning the sustainability of their care home. There was inequity in the level of healthcare support available to these care homes. The case study site had benefited from support offered by a geriatrician; however, this was not available to all. For some care homes such lack of support was offset by the GP visiting on a regular basis, yet once again this service was not available to all and a number of care homes had to struggle to access the

medical support they needed, including access to information concerning the medical needs of their residents. There were also issues over access to allied healthcare professionals for some care homes, with access appearing to be inequitable and GPs acting, for some, as gatekeepers to services.

As in the previous chapter, although the working relationship with the community nurses was reported as being a positive one, a number of issues were identified which suggested that this was not always the case, confirming what had been suggested in the previous chapter and that the support the service was providing to the residential care homes was not always sufficient, and possibly not fit for purpose. Community nurses were perceived to always be in a hurry, only providing care that focused on 'tasks'. They could be critical of the care staff, were failing at times to give feedback and had a limited understanding of the carers' role. What care staff really wanted was the opportunity to work together with their community nurses as a team, much as the community matron had done. The final findings chapter will explore whether the ignorance demonstrated by the researcher of the complexity present in these care homes was unusual, or if other community nurses were aware of its existence, as well as exploring the level of support they were providing to the care homes to manage the healthcare needs they were faced with.

CHAPTER 9: FINDINGS FROM COMMUNITY NURSES: 'IGNORANCE OF, OR IGNORING' COMPLEXITY

Introduction

This chapter presents data exploring the experiences and challenges of community nurses in supporting care staff to manage the healthcare needs they are faced with. As well as exploring whether the ignorance demonstrated by the researcher, of the complexity present in these care homes, was unique to her, or if it resonated with other community nurses. In order to add strength to the findings from the original case study and reflections of the practitioner researcher, the experiences of other community nurses were sought. Data in this chapter were generated from interviews carried out during both phases of the study. In Phase 1 interviews were conducted with four of the district nursing team that supported the case study care home. In the second phase a further 18 interviews were conducted with district nurses and specialist nurses from across The Trust. Those interviewed comprised two district nurse team leaders (DNTL), two district nurses (DN), ten primary care nurses (PCN), two healthcare support workers (HCSW), four community matrons (CM), and two clinical nurse specialists (CNS).

As in the previous chapter findings from the case study were used to direct these subsequent interviews. As previously described, an interview guide was prepared for each interview; however, it was not followed rigidly, but was used as an aide memoire. Once again interviews took the form of a free flowing conversation, allowing, where relevant, emergent topics to be explored in more detail. This chapter begins by presenting data that confirmed many of the researcher's thoughts and observations from her time spent at the original care home, confirming that as a district nurse she was not alone in having little understanding of the level of complexity, or the challenges facing these care homes. Next it will present data that did not confirm what she had found. Finally it will present data highlighting a number of new issues raised by the nurse participants, which either challenged the researcher's initial thoughts and observations, or of which she had been unaware of during her time spent at the original care home. As in the previous chapter, the same headings and sub-headings have been used, in order to make it clear how these findings relate to those in Chapter 6. The findings are also presented diagrammatically in Table 8.

Confirmed findings - Ignorance of complexity

This section will present data from the interviews with the nurse participants that add strength to the findings from the previous chapters. Confirming many of the reflections of the researcher from the case study and/or other care homes, as well as providing further evidence that the service provided by the district nurses risked failing to meet all the needs of residents or care home staff. This is summarised, once again, as:

- Level of need and degree of complexity present
- The added complexity that dementia brings
- Level of healthcare skills needed by care staff

- Level of healthcare support needed by residents
- Dissatisfied with the care home/district nurse relationship
- Funding pressures

Table 8: District nurses response to the complexity

Themes from case study	Sub headings	Confirmed Findings	Unconfirmed Findings	New Findings
Practitioners ignorance of the level of complexity	Level of need and degree of complexity	✓		Ignoring the complexity in residential care homes

Limited access to medical information |
	Added complexity that dementia brings	✓		
	Levels of healthcare skills that care staff possessed	✓		
	Level of healthcare support needed	✓		
	Dissatisfied with the Care Home/district nursing relationship	✓		
	Funding pressures	✓		
	Ignorance of complexity		✓	

Level of need and degree of complexity present

Other community nurses appeared ignorant of the level of need and complexity that was present amongst the residents, summarised as:

- Residents 'too complex'
- Ignorance of needs

Residents 'too complex'

Limited understanding was shown by district nursing participants of the changes that had taken place in terms of the residents now living in residential care homes. Assumptions were made by some that if a resident's needs increased greatly they would simply be transferred to a nursing home:

> …..and also I have found a lot of patients that are residential should not be residential they should be nursing......the amount that they need is not, they are not suitable for residential homes, they don't get enough...and there is not enough medical input at all, because they are run purely by carers and managers who have probably not got medical background…..P13, PCN, I

Opinions were expressed such as residents are '*too frail and too ill*', that care homes were '*taking on people who are far too complex*' and care staff '*can't deal with it*', referring to the health problems they were faced with. A couple of district nurses even expressed an opinion that financial considerations were playing a big part in why certain residents were admitted. There appeared to be little appreciation on the part of many of community nurses that rather than being inappropriately placed, as they believed, these residents were in fact typical of those living in a residential home today.

Ignorance of needs

Further evidence of ignorance on the part of the community nurses to the complexity present was demonstrated through the service provided to the residents, summarised as:

- 'Task orientated'
- 'Simple dressings'
- Role lacks clarity

'Task orientated'

Support provided by the district nursing service appeared, in these care homes, to focus on the meeting of 'tasks'. In the previous two chapters it was suggested that care staff were unclear of the role of a community nurse, believing that they provided care that was simply *'task focused'*. Sadly, the interviews with district nursing participants did little to dispel this notion, with a number of the nurses themselves using phrases such as *'focused on tasks'*, or *'task orientated'* to describe the care they provide to residents.

The most common reasons given for visits were for wound care and pressure area care. In certain teams insulin administration was also commonplace. Less frequently mentioned were catheter care, provision of equipment and management of constipation and rarely mentioned was palliative care provision, support, or advice. However, when challenged as to whether problems such as pressure sores, skin tears, leg wounds and constipation were likely to be a true reflection of the healthcare needs of frail, elderly residents, almost all those interviewed had to agree that this was unlikely to be the case. Given the care staff's ignorance regarding the community nurses' role, specific tasks may be all that care staff were referring to the service. However, this situation does not appear to be helped by the nurses themselves:

> *…..They probably do have other health problems but we have only just been asked to see, by the house manager or one of the carers, just asked oh… the patient fell the other night and do you mind just having a look at their leg, where they probably might have just put a plaster or something on it you know. So you know we might well be not asked to see them for things that maybe we should be…..P9, PCN, I*

> *…..I think we are a bit more aware of the ones that live out in the community because we tend to look at them sort of like holistically, whereas if you go to a care home....I know that it shouldn't be, they ask you to look at a leg and that is what you look at, that kind of thing. You don't tend to look at the whole picture as such because you know they have got food, you know they have got their medicine, you know they are kept clean, or they are supposed to be kept clean, so you don't tend to look at it that way, or how safe their home is because they are supposed to be in a safe environment........P15, DN, I*

As the above accounts demonstrate, participants would often focus on the problem for which they had been asked to visit and there was little evidence of a holistic approach to either

assessment or care being used. The reasons given for this were on the whole put down to time and caseload pressures and will be discussed in greater detail later. The perception by care staff that community nurses only dealt with certain tasks could also explain why the community matrons were often the first service approached for help and support, rather than community nurses.

'Simple dressings'

Some district nursing participants described their work in care homes as simple or straightforward, talking about providing care for 'minor' problems such as lacerations, red bottoms, or as one district nurse put it for '*simple dressings*'. Yet believing their role in a care home to be one in which they merely carry out simple tasks as quickly as possible suggests that more complex healthcare needs risk being missed:

> …..half the time the ones that are queuing up in the little surgery part….are only minor stuff, lacerations and things like that, so it is not that they need anything too complex; they are only needing simple, simple dressings….P18, DNTL, I

Visits appeared to focus on the meeting of physical needs. All but one of the nurses interviewed came from a general nursing background and a number acknowledged that they were either reluctant to, or lacked the confidence and skills, to manage certain health needs, in particular mental health issues. There was a tendency to deal only with physical problems and if other issues were noticed, such as the person appearing depressed for example, this would not always be followed up:

> …..At the moment I think the role of the DN is purely to go in and do the dressing of wounds, give injections. You know we have a remit and we tend to stick to the remit…I think we tend to put the onus back on the manager, or the owner, saying you know this person seems depressed get the GP in, get this one in, get that one, telling them what to do and maybe asking them 2 weeks later, oh what happened with that, whereas I don't think really we get too involved…..but maybe we should…P1, PCN, I

Role lacks clarity

Some participants felt their role in care homes lacked clarity, as evidenced by one nurse who mentioned that different district nursing teams were offering different levels of support to care homes, with one team taking on care that another would refuse to be involved with. Others suggested that they should be offering support to both care staff and relatives of residents, overseeing the care residents received, as well as providing teaching and education to care staff. However, as already discussed, there was little evidence of the existence of such a role. Instead the reality appeared to be a service that was focused on providing specific nursing interventions only, could only offer support to those who they had been asked to visit and was heavily reliant on care staff to pick up problems and refer them on, something that, as already mentioned, may not always happen.

Further evidence of a lack of clarity in regard to their role was demonstrated through the grade of nurse visiting these care homes. It was not uncommon for more junior staff to routinely visit, including HCSWs. What had been of surprise in Chapter 7 was that the team would send in HCSWs, yet this did not appear to be unusual. The HCSWs tended to carry out follow up visits for wound care, pressure area management, or catheter care. However, due to their skill set they were often simply duplicating the care given by the care home staff. Sending in this grade of staff could create problems, with one HCSW mentioning that care staff had been reluctant to take advice from someone who was not a qualified nurse:

> …..mainly scrapes or skin tears….pressure relieving, when they have pressure
> relieving equipment. I might do pressure area checks…..wound care. There might
> be catheters as well. But normally the care staff in a home change catheter bags
> and things like that. So I don't really, we just check to make sure that everything is
> going OK….P2, HCSW, I

Some of the senior district nursing participants and specialist nurses acknowledged that there was a need for more experienced district nurses to take on a bigger role in care homes, as the increasing levels of healthcare needs required input from nurses who were able to look at things from a different perspective, as well as pick up on issues possibly missed by more junior members of staff. However, this was not always possible and due to other demands the most senior district nurses, i.e. the team leaders, were rarely visiting these care homes, a situation possibly not helped by the decrease in the number of team leaders that had taken place over the course of the study, putting increasing demands, in terms of managerial responsibility, on their time:

> …..generally overseeing things. Because I had a team leader background that is
> what I used to do, looking at things, looking at a different perspective so I used to
> try to find out issues that hadn't been looked at…..I used to see things differently
> because I always used to go and.......see things that the staff nurses hadn't picked
> up so, things like......like someone with dementia not having a cot side, or the
> mattress or things like that, footwear things like that….P22, DNTL/CM, I

The added complexity that dementia brings

Evidence was presented in Chapter 7 of how, as a practitioner, I felt I lacked knowledge and experience of caring for those living with dementia. This was another finding that was confirmed, with the majority of nurse participants experiencing similar challenges, summarised as:

- 'It is depressing'
- Providing care can be challenging
- Care practices ignore dementia
- Need dementia training

'It is depressing'

Historically dementia care came under the umbrella of mental health teams, with general nurses having limited experience of dealing with this client group. The majority of participants felt they lacked the necessary knowledge and/or skills in dementia care, with many frustrated that they didn't always know how best to help patients living with dementia:

> *…..it is very challenging.......it is hard, extremely hard because you want to ask them, you want to ask them something but you don't get no reply, so you have to watch out for facial expressions.....any hand movements, anything like that. But it is, it is hard...extremely hard….P12, HCSW, I*

> *…..I find it depressing really because it is so sad to see them and.......I mean they think they are fine but they are not fine, they need an awful lot of help and support. I am not qualified in that area at all and I would like more information, like more study days, just something because it is, it is so sad…..P17, PCN, I*

The majority of nurses interviewed, whether working with the district nursing service, or as specialist nurses, had experienced some difficulty caring for this group of patients. Many would use negative words such as '*difficult*', '*challenging*', '*frustrating*', '*hard*', '*depressing*', '*demanding*' and even '*upsetting*' to describe their experiences of working with these patients. Those who had previously worked in social care, or on elderly care wards, were less likely to use such language.

Providing care can be a challenge

Participants identified a number of areas of care provision that they found particularly challenging. The one that appeared to present the biggest challenge was dealing with what was perceived to be challenging, or unpredictable behaviour and/or aggression. Many participants spoke of finding such behaviour difficult to cope with, especially if they were not supported by a member of care staff and, as they didn't want to inflame a situation, would walk away and try to visit again later in the day, putting further pressure on their time. Another challenge was residents who were 'non-compliant' with nursing care. An area that appeared to be especially problematic was the administration of insulin to a resident living with dementia. As this participant explained:

> *…..we had a lady with dementia…who we had to give her insulin, every day, every single day and this lady did not understand why she had to have insulin…and every time we went you had to try to explain to her….the minute she saw the needle she just flipped….one nurse went to give her the insulin and she just pushed the nurse and the nurse stuck the needle in herself, so you know that it was then, because of the injury to the nurse, that it was decided to, that they needed to do something about it. This had gone on for months and we had all been saying that we need to do something about this, so we finally got the diabetic nurses to look at it, to assess does this lady have to have her insulin this way and it*

turned out that no she didn't, that she could go on to tablets….This lady was much happier, the nurses were much happier and the staff were much happier, because they use to dread us coming in….P1 PCN, I

Patients requiring insulin would normally be visited at the beginning of the nurses' shift, the time when care staff could also be very busy and so were not always on hand to provide support. A number of district nursing participants gave examples of residents refusing care, or becoming, as they called it, agitated and even aggressive, resulting in nurses having to revisit, sometimes on numerous occasions, as the insulin could not be given. Some participants were particularly concerned that a lack of knowledge and skills in this field had resulted in them failing to pick up problems amongst this group of residents. They spoke of difficulties communicating with residents and as a result were unsure if needs were fully assessed. For this reason they were heavily reliant on the care staff to provide them with information and assistance. However, the situation was made more difficult if a member of care staff did not know the resident, or did not volunteer to accompany them when they visited the resident. This, it was reported, was more likely to happen if the resident was not living on a specialised dementia unit:

Issues such as these were made harder if participants then encountered difficulties accessing support from other healthcare professionals. Problems reported included assumptions made that care homes should be able to manage, as well as other healthcare professionals themselves lacking knowledge and skills in the field and unable to offer any useful support or guidance. One participant spoke of the frustration they had felt on being told by a specialist nurse, who was approached for advice, 'I *don't know, but when you figure it out ring me back*'. Anger was expressed by a couple of the nurses at the attitudes of certain healthcare professionals, especially with comments such as '*they've got dementia, what do you expect*'. Attitudes such as these had left these nurses feeling unsupported and unsure where to turn to for help or advice;

…..especially when they can't stop physical hitting, you have got the other residents to put into consideration as well….. the mental health team...are reluctant as well to take this patient in, you know into one of their wards because they believe that if it is not severe we can still manage it in the care home, or doing a risk assessment, putting everything in place to make sure that the other residents are not at risk and that is the time I keep on going in to that care home every day or on the phone just trying to get an update if the medication we are using to relax them, you know if it is effective, if it is working, if it is not working I am on the phone again to the consultant to say you know it is not working…..P5, CM, I

During the course of the study my knowledge of dementia increased greatly, as did my awareness of the needs of this group of residents. Of interest to me was this comment made by one district nurse:

…..because a lot of the time it doesn't pose a problem, it isn't until you come across a problem then dementia pops up you know. Like the lady who doesn't comply with her insulin. Because if she complied with her insulin that problem would never have arisen…you would just carry on……dementia don't normally pose a problem until it becomes problematic for us, when it stops us doing our job…..P15, DN, I

This suggested that no thought was given to the fact that a resident had diagnosis of dementia, unless it was presenting a problem to nurses, such as preventing care from being given. I found this interesting as it was a sentiment that previously I may well, as a district nurse, have related to, but as a result of the experience gained through this research was one that I would now be ready to challenge; encouraging nurses to recognise the impact that such a diagnosis may have on an individual and the care they may require.

Care practices ignore dementia

As a result of knowledge and insight gained during the case study it appeared that certain practices could fail to take into account the needs of this group of residents; one example being the assessment process and nursing notes. According to most district nursing participants, their assessment would not differ in any way from that used when a person had no CI. The assessment would concentrate almost exclusively on assessing physical needs and the same assessment tools would be used no matter the degree of CI. In fact there was no knowledge on the part of any of the district nurses interviewed of any assessment tools that were specific to the needs of a person living with dementia.

In terms of the specialist nurses, again no dementia specific tools were reportedly being used. Some community matrons spoke of using tools such as a depression scale and the mini mental state examination as part of their assessment process; although one matron mentioned that they had never received any training in the use of these specific tools. Roughly half of participants, including both district and specialist nurses, were questioned about their awareness of the idea of person-centred care. Of those questioned around a third had never heard of the concept. The remaining two thirds had heard of the term, however, most admitted having little idea of its meaning:

…..There was not a written care plan…..There was nothing in her plan to say that if this lady is low in mood, or reluctant to have her insulin then to try blah, blah, blah, which would have been useful…. No the plan itself was just a straight plan, you know, check the blood sugar, administer the insulin, get rid of the needles as per trust policy, nothing about this poor lady's mood, or anything…..P1, PCN, I

…..like one lady we saw she would, when you saw her she would have to take everything with her and we would say no, no. But it turned out she had been like a prisoner of war….and they had tried to take everything away from her. So every time she went everything had to come with her, from the table, everything, because

she thought you were going to.....but if I had known that I would have never have said leave it there......P13, PCN, I

In terms of the care provided, there appeared to be little appreciation of the importance of life history, the need to 'know' a resident, or to share what was known about them with others. A few participants reported that district nursing notes would, on the whole, contain information about a person's physical health problems and there would be little, if anything, regarding their life history. The same was also true of care plans, which would not necessarily make reference to a person having dementia, or the issues it may cause. Another participant reported reluctance on the part of some nursing colleagues to listen to advice given, such as how best to approach a certain resident, or the best time to visit. This could result in staff adopting a variety of different approaches, even when it was known that certain care practices worked best. The lack of such information had resulted in situations being poorly handled by nurses and the needs of residents not taken into account.

Need dementia training

The low levels of knowledge and skills acknowledged amongst participants could be attributed in part to limited training in dementia care. As a result of attending a 'Training for Trainers' course, during the course of the study the researcher had run a number of two-hour sessions covering basic dementia awareness. 59.1% (n=13) of the nurses interviewed had attended this limited training. However, when this training was excluded, then only 18.2% (n=4) had received any dementia training in either their present, or a previous role. Worryingly 18.2% (n=4) of the participants had never received any dementia training at all. Interestingly, four of the five nurses who were relatively newly qualified, i.e. qualified less than 5 years, had not received any dementia training during their nurse training either:

Interviewer: And do you think in terms of the training you have had, has it made you provide care in a different way, think any differently……?

P3: Probably made me think and sit back a little bit more…..

Interviewer: So what did it make you think about?

P3: You know the days that you are…. not rushing but giving them a little bit more time…and explaining more to them. Because they do understand but sometimes it is the way that they verbalise isn't it….P3, DN, I

There was a perception that even though this training had been limited, it had been of benefit, with participants suggesting that they had gained a better understanding of approaches to use when providing care, a greater awareness of the impact dementia could have on an individual, as well as the needs of a person living with dementia and the importance of looking at the whole person and not just concentrating on the physical side. A number of those interviewed spoke of their desire to undertake further training in this field, with suggestions made of possible topics

including: how to work with and support patients living with dementia, assessment tools for use in those living with dementia, the disease process, communicating with people living with dementia and how to manage behaviour that challenges such as aggression. They believed such training would not only equip them with a greater understanding of how best to work with the increasing numbers of people living with dementia they were seeing on their caseloads, but would also enable them to better support family members, as well as formal and informal carers. However, a couple of the participants questioned the feasibility of staff attending yet more training, especially training that was not mandatory, given the pressures the service was under.

Level of healthcare skills needed by care staff

Another confirmed finding was that other nursing participants had a limited understanding of the role of care staff, as well as the skills and support they needed to be able to fulfil their role, summarised as:

- Assumptions made
- 'They are paranoid'

Assumptions made

Evidence from the previous two chapters pointed to care staff taking on care provision that, in the past, would have been considered to be the responsibility of an RN. However, many nursing participants felt care staff were not always able to manage the healthcare needs they were taking on:

> …..sometimes we get a referral where someone I think is really, really poorly and you get referred for a laceration…....You go in and you think really we need to really be looking at the end stages of care for this patient and not just the laceration and really by which time the home needs to prepare not only the patient, the family and the staff to manage that…..and do they want to keep the patient or would the patient prefer to go somewhere else and there is a very small window to arrange and plan those care…....P11, DNTL, I

Areas of poor care reported included: poor infection control practices, failure to recognise early signs of pressure damage and act on this, poor or inappropriate use of pressure relieving equipment, failure to recognise that residents, especially those living with dementia, were in pain, significant damage following a fall not picked up, as well as care staff not appreciating the complexity of the situation they were attempting to deal with, resulting in support not sought soon enough. A number of reasons were put forward by participants to explain why care staff were failing to meet such healthcare needs which included: poor communication between nurses and care staff, care staff not given sufficient training, reluctance on the part of care staff to accept advice or training from nurses, or that their practices needed to change as they were out-dated and not evidence based. However, a failure to meet healthcare needs was not only attributable to the care staff, as the findings also demonstrated that ignorance on the part of the district nursing staff was contributing to the problem:

…..we assume that they have got some knowledge of these conditions that, but I think a lot of them they are not sure of themselves and that I think they don't ask you because they feel that they, it is a matter of saying that they don't know anything and so they are not very comfortable about you know sort of opening up…..P7, PCN, I

…..I think there is appalling ignorance on the other side of professionals who think that they have got skills and understanding……You know when you go into a family in a home…..and they are end of life you know that you need to support that family; you know that you need to explain certain things to that family and also help them to know what they need to be doing to care for that person…… and guiding them through what is happening in the dying process. But district nurses won't necessarily if they were going into somebody in a residential home, they wouldn't necessarily see it as their role to support the care staff in the same way….P19, CNS, I

Few participants had an understanding of the skill set of the care staff with whom they were working; instead there was a tendency to make assumptions about the skills they would possess, as demonstrated by the frequent use of the word assume by a number of those interviewed. Phrases used included '*I assume they have the skills*', '*we probably assume that they'll know*' and '*I think there is a level of assumption that they will do that*'. Assumptions were made that care staff would have received training, would possess the skills to be able to manage the healthcare needs they were faced with, and that they would recognise problems early and refer these on in a timely manner to community nurses. The community matrons for care homes suggested that community nurses did not appreciate that the training care staff received differed from that of the HCSWs based with the district nursing teams, in that it focused mainly on the management of social care needs. And that care staff needed to be well supported by community nurses if they were to manage the healthcare needs they were routinely faced with:

…..a district nurse goes in gives the insulin that is it......there is nobody monitoring whether their output is adequate, nobody monitoring if they are eating at the right times, you know, because that district nurse is going into do just the insulin. The carers are then expected to take up the whole of the slack of that patient's discharge. I mean he is being looked after and monitored in the hospital by carers and nurses doing everything and doctors and everybody coming in and suddenly he has got nothing…..P20, CM, I

'They are paranoid'

Participants from the district nursing service appeared both ignorant of the role of care staff in meeting healthcare needs, as well as of their own responsibilities in terms of supporting care staff. This resulted in nurses expecting care staff to take on care that fell outside their remit, or

165

for which they did not have the necessary skill set, e.g. care staff asked to wash a leg prior to it being redressed, which was likely to be seen as a 'simple' procedure by community nurses, yet had caused issues in a couple of care homes. Ignorance regarding the provision of equipment led a couple of participants to question why care homes weren't routinely expected to provide all their own equipment, in particular pressure relieving equipment.

> .....they are constantly saying can you have a look at somebody's bottom as it may be just a bit red and they are quite able to manage that but because of this reporting thing....they are worried they will get in to trouble they feel they can't manage that simple, when they know exactly what to do....P16, PCN, I

Of concern was the attitude of some district nursing participants who questioned why they were being called in to assess a resident at the first sign of a red mark, even suggesting that nurses were called in simply to cover the care staff, because they were 'paranoid', failing to appreciate that care staff may lack the knowledge or skills to deal with what they were seeing, or that they had been advised by others, such as specialist nurses, to do just this.

Such lack of clarity over the skill set of care staff resulted in some district nursing participants having unrealistic expectations as to what that care staff should be dealing with. Suggestions made included, for example, the monitoring of medication and even the monitoring of wounds, which goes far beyond their role. An example given by one specialist nurse was the expectation by some healthcare professionals that care staff would be able to recognise when a resident was approaching the end of their life and decide if they should be admitted to hospital for acute care, or kept at the care home to die, something that even qualified nurses find difficult. If community nurses have little idea of the skill set and knowledge base of care staff, then one has to question how, as a service, they are able to offer the necessary levels of support needed by care staff to manage the residents they are faced with. Such ignorance could also explain the existence of some of the poor practices mentioned previously, with nurses possibly handing over care without first checking that care staff had the knowledge and skills to take it on.

However, as noted in the previous chapters, ignorance concerning the role of care staff was not helped by different care homes providing what nurses perceived to be different levels of care. An issue causing particular concern for a couple of those interviewed was the administration of insulin, with certain care homes apparently performing this role, yet others not even permitted to carry out blood glucose monitoring. Such uncertainty left participants unsure whether care staff were permitted to perform certain procedures, whether they would be willing to take them on, or alternatively unwilling to pass certain care over to care staff:

> .....Some can do x amount and some can't do other amounts. It is like some care homes can give eye drops, change catheter bags, but other care homes can't...different care homes can do different things. It is like sometimes we go to care homes, we speak to the carers and they can quite happily change a catheter

bag. But then we will go into another care home and the care home manager will
say no you are not doing that, we will have to go in and do it…..P12, HCSW, I

Level of healthcare support needed to manage residents

There appeared to be little awareness, on the part of many of the community nurses, of whether other healthcare professionals were involved in the care of their patients in the care homes. It was also noted that the community nurses tended to focus their attention on the problem for which they had been asked to visit and would leave the care staff to involve any other healthcare professionals that were needed. It was also interesting to note that there appeared little evidence of joint working between the community nurses and the community matrons for care homes, with one of these community matrons admitting that they had only ever been referred one resident by the district nursing service. However, when a couple of community nurses had involved other healthcare professionals, frustration was expressed that these services had failed to communicate with them, regarding the outcome of the visit:

…..I don't think we even know what is going on, we would possibly know about the
clients that we go into see, especially if they have got things like Macmillan Nurses
involved, or tissue viability, but we wouldn't necessarily know…..physiotherapists
were going, occupational therapists, even the GP sometimes we are not too sure
what they are up to…..P6, PCN, I

Dissatisfaction with care home/district nursing relationship

The previous two chapters revealed how an undercurrent of tension and/or dissatisfaction on the part of the care home staff with the district nursing service they were receiving was adding to the complexity that they were facing. However, this was not limited to the care homes, with similar sentiments expressed by the nurses. These are summarised as:

- Relationship variable
- 'They are quite helpful'
- Don't provide support
- Ways the service could change

Relationship variable

Given the needs of the residents, the two services should be working together and supporting each other. Yet, once again, the working relationship these district nursing participants appeared to have with care staff suggested that this was not always happening. This could, in part, be due to the number of care homes that certain district nursing teams were expected to cover, with wide variations noted, from one team who had responsibility for two care homes, to another who supported eight, although two of these were for people with learning disabilities.

The relationship the community nurses appeared to have with these care homes was variable. Although one participant spoke of never having had a negative experience, this was unusual and others would use phrases such as '*it is mixed, 'it is variable'*, '*quite good', 'quite positive',*

'pretty good' and 'some are good and some are bad'. Interestingly those who spoke of a 'varied' experience all worked in the same part of The Trust, dealing with the same care homes:

> …..Some of the staff are very good as well. I mean they will say oh when I was washing her this morning I noticed she had a little scratch, will you just have a look at that. You know she was just wincing, I can't see anything but can you just check this out. Others you will go in and ask them and they will say I have no idea, don't know. Know nothing, saw nothing, can say nothing, go and ask somebody downstairs. So you get to know which ones that you can actually go to and ask….P1, PCN, I

> P4……and every time you go in there they are approachable and they will tell you if there is any change or they are always coming to ask you is it getting better, or can I come and see when you are ready to do it and………they always want to know and when you have seen a patient you go to them, you let them know how the patient is getting on, or has there been any progress or deterioration, always every time you go. Or they will come and ask you before you leave. But I find they, I find it quite good

> Interviewer: And is it a similar sort of experience in all the care homes?

> P4: It is getting there……they are improving; I find that one is probably one of the best. The others are doing it as well. Maybe not as, not with all the staff, but they have some very good staff as well and you are going to have that in a lot of places….P4, PCN, I

When describing the relationship they had with care staff, the community nurses were more willing to be critical than the care staff had been, which may have been down to the researcher being a nurse. Some nurses would put in a qualifying statement such as 'some are very caring and some haven't a clue', 'you have got good staff and bad staff everywhere', or 'most are trying to do their best but with the staff and the resources they have got'. But other nurses would be far more critical and would talk about care staff who 'don't care', 'lack skills', 'can't be bothered', have 'no empathy', or feel 'it is just a chore'.

'They are quite helpful'

As in Chapters 7 and 8, it was possible to identify aspects of the relationship that participants found to be beneficial. A positive relationship was described as one in which care staff appeared interested in the care the nurse was providing, were eager to learn, were approachable, would pick up problems and refer on in a timely manner and would seek feedback from the nurses following their visit:

> …..A good experience is if you instructed carers or the manager to do this and they followed it through that is a good experience, because they have done everything

to the way you wanted it, the plan, to go for that patient.....and they are willing to, if you can't find dressings and things like that they will tell you where it is, where the notes are, they will tell you where it is.....and if they want to bring the patient with you, they will escort them into the treatment room and if somebody is upstairs they will come with you, rather than struggling yourself, so I have found that they are quite helpful....P14, PCN, I

Interestingly, a positive experience often appeared to be directly related to the provision of support that made the community nurse's life easier, for example getting prescriptions when asked, ensuring that the care home was ready for the nurse's visit, knowing who the nurse was there to see, bringing the resident to the nurse and introducing them to the resident, bringing equipment such as notes and dressings to the nurse rather than her having to go looking for them and providing care as requested by the nurses.

Many participants acknowledged that they were heavily dependent on the care staff, relying on them to track down information, provide practical information about the resident and their health status, identify problems early and bring these to the attention of the nurses, provide practical support, as well as relying on them to monitor residents once the nurse had left. Nurses were especially reliant on care staff to support them when providing care to residents living with dementia and what was valued, but did not always happen, was care staff accompanying the nurse when they visited these residents.

Don't provide support

However, as previously mentioned, there was once again an undercurrent of tension and/or dissatisfaction between the nurses and care staff. Some participants suggested that care staff could be defensive at times, unwilling to interact with the nurses and, on occasion, easily offended following perceived criticism of the care they were giving. It was suggested that this situation was not helped by care staff who were either '*in awe*' of nurses, or unwilling to admit their ignorance. Other issues mentioned included care staff appearing disinterested, hostile to new suggestions and reluctant to take advice from nurses. Some district nursing participants found it especially frustrating when they were kept waiting, such as to gain entrance to the building, for dressings or notes to be found, or for residents to be put back to bed:

P3......you try as much as possible to build that rapport up and get to know but there is a bit of a barrier sometimes, in some circumstances... I think sometimes they feel that we are sort of going in and asking questions, you know we have to go in and ask questions because it is not our, in a sense it is not our patient is it. And I think sometimes they feel we are being a little bit intrusive, they get very defensive of their role......But it is really about us gaining more information, not criticising or we may have to offer advice, as at the end of the day we are qualified nurses and unfortunately they are not qualified nurses and they do have to rely on us for advice don't they.....P3, DN, I

A particular issue for many of the participants was feeling unsupported when they visited the care homes. Care homes participants had been annoyed that nurses were not feeding back to them before they left the care home. However, the community nurses painted a different picture. Some spoke of being admitted to a care home and the carer then simply disappearing. This was a particular problem if the nurse did not know the resident they were there to see, especially in the case of those living with dementia. Whether help was offered appeared to be dependent on the care home, with some always reportedly sending a member of staff with the community nurse. However, this was not standard practice. Whether they were accompanied was reportedly often down to the type of care to be given, with care staff more likely to leave the nurse alone when it was felt to be either a straightforward dressing, or for insulin administration. Yet it was provision of such care, and in particular insulin administration, that often appeared to be especially problematic for community nurses. If they were not accompanied, then finding a member of care staff to feedback to could prove problematic, especially in the larger care homes, and time pressures could force them to leave without talking to a member of the care staff:

> *P16…..you say can you help me on to the bed with them they will generally do that and I haven't had a problem with any member of staff who hasn't been willing to help in any way they can......*

> *Interviewer: But it might not be seen as automatic?*

> *P16: Oh it is not automatic sometimes, you know and in one particular place you can be in there ages running around looking for someone to help you which is really frustrating…..P16, PCN, I*

Of interest was the comment made by one district nurse who when challenged that care home staff were not able to help because they were under pressure too, replied '*perhaps, but that is not my problem'*, suggesting that community nurses may be unwilling to take on, or even think about, the challenges facing others, and in particular those in the care homes.

Ways the service could change

Interestingly, as in the previous two chapters, when participants were asked if anything could be done to improve the service given and the working relationship, a number of suggestions were forthcoming. A common suggestion was the holding of regular meetings with care staff. Most saw this as a way of not only improving care provision, but also of providing them with the opportunity to learn more about all residents in the home, not just those on their caseload, as well as improving the relationship they had with the care staff:

> *…..The care homes that we go into regularly, especially the ones where you are seeing more than one client I would actually find it helpful if we knew more about the clients. So if we did have, because their, all their clients are long term you know*

if occasionally we did have a meeting with them just to go through and was there anything going on, is there anything we should be aware of, because I think that would actually make life easier. And also I think that they would feel that we are taking more of an interest, because sometimes I think that they don't feel, we are going in there to do a job, we go in, we do it, we come out again that we are not really sort of bothered about what goes on, which isn't really true…P6, PCN, I

Other suggestions made included: the need for community nurses to think about sharing care, offering a more supportive role, offering education and training and the need for more senior nurses to visit. Continuity of the nurses visiting the care homes was seen as important. However, one team leader was frustrated that the size of her team, the result of reorganisation of the service into fewer, but larger teams, was making this hard to achieve. A suggestion made by a couple of participants was for nurses and care staff to attended training together so they could learn from each other:

…..it is the practicalities, for me personally….it is annoying because you go in and you can't find, in some homes you can't find anything, you can't find the notes. I think if you just see the patients in their bedrooms….with their notes, with their own dressings it would be like seeing someone in their home. But what you get is this situation where they have to lock it all away in a particular cupboard, you know it is rules and regulations and things like that and then you have to go and find someone to open the cupboard and it is all a bit, I find that, I just find that really annoying….P18, DNTL, I

As the above account demonstrates, suggestions were also made that were of a more practical nature and which would make the community nurses' role easier. These included being able to see residents in their room, having all notes and equipment at hand, care staff ensuring that dressings and notes were not lost and care staff accompanying nurses during their visit. However, if the service is to change then it is not only the responsibility of the individual community nurse to implement any such change, with employers and commissioners also having a part to play, as the following participant explained:

….I just think somehow or another we need…to think seriously about how we work with residential homes, particularly in terms of healthcare needs because I think we are not actually coming up with the goods…..I think we either have to find some way of getting district nurses to re-engage with what they are doing with homes, to actually start to understand that things have changed now and you know they do have a responsibility....they need to start thinking very differently about the residential homes. And of course you know to be fair to district nurses as well it is difficult for them because they are very, very pressurised, they are very, very short staffed often…..So I think for the people who manage and the people who are responsible for resourcing district nursing service they need to pay attention to this as well because you know nurses need to be given the time and the resources to

171

be able to actually do this, to actually give time....or they need to find a different
model…..P19, CNS, I

Funding pressures

Finally there appeared to be ignorance of the funding pressures facing the care homes, although the strength of this finding needs to be questioned as it was only mentioned by a small number of participants. There was an apparent lack of awareness of the financial constraints that care homes were operating under. One nurse expressed the opinion that care homes were earning a lot of money, yet were unwilling to invest in their staff. But, when pressed further, admitted having no idea of the level of fees care homes actually received. A couple of district nurses also questioned why these well-funded care homes weren't expected to provide all their own equipment. A typical example being the provision of pressure relieving equipment, which these nurses felt care homes should be providing, failing to understand that they were neither required to provide equipment to meet 'nursing needs', nor did they receive funds to do so:

….they are not giving them any training, they don't want to pay for any training for
them do they.....but they don't look after their staff, they are getting all this money
for these people….P18, DNTL, I

Unconfirmed findings - Awareness of the complexity present

In the previous section findings were presented revealing that many community nurses were, just as the researcher had been, ignorant of much of the complexity present in residential care homes. However, this was not the whole picture, as there was in fact a small group of nurses who did demonstrate an awareness of the complexity that these care homes were dealing with. Participants who had an understanding of the changes that had taken place and the pressures facing the care homes were the specialist nurses, whilst those nurses who had worked in a care home prior to entering nursing demonstrated a greater awareness of the challenges that dementia could add:

…..So you are finding like a 3 tier effect now where you find nursing homes taking
a higher calibre of patient, residential homes taking patients that as you rightly said
about 10 years ago would have been bordering on nursing home…..So that has a
knock on effect because if you do that and raise the calibre of the kind of
patient…..you are going to have to raise the standards of the care that is
provided……P10, CNS, I

…..I do think it (the community matron role) is a very necessary role especially for
care homes, for residential homes because there are so many patients there who
are getting older and the older they get the more complicated their cases, their
illnesses are and they are being expected to manage them at home now, with may
be very little input......P20, CM, I

The specialist nurses displayed a much greater awareness and appreciation of the complexity facing the care homes than the district nursing participants did. Possibly as a result of working closely in partnership with the care homes, something that many of the community nurses did not appear to be doing, largely as a result of caseload and time pressures, as evidenced by a couple of the community matrons, who had worked previously as community nurses and who commented that they now had the time to spend with their patients and as a result the care they were able to provide was more holistic. They spoke in depth about the issues facing care homes, the increasing levels of complex needs, the impact caring for these residents had on the care staff and the support needed by care staff to manage their residents. Of interest was the district nurse who had worked previously as a Macmillan Nurse, who agreed that working more closely with the care homes in this previous role had given her greater awareness of the issues facing the care homes and had affected her attitude to the care homes, as well as the care that she and her district nursing team would provide.

New findings – Not only ignorant

In this final section, data is presented identifying a number of new issues that were raised by the nursing participants, summarised as:
- Ignoring the complexity
- Limited access to medical information

Ignoring the complexity

This section presents data which challenges the suggestion made by the researcher that community nurses are ignorant of the complexity, as this did not appear to be the whole story. It suggests that rather than simply being ignorant as previously suggested, community nurses were, at times, ignoring the complexity that was present. This they appeared to be doing for the following reasons, which are summarised as:
- 'Time constraints'
- Residents are 'safe'
- Unsure who is responsible

'Time constraints'

One of the main reasons for community nurses ignoring the complexity was because of the pressures on the service. Time, or rather a lack of time, was mentioned by almost every nurse interviewed and it appeared to be having a significant impact on the level of care the service was able to provide:

> …..because of time constraints we just go and see who we are supposed to and rather than looking at the bigger picture and say oh there are all these people there who have got lots of problems, but then they haven't been referred so it isn't our problem…….I think most of the time we use the residential home, even if the patient needs 2 nurses we don't go in twos because we know there is a carer to

assist and the carer is not trained to do, to move the patient as we are and then it is quite difficult…..P7, PCN, I

…..time is always a factor. I mean I would quite happily, sort of like to me (the assessment) should be a lot longer than they normally are but I am very aware that I have probably got 10, 12 other patients waiting or…so no I could honestly say hands up that I am quite sort of like, I don't spend as much time with my patients as I should do so……at the back of my mind I am thinking I really should open this can of worms, I really should investigate it a lot further and what have you but I am thinking do I want to go there?...but no I mean to be quite honest I could probably do an awful lot more but it is time constraints….P8, PCN, I

Care that focused on the meeting of tasks was one result of such pressures. Others included limited time spent in care homes and as a result nurses unable to get to know residents well, nurses reluctant or unable to involve themselves with additional health problems, other than the problem for which they had been asked to visit, passing over responsibility for picking these up to the care staff and no longer able to provide any formal training to care home staff.

An issue raised by care home staff was the referral process, which, it was suggested, had made the community nurses less accessible. However, referrals from care homes were also a problem for the community nurses, but for a very different reason. From their point of view, continually being asked by care staff to see additional patients each time they visited was problematic, as it could have a significant impact on their already limited time:

…..where you go into the…care home and they say oh would you mind seeing Mrs Jones because she has not been well for the last 2 days and, but now we say oh no we can't see, we have got to have a referral and come through the central system because we are guided by the number of patients we see…..we miss that opportunity because whereas in the old days we could pop in and see Mrs Jones and we think oh gosh she might have a UTI you know get some sample, or you know little things that might prevent, so we have lost that….P11, DNTL, I

…..and we have tried to explain that we can't just keep adding extra people, especially in big care homes when you have already got about 5 or 6 people on your lists and then they are saying can you see this one…..P18, DNTL, I

Some participants agreed that they would see these residents, as they were concerned that there may be a serious problem. However, others would insist that a referral be sent through before they saw the resident. For some nurses, although they were reluctant to ask for these referrals first, it appeared to be their only means of limiting or managing the number of visits they had, as they often did not have the time to take on any further visits. The problem with such

an approach however, was that it could, reportedly, result in the opportunity to pick up a problem early being missed, as referrals were not always received the same day.

Residents are 'safe'

Many interviewees assumed that residents in care homes were 'safe'. A result of time pressures was a need, by community nurses, to prioritise care. Although a small number of participants commented that care practices should not vary depending on where someone lived, the majority acknowledged that they would prioritise the care of those patients living in their own homes:

> …..I think that because they have 24-hour support we don't worry about them because we know that there is somebody there 24-hours to keep an eye on them if anything untoward should happen to them, whereas if that person was in their own home, on their own, with just a little bit of family support, then you would concentrate more, you would be thinking more I need to do this, this, this, this…......because if they are in care homes it is like they are in a safe environment, there are staff there 24/7 so they are safe, so they are alright so we don't need to worry about them…P1, PCN, I

The majority of the community nurses perceived residents in care homes to '*be safe'*. Those who remained in their own home were seen as being at much greater risk and so resources and time were skewed in their favour. However, given that those entering care homes today are likely to be the most dependent and frail in society, they may equally be at risk, although the type of risk may differ. As a result of this belief nurses appeared to be delegating responsibility for much of the care provision to the care staff. The nurses didn't feel they had to worry about the residents, or get too involved, because there was, as they saw it, someone there to keep an eye on the residents. However, assuming that care staff were able to provide all necessary care and would notify the nurses when problems arose was, as mentioned previously, not always happening, as evidenced earlier by the existence of poorly managed healthcare needs.

Unsure who is responsible

Finally, community nurses were unsure with whom responsibility for residents lay. As a result of what I learnt from the case study I had started to question if the service provided by the community nurses needed to change. Interestingly, one team leader brought up the idea that community nurses needed to rethink the support the service gave to care homes, with a view to, as they put it, '*sharing care':*

> P11…..we provide nursing care as in clinical care and dressings and things like that, but I think it is very much of a more of a supportive role now…..I think in the sense that we are sharing care, rather than going in to say this is my patient…..So we are more supportive and guiding…. I think we need to spend more time really with the carers than the patient because rather than just going in to see the patient I think there is a lot of scope in spending more time working with the carer to care for the patient

Interviewer: That is really interesting.....and do you think most nurses would be happy with that, giving over control to.......

P11: I think some would be happier than others. But.......but again in the political climate as we are it is difficult to give things away when you are ultimately still responsible for the patient…..P11, DNTL, I

But, as this participant mentioned, giving over, or sharing care, care could prove difficult. Concerns were raised by a number of the other participants over lines of responsibility for residents and care given, leading one to suppose that any attempt to share care provision could be met with reluctance on the part of the community nurses. A particular concern for many was that nurses had no direct management responsibility for the staff in care homes, as they worked for a different employer, who was not even part of the NHS. For this reason many district nursing participants were reluctant to be involved in training and educating care staff, or even passing over care, as they didn't feel they were in a position to assess, monitor, or evaluate the competency levels of the care home staff, or the standard of care delivered:

…..we are having to supply the equipment so we are having to go in basically, so it is our responsibility…..and I would argue that it is wrong, if something happens to someone.......and they develop some sort of pressure ulcer is it our fault, we are not there all the time, we are not changing their pads, we are not turning them. I just find, but it all comes back on us….P18, DNTL, I

….because those staff have no responsibility directly to us, so we have got no, no say in much, what they have done, what they haven't done…..because we can't do supervision on them…..P21, DN/CM, I

Fears were expressed over who would be held accountable if care was passed over and something went wrong. Nurses were willing to pass on certain care practices to their HCSWs, as they were able to monitor any care given and could ensure that these staff were given only straightforward cases. But in the case of the care homes, nurses didn't feel they had this level of control, creating a potential barrier to care being shared more efficiently. A good example was in relation to the provision of pressure relieving equipment. It led one district nurse to question whether they should take on residents needing such equipment and why they had to provide and monitor this equipment and be held responsible if the resident developed a pressure sore, when they were not providing the bulk of the care. Although another district nurse felt it was equally unclear where they stood if they used equipment provided by the care home and the resident subsequently developed a pressure sore.

Limited access to medical information

An issue raised in Phase 2 was the difficulty many care home participants had in accessing information about a resident, and in particular their medical history. This was an issue that resonated with many nursing participants:

> …..a lot of them come from different areas….from a different PCT they come into this home and we have got no access to their medical records because when we ask the carers what medication are they on they are not sure….P7, PCN, I

> …..Because obviously a lot of these patients have gone into the residential home with you know needs for social care or are unable to meet their own personal needs at home and then as they stay in the residential home they have got more frailer and elderly and then they have got more nursing and then medical health, physical health problems so they are not really up to date with the patient so they get and it is hard to get information from them as well as the GP at times….P11, DNTL, I

Referral letters, whether from hospitals or GP surgeries, were reported by many to often contain little relevant past medical history, mentioning only the immediate problem for which they were being asked to visit. Accessing information from the resident's GP could prove difficult, with some surgeries reportedly reluctant to give out such information. This appeared to be dependent on the part of the trust in which the nurses worked, with some GP surgeries reported to be more helpful than others. Getting medical information appeared especially problematic when a resident's GP was outside The Trust, as the nurses then had no access to the medical notes held by the GP concerning the resident.

Participants reported relying on the care homes to have the information they needed, or to track it down for them. But, as previously mentioned, these care homes also had difficulty accessing such information. The situation was made more difficult, as one district nurse team leader explained, with residents aging in place and information no longer up to date, or when people were admitted for respite care, as little would be known about them in terms of, for example, their nursing needs. Such difficulties could, in part, also explain why community nurses could have little idea of the true level of need amongst residents.

Reflections of a practitioner researcher

As a practitioner researcher I once again reflected as I transcribed and analysed these interviews, on what I was able to learn from the nurses who took part in both phases of the study. I reflected on the findings that confirmed that community nurses could appear ignorant of the level of complexity present within todays residential care homes and those confirming what I felt I knew of the service offered by community nurses to care homes. I also reflected on those findings that challenged, or surprised me and made me question whether the service provided

to these care homes was truly able to support them to meet the healthcare needs of their residents, especially those residents living with dementia.

On the whole I was not surprised that there was a general level of ignorance when it came to the complexity that was present in these care homes. Many of the experiences and views of these participants mirrored my own, which had lead me in Chapters 7 and 8 to conclude that, as a district nurse, I was ignorant of much of the complexity that was present in residential care homes. I was certainly not surprised how little awareness there was of the 'typical' resident, or indeed of the pressures facing care homes, as often, in the past, I had heard community nurses criticise the care given by care homes and express opinions that they were being well paid for the care they were providing. But as the findings demonstrated, there was ignorance of the funding pressures that were facing many of these care homes. What did surprise me was how willing nurses were to suggest that a resident be moved on as their needs increased. This, I felt, showed little understanding that this was the person's home, that these care homes were allowed to care for greater levels of need than in the past, or even that providing a greater level of support to the care home may ensure that the person would be able to remain in their 'home'.

I hadn't had any real appreciation of the role of care staff until I was able to spend time in the original care home. So it was not really surprising that other nurses were also ignorant of their role and the skills that many possessed. It could also explain, in part, why healthcare needs were at times unmet, with community nurses possibly not checking that care staff were able to manage the care that was passed on to them. But what did surprise me were the unrealistic expectations, in terms of the problems that care staff should be able to deal with. Although, that said, the situation was not helped by the care homes themselves, with no obvious standardisation of the role, and different care homes offering different levels of care.

The fact that there were issues with the relationship was not really a surprise, although I was disappointed that some nurses appeared unwilling to take into account the pressures that many care staff were facing. Neither was I surprised by the service provided by the community nurses, with care provision focusing on the meeting of tasks and concentrating only on the problem for which they had been asked to visit. This I could understand given the increasing pressures the service was facing, although one could question how the community nurses were able to view the residents as 'safe' if they had little idea of the knowledge and skill set of the care staff they were working with. I also felt the use of the term a 'simple' dressing suggested that nurses were failing to understand the complexity they were faced with and as a result more junior members nurses were sent in as routine. What did surprise me, though, was that some district nursing teams would send HCSWs in to these care homes as the following field note reflected:

> …..Something that I have questioned in the past is why the healthcare assistants
> are sent into these care homes. I know they may have some slightly different skills
> to the care staff in the home, but at the end of the day they are all unqualified staff.
> So if we don't believe that the staff in the care home have the necessary skills why

are we then sending in someone of a similar grade. Do we not want someone who has some nursing skills to be going in so they are able to assess more fully what is going on with that person? …..FN 011, p98

A conclusion that could be drawn is that the district nursing service provided at present is not able to ensure that all the healthcare needs of residents are met. This was especially true in regard to those residents living with dementia. When this study began I lacked the knowledge, and many of the skills, needed to care for this particular group of patients. But it appeared that I was certainly not unusual and almost all those nurses who took part reported difficulties caring for these residents. Of interest was the suggestion made by one district nurse that she would give no thought to the fact that a resident had dementia, unless it was perhaps preventing the nurses from providing care, or treatment. Something I probably would have done in the past before embarking upon this journey.

The opportunity to spend time in the original care home, together with knowledge picked up over the course of the study, has been of great benefit to me as a practitioner and it has given me the opportunity to view the care we provide to this group of residents through a different lens and to question if certain care practices could result in unmet needs. Such as, an assessment process that doesn't take into account the persons level of cognition, which targets physical needs only, which fails to use any tools that are dementia specific and fails to recognise the importance of a person's life history, resulting in nurses who do not really 'know' the person, putting residents at risk of problems being missed. The use of notes and care plans that do not take into account the needs of that person, as well as nursing staff who fail to listen to colleagues and don't appear to understand that you need to work with the person living with dementia, that you can't just do something to that person when it suits you and expect them to always be fully compliant. An issue raised by the manager in the case study, who didn't feel able to suggest to the nurses the best time to visit, due to pressures on the service.

It also led me to question whether the service provided is either appropriate, or able to ensure that the needs of the person living with dementia are fully met, with nurses always in a hurry, rushing in and attempting to perform care in the shortest time possible and little or no continuity in terms of the nurse who visits. And whether by doing this we risk causing distress to the person and actually accomplish little. As a service we have to recognise and take into account the needs of those people living with dementia who are living in care homes and just as importantly, those who are living out in the community as the following entry in my research diary reflected:

….What is really important is the life history work, taking account of what care staff tell you. Ignoring what they tell you is not really appropriate as they know the person so much better than we do. To just carry on regardless may actually cause more distress to the resident. For example the resident who we are told is more settled in the afternoon. If they are more settled in the afternoon then shouldn't we

visit then because it will be far less distressing for them? Perhaps we could design a life history sheet, a one page document that we could use in our notes. Also we need to think about care plans that actually make mention of the dementia….Whilst this work is important for the care home residents it may be even more important for those patients who we see at home who may have no one to speak up for them…..RD 15, p235

Summary

This chapter has revealed that the ignorance shown by the researcher of the level of complexity in these residential care homes was not unique. It has shown that many community nurses have little appreciation of how residents have changed, or that increasingly dependent residents are able to remain in these care homes, rather than be transferred. It has also demonstrated ignorance amongst community nurses of the role of care staff in these homes, which results in assumptions being made, care staff expected to take on inappropriate care provision and unrealistic expectations held by nurses of the care these staff can provide.

Whilst previous research has shown that the level of support provided by community nurses to care homes is often insufficient, what these findings have done is to reveal that the support given was often poor, due to pressures placed on the service. Time and caseload pressures can result in community nurses ignoring the complexity that was present in these care homes. Residents were seen as 'safe', with all their needs met. This belief allowed the nurses to concentrate most of their time on those who were seen as being at greatest risk; those out in the community. These pressures had also resulted in an approach to service provision in care homes that was task focused, together with a reluctance, or inability, to consider anything more than the health problem for which they had been asked to visit.

These findings also revealed that the service currently provided by community nurses is concerning, when one takes into account the increasing number of residents living with dementia, who are being cared for in these particular homes. The service provided was typically rushed and focused on the meeting of physical tasks. As a result, community nurses knew little about the residents and were unlikely to develop a relationship with the residents or, if it comes to it, the care staff, which puts these particular residents at greater risk of their healthcare needs going unmet. The conclusion that can be drawn is that the service provided by the community nurses is not appropriate, especially if one takes into account the levels of complexity and need present in these care homes and one could actually go as far as to say that it is no longer 'fit for purpose'.

In the next chapter deeper analysis and interpretation of the findings takes place, with the findings discussed in relation to relevant literature and theoretical perspectives, drawing in particular on complexity thinking and complex adaptive systems

CHAPTER 10: APPLYING COMPLEXITY THINKING TO GENERATE NEW KNOWLEDGE

Introduction

In this chapter the study's findings are discussed in relation to the literature concerning residential care homes and district nursing. This chapter argues that one reason why healthcare needs of residents are not always met is a result of the complexity that is present in today's residential care homes, complexity that is not always recognised or acknowledged, especially by those supporting care homes, including the district nursing service. Due to the complexity facing these care homes, and the community nurses' response to it, this thesis will draw on complexity thinking, to better understand the complex nature of residential care homes and their relationship with the district nursing service. Complexity thinking did not drive the original design of the study, as it was only as a result of this emergent practitioner inquiry that the researcher became aware of the complexity that was present. But once aware of this complexity the findings were revisited, looking for evidence of whether the residential care homes or district nursing service were exhibiting characteristics of a complex adaptive system, as this could offer a potential way forward.

This chapter begins by outlining the strengths and limitations of this study. It defines complexity thinking and in particular the concept of complex adaptive systems (CASs) and evaluates its use in relation to healthcare studies. It analyses the findings in relation to complex adaptive systems, suggesting that residential care homes are diverse, embedded systems, which are constantly adapting, governed by simple rules, which are interpreted and applied differently by agents, according to context and individual interpretation. Characteristics, which others, including community nurses, can be unaware of, or fail to respond to. The chapter offers a 'complexity explanation' (Paley and Eva 2010), highlighting certain barriers, which, it will be suggested, are preventing the healthcare needs of residents from being fully met; including the suggestion that the behaviour of community nurses is also governed by simple rules, which may explain their response to this complexity. The chapter then goes on to use complexity thinking to offer possibilities for change, by encouraging participants to focus on behaviour and improving relationships with others, together with the environment in which they operate; rather than trying to control outcomes, which given the complex nature of these systems, are impossible to control. Finally it offers a number of issues for consideration, based on the findings from the study, and again informed, by complexity thinking.

Strengths and limitations of the study

One of the main strengths of this study is its use of practitioner research, with the researcher using themselves as a research instrument, as it allowed unique access to the care home setting, and gave helpful insight into the potential relevance of the findings to other community nurses. The use of this particular research method enabled the researcher to explore the type of care given in residential care homes, to uncover the complexity inherent within these homes, to

explore and better understand the working relationship that existed between community nurses and these care homes, and to question whether the service provided by these nurses was able to support these care homes to meet the needs of their residents. The strength of this approach was that it encouraged the researcher to draw on previous experience and tacit knowledge, paying attention to, and reflecting on, those findings that were a surprise or a shock. As a result the practitioner researcher may have uncovered findings that others, not in the field of district nursing, may not have felt to be of significance. By using an approach that encouraged reflexivity the researcher became aware of her own ignorance in regard to these care homes and started to question the district nursing care being provided. Her position as a district nurse also gave her clinical credibility to explore these insights with other community and specialist nurses, with the aim of understanding how the service provided may need to change.

The findings need to be treated with a degree of caution as there are limitations associated with PR, due to it being carried out by an 'insider'. The researcher may, for example, feel they know the culture, or hold certain beliefs or assumptions that can prevent objectivity during data collection and/or analysis. Or participants may be reluctant to talk to someone they know, and their answers may not fully reflect their true experiences or feelings. For example, given that the researcher was a district nurse, the care home participants may have been unwilling to criticise the service, or the community nurses reluctant to admit to anything that could cast their practice in a poor light. However, it did appear that it was precisely because she was an 'insider' that staff from the care homes were willing to accept her and to become involved in the study. Whilst those from the district nursing service, appeared willing to be open and honest, as evidenced by participants admitting that they were not always providing the standard of care that they would have liked. As an 'insider', the researcher had in-depth knowledge of the organisations and care practices. By paying attention to her feelings and also to what surprised her whilst working in the case study care home she was able to reflect on, question and challenge her own practice and the practice of others. Further strength was added to these findings by comparing her 'insider view' with the situation in other care homes. By checking whether the findings resonated with those from the case study, as well as seeking findings that did not confirm her original thoughts and reflections, the potential trustworthiness of the findings was strengthened. In addition the study was further strengthened by the researcher addressing possible bias through in-depth reflexive field notes, and by acknowledging her subjectivity in the study, for others to judge possible bias.

The use of a single case study, carried out in one local authority and NHS trust is another reason to treat the findings with caution, as they may not accurately reflect the situation in all other local authorities or trusts. However, to limit this affect, rich description and detail has been provided, so the reader can decide if the findings are applicable to their own situation. As only one case study was conducted, purposive sampling was used, to ensure that the case selected offered the potential for a greater understanding of the issues being explored; in this case, a greater understanding of the care required by residents living with dementia; an issue that is of relevance, given the high levels of dementia across the resident population. The use of a case

study also allowed a more thorough exploration of care provision in this care home than may have been revealed by simply carrying out interviews with staff; whilst the use of a variety of data collection methods deepened understanding of the case by providing insight into the day-to-day workings of the care home from a range of perspectives.

Another limitation of a case study is transferability of the findings, which is why the experiences of staff from other care homes, community nurses and specialist nurses were sought during the second phase; to identify findings that resonated with those from the case study, and reflections of the researcher, and if there were any gaps, again adding strength to the findings. Although the thoughts and experiences of staff across all grades were gathered from the case study care home, it was only possible, during the second phase, to gather the experiences of the more experienced senior care home staff, i.e. those in managerial positions, and so the findings may not necessarily reflect the experiences of other levels of care staff. It was possible to gather data from all grades in the district nursing service. Nonetheless the volume of in-depth data collected and saturation of emergent categories through the analysis gives additional confidence in the findings.

Although the findings cannot necessarily be transferred to all settings, they raise some important issues and one can be reasonably confident of their potential value to other settings. From the perspectives of staff involved in the day-to-day care of residents, the findings give an indication of the many challenges faced in meeting healthcare needs, together with evidence of a possible dysfunctional relationship between care homes and the district nursing service. The study highlights why nursing support to residential care homes needs to be addressed. Given the resonance of the findings to other practitioners, the findings could potentially inform the future direction of the district nursing profession.

Why complexity thinking?

When reflecting on the challenges facing the care staff in this study, a word that frequently sprang to mind was complex, with complexity apparent in the changing and increasing needs of residents, the nature of the workforce, which is low skilled, poorly paid and transcultural, and the challenges of the care home environment, which is independent of the NHS and marginalised by society. Residential care homes generally rely on the district nursing service for any nursing support they need. Evidence presented in Chapter 7 indicates the practitioner researcher was both surprised by, and ignorant of, the complex nature of the work in these care homes; however, as the findings in Chapter 9 suggest she is not unusual. Other community nurses appear either ignorant of the complexity present, or are at times choosing to ignore it, as they are often dealing with challenges of their own and, as a result, the service risks failing to fully meet the needs of either the care homes, or their residents, especially those living with dementia.

For years there have been repeated calls for primary care to better support care homes (Royal College of Physicians et al 2000, Goodman et al 2003b, Gladman et al 2010, Goodman et al 2013). Yet, as the findings suggest, the situation does not appear to have changed. If care homes are to be adequately supported to care for such complex residents this situation has to change, and the complexity they are faced with has to be recognised, acknowledged and explored. This is especially true for community nurses, who need to recognise and respond to the complexity that is now present in these care homes, otherwise residents risk not receiving the levels of nursing support required.

There is a tendency by many disciplines to adopt a reductionist approach when attempting to understand a system or problem, due to the belief that breaking down complexity into its component parts, as if it was a machine, and studying these parts in isolation, it is then possible to understand the whole (Gambino 2008, Heng 2008). The problem is, as this thesis argues, that such an approach is not always helpful and may actually limit our ability to fully understand a system or problem, as the whole is often more than the sum of its parts. This is especially true for living systems such as human organisations, as humans do not function as machine parts, because they have individual choice (Sturmberg and Martin 2009, Zimmerman 2009). Although reductionism has a role to play, there are times when it is only 'by comprehending the whole that the parts become meaningful' (Nash 2014).

This thesis suggests that complexity thinking, and in particular the concept of complex adaptive systems, offers the means to understand the challenges facing residential care homes in meeting healthcare needs of residents, and district nursing support of them. By recognising and acknowledging the complexity that exists Chapter 10, the present chapter, then offers possibilities for moving forwards, Bringing about change can be difficult and the reality is that, in healthcare systems, change often fails because the complex nature of systems is overlooked (McMillan 2004). Assuming that the same method and approach to change will always work ignores the fact that all organisations are different, as each will have their own unique culture, environment, set of rules and outcomes cannot be predicted. For this reason you can't simply transfer one model of service delivery to another and expect it to work. We have to move away from the idea that we can simply 'change' these systems, and approach change from a different angle, by looking for different ways that we can encourage these systems to 'evolve'. This thesis explores the applicability of complexity thinking, and in particular the concept of complex adaptive systems, to residential care homes and the district nursing service, whether it provides a better understanding of why these systems behave as they do and offers possibilities for change that may not have previously been considered, to ensure that residential care homes, their staff and residents, receive the level of support needed.

Defining complexity thinking and a complex adaptive system

Complexity science offers a different worldview, one that doesn't ignore the complexity inherent in many systems, but instead, seeks to understand it and how to work with it. As a science it is relatively new and can be difficult to define and its boundaries mapped (McMillan 2004). The

use in the literature of a variety of terms interchangeably, such as complexity, complexity theory, complexity science and complex adaptive systems can be confusing. For this reason, in terms of this study, it has been decided to use the term complexity thinking, a way of thinking about, seeking to understand and to explain the findings, which has been guided by the concept of complex adaptive systems.

Complexity emerged as a major area of scientific study through the work of a number of scientists during the late 1970s and early 1980s. The Santa Fe Institute in New Mexico was established in 1984, a scientific community of researchers, from a range of disciplines, including biology, physics, economics, chemistry, anthropology, computing and mathematics, dedicated to the study of the fundamental principles of complex adaptive systems (McMillan 2004, Lindberg and Lindberg 2008, Crowell 2011). Complexity science is not a single theory, but a collection of overlapping theories from a variety of sciences, including quantum physics, chaos theory and systems theory. It comprises the study of complex adaptive systems, the patterns of relationships within in them, how they are sustained and how they self-organise and outcomes emerge (Zimmerman 2009).

According to a recent review (The Health Foundation 2010) there is no single definition of what constitutes a CAS. For example Plsek and Greenhalgh (2001) define a CAS as *'A collection of individual agents with freedom to act in ways that are not always totally predictable, and whose actions are interconnected so that one agent's actions changes the context for other agents'*. For others it is the study of *'how relationships between components give rise to the behaviours of a system and how the system interacts and forms relationships with its environment'* (The Health Foundation 2010). However, whilst there appears to be no standard definition of a CAS, there are a number of principles and general properties, which it is agreed, are typical of a CAS, listed in Table 9. It is as a result of these properties that complexity, which may not necessarily be a characteristic of individual agents, can emerge at a systems level (Keshavarz et al 2010).

Table 9: Characteristics of a complex adaptive system

Characteristics	Description
Adaptation or Self-organisation	A CAS is open to influence from multiple forces, both from within and from outside
Agents	The numerous and diverse parts that make up a CAS
Co-evolution	The interdependent and co-ordinated evolution of two or more systems within a larger system
Diversity	Enables a system to adapt or change when confronted with a challenge
Embeddedness	Complex adaptive systems are embedded in other CASs
Emergence	Evolution takes place through the process of self-organisation
Nonlinearity	The ability of a small change in one agent, or between agents, to cause a large change to take place, or a large change to result in a negligible outcome
Simple rules	Guiding principles held by members of an organisation. Local application of simple rules can result in complex outcomes

(Adapted from Kernick 2002, Chaffee and McNeill 2007 and Lindberg and Lindberg 2008)

Complex vs. complicated

Complexity thinking suggests that the universe is full of systems e.g. weather systems, the nervous system, or social systems, which are complex and constantly changing or adapting to their environment (The Health Foundation 2010). Systems can be divided into four groups; simple, complicated, complex and chaotic, depending on the degree to which cause and effect relationships can be determined (Keshavarz et al 2010). Recognising that a system is complex, as opposed to say complicated, is important because complex systems demonstrate a number of characteristics that determine how they develop and evolve. Something that is complicated can have many components and be intricate, yet the relationship between components is fixed, clearly defined and can be accurately analysed (Cilliers 2000). Ultimately complicated systems are knowable, as outcomes can be predicted with a high degree of certainty and also reproduced e.g. launching a rocket into space (Lindberg and Lindberg 2008). Complex systems, on the other hand, are never fully knowable. Because they comprise numerous non-linear relationships and feedback loops, only certain aspects can be analysed at a time (Cilliers 1998). It is not possible to gather a complete or exhaustive description and no set of rules is able to fully capture their nature or working (Cilliers 2000), which is why outcomes are not predictable and solutions cannot be guaranteed to work, such as raising a child for example (Lindberg and Lindberg 2008). This thesis will be drawing on one particular complex system, that of a complex adaptive system (CAS).

Strengths and limitations of complexity thinking

The value of drawing, as this thesis has done, on the concept of CASs to inform ones thinking is that it encourages the researcher to think about and challenge how they see the world, rather than trying to always predict what might happen (The Health Foundation 2010). Complexity thinking encourages the gathering of information about the dynamics of, as well as the relationships, processes and outcomes within a system, information that can be used to develop a better understanding of why a system is behaving as it does, which in turn may be of use in informing service provision (Cilliers 2000, Paley 2007). And whilst, given the nature of complex systems, one is unable to predict the outcome of any change (Cilliers 2000, Kernick 2002), information gathered can be used to construct models of local interactions, which can provide one with a better understanding of what and why certain behaviour might be occurring, which can then be addressed (Paley 2010).

It is argued that a way of thinking, which challenges one to better understand organisations and the behaviour of agents in them, or associated with them, is of relevance to this thesis. Applying complexity thinking to this thesis is able to give a better understanding of residential care homes and the response of the district nursing service to them. An understanding of the nature of their relationship, why these services may be behaving as they do, what could encourage changes to the behaviour, as well as to gather some insight into why ultimately, any change may not necessarily succeed.

Certain authors have raised concerns about the appropriateness of applying complexity thinking unquestioningly. Keshavarz et al (2010) and Paley and Eva (2010) have queried whether it is appropriate to apply a loosely defined concept such as complexity theory, which arose from the field of biology and artificial life, to that of social structures and organisations. Others have argued against modelling an organisation's structures and processes on that of a complex system, because of a lack of rigorous research underpinning the concept, and concern that much of the literature is based on anecdotal evidence, case studies, or is still at the level of ideas, or theory development, with concern expressed that it may simply be a 'fad' (Stacey et al 2000, Rowe and Hogarth 2005, Paley 2007).

Concerns have also been raised, by Paley and Eva (2010), in relation to healthcare, and healthcare organisations in particular. Their argument being that complexity terminology has often been tacked on retrospectively, and used to make sweeping claims that organisations such as nursing, primary care practices, or the NHS are CASs. It is suggested (Paley 2007) that rather than seeking to 'make extravagant and purely speculative claims' it would more appropriate to look for CASs at a local level, much as this thesis has done. Paley and Eva (2010) also suggest that the term 'system' is a hindsight concept and that in many cases there is actually no clear boundary around a system. To counter this they argue that a 'system', rather than always being a physical entity, can also be an abstract concept. One is then justified in taking a 'conceptual slice' through the vast array of structures, processes and interacting elements that may be present, a slice that can itself be regarded to be a CAS. This is not to say that complexity thinking can't be applied to healthcare. The Health Foundation (2010) believes that complexity thinking could be used to good effect in a number of disciplines, including healthcare provision. Whilst McMillan (2004) suggests that evidence is growing of its usefulness, and applicability, offering valid explanations of real-life processes, as well as suggesting new ways of doing things, or why they don't work.

Given the criticism of how complexity thinking has previously been applied in healthcare research, attention has been paid in this thesis, to how it has been done. It is not enough to suggest that a residential care homes is a CAS. If one wishes to apply complexity thinking, three basic principles should be followed (Paley and Eva 2010). Firstly, recognition is needed that complexity is an explanatory concept, in that it seeks to explain how, for example, a specific structure or pattern of behaviour has arisen and in so doing offers an explanation. Secondly, this explanation of complexity belongs to a family of explanations, which are associated with the field of 'social mechanisms'. More specifically 'mechanism-based' explanations, which seek to open the 'black box' and examine the 'cogs and the wheels' i.e. the explanation is determined by connecting the input to the output, by exploring the mechanisms and interactions which lead from one to the other. Thirdly, local agents have no awareness of the impact of their behaviour, or the order that it produces. It is this behaviour that creates complex structures, and as a result the default link between order and design is severed, resulting in self-organisation.

This thesis has sought to address such criticism by presenting findings in Chapters 7 to 9, which are intentionally descriptive, giving insight into some of the relationships, processes and outcomes occurring within residential care homes, and with the district nursing service in particular. Chapter 10 then offers a description of the complex system, provided through a narrative account of both the complex nature of residential care homes and challenges that they and their staff are faced with, together with a discussion of their relationship with the district nursing service. It offers a possible explanation for certain behaviour that is occurring in this system, in particular, the response of the district nursing service to the complexity that is present. The result, it will be suggested, of certain rules, which appear to be influencing the behaviour of the service, which these nurses appear to be unaware of, but which could in part explain why community nurses are reacting to this complexity as they do. The researcher accepts that while in no way has she identified the true nature of this complex system, she is certainly able, through the data collected, to give a snapshot, or a 'conceptual slice' of some of the complexity that is present. This snapshot is presented diagrammatically in Figure 4.

Another criticism, that this thesis has sought to avoid, is that in previous healthcare research authors have failed to appreciate that there is no link between order and design (Paley and Eva 2011). As a result they will suggest that people get together, discuss their ideas, agree goals and plan a strategy, which misses the point of a complex system, as this restores the link between order and design. In a CAS outcomes are not the result of specific goals or plans, but are unintentional, the result of the environment, or of behaviour that is driven by, and conforms to the rules within the system (Paley 2007). By gathering a better understanding of what might be driving certain behaviour it then offers those involved in the system a possible way to influence subsequent outcomes; by, for example, making agents aware of the rules that are influencing their behaviour, or by changing something in the environment. As this thesis recognises that it is not the place of those applying complexity thinking to come up with solutions, the researcher has not made recommendations for future practice, education, or research, but has instead, given certain issues for consideration. She understands that by doing so, given the complex nature of the system, any suggestions that are adopted might result in unintended consequences. However, just as importantly she believes they may offer those involved possibilities for change that they may not have previously considered.

The complex nature of residential care homes

The findings suggest that the care homes in this study are demonstrating certain characteristics of CASs, which are discussed in greater detail in this section, and have been presented diagrammatically in Figure 4. This figure demonstrates the diverse nature of these care homes, the challenges they are faced with, as well as the embeddedness that is present both within, and across different systems, which results in the complexity that these care homes are dealing with on a daily basis. The diagram shows how individual agents within these systems, such as the residents, care staff, or individual care homes, can be complex in their own right, whilst at the same time presenting those who are caring for them, or working with them, with additional

Figure 4: The complex nature of residential care homes

The complex nature of residential care homes

Care staff
- Access to training
  - Cost
  - Language and literary skills of staff
  - Appropriate to needs of residents
  - Staff turnover
- Relationship with other healthcare staff
  - In a hurry – difficult to develop relationship
  - Ignorant of care staff role
  - Can be critical
  - Unrealistic expectations
- Skills and knowledge not recognised by others
  - Hidden workforce
- Ignorant of nursing support available
- Need healthcare skills
- Demands of families

Residents
- Dementia
  - Needs constantly changing
  - Prevalence
  - Respite admissions
  - Admitted later
  - Need to 'know' the person
  - Staff may lack knowledge and skills
  - Care provision challenging
- Healthcare needs
  - Older
  - Frailer
  - Increasing dependency
  - Complexity of needs
  - Multiple co-morbidities
  - Difficulties accessing information re medical history

Context
- Regulation
  - Parent organisation
  - CQC
  - Local authority
  - Policies and guidelines national and local
- staff
  - Wages
  - Cost of training
  - Staffing levels
  - Number of beds
- Funding
  - Block contract
  - Level of fees
  - No increase in fees
  - Unable to fund improvements
- Vacancies
  - Kept at home longer
  - Local authority cuts
  - Accepting inappropriate referrals
- Provider type

Healthcare support
- Accessing equipment needed
- Issues accessing support needed
  - Lack of clarity regarding DN role
  - A reluctance by some to visit
  - DN service under pressure
  - Referral process
- Lack knowledge and skills in dementia care
- Level of support hasn't changed
  - No input into service received
- Inequality in provision of healthcare support
- Ignorance on part of healthcare staff of context
- Benefit from specialist support
  - Specialist medical support
  - Community matron for care homes

189

challenges. The diagram also demonstrates the embedded nature of these systems, with care staff, care homes, healthcare professionals and healthcare services all impacted by, as well as having an impact on each other. It is also acknowledged that, given the nature of complex systems, it is unlikely that all the diversity and complexity present in the care homes has been uncovered, and is likely to be far greater than is presented here, suggesting that further research is warranted if a more complete picture is to be gathered.

Diversity in and between care homes

Firstly, the care homes appear to be comprised of numerous, diverse parts known as agents. An agent is often a person, but can also be something else entirely, such as a policy (Paley 2007). The findings highlight the diversity present in, and between, these care homes, in terms of agents, who are also influencing other agents within, and across other systems, contributing to the complexity present. As the findings and Figure 4 demonstrate, care staff are caring for a diverse range of residents. A typical resident in a care home today is older and frailer than ever before, with high levels of co-morbidity, CI, dependency and disability reportedly the norm, resulting in a unique set of needs, including healthcare needs, which can often be complex. This supports the findings of others (Heath 2007, RCN 2010 CQC 2012), who have also described high levels of co-morbidity and complex care needs, including healthcare needs, with the report by the BGS (2011) even suggesting the existence of a complex mix of healthcare needs unique to the care home population. High levels of dementia amongst the resident population appear to be adding to the diverse nature of the residents. The result of the complex nature of this illness; a continual interplay between physical health, neurological impairment and social and psychological factors, such as biography and lifestyle, which requires staff to 'know' or understand the person if their needs are to be fully met (Kitwood, 1997, Baldwin and Capstick 2007). As a result increasing levels of knowledge and skills are required by care staff, if needs of residents are to be fully met.

The nature of the workforce in these care homes is equally diverse, and appears typical of those working in social care, as described previously in Chapter 2, with differences apparent in terms of race, age, gender and background. There is also diversity in terms of the knowledge and skills of the workforce, which could explain differences in care provision noted between care homes, with some staff carrying out care that others may refuse to provide and which is again contributing to the complexity. Evidence suggests that opportunities for training can be limited in the residential care setting, and many staff may possess no social care qualifications (Eborall et al 2010, Skills for Care 2015). That was not the finding in this study, with the majority of those interviewed holding at least one NVQ, although given that most were in managerial positions they may not be typical of the wider workforce. Evidenced by the fact that staff were reportedly not always able to take up training opportunities due, for example, to poor language and literary skills. What was of particular interest, and appears to be adding to this diversity, is that many care staff in this study also held a professional qualification, resulting in what is suggested is a hidden registered nursing workforce, bringing with them knowledge and skills that can benefit the residents and other care staff. Certain findings suggest there is confusion amongst

community nurses, as staff in care homes may undertake differing levels of healthcare provision. Goodman et al (2013) suggested that care staff are more likely to provide 'nursing' care if there is a history of the staff having previously worked with, or been supported by, NHS staff. However, in this study another possible explanation could be this hidden workforce. Due to the low pay and reluctance of local people to engage with the residential sector, care homes tend to attract a migrant workforce (Experian 2007). Some of these migrant workers may be trained as qualified nurses in their own countries, but are not able to register as one in the UK. Policy prevents residential care homes using these nurses to provide any nursing care to residents, relying instead on community nurses for any support needed. But, as the findings indicate, the knowledge and skills of these nurses is used and their presence benefits both the care homes and residents, with problems picked up earlier, hospital admissions prevented and other care staff able to learn from them. Certain care homes are even actively seeking to employ nurses as social care staff.

No mention appears to have been previously made of the presence of RNs in residential care homes, or of the benefits that they can bring. The literature has only focused on the role of nurses within nursing homes (Perry et al 2003, Heath 2007, Jones et al 2007, Heath 2012), a role which, it has been acknowledged, can have a significant impact on the quality of care received. Studies carried out (Jones et al 2007, Heath 2010, 2012) have reported that, given the complex health and mental care needs of residents, that the healthcare knowledge and experience of registered nurses is essential for the health and well-being of residents, as well as influencing the environment, atmosphere, and quality of care in a care home. This is an issue that is worthy of further research to determine the extent and role of this hidden workforce and what the implications would be if they no longer chose to work in this setting. It also raises issues of workforce exploitation.

Finally, as the findings show, there is the diverse nature of the care homes themselves; a mixed economy, comprising numerous heterogeneous providers, many of whom are small businesses, with no standardisation in the level and type of care provided, reliant on external providers for healthcare support over whom they have little control, and who are struggling as a result of policy, regulatory and financial pressures. A finding supported by Owen et al (2012), who reported that managers of care homes can struggle to deal with numerous challenges from regulatory bodies and agencies, such as for example, levels of paperwork, which will not differ whether a home has 3 or 60 beds. Such diversity not only creates challenges and organisational issues for care homes and their staff, but can also have an impact on other services, due to the embedded nature of these systems.

Care homes are embedded structures

Secondly, the care homes appear to be embedded structures, which are both shaped by, and are shaping, other systems (Keshavarz et al 2010). Every CAS is embedded in a larger CAS. Take, for example, a member of care staff who is embedded in a care home, which is embedded in a parent organisation, which is embedded within a local authority. Each CAS is

shaped by, and will shape, the other CASs within which it is embedded. In order to understand a CAS one can't study agents individually; one needs to examine the whole, to gather an understanding of the order, structure and patterns of behaviour (Anderson and McDaniel 2000, Chaffee and McNeill 2007, Paley and Eva 2010). As Figure 4 demonstrates residential care home are being shaped from within by a diverse range of components, such as individual agents, formal policies and funding issues, which have an impact on levels of need, complexity of care required and knowledge and skills of staff. Care homes are also embedded within other larger systems, such as the NHS, including primary and secondary care services, parent organisations, local authorities, and regulatory bodies. Given the nature of these larger organisations many are also likely to be complex systems, which are shaping, or are being shaped by, the residential care homes.

The diversity of individual agents, e.g. residents, care staff, managers, managers/proprietors and family, is shaping the care homes, in terms of the care they provide and the challenges and demands they face. For example as the typical resident has changed so has their care needs. The literature acknowledges that staff, across the care home sector, are faced with complex needs (BGS 2011, Lievesley et al 2011, CQC 2012), yet few studies have examined the role of care staff in residential care homes, or the care they are expected to provide (Baldwin et al 2003, Perry et al 2003). Outsiders may assume, due to the repetitive nature of the care provided, that the work in care homes is somehow routine, trivial or unskilled (Sandvoll et al 2013). But this is far from the truth. The findings indicate that care staff are providing care that is often complex, due to the unpredictable nature of the work, the complexity in residents, especially those living with dementia and taking over care that was once the domain of registered nurses. All of which is made harder if care staff lack the knowledge and skills. This is an area that requires further research, if true levels of complexity when providing care are to be better understood.

Care homes do not work in isolation but are also embedded in other systems that guide and influence them through, for example, national policy, guidelines and regulation. One example is the CQC, who monitor and inspect all health and social care services to ensure that safe, compassionate and high quality care is being provided. The Registered Homes Act 1984 (Centre for Policy on Ageing 1996) stated that whilst residential care homes were to provide accommodation and personal care only, care staff could carry out 'nursing care', but only under the supervision of a community nurse or GP; hence their dependency on primary care services. But as the findings indicate although care homes are embedded with, and are reliant on primary care services, there are issues with the level of support provided, given the complexity of the needs experienced by older people.

Care homes require access to adequate and appropriate levels of support from healthcare professionals, as care staff can lack confidence in managing the healthcare needs they are faced with, and/or because of the complex nature of needs that are present. Yet, as the findings indicate, they are relying on external healthcare services that can be unpredictable in their

response. Studies (Royal College of Physicians et al 2000, Szczepura et al 2008, BGS 2011, Social Care Institute for Excellence 2013) continue to report that many residents are denied equitable access to primary and secondary care, with GPs, as the findings of this study also indicate, often acting as gatekeepers to other services (Gladman et al 2010, BGS 2011). Care homes rely on primary care to meet the medical and nursing needs of their residents, but, as this study found, the reality is that support is inequitable and far from ideal, with care homes struggling to access up to date medical information about residents and reliant on local arrangements for the provision of appropriate levels of clinical input, which is not always provided.

Given the embedded nature of these systems residential care homes are, in turn, having an impact on primary care services, largely the result of changes in the resident population. Take for example the increasing numbers of residents living with dementia in these homes. Managing the needs of these residents can present care staff with additional challenges; however, the findings suggest the situation is no better for community nurses, who may also struggle to meet their needs. Findings point to low levels of knowledge and skills on the part of many nurses, and care practices that may not always take dementia into account. For example the assessment process used by community nurses appears to ignore cognition and mental health problems and simply focuses on physical problems. Nurses had no awareness of any assessment tools specific to the needs of the person living with dementia, had limited awareness of the importance of life history, little awareness of the importance of person-centred care practices and current service provision could prevent many nurses from getting to 'know' or develop any sort of relationship with these residents; an area that warrants further research if gaps in knowledge, skills and practice are to be better understood.

A number of reports have highlighted the need for health and social care staff to have the necessary skills to care for people living with dementia (NICE/SCIE 2006, DOH 2009), yet, as the findings indicate, nurses have received little, if any, training in dementia care and as a result many feel they are unable to adequately support residents living with dementia, or mental health problems, an issue that needs to be addressed by those involved in the education of nurses. This is not unusual, as others have also suggested that primary care nurses lack knowledge in relation to mental health, and dementia in particular, resulting in limited detection and treatment of problems, and are able to deliver no more than basic level care (Bryans et al 2003, Manthorpe et al 2003, Haddad et al 2005, NAO 2007). It also suggests that nurses may not be in a position to support the care home staff to meet the nursing needs of these residents.

Relationships between agents

Thirdly, relationships within and between systems appear to play an important role in the services provided and the support received. Interactions and relationships occur amongst agents, at all levels and it is from relationships between agents that new ideas, patterns and structures emerge, and is what makes systems 'complex' (Anderson et al 2005, Paley 2007, Crowell 2011). Shared values and expertise within a system can facilitate relationships, for

example a system containing agents from the same professional group is likely to share a similar value systems and knowledge base. However, as the findings show, difficulties can arise when different professional groups work together, as differences in values and expertise between groups can result in conflict and tensions (Anderson and McDaniel 2000).

Access to primary care services is variable

Care homes are supported by primary and secondary healthcare services. The relationships that exist between health and social care systems are important given the complex needs of residents living in care homes, as no one agent is able to meet all the needs of residents, especially those residents living with dementia. Care has to be shared between various agents; however, as the findings indicate there can be issues with the services received and relationships with other healthcare professionals. Healthcare for residents is often inadequate (BGS 2011), as there are no national specific standards or models to guide the provision of primary, medical or allied healthcare support. It is then left to individual services, at a local level, to determine the level of support offered. But, as the findings reveal, this can mean that access to GPs, specialist medical support and allied healthcare professionals is variable, with inequalities in the level of GP support noted, issues accessing information or medical history and access to specialist consultants not uniform across The Trust.

Others have also highlighted difficulties faced by care homes, which are funded by social care, when accessing support from the NHS (Health 2007, BGS 2011, CQC 2012b, Owen et al 2010, Gage et al 2012). For example GP support is known to be variable, with the BGS (2011) reporting that 68% of residents do not have a regular planned medical review and 44% do not have a regular review of their medication, whilst the CQC (2012b) has reported that GPs undertake regular planned surgeries, or visits in only 44% of care homes. Although the majority of care homes have access to geriatricians and psycho-geriatricians, this is usually through the GP, and few have direct access (Glendinning et al 2002). As the findings indicate access to allied health professionals can be equally variable, with care homes reported to have limited access to a variety of health professionals e.g. physiotherapists, SALT teams and OTs, and variations in levels of charging for these services and levels of provision of these services by the NHS (O'Dea et al 2000, Sackley et al 2009, National Primary Care Research and Development Centre 2001). Goodman et al (2013) suggested that access to services and recognition of healthcare needs was a 'mediated and complex process', characterised by erratic and ill-defined models of service delivery, which focused on the individual resident encounter, and integrated working tended to work only if care home staff were prepared to adopt NHS patterns of working and priorities. All of which adds to the complexity that care homes have to deal with.

Nature of working relationship with community nurses

As discussed previously community nurses are the most frequent visitor to residential care homes (Goodman et al 2003a), yet little is known about the relationship between care staff and community nurses. Few studies have explored this subject, (Goodman et al 2003a, 2003b, 2005, Evans 2007, Dobie 2010 Handley et al 2014), with their focus, on the whole, on the experiences of community nurses when working with care staff, and limited attention paid to the

experiences of care staff. To deepen understanding of this relationship from the perspectives of both services, the second aim of this study was to explore with care home staff and community nurses whether the district nursing service was adequately supporting residential care homes to manage the healthcare needs of residents.

The findings indicate that both the care staff and community nurses describe their relationship as largely positive, much as Goodman et al (2005) had found. Care staff value nurses who are contactable, happy to give advice, who are willing to work as a 'team', and give guidance and feedback to care staff in respect of on-going care needs, supporting the findings of Evans (2007). Practical support is equally valued, such as providing equipment without question, and offering training to the care staff. However, as Goodman et al (2003a) also found, the care staff have little understanding of the services, or support that the district nursing service can offer, believing the role of district nurses to be the meeting of specific tasks. In terms of the community nurses the findings show that they appreciate care staff who pick problems up quickly, ask for feedback, appear eager to learn, and accompany them when visiting the residents. They also appreciate support that ensures their time is not being wasted e.g. having equipment, dressings or notes ready when they visit and not being kept waiting for admittance to the home.

The findings also indicate an undercurrent of dissatisfaction with the support each service provides, as both Goodman et al (2005) and Evans (2007) had found. The relationship and level of support given to care homes appears to vary both between and within district nursing teams. The district nursing service continues to appear under pressure and as a result visits are often hurried. But, as was also reported, care staff may try to limit demands on the nurses' time, suggesting that residents' needs may be missed. There is little recognition, or acknowledgment by these nurses, of the knowledge and experience of care staff, supporting the findings of Goodman et al (2005). However, this study also found that nurses possess little understanding of the care staff role, which, it is suggested, creates tensions and can result in unrealistic demands placed on care staff, an issue that may warrant further research to understand what is expected of care staff and whether expectations are realistic, but is certainly a matter that those involved in practice need to address.

There appears to be little evidence of partnership working, with poor communication between the two services, nurses failing to give feedback to care staff and being critical of care staff or their care, which undermines their confidence. A lack of continuity of district nursing staff may prevent nurses from developing relationships with either the residents, or the care staff and the referral process means that care homes are not always able to access the timely support they had previously valued. Frustration was expressed by nurses if care staff did not pick up problems early, asked the nurse to visit for superficial wounds, or continually asked them to see new patients when they visited the home, as Goodman et al (2003a, 2003b) had found. Other issues raised included: care staff who were defensive, unwilling to interact, hostile to new suggestions, reluctant to take advice, or unwilling to accompany the nurse during their visit.

Studies have reported that access to specialist nurses can be limited, depending on the speciality and type of care home, with residential care homes having less access, although this can be a reflection of the client groups and their needs (O'Dea et al 2000, Goodman and Woolley 2004). In this study the care homes were receiving support from a number of specialist nurses, who were more easily contactable and whose support was valued, especially in the case of the community matrons for care homes. Concern has been expressed at a lack of integration between specialist and district nursing roles (Griffiths 1996, Austin et al 2006, RCN 2013, QNI 2014a). This study found little evidence that these two nursing services were working together to support the care homes; although there was no evidence that services were duplicated, another concern often raised, with the two providing very different services. The community matron offered more of a supportive and liaison role, spending time in the care home, providing training when needed and acting as an intermediary with other healthcare professionals. But as is often the case with NHS initiatives this specialist role was short term and phased out during the course of the study, leading one to question if they are able to access such support from other services.

Failure to recognise embedded nature of systems

The findings provide some evidence to suggest that the district nursing service isn't recognising the embeddedness of these systems, and appears to be working in a 'silo', focusing mainly on the physical needs of residents, and leaving others to assess and treat any additional healthcare needs. Unfortunately silo working is common place across public sector organisations, a result of fixed boundaries and the commonly held belief, in health and social care, that it is possible to draw distinct lines which professionals do not cross, even though in reality this is not always possible (Walsh 2000), or appropriate, given the complexity present in older people, who require support that is truly multidisciplinary. The result, as the findings suggest, is that staff can be left caring for patients with little awareness of the decisions or actions of other professionals involved in their care (White and Begun 1996, Wiggins 2008). It has also been suggested (Haynes 2003) that managers and workers concentrate on their own organisations and will rarely acknowledge the world outside their own organisation, or profession, as evidenced by those community nurses who failed to recognise that care staff can be under similar pressures as themselves.

Given the complex nature of the systems involved in supporting the healthcare needs of the residents, as Figure 4 demonstrates, agents need to recognise that they belong to systems that are embedded within other systems. For example, although the community nurses value the support given to them by the care staff, they also need an understanding of the challenges faced by the care staff and to recognise that they may not be able to immediately drop what they are doing to help the nurse. Similar findings were reported by Anderson et al (2003), who used complexity science to understand how care provision in 164 nursing homes in the USA could be improved. They reported that care staff could be reluctant to interact with those who were considered to be of a different professional class, whilst nurses did not necessarily seek out the views of the care staff, or recognise the value of their input; even though the input of

both is just as important if a resident is to be well looked after. Health and social care services are embedded and healthcare professionals, including community nurses, need to recognise that they are part of larger systems, acknowledge their interdependency and consider how they collaborate with others, if service provision for residents is to improve.

Governed by simple rules

Fourthly, the care homes and their staff appear to be following certain rules, which are guiding the care they provide and their interactions with others. A CAS is governed by simple rules, which influence the behaviour of agents within the system (Keshavarz et al 2010). Simple rules are based on codes of practice, policy, or statutory requirements, which result in 'formal' rules that define an organisations roles and practices, and of which the agents are likely to be conscious of. As well as on historically established ways of doing things such as customs, or routines, i.e. 'informal' rules, which can vary between agents in the same organisation, and of which they are less likely to be aware (Paley and Eva 2010). Rules may not necessarily be shared, explicit, or even logical to other agents (Plsek and Greenhalgh 2001). They may also change over time, resulting in interactions that are continually changing and which may be hard to predict (Paley and Eva 2010). Behaviour of a system is the result of agents conforming, or following both types of rules (Paley 2007). In this study there is evidence of the presence of both formal and informal rules which are influencing behaviour.

Formal rules

Examples of formal rules include the fundamental standards set by the CQC, which govern the care that is expected, with inspections carried out to ensure that care homes are complying with these standards and action taken if not. In addition local authorities, together with parent organisations, or proprietors will also set standards, policies and guidelines for practice; often based on national policy, such as defining a 'minor' nursing task, guided by The Registered Homes Act 1984. A wide range of policies and guidelines directed the care provided by staff at the case study site. Such polices included: record keeping, 'nursing care', care of a dying resident, pressure damage prevention, changing of a dressing and nutrition management. They set out explicitly what was expected of the care staff in terms of care to be provided, frequency of assessments and monitoring of care, what to do in case of a problem and when healthcare professionals should be involved. Care staff were also guided by a 'role profile' which outlined their role, together with core competencies, knowledge, skills and experience required for that position. Although often based on national guidance, such policies and guidelines are likely to differ, as they are drawn up by individual organisations. This could partly explain differences in care provision between care homes. The findings indicate that one care home can be happy for care staff to carry out routine observations, whilst another will not allow staff to record observations, yet is willing to allow them to carry out blood glucose analysis for example. As a result there is no consistency in the care staff role, and it can be unclear to those from the outside what the role entails.

This is not uncommon. The majority of literature exploring the role of a care worker has been carried out within the hospital setting. However, defining their role, even within the NHS, has proved problematic, due to widespread variation in titles, roles, functions, education, training and competencies across this workforce (Perry et al 2003, McKenna et al 2004, RCN 2007, Griffiths and Robinson 2010). The few studies carried out in nursing homes give little insight into the role of care staff, with Perry et al (2003) reporting that care assistants define their role in terms of what they are not allowed to do, whilst Baldwin et al (2003) reported similarities between the roles of care assistants and RNs in nursing homes, with both engaged in the same type of work. Interest has been shown in the role of HCSWs in hospitals, and to a lesser extent in nursing homes, because these workers are increasingly undertaking nursing activities (Wild et al 2011). However, in these settings any care provided is done so under the supervision of RNs. What is concerning is that little, if any interest, has been taken of care staff working in residential care homes (Wild et al 2011). Even though, as the findings indicate, nursing activities are increasingly being delegated to them, they do not have the benefit of regular nursing support or supervision, and may have received limited training. An area that warrants further research if both residents and care staff are to be better supported in the future.

Informal rules

Differences in care provision between care homes could also be explained by the presence of informal rules, based on an individual's knowledge, experience, and individual interpretation of formal rules. With different care homes appearing to provide different levels of care, confusion was expressed by the community nurses in regard to what care could, or should be provided by care home staff. It was suggested previously that differences in formal rules could explain variations in care. However another explanation is that individual care homes, and/or care staff are interpreting these rules differently, resulting in informal rules, which are also governing care provision. One example appears to be the presence of RNs in the care homes. Residential care homes are expected to rely on primary care for nursing support. Yet the findings indicate that certain care homes are actively seeking to employ RNs as care staff. Although not formally permitted to provide nursing care, there is evidence that the experience, knowledge and skills these nurses bring are being used by the care homes to the benefit of the organisation, other staff and residents.

Another example is the belief held by the majority of care staff that community nurses only manage certain tasks, such as wound care, or insulin administration. Care homes are unlikely to have been told that this is all the service does, as the written referral criteria for the local service describes a wide range of services which are provided. However, it would appear that this belief is commonly held and as a result care staff are likely only to refer specific tasks to the community nurses, with support and advice often sought from other services. This study has only uncovered a small number of rules and there are likely to be many more governing care homes and the behaviour of their staff and is an area that warrants further research, in order to make agents aware of them and the effect they are having on their behaviour (Paley and Eva 2010). If things are not going to plan in a system the default position can often be that the

agents must be doing something wrong, the 'deficiency explanation'. However, if the behaviour of agents is reasonable, and they are following formal and informal rules, then their behaviour should not be viewed as being faulty (Paley and Eva 2010).

Care homes are dynamic and continually adapting

Fifthly, the care homes appear to be continually adapting to internal and external influences. Diversity within a system, arising from factors such as ethnicity, education, or training, allows a CAS to learn and adapt in response to a new challenge (Keshavarz et al 2010, Lipsitz 2012). Traditional systems theory believes that if disturbed a system will try to return to a prior state, or equilibrium, in order to maintain the status quo. However, in complexity thinking because a systems' behaviour cannot be anticipated, or directly deuced from the behaviour of agents it can result in the evolution of a completely new state (Paley 2007, Crowell 2011). Adaptation is necessary if a system is to survive, however, outcomes may not always be positive, especially on other parts of the system (Keshavarz et al 2010).

When residential care homes were first established, their remit was to provide a home for those requiring care and supervision only (Davies and Seymour 2002). But over the years, continual changes to health and social care provision have seen residential care homes evolving to care for a very different population. As Figure 4 demonstrates, care homes have evolved in response to changes in the resident population, admitting residents who are older, frailer and sicker than ever before, with high levels of complex needs not uncommon. As the incidence of dementia in the general population has increased residential care homes have again responded, becoming the main provider of their care; as evidenced in this study with a high incidence of dementia, even in those homes not providing specialist care.

In response to the increasingly complex healthcare needs of many of these residents the skill set of care staff has also had to adapt and change, requiring greater levels of knowledge and skills amongst the staff. The findings indicate that care staff are increasingly taking on care provision that would be the domain of RNs in other settings (O'Kell 1996, Cavendish 2013), including wound care, pressure area care, catheter care, monitoring of blood glucose levels and even palliative care, including advance care planning. Caring for residents living with advanced dementia is presenting care staff with additional challenges, especially in those homes not providing specialist care. Previous studies have explored the impact that caring for this particular population can have on care staff, with the presence of high levels of stress, emotional exhaustion and even burnout reported amongst staff (Zimmerman et al 2005, Duffy et al 2009). This situation is not helped by a poor understanding of dementia, with research showing that if staff feel they are well trained and supported they experience increased job satisfaction and are more likely to demonstrate person-centred care practices (Zimmerman et al 2005). However, despite repeated calls and changes in the population, there is still no requirement for mandatory dementia training for social care staff, or if it comes to it, healthcare staff either (Alzheimer's Society 2007a, 2013).

The findings also give some understanding of the response of primary care services, and district nursing in particular, to these changes. As discussed in Chapter 2, primary care has also had to adapt to policy changes in the NHS and challenges facing the service. However, it would appear that adaptations have not always been of benefit to the care home sector. Take district nursing for example, where the service appears to have adapted to the increasing needs of patients receiving care in their own home, but not for those in a care home. Some nurses appear unaware of the changes that have taken place within care homes, or of the typical resident found in residential care today. They would suggest that if a resident's needs increased they should be transferred to a nursing home, with little apparent understanding that residential care homes are now allowed to care for residents with significant levels of complex needs, although given the small sample size it is difficult to comment further without additional research. Not much thought appears to be given to the level or type of support provided, with community nurses continuing to focus on managing specific tasks and expecting care staff to manage residents' complex care needs proactively, much as Evans (2007) found. As mentioned previously the increasing numbers living with dementia are also having an impact on the service, with community nurses reporting that they lack knowledge and skills to manage all their needs and care practices that do not appear to have responded to the changes in the care home population, yet few have received much dementia training.

Evidence of non-linearity

Sixthly, within these systems, there is evidence to suggest that implementation of change can result in unintended consequences. A small change in, or between agents, can result in a large change occurring, or a large change can produce a negligible outcome, known as non-linearity (Kernick 2002, Crowell 2011). Non-linearity means that it is not possible to predict the outcome of any change with any certainty, as to accurately predict an outcome requires a detailed understanding of the system and the relationships that may be present, which is simply not possible, given the complex nature of these systems. Take for example the impact of government policy keeping people at home for longer, especially in regard to those admitted who have dementia. The findings suggest that residents are admitted later in the disease process, in a poorer state of health, often with multiple healthcare needs. This drive to care for people at home for as long as possible means that it can be harder for staff to get to know these residents and as a consequence to meet their needs. A finding supported by the Alzheimer's Society (2013), who suggest that people are often admitted later than would be in their best interests and that, as a consequence, it can be challenging for the resident to adapt to a new environment and for care homes to manage their needs. Such residents have also, given the embedded nature of care homes, had, as previously discussed, an impact on the levels of knowledge and skills required by care staff, as well as the level of support and type of services required from primary care. Yet care homes can struggle to access the training and support needed to ensure that residents' needs are fully met, due to financial constraints, and healthcare services have not always responded to changes in the resident population.

Then there is the impact of block contracts on the smaller care homes. The findings show that the majority of care homes were facing funding pressures. Certain care homes were sheltered to some degree, through block contracts with the local authority, ensuring that fees were paid even when beds were unoccupied. But the unintended consequence of this contract was that some independent care homes were then struggling to fill their beds. A few care homes had to seek additional funding streams e.g. offering respite care, which could then see them struggle to manage the needs of these particular residents, including the raising of safeguarding concerns, whilst others were reluctant, or unable to release staff to attend training, or fund improvements to the home.

Another example of unintended consequences on other services can be seen in the changes to the district nursing referral process. The referral process was introduced to manage referrals to the service, with a central referral office established to gather information about the patient and allocate referrals to the appropriate team. However, as the findings indicate, this has had an impact on the care homes, as care staff are not always able, as they once were, to access support from the nurse when they are visiting the home, as they can be asked to refer the resident through the referral centre. As this process may take time there is a risk that nursing support is not provided as early as it could be and treatment may be delayed. This is of particular relevance to residents living with dementia. The findings indicate that as care staff know residents so well they can often pick up an issue or problem at an early stage, e.g. a resident may have stopped drinking and as a result could be at risk of developing a urine infection, becoming constipated, or less mobile. Yet if care staff are unable to identify a specific nursing need then the referral may not be accepted by the central office and so the opportunity to proactively deal with a problem may well be missed. Whereas if they are able to refer directly and talk through their concerns with the nurse when in visiting other residents, this may mean the issue is acted on more quickly. This is a concern previously raised by Parkinson (2006), who suggested that the use of referral criteria for access to district nursing services could exclude people who did not have easily identifiable needs, or who may have benefited from a holistic assessment by a district nurse which could have identified underlying medical conditions, such as in the case of older people.

Care homes are context dependent

Finally, the care homes appear to be influenced by the context in which they are operating. A CAS is highly context dependent in terms of time, history and space (Keshavarz et al 2010), with the action of individual agents directed and influenced, to a large extent, by the context in which they are operating, which in this case included financial factors, resources, or guidelines and policies set by organisations such as CQC, local authorities, parent organisations or individual proprietors. This context adds to the complexity that care homes are dealing with. The findings suggest that many care homes are struggling because of the pressures on social care funding, over which they have no control, but which have a significant impact on their ability to provide a service. The present economic climate has resulted in a significant drop in the levels of fees paid to care homes (Owen et al 2012) and it has been estimated that local authorities

are paying around £50-£140 per week below a 'fair market price' per resident (Independent Age 2013), although there is a suggestion that there has been a legacy of underfunding stretching back over 20 years (Dudman 2007, BUPA 2011). The findings highlight the impact that underfunding is having, especially on smaller, family run homes, with care homes inappropriately accepting residents with high levels of needs, whilst struggling to maintain staffing levels, pay for external training, provide specialist equipment, fund capital improvements within the home, or even simply to stay afloat.

As previously mentioned, national policy governs the nursing care that care home staff can provide and at the case study site there were written guidelines clearly stating what minor 'nursing' tasks could be taken on. Equally explicit was what was expected from the district nursing service to support care staff to take on such care. However, it would appear that such guidelines have not been widely shared, as evidenced by those nurses who are unaware of their responsibility towards the care staff. For other homes it can be the regulator, local authority, or even their own parent organisation who are placing additional pressures and demands on them, in terms of raising safeguarding concerns, audits and monitoring, levels of paperwork, inspection visits, or the drive for full occupancy.

The importance of context was raised by Owen et al (2012), exploring the lessons learnt from implementing best practice in care homes, in particular promoting 'voice, choice and control' and the development of leadership within the care home sector. Managers identified multiple obstacles that it was felt were impacting on their role and preventing improvements in practice from taking place. These included: the challenging relationship between health and social care and the regulatory system, with managers often finding themselves dealing with attitudes of mistrust and blame, supporting positive risk taking by residents, problems working with safeguarding teams, a lack of support from care home owners or provider organisations, a lack of trust from the public, unmotivated staff and a lack of independent support. One reason given by managers for 'voicing' such obstacles was so that society would better understand the context of their work and how hard it can be to deliver best practice in the complex environment in which they are working.

This section has argued that the residential care homes in this study demonstrate many of the characteristics of CASs, with evidence suggesting that they are diverse, embedded systems, which are constantly adapting, are highly context dependent, and are governed by simple rules, which are interpreted and applied differently by agents. Properties that are contributing to the complexity present, but which, other systems, such as the district nursing service, can be unaware of and fail to respond to. Although, as mentioned previously, this study has only uncovered a small part of the complexity that may well be present. Paley and Eva (2010) argue that it is not enough to simply suggest that something is a CAS, but that when referring to a complex system an explanation is also needed of the structure or behaviour that has arisen. The following section offers a possible explanation for why, as a result of this complexity, the

healthcare needs of residents are not always met, focusing in particular on the behaviour of the district nursing service in response to the complexity present.

A complexity explanation

In seeking what Paley and Eva (2010) call a complexity explanation, the findings also indicate certain barriers that may be preventing the healthcare needs of residents from being fully met. These include: the complexity in care homes overlooked and treating care homes as if they were a homogenous unit, rather than recognising they are diverse, embedded systems that can face very different challenges, little understanding of the importance of context and its effect on the care home sector and ignorance of 'rules' governing the behaviour of agents.

Complexity in care homes overlooked

It was previously suggested that agents who are involved in, or are supporting care homes, may not always be aware of, or respond to the complexity identified; evidenced in this study, by levels of healthcare support that are variable, a reluctance to share information e.g. medical history between systems, little understanding of the care home sector or the role of care staff and services that have not responded to changes in the resident population. For example, care homes have been continually adapting and the resident population changing, yet, as this study found, care home managers have never been asked about the type of service or support they would benefit from, whilst the district nursing service shows little evidence of adapting to the changes that have taken place. Care homes continue to receive a service that appears to be task focused, hurried and which offers little in terms of support, or partnership working. Yet, what those in practice and education need to recognise is that they would actually like a service that works in partnership with them, gives timely advice, is willing and able to provide any support or training that is needed and which understands and is able to manage the needs of all residents. The type of service that had been offered by the community matrons, who appeared to have a greater awareness of the complex needs of the residents and were able to spend time building relationships with the residents and care home staff. Although this could simply suggest that they are not experiencing the same type of pressures that the district nursing service is reportedly under.

However, such a response is not unusual, as when one looks at literature, policy documentation or guidelines regarding care homes, there is a tendency to overlook, or ignore, any complexity present, focusing instead on a single issue, such as the increasing needs of residents, or lack of relevant training for care staff. An example of this can be seen in relation to the definition of 'personal care'. On the CQC website a residential care home is defined as 'one which provides personal care and accommodation' only. Personal care is defined in The Health and Social Care Act (2008) as:

> (a) *physical assistance given to a person in connection with:*
> * *eating or drinking (including the administration of parenteral nutrition)*

- *toileting (including in relation to the process of menstruation)*
- *washing or bathing*
- *dressing*
- *oral care*
- *the care of skin, hair and nails (with the exception of nail care provided by a chiropodist or podiatrist)*

(b) the prompting, together with supervision, of a person, in relation to the performance of any of the activities listed in paragraph (a), where that person is unable to make a decision for themselves in relation to performing such an activity without such prompting and supervision

This definition gives the impression that personal care can be easily broken down into a list of definable tasks, involving physical needs and leaves readers with the impression that care staff are providing simple, or basic care. The issue with breaking care down in this way is that the complexity involved in providing what they term 'personal care' is lost. As the findings indicate, care staff are not simply providing 'physical assistance, or supervision', but are reported to be providing care that is often complex, which includes meeting complex physical, emotional and psychological needs, as well as taking over care that was previously the responsibility of RNs. Care staff can be criticised for not meeting the needs of residents yet, it is argued, the issue with such criticism is that there is often little, if any, acknowledgement of the complex nature of the care that this largely unqualified workforce is now routinely expected to provide. An argument supported by the Cavendish Review (Cavendish 2013), which examined the role of healthcare assistants in NHS and social care settings, and which also argued that any suggestion that social care staff were providing 'basic care' clearly underestimated the care they were providing.

Where studies have sought to understand the complex nature of care homes, this has resulted in a better understanding of the array of challenges that need to be considered if quality care is to be provided; unfortunately very few studies have sought to do this, an issue that needs to be addressed. For example, complexity theory has only been applied to the care home sector in the US, where it was used in two studies to understand how care provision in nursing homes could be improved (Anderson et al 2003, 2004, Colón-Emeric et al 2006). Suggestions included moving away from an authoritarian management approach, to one that was less formalised and adopting open, rather than closed, vertical communication patterns between frontline staff. The result being better interaction amongst agents, reduced staff turnover, the free flow of information, and ultimately improved care provision. No studies have applied complexity theory to care homes in the UK, although some have sought to understand the complex nature of their work. For example Owen et al (2012) identified multiple obstacles, including issues working with the regulatory system, a lack of public trust and a lack of independent support, which had an impact on the role of care home managers and prevented improvements in practice from taking place. Whilst the PANICOA study - Prevention of Abuse and Neglect in the Institutional Care of Older Adults (Lupton and Croft-White 2013), comprising eleven studies, identified the complex

nature of abuse, and suggested that mistreatment is the result of a number of factors, including negative staff attitudes, as well as the organisational culture in which residents live, and care staff work.

Little understanding of the importance of context

Another barrier that could be preventing the meeting of healthcare needs is the failure by many to recognise the importance of context. Different contexts influence the way in which agents' function, and can add more complexity when trying to introduce change (Keshavarz et al 2010). Take for example the suggestion, frequently made in the literature, that healthcare needs would be better met if only care staff were given access to training (Benbow et al 1997, Mann et al 2000, Hancock et al 2006). It is certainly true that care staff benefit from training, but as the findings in Chapters 7 and 8 indicate this is a gross simplification, which ignores the raft of other factors preventing healthcare needs from being met. Even accessing training is not, the findings suggest, straight forward, with care homes struggling to free up care staff to attend externally run training, a finding supported by Goddard et al (2013). Staffing, financial and cost pressures mean that training is often run in-house and given by the care home manager themselves, which is not unusual (Alzheimer's Society 2013), although concern has been expressed about the quality of such training, and it was recommended in 2001 that training should only be given by people who have been assessed and accredited (Dalley and Denniss 2001). The language and literacy skills of care staff are another issue, as in certain parts of the country the social care workforce is predominantly non-UK born (Experian 2007, Eborall et al 2010).

The type of training available is also of importance. Given the high levels of healthcare needs now present, evidence suggests that there are benefits to care staff receiving training in healthcare skills (Moriarty et al 2010, Handley et al 2014). Nelson et al (2009) reported that when care staff were trained to provide certain basic nursing skills such as monitoring BP, or simple dressings, alongside NVQ level 3 training, hospital admissions were prevented, early discharges facilitated and illnesses identified sooner. The majority of care home participants held at least one NVQ, although concern has been expressed (Eyers and Bryan 2006, Wild et al 2010) that NVQs do not equip care staff with the clinical skills needed to manage the complex healthcare needs they are faced with and although training of the social care workforce has recently been revised (Skills for Care 2010), the focus of new standards is still concentrated upon social care skills. Many care staff report receiving healthcare training from trust staff, yet certain findings suggest that access to this training is inconsistent.

It is argued that provision of appropriate training is not the only answer, but is far more complex than this, as evidenced by findings which suggest that even if care staff have access to healthcare training, poor care practices can persist. The findings and Figure 4 indicate a range of issues that may need to be addressed if healthcare needs are to be better met. Care staff need access to up to date medical information concerning residents, a finding supported by Brand (2013), who suggests that free exchange of information between all stakeholders in care homes is central to achieving best practice. Care homes need access to training that is

affordable, quickly accessible and pertinent to the residents in the care home at the time (Owen et al 2012, Cavendish 2013). They need access to healthcare support that is both equitable and appropriate to the needs of the residents and staff. They also need information regarding the roles and responsibilities of different services available to them, so they are able to access support from the appropriate service. Wild et al (2010) recommended that input from registered nurses was essential to support care staff who were asked to take on new roles providing 'nursing' care and there is limited evidence indicating that such support is missing, with care staff reportedly experiencing difficulties putting healthcare knowledge into practice, suggesting that further research is needed in this area. Finally, there is a need for the care home sector to be adequately funded, so that it can afford to access the training needed, maintain adequate staffing levels and fund service improvements, an issue that policy makers need to bear in mind.

Ignorance of the rules governing behaviour

A third barrier appears to be a lack of awareness, on the part of agents, of how their behaviour may be conforming to certain rules, which in turn, govern the behaviour of the system (Paley 2007). The findings in Chapter 7 indicate that the researcher was both surprised by, and ignorant of, much of the complexity facing these care homes. Yet, as the findings in Chapter 9 indicate, she is not unique, with many other nurses also demonstrating ignorance of the complexity present. The findings also indicate that the district nursing service is not always responding to the needs of the residents, and that as a result there is a risk that care homes are not receiving the level of support needed to meet the increasingly complex healthcare needs of their residents. It is suggested that a possible explanation for the response of the nurses to this complexity is the existence of 'rules', which appear to be guiding their behaviour.

As discussed previously the behaviour of a CAS is the result of a set of simple rules. In the previous section it was suggested that certain rules appeared to be governing the behaviour of the care homes and staff. Primary care services are also likely to be governed by their own sets of rules, which inform individual services and agents, but which, due to the embedded nature of systems, may also govern the services provided to others, in this case residential care homes. Take for example GP support of care homes. As there are no specific standards or models that specify the service that should be provided by a GP surgery, the findings indicate that each GP surgery is providing a different level of service. As a result some are visiting weekly, others fortnightly, some are willing to visit whenever asked, whilst others will question why they are asked to visit in addition to prearranged visits. Such diversity in service provision could be the result of informal rules held by the surgeries, and/or individual GPs, which dictate the level of service or support that each is willing to provide.

This thesis suggests that the findings give an indication of certain rules that may be guiding the behaviour of the community nurses in this study. Rules which it is argued, may possibly explain the response of these nurses to the complexity in these care homes and why, as a result, the service is not always providing the level of support that is required. Unfortunately it has only been possible to identify a small number of rules from the data. Firstly because complexity

thinking did not drive the original design of the study and so the researcher was unaware of the need to identify any rules that could be driving care provision and secondly because this study only explored one single aspect of district nursing practice, in terms of the support provided to residential care homes. It is likely that that the behaviour of community nurses may be guided by many more rules, indicating the need for further research to identify the existence of other rules and explore their impact on the service that is being provided. It is unlikely that the community nurses are aware that their behaviour and the service that they are providing may be guided by rules. In highlighting their existence, certain behaviour can start to be challenged, and as a result, it may be possible to encourage change.

Formal rules – focus on tasks

The behaviour of nurses in the study will governed by a number of formal rules, which are guided by policies and guidelines drawn up by, amongst others, regulatory bodies, professional organisations and the NHS trust which employs them. As RNs participants follow a code of practice, set out in a series of professional standards from the NMC (2015), which promote safe and effective practice. For example nurses must provide care that is based on the best available evidence, are accountable for care that is delegated to others and must work within the limits of their training and competence. Failure to uphold this code can result in action taken by the NMC. District nurses are also governed by the standards for specialist education and practice (NMC 2001). Locally the district nursing service is guided by their service specification, comprised of a service description and eligibility and referral criteria. For each role within the service there is also a job description, setting out the main clinical, managerial, leadership and professional duties and responsibilities, as well as qualifications, experience, knowledge and skills expected for each role.

It has been unfortunate that over the years there has been a tendency to view the district nursing service in terms of the tasks they perform (Hockey 1997, Audit Commission 1999). A situation not helped when the Audit Commission (1999) and RCN (2003) suggested the need for clear referral processes and explicit criteria, to prevent inappropriate referrals and manage demand across the service as a whole. As a result any patient referred to the service must have a specific nursing need, with a rigid list of categories of patients who they will and will not provide care to, guiding the service the nurses are permitted to provide. For example in the case of a chronically ill patient an assessment can be made to identify any nursing need however, nurses are not able to carry out 'check' visits. The drawback of such criteria is that they comprise a list of tasks, which ignores the knowledge, skills and complex care that community nurses are able to offer to those in the community (Bryans 1998, Hallett et al 2000), and may suggest to those outside that this is all that the service is able to offer. Asking for an identified nursing need also requires the referrer to identify the need, rather than leaving it to the nurse to make an initial assessment of the patient's needs. This is of concern to the QNI (2009), who argue that, as a result, the role of the district nurse is being further eroded. There is also a risk that if those making the referral are unclear of the community nurse role, which is often the case, then all they are likely to refer is specific nursing tasks.

The lack of any formal policy or standards informing the provision of care and support by primary care services, to residential care homes (BGS 2011), means there are no formal rules to guide service provision. As a result support is likely to be based on the informal rules of individual teams, or agents. Such rules tend to be based on either local 'customs' or practice, or on an individual's 'internalised' set of rules which guide their actions and help them to anticipate and predict (Rowe and Hogarth 2005). This could possibly explain some of the differences reported in terms of level of support offered, and relationships formed, by different teams and individual agents; the result of varied understanding by agents of professional roles and working practices, as well as differences in knowledge and skill sets (Rowe and Hogarth 2005). For example a team or individual may view the care home sector in a negative light, believing, as many do, that they are making large profits whilst avoiding providing care (BGS 2011). This may then have an impact on the support they are willing to provide, as evidenced in this study, with certain district nurses questioning the need, and reluctant on occasion, to provide equipment to the care homes, as it was suggested that they should purchase it themselves. A situation not helped if nurses have little understanding of the care home sector and no awareness of the skills and knowledge of the staff.

Informal rules- residents are not at risk

The response of the community nurses in this study is, it is also suggested, governed by certain informal rules.

Care is simple

The first informal rule appears to be the belief held by many nursing participants that care in residential care homes is straightforward. Evidenced, it is argued, by the provision of a service that focuses on the meeting of tasks, which is delivered by more junior nurses and considers much of the care in care homes to be 'simple'. When district nurses are asked to identify the most important aspects of their role, the one aspect most commonly cited is 'holistic assessment' (Barrett el al 2007, QNI 2009), yet, the findings provide little evidence in these care homes of an assessment process, or care practices that are truly holistic. The findings indicate that although referrals from care homes tend to be task focused, task is also a word commonly used by the nurses to describe the nature of their work in these homes, other words also used include simple, or minor. The community nurses suggested that the focus of their care was mainly on tasks, concerning physical problems such as skin tears, pressure ulcers, or the administration of insulin. The findings also suggest that community nurses can be unclear of their role in regard to residential care homes, which is why it might be easier to describe their work in terms of specific tasks. However, when challenged they acknowledge that such tasks are unlikely to be representative of the needs of this patient group, but for certain reasons they appear to focus on managing only the specific need that the resident has been referred for.

The first reason, as discussed previously, is because they may have little understanding of the care home sector and the changes that have taken place in respect to the residents; and as a result appear unaware of the complexity that may be present in the care home population. The

second reason appears to be the result of pressures on the service. As discussed in Chapter 3 demand for district nursing is steadily increasing, the result of a variety of factors including the move from hospital to community based care and an ageing population, often with multiple co-morbidities. Caseloads are increasing, however, this hasn't been accompanied by an increase in the district nursing workforce and community nurses can struggle to manage demand (National Nursing Research Unit 2013). The findings indicate that time and caseload pressures appear to be having a significant impact on care provision, resulting, as previously discussed, in a service that appears to be focusing on the meeting of specific tasks. Interestingly, one manager mentioned that district nurses could be reluctant to visit the care home on a daily basis, an issue that if true needs to be addressed by those involved in practice.

Goodman et al (2005) suggested that district nurses used task based care as a means to limit demand on their caseloads, a suggestion supported by the findings of this study, with community nurses admitting to limiting the time they spend in care homes, by focusing only on the immediate problem for which they are visiting. The belief that care is simple can also result in them relying on the care staff to bring to their attention any new problems, rather than seeking these out for themselves. There is a wealth of research suggesting that the quality of the nurse-patient relationship is at the heart of nursing (Luker et al 2000, Speed and Luker 2004). Central, in the past, to the assessment and planning of care by district nurses was 'personal knowing' of the patients (Luker 2006). Unfortunately, a consequence of social services taking over care previously considered to be the responsibility of nurses has been that such knowledge has too often been replaced by 'knowing-about' or 'knowing-by-proxy', with concern expressed that such 'second hand' knowledge can be inadequate (Speed and Luker 2004). The risk when relying on others for such knowledge is that they may not know the person well, may not appreciate the significance of changes in the person's health or, as was happening on occasion, the two services may not communicate with each other. As a result there is a risk of healthcare needs being missed.

Another way of limiting demand appears to be by ignoring requests to see additional residents and using the referral process as a reason why they cannot see new patients immediately. Goodman et al (2005) also reported that district nurses would seek to limit their time in care homes, but in their study it was achieved by discouraging requests to see residents who were not registered with the GP with whom they worked. A consequence of appearing busy is that, as Nagington et al (2013) found, it can stop patients, or in the case of this study, care staff, from asking for the care or level of support that they require.

The grade of nurse visiting these care homes may be further evidence, it is argued, of the belief that care needs tend to be straightforward, with more junior members of the team routinely visiting. Evans (2007) suggested that more junior nurses could struggle to deal with the changeable nature of residents' needs, due to a lack of expertise and confidence. But, as the findings suggest, the most experienced district nurses have little input into the care homes, leaving much of the care provision to the staff nurses, or even HCSWs. This is likely, in part, to

be the result of the workload pressures, but may also be due to skill mix, which has resulted in a dilution in the level of expertise available (QNI 2011), as evidenced during the course of this study with a significant reduction in the number of district nurse team leaders. As a result residents may not necessarily have regular access to the specialist knowledge and skills of the more experienced district nurses. Studies suggest that community nurses draw on range of knowledge, when assessing and planning a patient's care (Griffiths and Luker 1997, Hallett et al 2000, Kennedy 2000), including theoretical and practical knowledge and intuition, gained in the case of experienced nurses, from years of professional practice. Such knowledge enables expert practitioners to pick up subtle clinical changes and cues that those who are less experienced may miss (Benner 2001, Kennedy 2000). Yet if residents tend to be assessed and supported by less experienced nurses, there is a risk that needs and problems may be missed, as they may lack the 'know-how' knowledge or 'professional artistry' that comes from experience and specialist training (McIntosh 1996). A suggestion supported by McIntosh et al (1999), who reported that senior nurses would focus on more than just the physical condition of the patient, and that RNs were better able to identify risk than HCSWs.

Another possible explanation could be community nurses' view of their role in care homes, which is informing their internalised rules. Abbott (1988) in 'The System of Professions' suggested that professionals tend to divide work into routine and non-routine elements, with the two falling to very different groups. He suggested that routine work is often seen as work of lower status, and is given to lower segments of the professional group, such as juniors, trainees, or even to those outside the professional group altogether. There is some evidence to suggest that community nurses may regard the work in care homes as largely routine, or of a lower status, with talk of simple wounds, or minor problems, and could indicate why they are willing to hand this care over to more junior staff, including to care staff. However, it is difficult to make any further comment without additional research.

Research in the past revealed that district nurses often carried out work for which they were over qualified (Hockey 1999), and with fewer experienced district nurses it is important that their knowledge and skills are utilised effectively. However, it is also important that there is recognition by the district nursing service that the needs of residents may not always be simple and straightforward. This is a vulnerable population, often with complex healthcare needs, who could benefit from regular assessment by the more experienced members of the team (Kennedy 2000).

They are safe
A second informal rule that appears to be guiding service provision is the commonly held belief that residents in care homes are safe. The district nursing service specification states that the aim of the service is 'to provide nursing care to those in their own homes, residential care and other community settings'. However, it appears that community nurses may be providing differing levels of care, depending where the person lives, with priority given to those who remain in their own home. Their justification for doing this is that a patient living in a care home

is safe, as they are in a safe environment, with staff available 24 hours a day to identify and respond to their needs. This is not an unreasonable assumption, given that large numbers of frail, older people are living on their own, many of whom are increasingly dependent and are reliant on domiciliary services, which are increasingly stretched. Evidenced by studies, which report an increase in commissioning of short visits, i.e. between 15-30 minutes, local authorities commissioning on price rather than quality and high staff turnover, the result of low pay (UKHCA 2012, Cavendish 2013). Similar findings were reported by Goodman et al (2003a) and Evans (2007) who suggested that older people in care homes were not automatically seen as the responsibility of primary healthcare providers as they were being 'looked after' and there was an assumption that the presence of care staff meant that needs would be met and changes detected.

Time and caseload pressures mean that decisions often have to be made in regard to prioritising visits. In the case of this study, the belief that residents are safe means that nurses are then able to prioritise those patients in their own home. The suggestion that community nurses prioritise the needs of certain patients is not new. Luker (2006) reported that the needs of palliative care patients were often prioritised, with care taken that visits to such patients did not appear rushed and nurses who would go 'over and above' for them. However, this meant that other patients missed out and additional demands were placed on other colleagues.

The idea that residents are safe needs to be questioned, given that, as the findings indicate, community nurses have little understanding of whether this is true or not, as they know little about the care home sector or the care provided by care staff, have little awareness of the skill and knowledge set of the care staff, and report that care staff are not always managing the healthcare needs they are faced with. Certain community nurses were reluctant to formally hand over care, or provide training to care staff, due to concerns over responsibility for residents' care, findings that warrant further exploration. However, these latter concerns are not universal, and the findings suggest that community nurses can typically focus on the problem for which they had been asked to visit, usually a specific task, make assumptions that care staff are able to provide all necessary care and pass responsibility for identifying other healthcare problems over to others, including care staff. An issue previously raised by Evans (2007), who suggested that district nurses assume that the presence of care staff, and their involvement with residents, enables them to detect changes in the wellbeing of residents, as well as manage the care they require.

The findings of this study suggest community nurses may be doing this because they have little understanding of the role, knowledge, or even skill set, of the care staff with whom they are working. Goodman et al (2005) suggested that the majority of the work of district nurses in care homes is defined by what care staff are not allowed to do. This thesis argues that this is not in fact the whole story, as the findings indicate that community nurses have little idea of what care staff can and cannot do and are instead simply making assumptions, for example, that care staff are able to meet all the care needs of residents, or provide anticipatory care, and expecting

them to take on care provision that is beyond their ability, skill set, or role, allowing community nurses to concentrate on their patients in the community.

As district nurses have little idea of the skill set, or role of care staff, this means that they are also unclear of their role within care homes, an issue reported by Goodman et al (2005) and Davies and Goodman (2008). This can result in different levels of support provided by different teams of nurses and care staff who are viewed as 'paranoid' if they ask for support to manage problems which nurses feel are straightforward or simple. This issue appears to be the result of continuing confusion in regard to lines of responsibility for someone who is being cared for by both health and social care. Both Griffiths (1997) and Goodman et al (2005) suggested that district nurses had difficult defining their role when patients were receiving care from both health and social care services. The findings from this study suggest that over a decade later little has changed. The role of district nursing in residential care homes remains unclear. A situation not helped by a lack of national or local guidelines, clarifying NHS responsibilities for those in care homes (Goodman 2016). As a result the support provided appears to be guided by local customs and 'rules', with individual teams and nurses deciding on what level of support they are willing to offer, and resulting in service provision that can be inequitable. This is an issue that may be addressed given that The Care Act 2014 calls on health and social services to provide joined up care. However, given that there have been repeated calls for integrated or partnership working between primary care and care homes and little has changed, we will have to wait and see.

The value of applying complexity thinking to this study's findings has been that it has given a better understanding of the diverse and embedded nature of residential care homes, together with a possible explanation for the district nursing response, in particular the suggestion that service provision may be governed by rules, both formal and informal, guiding the level and type of support provided, but of which community nurses are unaware. This is the first time it has been suggested that simple rules may be governing the service provided by community nurses to care homes and their staff; however, it is not the first time that rules have been reported in regard to district nursing. Griffiths and Luker (1994, 1997) highlighted certain organisational and 'etiquette' rules governing the interactions of district nurses with patients, other professionals and each other. These rules were uncovered during an ethnographic study of district nursing work by Griffiths (1996), who as a district nurse herself, felt there were invisible rules guiding how district nurses interacted with each other, to ensure that they did not interfere with each other's work and that the team ran smoothly. Rules identified included, not challenging or changing the care given by a colleague, presenting a united front and not undermining other colleagues. There was also a suggestion that these rules were determining patient care, rather than the needs of the patients themselves. The existence of rules, which agents may well be unaware of, highlights the need for further research, to uncover other rules that may be guiding behaviour across the service. As both this study, and that of Griffiths (1996), were carried out by practitioners, with an understanding of and experience in a field of district nursing, they also

highlight the value of research conducted by a practitioner, in both cases uncovering certain practices, or rules, which others outside the profession may not recognise.

This section has sought to demonstrate how complexity thinking provides a possible explanation of why the healthcare needs of residents may not be fully met. The result, it has been suggested, of certain barriers which mean that the complexity present in residential care homes can be often overlooked. The following section raises a number of contextual and behavioural issues that could be considered, if residential care homes are to be better supported by the district nursing service in the future.

Using complexity thinking to offer possibilities for change

When applying complexity thinking it is not appropriate, as part of a complexity explanation, to offer solutions to any challenges, or issues that have been uncovered. But that is not to say that change can't take place, it can, through an adjustment to any rules, or by changing something in the environment (Paley 2007). The findings suggest that residential care homes are diverse, embedded systems that are constantly adapting and are governed by simple rules. Characteristics which community nurses can be unaware of, or fail to respond to. Instead of providing the type and level of support that may be needed by care homes and their residents, community nurses are providing a service that can be driven by caseload and time pressures, may be ignorant of the complexity present, fails to recognise the embeddedness of the two services, and which is guided by their own rules, governing the behaviour of the agents and the system, rather than necessarily the needs of the residents or the staff. Concerns regarding district nursing support of care homes were raised over 10 years ago (Goodman et al 2003b) and the fact that similar findings have been found in this study is concerning, given that residents' healthcare needs have increased significantly over this period of time. Community nurses continue to provide the same type and level of support as they did over a decade ago; support which back then was flagged as inadequate.

There can be a tendency if outcomes are poor, or are not what is expected, to blame those within a system, believing that if the wrong outcome is achieved then it must be because they are doing something wrong (Paley and Eva 2010). Yet if agents are doing what is reasonable in the circumstances and are complying with, and following the rules, then it is not the 'fault' of agents. In this study, for example, is it reasonable to criticise the district nursing service if the level of care provided is not always sufficient, given the pressures faced by the service and that behaviour of agents within the service is guided by rules. In this case, a service specification that focuses on tasks and a lack of any formal policy outlining their role in relation to care provision in residential care homes, leaving nurses to offer a service based on their own set of internalised rules, which can, unfortunately, result in a service that is inequitable.

District nursing support of residential care homes needs to be addressed and complexity thinking offers possible ways in which change could be encouraged. These two complex

systems have to understand that they are embedded, as they are caring for the same group of people and community nurses need to recognise, and have an understanding of, the complexity present in these care homes. Healthcare needs of residents are often complex, typified by the presence of multiple, chronic conditions, together with increasing levels of functional and CI and are unlikely to fall neatly into boxes, or to be adequately met using a task focused approach. The presence of such complexity also means that care staff require greater levels of support than in the past, as the care needed requires levels of knowledge and skills that not all care staff will possess, or should be expected to possess. The current service provided by district nursing not only risks failing to adequately support the staff in these care homes but, more importantly, it risks failing to adequately meet the needs of residents, especially those living with dementia. The two services have to work together to find ways to improve their relationship and encourage greater partnership working, as it will only be by doing this that the healthcare and nursing needs of residents are likely to be better met.

A short term fix is not the answer

The need for better partnership working between health and social care has been a cornerstone of current policy for at least 15 years (Cameron et al 2012); with repeated calls for primary care to better support the care home sector. Evidence suggests that primary care services are beginning to recognise the need to work more collaboratively with the care home sector (Dudman and Meyer 2012), with a search of the literature and internet revealing an array of joint initiatives, many of which have, reportedly, had positive benefits, as well as improving relationships between the two sectors. However, much of this literature is descriptive in nature, has little scientific rigour, little evidence of any formal evaluation and no recent studies have focused solely on district nursing support of residential care homes.

Cameron et al (2012) agreed with this observation, suggesting that the evidence base underpinning joint and integrated working was less than compelling. The report by the BGS (2011) cited a number of initiatives taking place across the UK, including in-reach teams and specialist nurses for care homes, but also highlighted that many were short-term, temporary initiatives, driven by financial reasons, such as inappropriate hospital admissions. Whilst a systematic review of the effectiveness of integrated working between healthcare services and care homes (Davies et al 2011) was only able to identify a limited number of studies where interventions had supported integrated working between care homes and primary care, with interventions often focused on achieving a specific outcome which did not reflect all the needs of the care home population and outcome measures that reflected the priorities of healthcare professionals, rather than residents or care home staff. These studies suggest that long-term change, and integrated working in particular, is not being achieved. For this reason a different approach needs to be adopted, one that aims to bring about permanent change, rather than a quick fix.

Addressing contextual and behavioural issues

Although the literature recognises that primary care support of the care home sector has to change, and will talk in particular, about the need for greater partnership working, there is often little suggestion of how this might be achieved and an assumption that it will just happen. This thesis suggests that complexity thinking offers a possible solution, by developing an understanding of the complex nature of these systems and a greater awareness of the contextual and behavioural issues that may need to be acknowledged and addressed if the healthcare needs of residents are to be better met. In this case the nature of the interactions and relationships between the systems, an understanding of the rules that may be guiding behaviour, and consideration given to environmental changes that may be needed. Complexity thinking also acknowledges that achieving change can be a challenge, that there is no guarantee of success and one may not end up with the outcomes that had been hoped for, which is why it also encourages the focus to be shifted from outcomes, to understanding of processes and rules and addressing the environment.

Previous research has suggested that improving working relationships between health and social care providers is not easy (Cameron et al 2012, Goodman et al 2013). A few studies have suggested ways of achieving closer working between care homes and community nurses, including clarification of their role in care homes, changing traditional working patterns, shared assessment processes, improved communication, and negotiation of roles (Goodman et al 2003b, Evans 2007, Davies and Goodman 2008, Dobie 2010). However, the findings of this study suggest that the relationship between the two services is still often poor, and few, if any, such changes have ever been implemented. This thesis suggests that if change is to be encouraged that the behaviour of and relationships between agents and their environment need to be addressed, with consideration paid to:

- Importance of relationship-centred care
- Recognition of the complex nature of systems
- Respecting and valuing others
- Provision of support
- Provision of training and encouraging learning
- Better communication
- Understanding of context
- Small changes

Importance of relationship-centred care

Good relationships are vital, yet, as the findings suggest, both parties appear unhappy at some level, with the support and relationship on offer, but appear unwilling to rock the boat, with no apparent attempt made by either service to address any issues they have. There is evidence of factors that hinder partnership working (Davies et al 2011, Cameron et al 2012) including a lack of shared values, a lack of clarity regarding roles and responsibilities and poor personal relationships. If the healthcare needs of residents are to be better met this can no longer carry on, and these two services have to address their relationship and work together at improving it.

One way this could be achieved is by encouraging them both to understand the importance of providing Relationship-Centred Care. This term was first coined by Tresolini and the Pew-Fetzer Task Force (1994), who suggested that '*practitioners' relationships with their patients, their patients' communities, and other practitioners are central to health care*' and called on practitioners to be committed to working together, if a patient's needs were to be met. Imposing change on either service is unlikely to work and if the relationship between the care homes and district nursing service is to improve there needs to be a dialogue between them, with any concerns or issues that either service have raised, listened to and addressed together. A suggestion that is supported by Tresolini and the Pew-Fetzer Task Force (1994), who identified the knowledge and skills needed by practitioners if they were to develop an effective relationship with others, which included self-awareness, listening openly to others, effective communication, knowledge of other professions, awareness of the importance of team and community building and the working dynamics of groups, teams and organisations. Both services also have to be willing to invest their time, if such a relationship is to be fostered.

 The building of relationships is just as important when caring for older people. Nolan et al (2006a) suggested that care for this group should be based on the ideals of both Relationship-Centred Care and the Senses Framework. This framework comprises six senses; security, belonging, continuity, purpose, achievement and significance, which they argue are prerequisites for any relationship, and quality care is dependent on all 'senses' being experienced, not only by the older person, but also by staff. A systematic review by Bridges et al (2010) again highlighted the importance of relationships for older people who were receiving acute health care; whilst older people took for granted the quality of technical care, what was of concern to them was the relational aspects of their experience. Three key features of care were linked to more a positive experience, these were: 'connect with me', 'see who I am' and 'involve me', with older people wanting a connected and reciprocal relationship, staff to have knowledge about them as an individual and their needs, and to be involved in any decision making. Although the work by Nolan was carried out with nurses, and the review by Bridges focused on acute care, there is no reason why their conclusions are not relevant across disciplines and care settings, highlighting the importance for all, of developing relationships with both those living and working in care homes.

Recognition of the complex nature of systems
There needs to be an understanding of the complex nature of the two systems. For example, an awareness of the rules that may be guiding the behaviour of agents, the diverse nature of the systems, the impact that such diversity can have, both on their own, and on other systems, as well as the impact of change on other systems. This is important as agents embedded within a system may not be aware of the complexity present, the impact of their behaviour on the system, or how it may be adding to the complexity. Take for example district nursing support of residents living with dementia. Caring for a person living with dementia is a highly skilled job, because of the complex nature of the disease, and a poor understanding of dementia can lead to an inadequate care response, as evidenced by certain district nursing practice which risked

failing these residents. Nurses have often received little training in dementia care, suggesting they may lack the knowledge and skills needed to adequately care for a person living with dementia, no matter where they live, and as a result their behaviour could be contributing to the behaviour of residents that was perceived to be 'challenging'. In dementia there is a continual interplay between physical health, neurological impairment, social and psychological factors; therefore any service that is rushed, which focuses on managing physical needs and knows little about a person's life history is unsatisfactory, and runs the risk of failing to pick up on, or meet, all the needs of these people.

The findings indicate that nurses lack knowledge and skills in regard to dementia care, for example few nurses are aware of what is meant by person-centred care in relation to dementia, although person-centred care, which views the person as an individual, recognises that they have worth, value and dignity and encourages good communication and relationships to be fostered, is widely acknowledged as the cornerstone of good care (Kitwood 1997, Brooker 2007, Adams 2008). Interestingly, Nolan et al (2006b) argue that Kitwood's original vision of person-centred care has been somewhat lost over the years and suggest that a relationship-centred approach may be more appropriate. In terms of the residents there is little evidence of community nurses providing care which is either person or relationship-centred, with care largely task focused, rather than holistic in nature, and documentation and care plans failing to recognise or acknowledge the presence of dementia, or its impact on the individual. Because community nurses are providing a service that is often rushed, which offers little in terms of continuity of nurses and takes little account of a resident's life history, this suggests that communication is likely to be poor and building any type of relationship is likely to prove difficult, especially with those residents living with dementia.

The findings also indicate that nurses can struggle to meet the needs of residents living with dementia, with non-compliance and challenging behaviour reportedly presenting them with particular challenges. The fact that nurses are frequently meeting such challenges could suggest that certain care practices may be having a negative impact on residents, which is expressed through such behaviour. Continually rushing to provide care, and trying to hurry residents may well be putting the well-being of residents at risk, as evidenced by the difficulties repeatedly described when administering insulin to this particular group of residents. Such care practices may even be contributing to what Kitwood (1997) termed Malignant Social Psychology, a range of interactions endemic within an organisation, which, although often unintentional, can undermine a person's well-being. Community nurses are, as the findings indicate, heavily reliant on the care staff if they are to meet the needs of residents, especially those living with dementia, relying on them for both information and support. Unfortunately support is not always forthcoming, especially if the resident is not on a specialised unit and community nurses can be left unsupported by care staff. This is not ideal, but is behaviour that can be addressed and which can change.

Respecting and valuing others

It is important that care staff and community nurses respect and value each other. To achieve this there needs to be an understanding of each other's roles and responsibilities and recognition of, and respect for, the knowledge and skills that each service possesses. Care staff need a clearer understanding of the service and support that community nurses are able to offer, and to understand that district nurses are able to provide a role that is more than simply task focused. In turn, nurses have to recognise that task focused care is not appropriate in this care setting and must make it clear to care staff what services and support they can provide, as well as providing practical information about the service. When multiple agencies, such as district nursing and community matrons, are involved, the roles and responsibilities of each need to be made clear and they should work together to avoid duplication of services. Community nurses need a better understanding of care homes, including an awareness of the roles and responsibilities of care staff, rather than making, as they do at present, assumptions about the care that care staff are able to provide. In turn care staff have to make clear to nurses what their role entails, how policies and guidelines govern this role and the care they are able to provide. Nurses also need to be aware of the knowledge and skill set of care staff they are working with, so that appropriate care is handed over and care staff are not expected to take on care that is beyond their skill set.

Provision of support

There needs to be recognition, by both services, of the level and type of support that the other requires, together with a better understanding of the rules that may be guiding service provision. It has been suggested that certain rules are guiding the behaviour of community nurses and that, as a result, care homes have not always received the level of support that is needed, or desired. The benefit of uncovering such rules means that community nurses can then begin to address their behaviour, with a view to encouraging a change in service provision. For example community nurses need a better understanding of today's resident population, greater awareness of the policies and guidelines that regulate the type and level of care that care staff are allowed to provide, and to consider how they could better support care staff to manage the increasing levels of healthcare needs they are faced with. This could include increasing frequency of visits, providing training, or offering advice over the phone. Consideration needs to be given to the grade of nurse who visits, recognising that there is a need for senior district nurses to visit more frequently, as well as some degree of continuity in terms of those who visit. The study by Kennedy (2000) identified the importance of building relationships with patients, if particular information, such as social and psychological needs, was to be gathered. With the care home sector becoming a major provider of end-of-life care, residents need, for example, to be given the opportunity to talk about any wishes or preferences they may have. Care staff may lack the necessary skills, or be reluctant to broach such subjects, yet if there is no continuity of nurses, there is a risk that such information may not be gathered and needs missed.

Support by care staff is just as important, for example handing over relevant information about a person's life history, and practical support provided, such as accompanying nurses when

providing care to residents living with dementia, or ensuring that notes are not mislaid and prescriptions are collected and to hand. Community nurses need to be aware of the pressures care staff are facing, and understand that care staff are not always able to drop what they are doing to attend to them. Nurses have to recognise that the complex needs of residents can change quickly, which means care staff can need access to timely help and support, which is why additional residents may be referred when the nurse is visiting the home. On the other hand, care staff need to understand why doing this can be an issue for nurses, as not only will they have to provide any treatment, but they will also have to complete a full assessment, which can be time consuming. This underlines why the two services have to talk to each other, address any problems and seek possible solutions that are mutually beneficial.

Provision of training and encouraging learning

If community nurses encourage, or ask, care staff to take on responsibility for managing certain 'nursing' needs, then they have to ensure that these staff have the knowledge and skills to do so. If they don't, then nurses have a duty to provide them with the skills needed to ensure that they are able to take on care safely; this may include providing training to care staff. The provision of training by community nurses is likely to be beneficial; as it can be done informally, when needed by care staff and can respond to the needs of the residents in the home at the time, rather than care homes being expected to access training weeks, or months down the line, when it is no longer of relevance. Although given the pressures facing the service there needs to be recognition by those managing district nursing that this would require more time to be spent in the care homes. However, it has to go further than just providing training; consideration also needs to be given to the provision of on-going support, so that care staff feel supported and able to gain the confidence needed to use new skills. Learning is not a one-way street and community nurses should recognise that care staff can have a wealth of knowledge and experience too, especially in the field of dementia care, and there is much that nurses could also learn from them.

Better communication

Developing good relationships also demands that patterns of communication improve. Community nurses need to recognise that not feeding back to care staff is inappropriate, whilst care staff need to accept that failing to accompany nurses who are unfamiliar with, or to the residents, especially those with dementia, risks the well-being of residents. There needs to be a dialogue between the two services as various issues are causing friction, for example care homes miss being able to informally refer residents who they have concerns about, community nurses can struggle if repeatedly asked to see additional patients, the loss of dressings or notes can impact on the nurses' ability to provide care, and care staff are frustrated when their knowledge and skills are ignored. The services need to raise, and talk to each other about, such issues, understanding them from the others' perspective, as it will only be by doing this that they can come up with ways of dealing with these issues, rather than services feeling they are not understood, or supported by the other. One way to achieve this could be by holding regular meetings, a suggestion that would be welcomed by many participants. Such meetings may encourage their relationship to develop, as it will provide them with the opportunity to get to

know each other better. It could also mean that care homes feel better supported, as the needs of all residents can be discussed and plans of care drawn up, resulting in the provision of care that is proactive, rather than reactive, as tends to happen at present. But this again will have implications for a service that is already stretched.

Understanding of context

Community nurses need a greater awareness of the context in which care homes operate, including knowledge of the regulations governing care homes, the nature of their work, the type of resident that they are able to care for, the care that staff are permitted to provide, as well as understanding the pressures that care homes face, such as financial constraints, which impact on their ability to provide equipment or fund training. There is also a need for greater clarification of regulations and role boundaries. If, as this study found, community nurses are unclear about, or have concerns regarding, where responsibility lies when handing over nursing care to care staff, this suggests that guidelines may need to be drawn up, addressing any such concerns and outlining their roles and responsibilities when supporting care homes, or working with social care staff. Consideration could also be given to whether it would be possible to make use of the knowledge and skills of RNs working in the care homes.

Small changes

Complexity thinking also recognises that imposing wholescale change on a service is unlikely to be successful; instead new ways of encouraging services to evolve need to be considered. The complexity that is present may appear to many to be overwhelming, with those involved unsure how to address the issues, and as a result nothing may change, with staff preferring the status quo. For this reason the introduction of small-scale changes, which are negotiated between individual care homes and district nursing teams, could also be an answer, such as making explicit and discussing competing agendas, or finding common goals and interests. A suggestion supported by work carried out in an acute care setting, A&E, in which it was reported that the care of older people was improved if staff focused on the 'little things' (Spilsbury et al 1999). The findings suggest that the knowledge and skills of care staff vary between care homes, as does the relationship between nursing teams and care homes; for these reasons service innovations may need to be based on the needs of specific care homes and district nursing teams. There also needs to be an acceptance that any change introduced may work, or it may not, but what complexity thinking teaches us is that systems need to be able, and encouraged to, experiment with different ways of doing things, permitted to try out new ideas and find their own ways working and learn from these attempts (McMillan 2004). Although any change achieved in this way may only be small, as McMillan (2004) points out, it is possible that large scale change can arise from numerous small scale changes.

Organisational change needed

If these systems are to be encouraged to change then it is not only at an individual, or micro level, that this has to take place, change will also need to be fostered at both an organisational (meso), and structural (macro) level too (Glasby et al 2011, Goodman et al 2013). Even though complexity thinking suggests that systems are able to transform and adapt themselves to a

changing environment, there is no guarantee that adaptation will happen, as the environment may constrain or inhibit the behaviour that is necessary for any adaptation to take place (McMillan 2004). If change is to be more likely to succeed then an organisation needs to become what Kernick (2002) and McMillan (2004) term as a 'learning organisation'. Such organisations do not depend on control or distrust, but instead promote interaction amongst agents and encourage learning, adaptation and innovation to take place in response to new challenges. Organisations need to give permission to those working within them to think and behave differently, as well as to experiment and learn from each other (McMillan 2004), as it is only by encouraging agents to learn with, and from each other, that they are then better able to respond effectively to any other situation or problem that they are faced with (Vicenzi et al 1997, Wiggins 2008).

The findings suggest that for change to occur there needs to be a dialogue within and between the services; however, this cannot only take place at the level of individual care homes and district nursing teams, but also needs to occur at the level of the provider and commissioning organisations, especially if issues regarding the environment are to be addressed. If the healthcare needs of residents are to be better managed there needs to be recognition, not only by individual community nurses, but also by providers and commissioners of this service, that the needs of residents have changed markedly and that the service currently provided by primary care often fails the residents. There needs to be discussions, at all levels regarding the service that care homes feel they would benefit from, the type and level of service that could be provided, together with the provision of training and resources to encourage this to happen. A suggestion supported by Davies et al (2011), who reported that although integration of services occurred most frequently at a micro level, it was when initiatives were integrated at meso and macro levels that more positive outcomes were shown, such as hospital avoidance, or the ability to offer on-going support and training for care home staff. This study raises certain issues, regarding nursing support of residential care homes, that may need to be considered at an organisational level.

Reviewing nursing support to residential care homes
Seeking to improve the relationship between residential care homes and community nurses is, it is suggested, not the only solution that may need to be considered. It may be time to accept that the present model of nursing support may no longer be fit for purpose and to consider whether a new model of nursing provision would be more appropriate to meet the needs of today's residents. A small change in a CAS can have a large impact on another and if community nurses are to provide the type of service that may be needed, this could be time consuming and they do not appear to have a lot of time to spare, as evidenced by current working practices. Working with residential care homes is only one aspect of their role and if they are asked to spend more time in care homes then something else will have to give. A recent report by the DOH (2013b) outlined the expected role of a district nurse as care is moved out into the community, with talk of enhanced partnership working between health, social care and voluntary sectors, promotion of self-care, tackling social isolation, meeting mental and physical healthcare

needs, working as a team leader and case manager for patients with complex care needs, as well as managing long term conditions and palliative care needs. Caseload size and the complexity of those cared for at home is also increasing, and all of this is happening as district nursing services are being diluted through skill mix (QNI 2009), suggesting that they may be unwilling, or unable, to provide the increased levels of support that may be needed by care homes.

Supporting others to provide nursing care

Consideration has to be given to whether nursing support could be provided in a different way and rather than arguing about who should be doing what, thought needs to be given to who would be best qualified to provide nursing care. One option is that, instead of providing the majority of nursing care themselves, community nurses consider educating and supporting care staff to provide more of the care, leaving them to provide a role that is largely supportive, similar to that of the community matron. Healthcare professionals, including community nurses, actively encourage family members to take on aspects of a patient's care, providing the support and education needed to take on this role (Pickard et al 2003), so why not do the same for care staff? This is not an unreasonable suggestion given that, as the findings indicate, there are RNs working in many of these care homes and it would make sense to openly use their knowledge and skills. This could certainly benefit residents, particularly those living with dementia, as they will receive care from staff who they know, and more importantly who know them and know how best to approach and work with them. It would also mean that nursing care is given at a time that most suits the needs of residents, rather than, as at present, when it is convenient for community nurses. Consideration would, however, need to be given to what care the staff could possibly take on, what skills they would need to be able to do so, what support they would need, who would be responsible for care provision, what would happen if something did go wrong, and services would need to be willing, and able, to work with the uncertainty that such a new role could bring.

Need for a continual nursing presence

Another option is for a permanent RN presence in these particular care homes. When originally established, residential care homes were supporting older people who needed care and attention only, yet this is no longer the case, and they are caring for people who are older, frailer and sicker than ever before, with complex health and social care needs commonplace. As levels of need have increased there has been no corresponding change in levels of health or nursing support, and residents continue to be cared for by a workforce which is skilled in the provision of social care, even though the care home population now more closely resembles that of a nursing home, where residents have 24-hour access to RNs. Unfortunately financial pressures, rather than clinical need, have often dictated residential care placement, with continual attempts by health and social providers to shift responsibility for care provision, especially for frail older people (Lewis 2001). It may be time to finally end the distinction between nursing and residential care homes, as it is outmoded and consider, given that the resident populations are so similar, whether a permanent nursing presence is needed in all care homes, a suggestion supported by others (Lievesley et al 2011, Demos 2014, Gordon et al 2014b).

Care for some of the frailest and sickest members of society has been handed over to a workforce that is largely unqualified, as a recent report highlights (Demos 2014), with 36.9% of care staff having no qualifications. Residential care is aligned to a social model of care, which focuses on personalisation, ability, resident empowerment, person-centred care, and leadership that is creative and transformative (Phelan and McCormack 2013) and although this model has many advantages for older people, the reality is that care staff are no longer managing only social care needs. By 2015 it is estimated that average length of stay will only be one year for a person living with dementia and under nine months for a frail older resident (Lievesley et al 2011), suggesting that most are likely to require significant levels of health and nursing care, especially palliative care. A suggestion echoed by Harrison-Dening (2011) who points out that care homes have become the major providers of end-of-life care for people living with dementia. We have to ask ourselves if this was a group of people with terminal cancer whether their care would be left to a largely unqualified workforce, to which the answer would be no.

It is for reasons such as these that commissioners, service providers, policy makers and even society need to question the nursing support that people in residential care homes receive. Recognition is needed of the value and expertise that RNs bring to care homes and the care of older people (Phelan and McCormack 2013). Studies have shown that a registered nursing presence is associated with improved resident outcomes and, it has been argued, is essential for the health of residents (Horn 2008, Heath 2010, Phelan and McCormack 2013), strengthening the call for a registered nursing presence across the care home sector. This suggestion is supported by a recent report 'The Commission on Residential Care' (Demos 2014), which called for the implementation of a vocational nursing role in what they term 'housing with care'. Their vision is a little unclear, as they suggested that such nurses be trained in these care settings, away from hospitals and universities, which could result in two tiers of nurses, one of which is less highly regarded than the other, however, they did recommend that there is a need for a nursing presence in every care home, to ensure that people get access to the healthcare provision that they need.

This section has suggested that, if the district nursing service is to better support the care homes to meet the healthcare needs of their residents, complexity thinking offers possibilities for change. By encouraging these systems to focus on behaviour, recognising the importance of relationship-centred care, respecting and valuing others, better communication, providing support, training and encouraging learning and accepting that small changes maybe the answer. It has also suggested that there is a need to consider the environment in which these systems are operating, recognising the complex nature of these systems, understanding the impact of context on the care homes, as well as considering whether there is a need, given the health and nursing needs of residents, to end the arbitrary division between care home types and to recognise the value that a permanent nursing presence could bring. Whatever is decided the two services have to be encouraged to work together, trying out new ways of working and

learning from these attempts, if the healthcare needs of the residents are to be better met in future.

Issues for consideration

Although it is not the place when applying complexity thinking to a system to offer solutions, or concrete plans to change practice, a number of issues for consideration have been raised in terms of practice, education, policy making and research, addressing some of the simple rules and contextual and behavioural issues raised during the course of the study and discussion of the findings.

Issues for practice

- Greater understanding is needed of residential care homes, including the diversity that is present in terms of the residents, workforce and the sector itself, the nature of their work, the embeddedness of systems, the importance of relationships, the existence of rules guiding behaviour and the impact of the context in which they operate, including awareness of the regulations and policies governing care homes; all of which are contributing to the complex nature of these systems

- Greater understanding is needed by those involved in the provision of health care of the type of service that is required by care homes, to ensure that residents, as well as care homes receive support that is both appropriate and equitable

- Greater emphasis placed on the importance of developing meaningful and positive relationships, not only between staff, but also with residents, especially when CI is involved. Basing service provision on the principals of Relationship-Centred Care and the Senses Framework may be a way of promoting this. Services should be encouraged to respect and value each other, recognising that each service has a valuable role to play in supporting the residents. Particular attention should be paid to improving the communication between services

- Community nurses need a greater understanding of any rules guiding their behaviour. They need to accept that care is not always straightforward and shouldn't assume that residents are necessarily 'safe'. To recognise the need for more experienced nurses to have a greater role in these care homes and that some degree of continuity is important in terms of nursing staff visiting care homes, so that relationships can be developed, both with residents and the staff who are caring for them. For this to happen they need to have the time to spend in these care homes

- Health and social care staff need to be prepared, in terms of knowledge and skills, to deal with the health and social care needs they are routinely faced with. If community nurses hand over 'nursing care' they need to ensure that the care staff have the knowledge and skills and are supported to take on such care

- Community nurses may need to offer training to care staff on an ad-hoc basis, which is responsive to the needs of the residents. They may also need to support social care

staff put knowledge and skills gained into practice, for example through a process of mentorship. Such support has to be on-going, as skills may not be routinely used

- Given the complex nature of the healthcare needs of residents, health and social care staff need to be able to easily access up to date medical information
- Nursing practice needs to recognise the specific needs of people living with dementia. Assessment practices need to use appropriate tools and recognise the importance of life history, all documentation needs to acknowledge and record the affect that dementia has on the person and service provision needs to be more person-centred.

Issues for education

- Health and social care staff need to be prepared, in terms of knowledge and skills, to care for older people, especially those living with dementia, so they feel comfortable dealing with this particular client group and are able to assess and manage their needs, which may be complex in nature. They need knowledge of person and/or relationship-centred care, to recognise the value of life history work, knowledge of tools that are specific to the needs of those living with dementia and to be in a position to recognise when practice is good, or is failing the older person, so they are able to offer any necessary support
- Social care staff need to be given training in the management of the healthcare needs they are routinely dealing with, such as the management of simple wounds, pressure area care and management of urinary catheters. Training needs to be easily accessible, affordable and on-going, with care staff supported so they feel competent and confident to put knowledge into practice
- Nursing staff need to be prepared, in terms of knowledge and skills, to support and educate others, such as social care staff, to develop the skills needed if providing nursing care
- Any nurse involved with care homes could benefit from a better understanding of the care home sector
- Health and social care staff need to be prepared so they understand the importance of, and are willing to work in, health and social care systems that are fully integrated. They need to understand that silo working is not appropriate and if the needs of older people are to be fully met they have to be at the heart of these systems, with multidisciplinary and partnership working seen as the norm rather than the exception
- Training in relation to complexity science and the concept of CASs may be of value, in particular the influence of rules, especially informal rules, on practice and service provision.

Issues for policy makers

- There needs to be recognition that the care home sector is not always able to meet all the needs of their residents unless well supported

- There needs to be recognition that some care homes may be struggling to cope, together with an open and honest discussion of what is expected from the care homes
- Recognition is needed that residential care homes are not simply providing 'personal care'. The level of complexity present in these particular care homes needs to be acknowledged and discussions had regarding how to move forward. If care homes are expected to care for residents who have similar levels of need and dependency as those in nursing homes then there could be an argument for a permanent nursing presence. If so, this has cost implications, in terms of staff, training and resources.
- There needs to be recognition by all those involved with the care home sector, including policy makers, the Civil Service and Government that health and social care may be complex systems, and as such are governed by certain rules, which could explain why outcomes are often unpredictable and change often unsuccessful
- The focus in health and social care systems needs to move away from outcomes, to the processes involved in achieving change. They should be encouraged to experiment with, and adapt to, new ways of working so that lessons can be learnt about what works and what doesn't. There is also a need to move away from the continual imposition of whole scale changes, focusing instead on small changes, driven by local pressures, as these may be more successful, and lessons learnt from such initiatives may be of relevance to the wider community.

Future research

- There is a need for further exploratory research to uncover more of the complexity that may be present in care homes across different settings and provider types, the impact of diversity on the workforce and their ability to care for their residents, as well as the simple rules guiding service provision by all those involved in supporting care homes. Such research should be multidisciplinary, involving those from the care home sector in particular
- Further research is needed to explore the role, knowledge and skills of care staff and the extent to which the role can differ across the sector, with a view to informing policy and practice guidelines
- Research is needed to explore the impact that the hidden workforce is having on residential care homes, to identify how many nurses are working in these care homes, what they are doing and if they were not there, what impact this would have on care provision and whether this is the reason why residential care homes are willing to support healthcare needs or not
- Further qualitative research is needed to explore the attitudes of healthcare professionals towards care homes, their knowledge of the role of care staff and their expectations of the type of care that should and is provided, so that any misconceptions that are held can start to be addressed
- There is a need for action research that seeks to address the relationship between care homes and community nurses by, for example, exploring the behaviour of and

relationships between agents, whether it is possible to improve relationships, and what lessons can be learnt from this process

- There is a need for more research to be carried out into all aspects of district nursing practice, research that is conducted by practitioners themselves.

Conclusions

This thesis set out to explore the challenges faced by care staff in managing the healthcare needs of residents in residential care homes, in particular those living with dementia, as well as the challenges for the district nursing service in supporting them to meet these healthcare needs. This thesis suggests that complexity thinking can offer a better understanding of why care staff and community nurses may experiences difficulties in meeting the healthcare needs of residents, by encouraging one to view the whole, rather than focus on specific parts only. It argues that contrary to popular belief, life in a residential care homes is complex and unpredictable, a result of the diverse and embedded nature of these systems, which are constantly adapting, governed by simple rules, that are interpreted and applied differently by agents, according to context and individual interpretation. Characteristics, which others, including community nurses, may be unaware of, or fail to respond to. As discussed in Chapter 6, there is reasonable confidence that the findings from this study are transferrable to other settings. However, in addition the researcher has also provided rich contextual detail so the reader may judge if the findings are of relevance to their own situation. It is also argued that, with many of the findings supported by the literature the complexity that was uncovered was not unique.

It suggests that the certain barriers may be preventing the healthcare needs of residents from being fully met. These include the complexity in care homes being overlooked, little understanding of the importance of context and its effect on the care home sector and ignorance of 'rules' governing the behaviour of agents, including the suggestion that the service provided by community nurses is guided by rules, i.e. the belief that the needs of residents are simple and that residents are safe, which offers a possible explanation for the response of these nurses to the complexity that is present. As a result the service provided can tend to be driven by rules and caseload pressures, rather than the needs of either the residents, or the care staff.

It argues that previous attempts to address primary care support of care homes have largely been unsuccessful and suggests that complexity thinking also offers possibilities for change, as it encourages one to focus on behaviour, relationships and the environment in which systems operate. Rather than focusing, as is often the case in the NHS, on tasks and trying to control outcomes, as highlighted by The Francis Report (2013), which given the complex nature of these systems, are impossible to control. As a result this thesis has suggested areas of behaviour that may need to be addressed by the workforce and raised contextual issues, in particular in regard to nursing support of residential care homes, which could be worthy of consideration at an organisational level, if the healthcare needs of residents are to be better met

by the district nursing service. It then offers a number of issues for consideration, rather than recommendations, based on the study's findings and informed by complexity thinking.

This thesis concludes by summarising how this study has contributed to the body of knowledge, in terms of practice based and theoretical knowledge, and links to the issues for consideration made earlier. This study adds to the existing literature regarding residential care homes, by contributing to our understanding of the diverse and embedded nature of these organisations, in terms of the residents and their needs, the care that the largely unqualified workforce is being asked to provide, the complex nature of the relationships they have with others and the impact of the environment in which they are operating, complexity that is often overlooked or ignored by those who are supporting them. It has also contributed further to our understanding of the working relationship that exists between care home staff and district nurses, a relationship which both services are often dissatisfied with and has provided further evidence of why nursing support to residential care homes may need to be revisited.

This thesis has also added to the existing literature on practitioner research, demonstrating the value to be had when an experienced district nurse uses herself as a research instrument to carry out research. An approach that allowed the researcher to reflect on the findings in relation to her knowledge, experience and practice and to challenge preconceptions previously held. As a result her own practice and that of the team with which she is based, has been influenced and demonstrates how practitioner research is able to draw on the tacit knowledge of experienced practitioners, as well as to narrow the gap between research and practice.

This study has added to the body of knowledge through its use of complexity thinking to better understand the complexity that was uncovered, suggesting that residential care homes demonstrate many of the characteristics of a CAS and to identify certain barriers, which it is suggested, may be preventing the healthcare needs of residents from being fully met. This thesis has added to the body of district nursing knowledge by suggesting that the service provided by community nurses to residential care homes is guided by certain rules, which may explain their response to the complexity that was uncovered. This study has also added to practice based knowledge by suggesting a number of behavioural and contextual issues that may need to be addressed if nursing support of these care homes is to possibly change.

This study has been able to add to the body of theoretical knowledge through its use of complexity thinking, which has not previously been applied to the care home sector in the UK, or district nursing. This study's use of complexity thinking adds to our understanding of why the use of a reductionist approach is not always appropriate when seeking to understand systems that are complex. It has also contributed to our understanding of the implementation of change, suggesting a shift of focus from outcomes, which given the complexity of the systems involved, are unpredictable and often unsuccessful, to processes, rules, behaviour and relationships, from which there is much that can be learnt. This study has also contributed to knowledge by suggesting that the implementation of small changes, driven by local needs, may be more

successful, than trying to impose whole scale change across these complex systems, a suggestion that those involved in implementing change within both health and social care, at both a practice and policy level, might do well to bear in mind.

Although this thesis has provided a greater understanding of the complexity that is present in residential care homes, and the challenges facing care staff and the district nursing service, it is in no way a complete picture and further research is needed if the healthcare needs of residents are to be better met in the future. It may also be the case that complexity thinking does not hold all the answers to the system issues identified in this study. But encouraging those within systems to make explicit and discuss competing agendas, together with common goals and interests, could be a starting point, offering possibilities for moving forwards. Finally, this study has suggested that district nursing support of residential care homes may need to be addressed, as it may no longer be fit for purpose, an issue that needs to be acknowledged and addressed at all levels if the healthcare and nursing needs of some of the frailest and sickest members of our society are to be adequately met.

REFERENCES

Abbott A (1998). *The System of Professions. An Essay on the Division of Expert Labour.* Chicago: The University of Chicago Press.

Adams T (2008). Nursing people with dementia and their family members. In: Adams T (ed) *Dementia Care Nursing.* Basingstoke: Palgrave Macmillan.

Age UK (2011). *Care in crisis: causes and solutions.* (Online) Available from: http://www.ageuk.org.uk/Documents/EN-GB/Campaigns/Care%20in%20Crisis%20-%20FINAL.pdf?dtrk=true (Accessed 06.12.14)

All-Party Parlimentary Group on Dementia (2009). *Prepared to care. Challenging the dementia skills gap.* (Online) Available from: http://www.nationalcareforum.org.uk/content/APPG%20Report%20PDF%20version.pdf (Accessed 06.12.10)

ALNA (2009). Scope and Standards of Assisted Living Nursing Practice. http://www.alnursing.org/alnursecert/SCOPE_AND_STANDARDS_FINAL2_09-19-06.pdf (Accessed 4.12.14)

Alzheimer's Society (2004). When does the NHS pay for care? London: Alzheimer's Society.

Alzheimer's Society (2007a). *Dementia UK: The Full Report.* London: Alzheimer's Society.

Alzheimer's Society (2007b). *Home from Home.* London: Alzheimer's Society.

Alzheimer's Society (2013). *Low expectations. Attitudes on choice, care and community for people with dementia in care homes.* London: Alzheimer's Society.

Alzheimer's Society (2014a). *Dementia 2014: Opportunity for change.* London: Alzheimer's Society.

Alzheimer's Society (2014b). *Dementia UK: Second edn.* London: Alzheimer's Society.

Aminzadeh F, Dalziel W, Olnar F, and Alie J (2004). An Examination of the Health Profile, Service Use and Care Needs of Older Adults in Residential Care Facilities. *Canadian Journal on Aging*, 23(3):281-294.

Anderson R and McDaniel R (2000). Managing Health Care Organizations: Where Professionalism Meets Complexity Science. *Health Care Management Review*, 25(1):83-92.

Anderson R, Issel L, and McDaniel R (2003). Nursing Homes as Complex Adaptive Systems. *Nursing Research*, 52(1):12-21.

Anderson R, Corazzini K, and McDaniel R (2004). Complexity Science and the Dynamics of Climate and Communication: Reducing Nursing Home Turnover. *The Gerontologist*, 44(3):378-388.

Anderson R, Crabtree B, Steele D, and McDaniel R (2005). Case Study Research: The view from complexity science. *Qualitative Health Research.* 15(5): 669-685.

Andrews G and Phillips D (2000). Moral dilemmas and the management of private residential homes: the impact of care in the community reforms in the UK. *Ageing & Society*, 20:599-622.

Anthony S and Jack S (2009). Qualitative case study methodology in nursing research: an integrative review. *Journal of Advanced Nursing*, 65(6):1171-1181.

Appleton J and King L (1997). Constructivism: A Naturalistic Methodology for Nursing Inquiry. *Advances in Nursing Science*, 20(2):13-22.

Arnold P, Topping A, and Honey S. (2004) Exploring the contribution of district nurses to public health. *British Journal of Community Nursing*, 9(5):216.

Asselin M (2003). Insider Research Issues to Consider When Doing Qualtiative Research in Your Own Setting. *Journal for Nurses in Staff Development*, 19(2):99-103.

Atkinson P and Hammersley M (2007), *Ethnography: Principles in practice.* 3rd Edn, Routledge, London.

Audit Commission (1999). *First Assessment - a review of district nursing services in England and Wales.* London: Audit Commission.

Austin L, Luker K, Caress A, and Hallett C (2000) Palliative care: community nurses' perceptions of quality. *Quality in Health Care*, 9:151-158.

Bain H and Baguley F (2012) The management of caseloads in district nursing services. *Primary Health Care*, 22(4):31-38.

Bajekal M (2002). *Health Survey for England 2000: Care Homes and Their Residents.* London: The Stationery Office.

Balbes J (2014). *The practice of GPs charging retainers to care homes*. London: Care England. (Online) Available from: http://www.careengland.org.uk/paying-health-care-reality-many-care-homes (Accessed 13.11.14).

Baldwin C and Capstick A (eds) (2007). *Tom Kitwood on Dementia: A reader and critical commentary*. Maidenhead: Open University Press.

Baldwin J, Roberts J, Fitzpatrick J, While A, and Cowan D (2003). The role of the support worker in nursing homes: a consideration of key issues. *Journal of Nursing Management*, 11:410-420.

Ball J, Philippou J, Pike G, and Sethi G (2014). *Survey of district and community nurses in 2013: report to the Royal College of Nursing.* London: NNRU. (Online) Available from: http://www.rcn.org.uk/__data/assets/pdf_file/0010/580744/14.14_Survey_of_district_and_community_nurses_in_2013_Report_to_the_Royal_College_of_Nursing.pdf (Accessed 1.7.14)

Banerjee S, Murray J, Foley B, Atkins L, Schneider J, and Mann A (2003). Predictors of institutionalisation in people with dementia. *Journal of Neurosurgical Psychiatry*, 74:1315-1316.

Barley R (2011). *Why familiarise?* (Online) Available from: http://sru.soc.surrey.ac.uk/SRU62.pdf (Last accessed 24.09.15)

Barley R and Bath C (2014). The importance of familiarisation when doing research with young children. *Ethnography and Education*, 9 (2): 182-195

Barrett A, Latham J, and Levermore J (2007). Defining the unique role of the specialist district nurse practitioner. *British Journal of Community Nursing*, 12(10):442-448.

Barry H, Parson C, Passmore P, and Hughes C (2015) Pain in care home residents with dementia: an exploration of frequency, prescribing and relatives' perspectives. *International Journal of Geriatric Psychiatry*, 30:55-63.

Bebbington A, Darton R and Netten A (2001). *Care Homes for Older People.Vol 2. Admissions, needs and outcomes.* Canterbury: PSSRU.

Benbow S, Walsh A, and Gill G (1997). Diabetes in institutionalised elderly people: a forgotten population? *BMJ*, 314(7098):1868-1869.

Benner P (2001). *From Novice to Expert. Excellence and Power in Clinical Nursing Practice.* New Jersey: Prentice Hall Health.

Bergen A and While A (2000) A case for case studies: exploring the use of case study design in community nursing research. *Journal of Advanced Nursing*, 31(4):926-934.

Black B, Finucane T, Baker A, Loreck D, Blass D, Fogart L, Phillips H, Hovanec L, Steele C, and Rabins P (2006). Health Problems and Correlates of Pain in Nursing Home Residents With Advanced Dementia. *Alzheimer Disease & Associated Disorders*, 20(4):283-289.

Blythe S, Wilkes L, Jackson D, and Halcomb E (2013) The challenges of being an insider in storytelling research. *Nurse Researcher*, 21(1):8-13.

BMA (2016). *Government needs to address problems facing care home services, warns GP leaders. Press release,* http://web.bma.org.uk/pressrel.nsf/wall/FA1CFCAAA2B8AD3C80257F4C003B5F3F?OpenDocument (Accessed 16.02.16).

Bonner A and Tolhurst G (2002). Insider-outsider perspectives of participant observation. *Nurse Researcher*, 9(4):7-19.

Bowman C (2003) The new imperative of long-term care. *Age and Ageing*, 32(3):246-247.

Bowman C (2009). Are care homes the community hospitals of the future? *Journal of Care Services Management*, 3(4):375-379.

Bowman C, Johnson M, Venebles D, Foote C, and Kane R (1999). Geriatric care in the United Kingdom: aligning services to needs. *BMJ*, 319:1119-1121.

Bowman C, Whistler J, and Ellerby M (2004). A national census of care home residents. *Age and Ageing*, 33:561-566.

Brand P (2013). *Improving access to and experience of GP services for older people living in care homes: practice survey.* London: Social Care Institute for Excellence.

Braun V and Clarke V (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3:77-101.

Briggs D and Bright L (2015) Reducing hospital admissions from care homes: considering the role of a local enhanced service from GPs. *Working with Older People*, 15(1):4-12.

Bridges J, Flatley M, and Meyer J (2010). Older people's and relatives' experiences in acute care settings: Systematic review and synthesis of qualitative studies. *International Journal of Nursing Studies*, 47:89-107.

British Geriatrics Society (2011). *Quest For Quality. An Inquiry into the Quality of Healthcare Support for Older People in Care Homes: A Call for Leadership, Partnership and Quality Improvement.* London: British Geriatrics Society.

Brodsky A (2008). Fieldnotes. In: Given L (ed) *The SAGE Encyclopedia of Qualitiative Research Methods.* Thousand Oaks: SAGE Publications.

Brooker D (2007). *Person-Centred Dementia Care. Making Services Better.* London: Jessica Kingsley.

Brooker R and Macperson I (1999). Communicating the processes and outcomes of practitioner research: an opportunity for self-indulgence or a serious professional responsibility? *Educational Action Research.* 7(2):207-221.

Brown Wilson C (2007). *Exploring Relationships in Care Homes: A Constructivist Inquiry.* Unpublished PhD thesis. University of Sheffield.

Bryans A (1998). *The nature and application of professional knowledge in community nursing assessment.* Unpublished PhD thesis. Glasgow Caledonian University.

Bryans A (2000). Providing new insight into community nursing know-how through qualitative analysis of multiple sets of simulation. *Primary Health Care Research and Development.* 1: 79-89.

Bryans A and McIntosh J (1996). Decision making in community nursing: an analysis of the stages of decision making as they relate to community nursing assessment practice. *Journal of Advanced Nursing.* 24: 24-30.

Bryans M, Keady J, Turner S, Wilcock J, Downs M, and Iliffe S (2003). An exploratory survey into primary care nurses and dementia care. *British Journal of Nursing*, 12(17):1029-1037.

Bryar R (1999a). An examination of case study research. *Nurse Researcher*, 7(2):61-78.

Bryar R (1999b) Using research in community nursing. In: McIntosh J (ed) *Research Issues in Community Nursing.* Basingstoke: Macmillan.

BUPA (2011). *Funding Adult Social Care Over The Next Decade: Who Cares?* (Online) Available from: http://www.bupa.com/jahia/webdav/site/bupacom/shared/Documents/PDFs/our-commitment/publication/Care_Brochure_web.pdf (Accessed 23.6.11)

Burns N and Groves S (2001). *The Practice of Nursing Research. Conduct, Critique & Utilization.* 4th edn, Philadelphia: W B Saunders Company.

Cameron A, Lart R, Bostock L, and Coomber C (2012). *Factors that promote and hinder joint and integrated working between health and social care services.* No.Research briefing 41. London: Social Care Institute for Excellence.

Campbell, A. (2007) Practitioner Research. London: TLRP. (Online) Available from: http://www.tlrp.org/capacity/rm/wt/campbell (Last accessed 15.09.2015)

Campbell A, McNamara O, and Gilroy P (2004). *Practitioner Research and Professional Development.* London: Sage Publishing.

Care Quality Commission (2009a). *A new system of registration.* London: Care Quality Commission.

Care Quality Commission (2009b). *The quality and capacity of adult social care services. An overview of the adult social care market in England 2008/2009.* London: Care Quality Commission.

Care Quality Commission (2010). *Your quick guide to registration.* London: Care Quality Commission.

Care Quality Commission (2012). *The state of health care and adult social care in England.* London: The Stationery Office.

Care Quality Commission (2014). *Cracks in the Pathway.* London: Care Quality Commission.

Carlson J (2010). Avoiding Traps in Member Checking. *The Qualitative Report*, 15(5):1102-1113.

Casey D (2006). Choosing an appropriate method of data collection. *Nurse Researcher*, 13(3):75-92.

Cavendish C (2013). *The Cavendish Review.* (Online) Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/236212/Cavendish_Review.pdf (Accessed 06.02.14)

Centre for Policy on Ageing (1996). *A Better Home Life.* London, Centre for Policy on Ageing.

Chaffee M and McNeill M (2007). A model of nursing as a complex adaptive system. *Nursing Outlook*, 55(5):232-241.

Chalmers J and Pearson A (2005). Oral hygiene care for residents with dementia: a literature review. *Journal of Advanced Nursing*, 52(4):410-419.

Chang E, Daly, J, Johnson, A, Harrison, K, Easterbrook, S, Bidewell J, Stewart H, Noel M, and Hancock, K. (2009). Challenges for professional care of advanced dementia. *International Journal of Nursing Practice*, 15:41-47.

Cilliers P (1998). *Complexity and Postmodernism: Understanding complex systems.* Abingdon: Routledge.

Cilliers P (2000). What Can We Learn From A Theory of Complexity? *Emergence*, 2(1):23-33.

Coffey A and Atkinson P (1996). *Making Sense of Qualitative Data.* Thousand Oaks: Sage.

Cohen D and Crabtree B (2006). Qualitative Research Guidelines Project: Member Checks.(Online) Available from: http://www.qualres.org/HomeMemb-3696.html (Accessed on 13.01.14)

Colón-Emeric C, Ammarell N, Bailey D, Corazzini K, Lekan-Rutledge D, Piven M, Utley-smith Q, and Anderson R (2006). Patterns of Medical and Nursing Staff Communication in Nursing Homes: Implications and Insights From Complexity Science. *Qualitative Health Research*, 16(2):173-188.

Comas-Herrera A, Wittenberg R, Pickard L, Knapp M, and MRC-CFAS (2003). *Cognitive Impairment in older people: its implications for future demand for services and costs.* Canterbury: PSSRU.

Cook R (2006). Making the invisible workforce visible again. *Nursing in Practice*, 27 (Online) Available from: http://www.nursinginpractice.com/default.asp?title=Makingtheinvisibleworkforcevisibleagain&page=article.display&article.id=626

Corroon-Sweeney E, Murphy C, and Collins D. (2009). Caring for nursing home patients-a primary care perspective. *Irish Medical Journal*, 102(10):317-320.

Cowan D, Fitzpatrick J, and Roberts J. (2003). The assessment and management of pain among older people in care homes: current status and future directions. *International Journal of Nursing Studies,* 40(3):291-298.

Crotty M (1998). *The Foundations of Social Research. Meaning and Perspective in the Research Process.* London: Sage.

Crowell D (2011). *Complexity Leadership: nursings' role in healthcare delivery.* Philadelphia: F A Davis.

Dalley G and Denniss M (2001). *Trained to care? Investigating the skills and competencies of care assistants in homes for older people.* London: Centre for Policy on Ageing.

Darton R, Netten A, and Forder J (2003). The cost implications of the changing population and characteristics of care homes. *International Journal of Geriatric Psychiatry*, 18:236-243.

Davies S and Goodman C (2008). Supporting quality improvement in care homes for older people: the contribution of primary care nurses. *Journal of Nursing Management*, 16(2):115-120.

Davies S, Goodman C, Bunn F, Victor C, Dickinson A, Illife S, Gage H, Martin W, and Froggatt K (2011). A systematic review of integrated working between care homes and health care services. *BMC Health Services Research*, 11(1):320. (Online) Available from: http://www.biomedcentral.com/1472-6963/11/320

Davies S and Seymour J (2002). Historical and Policy Contexts. In: Open University Press (ed) *Palliaitve Care for Older People in Care Homes.* Open University Press, Buckingham.

DeNDRoN (2013). *Reasons for working with care homes*. (Online) Available from: http://www.enrich.dendron.nihr.ac.uk/research-community/reasons-for-working-with-care-homes.html (Accessed 13.11.14)

de Wet J and Erasmus Z (2005). Towards rigour in qualitative analysis. *Qualitative Research Journal*, 5(1):27-40.

Denzin N and Lincoln Y (2003) *The landscape of qualitative research, Vol 1, Theories and issues.* 2nd edn, Thousand Oaks: Sage.

Dearnley C (2007). A reflection on the use of semi-structured interviews. *Nurse Researcher*, 13(1):19-28.

Demos (2014). *The Commission on Residential Care.* London: Demos.

Department of Health (2000). Care Standards Act. London: The Stationery Office.

Department of Health (2006). *Our health, our care, our say: a new direction for community services.* London: The Stationery Office.

Department of Health (2009). *Living well with dementia: A National Dementia Strategy.* London: Department of Health.

Department of Health (2012). *Prime Minister's challenge on dementia.* London: Department of Health.

Department of Health (2013a). *Prime Minister's challenge on dementia: Annual report of progress.* London: Department of health.

Department of Health (2013b). *Care in local communities - district nurse vision and model.* London: Department of health. (Online) Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213363/vision-district-nursing-04012013.pdf (Accessed 11.2.14)

Dickson C, Bliss J, and Bowers B (2015) Shaping future delivery of care: district nurses seizing the day! *British Journal of Community Nursing*, 20(6):266-267.

Di Giulio P, Toscani F, Villani D, Brunelli C, Gentile S, and Spadin P (2008). Dying with Advanced Dementia in Long-Term Care Geriatric Institutions: A Retropsective Study. *Journal of Palliative Medicine*, 11(7):1023-1028.

Dobie J (2010). Palliative care provision for older people in care homes. *British Journal of Community Nursing*, 15(4):170-176.

Donald I, Cope B, and Roberts S (2002). District nursing and care homes-a census view of care delivery in Gloucestershire. *Journal of Community Nursing*, 16(7):15-18.

Donini L, Neri B, De Chiara S, and Poggiogalle E (2013) Nutritional Care in a Nursing Home in Italy. *PLoS One*, 8(2):1-10.

Doyle S (2014). Member Checking With Older Women; A Framework for Negotiating Meaning. *Health Care for Women International*, 28:888-908.

Dudman J (2007). Context. In: Help the Aged and National Care Homes Research and Development Forum (eds) *My Home Life: Quality of Life in Care Homes. Review of the Literature.* London: Help the Aged.

Dudman J and Meyer J (2012). Understanding residential home issues to meet health-care needs. *British Journal of Community Nursing*, 17(9):434-438.

Duffy B, Oyebode J, and Allen J (2009). Burnout among care staff of older adults with dementia. *Dementia*, 8(4):515-541.

Eborall C, Fenton W, and Woodrow S (2010). *The state of the adult social care workforce in England, 2010 executive summary.* Leeds: Skills for Care. (Online) Available from: http://www.skillsforcare.org.uk/research/research_reports/annual_reports_SCW.aspx (Accessed 11.8.10)

Edwards S (2001). *Philosophy of Nursing: An Introduction.* Basingstoke: Palgrave Macmillan.

English Community Care Association, P&G Professional, and Laing and Buisson (2004). *Improving Lives, Improving Life: A Summary.* (Online) Available from: http://www.housingcare.org/downloads/kbase/2440.pdf (Accessed 11.8.10)

Evans C (2007). *The analysis of experiences and representations of older people's health in care homes to develop primary care nursing practice.* Unpublished PhD thesis. King's College, London.

Experian (2007). *Overseas Workers in the UK social care, children and young people sector.* Leeds: Skills for Care.

Eyers I and Bryan K (2006). Professionalising the care of older people: Transforming the workforce. *Quality in Ageing,* 7(4):37-45.

Ferrell, B.A, Ferrell, B.R and Rivera, L. (1995). Pain in cognitively impaired nursing home patients. *Journal of Pain & Symptom Management*, 10(8):591-598.

Fish D (1998). *Appreciating Practice in the Caring Professions.* Oxford: Butterworth Heinemann.

Flyvbjerg B (2006). Five Misunderstandings About Case-Study Research. *Qualitative Inquiry*, 12(2):219-245.

Fossey J (2008). Care Homes. In: Downs M and Bowers B (eds) *Excellence in Dementia Care.* Maidenhead: Open University Press.

Francis R (2013). *Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry.* London: The Stationery Office. (Online) Available from: http://www.midstaffspublicinquiry.com/sites/default/files/report/Executive%20summary.pdf (Accessed 19.9.14)

Fraser M (1999). *Improving Services for Older People. Staff development in dementia care.* Cheltenham: Stanley Thorne.

Froggatt K, Davies S, and Meyer J (2009) *Understanding Care Homes: A research and development perspective.* London: Jessica Kingsley.

Fuchs-Lacelle, S, Hadjistavropoulos, T and Lix, L. (2008). Pain assessment as intervention: a study of older adults with severe dementia. *Clinical Journal of Pain*, 24(8):697-707.

Gagnon Y (2010). *The Case Study as Research Method. A Practical Handbook.* Quebec: Presses de l'Universite du Quebec.

Gambino M (2014). Complexity and Nursing Theory. In: Lindberg C, Nash S, and Lindberg C (eds) *On the Edge: Nursing in the Age of Complexity.* Bordentown, New Jersey: Plexus Institute Press.

Gamiz R and Tsegai A (2014). Beyond practitioner-research: integration to outcomes. *Journal of Integrated Care.* 22 (3): 108-116.

Gangeness J and Yurkovich E (2006). Revisiting case study as a nursing research design. *Nurse Researcher*, 13(4):7-18.

Gerring J (2007). *Case Study Research. Principles and Practice.* Cambridge: Cambridge University Press.

Gibbs G (2007). *Analyzing Qualitative Data.* London: Sage.

Gladman, J, Logan P, Robbins I, Gordon A, and Goldberg S (2010). *Medical Crises in Older People.* Nottingham, The University of Nottingham.

Glasby J, Dickinson H, and Miller R (2011). Partnership working in England - where we are now and where we have come from. *International Journal of Integrated Care*, 11:1-8.

Glendinning C and Means R (2004). Rearranging the deskchairs on the Titanic of long-term care - is organizational integration the answer? *Critical Social Policy*, 24(4):435-457.

Glendinning, C, Jacobs, S, Alborz, A, and Hann, M. (2002). A survey of access to medical services in nursing and residential homes in England. *British Journal of General Practice*, 52(480):545-548.

Goddard C, Stewart F, Thompson G, and Hall S (2011). Providing End-of-Life Care in Care Homes for Older People: A Qualitaitve Study of the Views of Care Home Staff and Community Nurses. *Journal of Applied Gerontology*, 32(1):76-95.

Godlove C and Mann A (1980). Thirty years of the welfare state: current issues in British social policy for the aged. *Aged Care and Services Review*, 2(1):1-12.

Goffman E (1961). *Asylums.* Penguin Books, London.

Goodman C (1996). District nursing and the National Health Service reforms: a case for clarification. *Journal of Nursing Management*, 4:207-212.

Goodman C (2014). 'We need to know how best to provide healthcare in care homes'. (Online) Available from: http://www.nursingtimes.net/claire-goodman-we-need-to-know-how-best-to-provide-healthcare-in-care-homes/5067398.article (*Last* accessed 03.09.15)

Goodman C (2016). Care homes and health services: an uneasy alliance. *Journal of Health Services Research.* 21(1): 1-3.

Goodman C, Davies S, Dickinson A, Gage H, Froggatt K, Morbey H, Victor C, Masey H, Martin W, and Iliffe S (2013). *A study to develop integrated working between primary health care services and care homes.* London: NIHR Service Delivery and Organisation Programme.

Goodman C, Evans C, Wilcock J, Froggatt K, Drennan V, Sampson E, Blanchard M, Bissett M, and Iliffe S (2009). End of life care for community dwelling older people with dementia: an integrated review. *International Journal of Geriatric Psychiatry*, 25(4):329-337.

Goodman C, Gordon A, Martin F, Davies S, Bowman C, Schneider J, Meyer J, Victor C, Gage H, Gladman J and Dening T (2014). Effective health care for older people resident in care homes: the optimal study for realist review. *Systematic Reviews,* 3: 49-54.

Goodman C, Robb N, Drennan, V, and Woolley R (2005). Partnership working by default: district nurses and care home staff providing care for older people. *Health and Social Care in the Community,* 13(6):553-562.

Goodman C, Ross F, Mackenzie A and Vernon S (2003c). A portrait of district nursing: its contribution to primary health care. *Journal of Interprofessional Care.* 17 (1): 97-108.

Goodman C and Woolley R (2004). Older people in care homes and the primary care nursing contribution. *Primary Health Care Research and Development*, 5:211-218.

Goodman, C, Woolley, R, and Knight, D. (2003a). District nurse involvement in providing palliative care to older people in residential care homes. *International Journal of Palliative Nursing*, 9(12):521-527.

Goodman C, Woolley R, and Knight D (2003b). District nurse's experiences of providing care in residential care home settings. *Journal of Clinical Nursing*, 12:67-76.

Gordon A, Goodman C, Dening T, Gladman J, Bell B, Handley M, Meyer J, Bowman C, Gage H, Iliffe S, Martin F, Schneider J and Victor C (2014a). The optimal study: describing the key components of optimal health care delivery to UK care home residents: a research protocol. *Journal of the American Medical Directors Association,* 15(9):681-686.

Gordon A, Franklin M, Bradshaw L, Logan P, Elliott R, and Gladman J (2014b). Health Status of UK care home residents: a cohort study. *Age and Ageing*, 43:97-103.

Gough D (2007). Weight of evidence: a framework for the appraisal of the quality and relevance of evidence. In Furlong, J and Oancea A (Eds). Applied and Practice-based Research. Special Edition of *Research Papers in Education,* 22 (2); 213-228.

Gray D (2009). *Doing Research in the Real World.* London: Sage.

Gray D (2014). *Doing Research in the Real World. 3rd Edn,* London: Sage.

Grbich C (2007). *Qualitative Data Analysis: An introduction.* London: Sage.

Griffiths J (1996). *An Ethnographic Study of District Nursing Work.* Unpublished PhD Thesis. University of Liverpool, Liverpool

Griffiths J (1998). Meeting personal hygiene needs in the community: a district nursing perspective on the health and social care divide. *Health and Social Care in the Community*, 6(4):234-240.

Griffiths J (2013). Early support visits by district nurses to cancer patients at home: A multi-perspective qualitative study. *Palliative Medicine*, 27(4):349-357.

Griffiths J and Luker K (1994). Intraprofessional teamwork in district nursing: in whose interest? *Journal of Advanced Nursing*, 20:1038-1045.

Griffiths J and Luker K (1997). A barrier to clinical effectiveness: the etiquette of district nursing. *Clinical Effectiveness in Nursing*, 1:121-130.

Griffiths J, Ewing G, and Rogers M (2010). "Moving swiftly on." Psychological support provided by district nurses to patients with palliative care needs. *Cancer Nursing*, 33(5):390-398.

Griffiths P and Robinson S (2010). *Moving forward with healthcare support workforce regulation.* London: National Nursing Research Unit.

Groom L, Avery A, Boot D, O'Neill C, Thornhill K., Brown K., and Jones R (2000). The impact of nursing home patients on general practitioners' workload. *British Journal of General Practice*, 50(455):473-476.

Gruber-Baldini A, Zimmerman S, Boustani M, Watson L, Williams C, and Reed P (2005). Characteristics Associated With Depression in Long-term Care Residents With Dementia. *The Gerontologist*, 45(1):50-55.

Haddad M, Plummer S, Taverner A, Gray R, Lee S, Payne P, and Knight D (2005). District nurses' involvement and attitudes to mental health problems: a three-area cross-sectional study. *Journal of Clinical Nursing*, 14(8):976-985.

Hallett C, Austin L, Caress A, and Luker K (2000). Wound care in the community setting: clinical decision making in context. *Journal of Advanced Nursing*, 31(4):783-793.

Hallett C and Pateman B (2000). The 'invisible assessment': the role of the staff nurse in the community setting. *Journal of Clinical Nursing*, 9:751-762.

Hancock G, Woods B, and Challis D (2006). The needs of older people with dementia in residential care. *International Journal of Geriatric Psychiatry*, 21(1):43-49.

Handley M, Goodman C, Froggatt K, Mathie E, Gage H, Manthorpe J, Barclay S, Crang C, and Iliffe S (2014). Living and dying: responsibility for end-of-life care in care homes without in-site nursing provision - a prospective study. *Health and Social Care in the Community*, 22(1):22-29.

Harrison-Dening K (2011). People with dementia need care champions. *Nursing Older People*, 23(10):8.

Hart C (1998). *Doing a literature review.* London: Sage.

Hays R, Clarkson P, Tucker S, and Challis D (2012) Healthcare support services for care home residents. *Nursing Older People*, 24(10):26-30.

Haynes P (2003). *Managing complexity in the public services.* Maidenhead: Open University Press.

Health Education England (2015). *District Nursing and General Practice Nursing Service Education and Career Framework.* London, HEE. (Online). Available at: https://hee.nhs.uk/sites/default/files/documents/Print-ready%20PDF.pdf. (Accessed 29.12.15).

Heath, H. (2007). Health and healthcare services. In: Owen T and NCHRDF (eds) *My Home Life: Quality of life in Care Homes - Review of the literature.* London: Help the Aged.

Heath H (2010). Outcomes from the work of Registered Nurses working with older people in UK care homes. *International Journal of Older People Nursing*, 5(2):116-127.

Heath H (2012). How to optimise the registered nurse contribution in care homes. *Nursing Older People*, 24(2):23-28.

Heng H (2008). The Conflict Between Complex systems and Reductionism. *American Medical Association*, 300(13):1580-1581.

Hewitt-Taylor J (2002). Inside knowledge: issues in insider research. *Nursing Standard*, 16(46):33-35.

HM Government (2012). *Caring for our future: reforming care and support.* London: The Stationery Office.

Hockey L (1966). *Feeling the Pulse: A survey of district nursing in six areas.* London: QNI.

Hockey L (1979). *A Study of District Nursing: The development and progression of a long-term research programme*, Unpublished PhD Thesis, City University, London.

Hockey L (1999). Research questions and themes in district nursing. In: McIntosh J (ed) *Research Issues in Community Nursing.* Basingstoke: Macmillan.

Holden C (2002). British government policy and the concentration of ownership in long-term care provision. *Ageing & Society*, 22:79-94.

Horgas A and Tsai P (1998). Analgesic Drug Prescription and Use in Cognitively Impaired Nursing Home Residents. *Nursing Research*, 47(4):235-242.

Horn S (2008). The Business Care for Nursing in Long-Term Care. *Policy, Politics & Nursing Practice*, 9(2):88-93.

Houghton C, Casey D, Shaw D, and Murphy K (2013). Rigour in qualitative case-study research. *Nurse Researcher*, 20(4):12-17.

Iliffe S, Davies S, Gordon A, Dening T, Bowman C, Gage H, Martin F, Gladman J, Victor C, Meyer J, Goodman C (2015). Provision of NHS generalist and specialist services to care homes in England: review of surveys. *Primary Health Care Research and Development, 5th May,* p1-16 (online source).

Independent Age (2013). *Short Changed: the Care Bill, top-ups and the emerging crisis in residential care funding.* (Online) Available from: http://www.independentage.org/media/616143/short-changed-top-ups-report.pdf (Accessed 18.4.14)

Innes A (2002). The social and political context of formal dementia care provision. *Ageing & Society*, 22:483-499.

Innes A (2009). *Dementia Studies: A Social Science Perspective.* London, Sage.

Innes A, Campion P, and Griffiths F (2005). Complex consultations and the 'edge of chaos'. *British Journal of General Practice*, 55:47-52.

Jacobs S, Alboroz, Glendinning C, and Hann M (2001) *Health Services for Homes. A survey of access to NHS services in nursing and residential homes for older people in England.* Manchester: NPCRDC.

Jacobs S and Rummery K (2002). Nursing Homes in England and their Capacity to Provide Rehabilitation and Intermediate Care Services. *Social Policy & Administration*, 36(7):735-752.

Jarvis P (2000). The practitioner-researcher in nursing. *Nurse Education Today*, 20:30-35.

Johnson J, Rolph S and Smith R (2012). *Residential Care Transformed. Revisiting 'The Last Refuge'.* Palgrave Macmillan: Basingstoke.

Joint Strategic Needs Assessment working group (2008). *Joint Strategic Needs Assessment.*

Jones R and Trigg R (2007). *Dementia and serious sight loss.* No.11. Chiswick: Thomas Pocklington Trust. (Online) Available from: http://www.pocklingtontrust.org.uk/Resources/Thomas%20Pocklington/Documents/PDF/Research%20Publications/OP11.pdf

Jones T, Matias M, Powell J, Jones E, Fishburn J, and Looi J (2007). Who cares for older people with mental illness? A survey of residential aged care facilties in the Australian Capital Territory: Implications for mental health nursing. *International Journal of Mental Health Nursing*, 16:327-337.

Joseph Rowntree Foundation (2008). *Providing nursing support within residential care homes.* London: Joseph Rowntree Foundation.

Kaasalainen S, Brazil K., Ploeg J, and Martin L (2007). Nurses' perceptions around providing palliative care for long-term care residents with dementia. *Journal of Palliative Care*, 23(3):173-181.

Kennedy C (2000). *The nature and use of knowledge by district nurses in decision making relating to first assessment visits*, Unpublished PhD Thesis. Queen Margaret University College, Edinburgh.

Kennedy C (2002). The work of district nurses: first assessment visits. *Journal of Advanced Nursing*, 40(6):710-720.

Kennedy C (2004). A typology of knowledge for district nursing assessment practice. *Journal of Advanced Nursing*, 45(4):401-409.

Kennedy C (2005). District nursing support for patients with cancer requiring palliative care. *British Journal of Community Nursing*, 10(12):566.

Kernick D (2002). Complexity and healthcare organisation. In: Sweeney K and Griffiths F (eds) *Complexity and healthcare. An introduction.* Abingdon: Radcliffe Medical Press.

Keshavarz N, Nutbeam D, Rowling L and Khavarpour F (2010). Schools as social complex adaptive systems: A new way to understand the challenges of introducing the health promoting schools concept. *Social Science and Medicine.* 70: 1467-1474.

Kinley J, Hockley J, Stone L, Dewey M, Hansford P, Stewart H, McCrone P, Begum A, and Sykes N (2014) The provision of care for residents dying in UK nursing care homes. *Age and Ageing*, 43:375-379.

Kitwood T (1997). *Dementia Reconsidered.* Maidenhead: Open University Press.

Koch J, Datta G, Makhdoom S, and Grossberg G (2005). Unmet visual needs of Alzheimer's disease patients in long-term care facilities. *Journal of the American Medical Directors Association*, 6(4):233-238.

Kopetz S, Steele C, Brandt J, Baker A, Kronberg M, Galik E, Steinberg M, Warren A, and Lyketsos C (2000). Characteristics and outcomes of dementia residents in an assisted living facility. *International Journal of Geriatric Psychiatry*, 15(7):586-593.

Kraszewski S and Norris K (2014). The modern renaissance of the district nurse. *Primary Health Care*, 24(9):26-30.

Laing and Buisson (2009a). *Dementia Care Services. UK Market Briefing 2009.* London: Laing and Buisson.

Laing and Buisson (2009b). *Laing's Healthcare Market Review 2009-2010.* 22nd Edn. London: Laing and Buisson.

Laing and Buisson (2010). *Laing's Healthcare Market Review 2010-2011.* 23rd Edn. London: Laing and Buisson.

Laing and Buisson (2014a). *Care of Older People: UK Market Report 2013-2014.* 26th Edn. London: Laing and Buisson.

Laing and Buisson (2014b). *LaingBuisson Healthcare Market Review 2013-2014.* 26th Edn. London: Laing and Buisson.

Laing and Buisson (2016). *Care of Older People: UK Market Report 2015.* 27th Edn. London: Laing and Buisson.

Leong I and Nuo T (2007). Prevalence of Pain in Nursing Home Residents with Different Cognitive and Communicative Abilities. *Clinical Journal of Pain*, 23(2):119-127.

Lewis J (2001). Older People and the Health-Social Care Boundary in the UK: Half a Century of Hidden Policy Conflict. *Social Policy & Administration*, 35(4):343-359.

Lewis Cleary B (2004). *Conducting Research in Long-term Care Settings.* New York: Springer.

Lietz C, Langer C, and Furman R (2006). Establishing Trustworthiness in Qualitative Research in Social Work. *Qualitative Social Work*, 5(4):441-458.

Lievesley N, Crosby G, and Bowman C (2011). *The changing role of care homes.* London: Bupa and Centre for Policy on Ageing.

Lincoln Y and Guba E (1985). *Naturalistic Inquiry.* Newbury Park California: Sage.

Lindberg C and Lindberg C (2008). Nurses Take Note: A Primer on Complexity Science. In: Lindberg C, Nash S, and Lindberg C (eds) *On the Edge: Nursing in the Age of Complexity.* Bordentown, New Jersey: Plexus Institute Press.

Lipsitz L (2012). Understanding Health Care as a Complex System. *Journal American Medical Association*, 308(3):243-244.

Livingstone G, Pitfield C, Morris J, Manela M, Lewis-Holmes E, and Jacobs H (2011). Care at the end of life for people with dementia living in a care home: a qualitative study of staff expereince and attitudes. *International Journal of Geriatric Psychiatry*, 27(6):643-650.

Lou M, Dai Y, and Huang G (2007). Nutritional status and health outcomes for older people with dementia living in institutions. *Journal of Advanced Nursing*, 60(5):470-477.

Luff, R, Ferreira Z, and Meyer J (2011). *Methods Review 8: Care Homes.* London: NIHR School for Social Care Research. (Online) Available from: www.sscr.nihr.ac.uk (Accessed 25.2.11)

Lupton C and Croft-White C (2013). *Respect and Protect: The experiences of older people and staff in care homes and hospitals.* London: Comic Relief.

Luker K (2006). Challenges for home care nurses in providing quality care. *Primary Health Care Research and Development.* 7: 291-298.

Luker K, Austin L, Caress A, and Hallett C (2000). The importance of 'knowing the patient': community nurses' constructions of quality in providing palliative care. *Journal of Advanced Nursing*, 31(4):775-782.

Luker K and Kenrick M (1992). An exploratory study of the sources of influence on the clinical decisions of community nurses. *Journal of Advanced Nursing*, 17:457-466.

Macdonald A and Carpenter G (2003). The recognition of dementia in 'non-EMI' nursing home residents in South East England. *International Journal of Geriatric Psychiatry*, 18:105-108.

Madjar I and Higgins I (1996). Of ethic committees, protocols, and behaving ethically in the field: a case study of research with elderly residents in a nursing home. *Nursing Inquiry*, 3: 130-137

Mann A, Schneider J, Mozley C, Levin E, Blizard R, Netten A, Kharicha K, Egelstaff R, Abbey A, and Todd C (2000). Depression and the response of residential homes to physical health needs. *International Journal of Geriatric Psychiatry*, 15(12):1105-1112.

Manthorpe J, Iliffe S, and Eden A (2003). Early recognition of dementia by nurses. *Journal of Advanced Nursing*, 44(2):183-191.

Martin M D, Hancock G A, Richardson B, Simmons P, Katona C, Mullan E, and Orrell M (2002). An evaluation of needs in elderly continuing-care settings. *International Psychogeriatrics*, 14(4):379-388.

Martin-Garcia S, Rodriguez-Blázquez C, Martinez-López, Martinez-Martin P, and Forjaz M (2013). Comorbidity, health status, and quality of life in institutionalized older people with and without dementia. *International Psychogeriatrics*, 25(7):1077-1084.

McCormack B (2003). Knowing and acting - A strategic practitioner-focused approach to nursing research and practice development. *NT Research*, 8(2):86-100.

McCormack B (2009). Practitioner Research. In: Hardy S, Titchen A, McCormack B, and Manley K (eds) *Revealing nursing expertise through practitioner inquiry.* Chichester: Wiley-Blackwell.

McDonnell A, Jones M, and Read S (2000). Practical considerations in case study research: the relationship between methodology and process. *Journal of Advanced Nursing*, 32(2):383-390.

McGloin S (2008). The trustworthiness of case study methodology. *Nurse Researcher*, 16(1):45-55.

McIntosh J (1996). The question of knowledge in district nursing. *International Journal of Nursing Studies*, 33(3):316-324.

McIntosh J (2000). The invisible work of the district nursing team: methodological problems associated with exploring skills. *Primary Health Care Research and Development*, 1:103-112.

McIntosh J, Lugton J, Moriarty D, and Carney C (1999). Exploring district nursing skills through research. In: McIntosh J (ed) *Research Issues in Community Nursing.* Basingstoke: Macmillan.

McKechnie L (2008). Unstructured observation. In: Given L (ed) *The SAGE Encyclopedia of Qualitiative Research Methods.* Thousand Oaks: Sage Publications.

McKenna H, Hasson H, and Keeney S (2004). Patient safety and quality of care: the role of the healthcare assistant. *Journal of Nursing Management*, 12:452-459.

McMillan E (2004). *Complexity, Organizations and Change: An Essential Introduction.* London: Routledge.

Means R (2001). Lessons from the history of long-term care for older people. In: Robinson J (ed) *Towards a New Social Compact for Care in Old Age.* London: Kings Fund.

Means R, Richards S, and Smith R (2008). *Community Care.* 4th edn, Basingstoke: Palgrave Macmillan.

Meyer J (2000). Using qualitative methods in health related action research. *BMJ*, 320:178-181.

Meyer J, Ashburner C, and Holman C (2006). Becoming connected, being caring. *Educational Action Research*, 14(4):477-496.

Miles M and Huberman A (1994). *Qualitative Data Analysis.* 2nd edn, Thousand Oaks: Sage.

Mitchell S, Kiely D, and Hamel M (2004a). Dying with Advanced Dementia in the Nursing Home. *Archives of Internal Medicine*, 164:321-326.

Mitchell S, Morris J, Park P, and Fries B. (2004b). Terminal care for persons with advanced dementia in the nursing home and home care settings. *Journal of Palliative Medicine*, 7(6):808-816.

Moriarty J, Kam M, Coomber C, Rutter D, and Turner M (2010). *Communication training for care home workers: outcomes for older pople, staff, families and friends.* No.34. London: Social Care Institue for Excellence. (Online) Available from: http://www.scie.org.uk/publications/briefings/files/briefing34.pdf (Accessed 10.2.10)

Moss M, Braunschweig H, and Rubinstein R (2002). Terminal care for nursing home residents with dementia. *Alzheimer's Care Quarterly*, 3(3):233-246.

Mozley C, Sutcliffe C, Bagley H, Cordingley L, Challis D, Huxley P, and Burns A (2004). *Towards Quality Care. Outcomes for Older People in Care Homes.* Aldershot: Ashgate.

Mulholland J (2007). Understanding the self as instrument. In Taylor P and Wallace J (eds). *Contemporary Qualitative Research: Exemplars for Science and Mathematics Educators*, 45-47.

Naggington M, Luker K and Walshe C (2013). 'Busyness' and the preclusion of quality palliative district nursing care. *Nursing Ethics.* 20 (8): 893-903.

Nash S (2014). Walking Beside Families. In: Lindberg C, Nash S, and Lindberg C (eds) *On the Edge: Nursing in the Age of Complexity.* Bordentown, New Jersey: Plexus Institute Press.

National Audit Office (2007). *Improving services and support for people with dementia.* London: The Stationery Office.

National Care Forum (2010). *NCF Personnel Statistics 2010.* (Online) Available from: http://www.nationalcareforum.org.uk/content/NCF%20Personnel%20Statistics%20Report%202010.pdf (Accessed 12.8.10)

National Collaborating Centre for Mental Health (2007). *Dementia. A NICE-SCIE Guideline on supporting people with dementia and their carers in health and social care.* London: The British Psychological Society and Gaskell.

National Council for Palliative Care (2007). *Progress with Dementia.* London: NCPC.

National Nursing Research Unit (2013). *District nursing - who will care in the future.* London, Kings College London.

National Primary Care Research and Development Centre (2001). *Health services for homes: a survey of access to health care by nursing and residential homes for older people in England.* Executive Summary 24. Manchester: National Primary Care Research and Development Centre.

Nazarko L (2000). A New Broom. The Care Standards Act. *Nursing Management*, 7(8):6-9.

Nelson S, Wild D, and Szczepura A (2009). The forgotten sector: the impact of change on workforce development in residential care for older people. *Nursing and Residential Care*, 11 (4):200-204

Netten A, Bebbington A, Darton R, and Forder J (2001). *Care Homes for Older People. Volume 1. Facilities, Residents and Costs.* Canterbury: PSSRU.

NHS England (2014). *Five Year Forward View.* Redditch: NHS England. (Online) Available from: http://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf (Last accessed 03.09.15)

NICE/SCIE (2006). *Dementia: Supporting people with dementia and their carers in health and social care.* London: The Stationery Office.

NMC (2001). *Standards for specialist education and practice.* NMC, London

NMC (2015). *The Code: Professional standards of practice and behaviour for nurses and midwives.*(Online) Available from*:* http://www.nmc.org.uk/standards/code/ (Last accessed 24.09.15)

Noble H, Bridges J, and Meyer J (2009). Using practitioner research to study vulnerable patients. *European Journal of Palliative Care*, 16(6):270-273.

Nolan M, Brown J, Davies S, Nolan J, and Keady J (2006a). *The Senses Framework: Improving Care for Older People Through a Relationship-Centred Approach.* Getting Research into Practice (GRIP) Report No 2. Sheffield: University of Sheffield.

Nolan M, Davies S, and Brown J (2006b). Transitions in care homes: towards relationship-centred care using the 'Senses Framework'. *Quality in Ageing,* 7(3):5-14.

Nygaard H, and Jarland M (2005). Are nursing home patients with dementia diagnosis at increased risk for inadequate pain treatment? *International Journal of Geriatric Psychiatry,* 20(8):730-737.

O'Dea G, Kerrison S H, and Pollock A M (2000). Access to health care in nursing homes: a survey in one English Health Authority. *Health and Social Care in the Community*, 8(3):180-185.

O'Kell S (1996). How education can work to improve care standards. *Nursing Times*, 92(31):38-39.

Office of Fair Trading (2005). *Care homes for older people in the UK. A market study.* London: Office of Fair Trading.

Office of National Statistics (2013). *UK 2011 Census: Usual resident population by single year of age.* (Online) Available from: http://www.ons.gov.uk/ons/datasets-and-tables (Accessed 09.08.13)

Office of Public Sector Information (2000). Care Standards Act 2000.

Owen T, Meyer J, Cornell M, Dudman P, Ferreira Z, Hamilton S, Moore J, and Wallis J (2012). *My Home Life: Promoting Quality of Life in Care Homes.* London: Joseph Rowntree Foundation.

Paley J (2007). Complex adaptive systems and nursing. *Nursing Inquiry.* 14 (3); 233-242.

Paley J and Eva G (2011). Complexity theory as an approach to explanation in healthcare: A critical discussion. *International Journal of Nursing Studies*, 48:269-279.

Parkinson W (2006). Are district nurses too task orientated to meet the needs of the 21st century? *Journal of Community Nursing*, 20(8):4-8.

Payne J, Sheppard J, Steinberg M, Warren A, Baker A, Steele C, Randt J, and Lyketsos C (2002). Incidence, prevalence and outcomes of depresion of residents of a long-term care facility with dementia. *International Journal of Geriatric Psychiatry*, 17:247-253.

Payne S, Field D, Rolls L, Hawker S, and Kerr C (2007). Case study research methods in end-of-life care: reflections on three studies. *Journal of Advanced Nursing*, 58(3):236-245.

Peace S, Kellaher L, and Willcocks (1997). *Re-evaluating residential care.* Open University Press: Buckingham.

Pegram A (1999). What is case study research? *Nurse Researcher*, 7(2):5-16.

Pell J, and Williams S (1999). Do nursing home residents make greater demands on GPs? A prospective comparative study. *British Journal of General Practice*, 49(444):527-530.

Perry M, Carpenter I, and Hope K (2003). Understanding the roles of registered general nurses and care assistants in UK nursing homes. *Journal of Advanced Nursing*, 42(5):497-505.

Phelan A and McCormack B (2013). *Exploring Nursing Expertise in Residential Care for Older People in Ireland.* Dublin: Nursing Homes Ireland. (Online) Available from: http://www.aigna.ie/newsAttachments/1362129389ExploringNursingExpertiseinResidentialCareforOlderPeople.pdf?PHPSESSID=b1e4399b6bd68d9b5fbe32cd6bf92fe4 (Accessed 1.9.14)

Pickard S, Jacobs S, and Kirk S (2003). Challenging Professional Roles: Lay Carers' Involvement in Health Care in the Community. *Social Policy and Administration*, 37(1):82-96.

Plsek P and Greenhalgh T (2001). The challenge of complexity in health care. *BMJ*, 323:625-628.

Polit D and Tatano Beck C (2008). *Nursing Research. Generating and assessing Evidence for Nursing Practice.* 8th edn, Philadelphia: Lippincott Williams and Wilkins.

Proctor S (1995). The contribution of inductive and deductive theory to the deleopment of pracittioner knowledge. In: Reed J and Proctor S (eds) *Practitioner Research in Health Care.* London: Chapman & Hall.

Proctor, W. and Hirdes, J. (2001). Pain and cognitive status among nursing home residents in Canada. *Pain Research & Management*, 6(3):119-125.

Public Health England (2014). *The Older People's Health and Wellbeing Atlas.*(Online) Available from: *http://www.wmpho.org.uk/olderpeopleatlas/Atlas/atlas.html (Accessed 25.7.14)*

Public Health Team (2013). *Executive Summary of the Joint Strategic Needs Assessment 2012.*

Queens Nursing Institute (2009). *2020 Vision: Focusing on the future of district nursing.* London: The Queen's Nursing Institute.

Queens Nursing Institute (2012). *Nursing People at Home. The issues, the stories, the actions.* London: QNI. (Online) Available from: http://www.qni.org.uk/docs/RNRS_report_WEB.pdf (Accessed 9.6.14)

Queens Nursing Institute (2013). *Report on District Nurse Education in England, Wales and Northern Ireland 2012/13.* London: QNI. (Online) Available from: http://www.qni.org.uk/docs/DN_Education_Report_2012-13.pdf (Accessed on 9.6.14)

Queens Nursing Institute (2014a). *2020 Vision. 5 Years On.* London: QNI. (Online) Available from: http://www.qni.org.uk/docs/2020_Vision_Five_Years_On_Web1.pdf (Accessed 9.6.14)

QNI (2014b). *Report on District Nurse Education in the United Kingdom 2013-14.* London: QNI. (Online) Available from: http://www.qni.org.uk/docs/District_Nurse_Education_Report_2014_web.pdf (Accesed 4.8.14)

QNI/NHSE (2014). *Developing a national District Nursing Worforce planning framework.* London: QNI

QNI/QNIS (2015). *The QNI/QNIS voluntary standards for district nurse education and practice.* London, QNI. (Online). Available from: http://www.qni.org.uk/docs/DN_Standards_Web.pdf (Accessed 29.12.15).

Quinn M, Johnson M, Andress E, McGinnis P, and Ramesh M (1999). Health characteristics of elderly personal care home residents. *Journal of Advanced Nursing*, 30(2):410-417.

Quinn M, Johnson M A, Andress E, and McGinnis P (2003). Health Characteristics of Elderly Residents in Personal Care Homes: Dementia, Possible Early Dementia and No Dementia. *Journal of Gerontological Nursing*, 29(8):16-23.

Rabins P (2006). *Practical Dementia Care.* 2nd ed. Oxford University Press, Oxford.

RCN (2003). *Developing referral criteria for district nursing referrals.* London: RCN.

RCN (2004). *Nursing assessment of older people.* London: RCN.

RCN (2007). *The Regulation of Healthcare Support Workers.* London: RCN Policy Unit.

RCN (2010). *Care homes under pressure - an England report.* London: RCN.

RCN (2013). *District nursing - harnessing the potential.* London; RCN.

Reed J (1995). Practitioner knowledge in practitioner research. In: Reed J and Proctor S (eds) *Practitioner Research in Health Care.* London: Chapman & Hall.

Reed J and Proctor S (1995). Practitioner research in context. In: Reed J and Proctor S (eds) *Practitioner Research in Health Care.* London: Chapman & Hall.

Reed P, Zimmerman S, Sloane P, Williams C, and Boustani M (2005). Characteristics Associated With Low Food and Fluid Intake in Long-Term Care Residents With Dementia. *Gerontologist*, 45(1):74-80.

Reynolds K, Hanson L, and DeVellis R (2008). Disparities in pain management between cognitively intact and cognitively impaired nursing home residents. *Journal of Pain & Symptom Management,* 35(4):388-396.

Rolfe G (1998). The theory-practice gap in nursing: from research-based practice to practitioner-based research. *Journal of Advanced Nursing*, 28(3):672-679.

Rolfe G (2003). While the concept of practitioner research can be interpreted in many ways, all approaches share a common aim, that of closing the practice-theory gap. *NTresearch*, 8 (2): 132-133.

Rosenberg J and Yates P (2007). Schematic representations of case study research designs. *Journal of Advanced Nursing*, 60(4):447-452.

Rowe A and Hogarth A (2005). Use of complex adaptive systems metaphor to achieve professional and organizational change. *Journal of Advanced Nursing*, 51(4):396-405.

Royal College of Physicians, Royal College of Nursing, and British Geriatric Society (2000). *The health and care of older people in care homes.* London: Royal College of Physicians.

Sackley C, Hoppitt T, Cardoso K, and Levin S (2009). The availability and use of allied health care in care homes in the Midlands, UK. *International Journal of Therapy & Rehabilitation*, 16(4):218-225.

Saldaña J (2009). *The Coding Manual for Qualitative Researchers.* London: Sage.

Sandvoll A, Kristofferson K, and Hauge S (2013). The double embarrassment: Understanding the actions of nursing staff in an unexpected situation. *International Journal of Nursing Practice*, 19:368-373.

Savin-Baden M and Howell Major C (2013). *Qualitative Research: The essential guide to theory and practice.* London: Routledge.

Seawright J and Gerring J (2008). Case Selection Techniques in Case Study Research. *Political Research Quarterly*, 61(2):294-308.

Sharp K (1998). The case for case studies in nursing research: the problem of generalisation. *Journal of Advanced Nursing*, 27 (4):785-789.

Simons H (2009). *Case study research in practice.* London: Sage.

Sinclair A, Allard I, and Bayer A (1997). Observations of diabetes care in long-term institutional settings with measures of cognitive function and dependency. *Diabetes Care*, 20(5):778-784.

Skills for Care (2007). *National Survey of Care Workers FINAL Report.* (Online) Available from: http://www.skillsforcare.org.uk/research/research_reports/national_survey_of_care_workers_2007.aspx (Accessed 12.8.10)

Skills for Care (2009). nm*ds-sc briefing - older people.* (Online) Available from: https://www.nmds-sc-online.org.uk/news/View.aspx?546 (Accessed 9.6.14)

Skills for Care (2010). *New qualifications for the adult social care sector.* (Online) Available from: http://www.skillsforcare.org.uk/qualifications_and_training/qualificationsandcreditframeworkQCF/qualificationsandcreditframeworkQCF.aspx (Accessed 12.8.10)

Skills for Care (2011). *nmds-sc briefing - migrant workers.* (Online) Available from: https://www.nmds-sc-online.org.uk/Get.Aspx?Id=%20648745 (last accessed 9.6.14)

Skills for Care (2013). *nmds-sc briefing: Issue 20 - Meeting the future workforce challenges of adult social care.* No.Issue 20. (Online) Available from: https://www.nmds-sc-online.org.uk/Get.aspx?id=780048 (Accessed 3.3.14)

Skills for Care (2015). *The state of the adult social care sector and workforce in England.* (Online) Available from: http://www.skillsforcare.org.uk/Document-library/NMDS-SC,-workforce-intelligence-and-innovation/NMDS-SC/State-of-2014-ENGLAND-WEB-FINAL.pdf. (Accessed 03.12.15).

Sloane P, Zimmerman S, Williams C, and Hanson, L (2008). Dying With Dementia in Long-Term Care. *The Gerontologist*, 48(6):741-751.

Sloane P, Zimmerman S, Gruber-Baldini A, Hebel J, Magaziner J, and Konrad T (2005). Health and functional outcomes and health care utilization of persons with dementia in residential care and assisted living facilities: comparison with nursing homes. The *Gerontologist*, 45 Spec No 1(1):124-132.

Smith J, Wood J, and Elias J (2009). *Beyond Practice-based Commissioning: The Local Clinical Partnership.* London: The Nuffield Trust.

Social Care Institute for Excellence (2013). *GP services for older people: a guide for care home managers.* London: Social Care Institute for Excellence.

SPAIN (2005). What Price Care in Old Age? Three years on from SPAIN's 'Underfunding of social care' paper, what has changed? (Online) Available from: http://www.cpa.org.uk/cpa/cpa_what_price_care.pdf (Accessed 20.9.14)

Speed S (2003). *An Ethnographic Study of the Organisation of District Nurses' Work*, Unpublished PhD Thesis, University of Liverpool.

Speed S and Luker K (2004). Changes in patterns of knowing the patient: the case of British district nurses. *International Journal of Nursing Studies*, 41:921-931.

Spilsbury K, Meyer J, Bridges J, and Holman C (1999). 'The little things count'. *Emergency Nurse*, 7(6):24-31.

Stanley D and Reed J (1999). *Opening up care: Achieving principled practice in health and social care institutions.* London: Arnold.

Stake R E (1995). *The Art of Case Study Research.* Thousand Oaks: Sage Publications.

Stenhouse L (1975). *An introduction to curriculum research and development.* London: Heinemann.

Stenhouse L (1981). What counts as research? *British Journal of Educational Studies*, 29(2):103-114.

Steves C, Schiff R, and Marting F (2009). Geriatricians and care homes: perspectives from geriatric medicine departments and primary care trusts. *Clinical Medicine*, 9(6):528-533.

Stewart R, Hotopf M, Dewey, Ballard C, Bisla J, Calem M, Famhy V, Hockley J, Kinley J, Pearce H, Saraf A, and Begum A (2014). Current prevalence of dementia, depression and behavioural problems in the older adult care home sector: the South East London Care Home Survey. *Age and Ageing*, 43:562-567.

Stringer E and Genat W (2004). *Action Research in Health.* New Jersey: Pearson Education.

Stroebel C, McDaniel R, Crabtree B, Miller W, Nutting P, and Stange K (2005). How Complexity Science Can Inform a Reflective Process for Improvement in Primary Care Practices. *Journal on Quality and Patient Safety*, 31(8):438-446.

Sturmberg J and Martin C (2009). Complexity and health - yesterday's traditions, tomorrow's future. *Journal of Evaluation in Clinical Practice*, 15:543-548.

Suominen M, Laine A, Routasalo P, Pitkala K, and Räsänen L (2004). Nutrient Content of Served Food, Nutrient Intake and Nutritional Status of Residents with Dementia in a Finnish Nursing Home. *Journal of Nutrition, Health & Aging*, 8(4):234-238.

Sweet H and Ferguson R (2000). District Nursing History. In: Lawton S, Cantrell J, and Harris J (eds) *District Nursing: Providing care in a supportive context.* Edinburgh: Churchill Livingstone.

Szczepura A, Clay D, Hyde J, Nelson S, and Wild D (2008). *Models for providing improved care in residential care homes: A thematic literature review.* Coventry: University of Warwick.

Tesch R (1990). *Qualitative Research Analysist Types & Software Tools.* New York: The Falmer Press.

The Health Foundation (2010). *Evidence scan: Complex adaptive systems.* London, The Health Foundation.

The Kings Fund (2013). *Paying for social care. Beyond Dilnot.* London, Kings Fund

Tilly J and Fok A (2008). Policy Barriers to Quality End-of-Life Care for Residents With Dementia in Assisted Living Residences and Nursing Homes. *Alzheimer's Care Today*, 9(2):103-112.

Toofany S (2007). District Nursing past, present and future. *Primary Health Care*, 17(9):18-21.

Townsend P (1962). *The Last Refuge.* London: Routledge & Kegan Paul.

Tracy S (2010). Qualitative Quality: Eight 'Big-Tent' Criteria for Excellent Qualitative Research. *Qualitative Inquiry,* 16 (10); 837-851.

Tresolini C P and The Pew-Fetzer Task Force (1994). *Health professions, education and relationships-centred care: A report of the Pew-Fetzer Task Force on Advancing Psychological Education.* San Francisco: Pew Health Professions Commission.

Turrell A, Castleden C, and Freestone B (1998). Long stay care and the NHS: discontinuities between policy and practice. *BMJ*, 317:942-944.

UKHCA (2012). *Care is not a commodity.* London: United Kingdom Homecare Association.

Vicenzi A, White K, and Begun J (1997). Chaos in Nursing: Make it Work for You. *American Journal of Nursing*, 97(10):26-31.

Voyer P, Richard S, Doucet L, Danjou C, and Carmichael P (2008). Detection of delirium by nurses among long-term care residents with dementia. *BMC Nursing*, 7(4):-14p.

Wallace Williams S, Williams, C, Zimmerman S, Sloane P, Preisser J, Boustani M, and Reed P (2005). Characteristics Associated With Mobility Limitation in Long-Term Care Residents With Dementia. *The Gerontologist*, 45(1):62-67.

Walsh M (2000). Chaos, complexity and nursing. *Nursing Standard*, 14(32):39-42.

Walshe C and Luker K (2010) District nurses' role in palliative care provision: A realist review. *International Journal of Nursing Studies*, 47:1167-1183.

Weaver K and Olson J (2006). Understanding paradigms used for nursing research. *Journal of Advanced Nursing*, 53(4):459-469.

Webb C (1992). The use of the first person in academic writing: objectivity, language and gatekeeping. *Journal of Advanced Nursing*, 17:747-752.

White K and Begun J (1996). Profession Building in the New Health Care System. *Nursing Administration Quarterly*, 20(3):79-85.

Wiggins M (2008). The Challenge of Change. In: Lindberg C, Nash S, and Lindberg C (eds) *On the Edge: Nursing in the Age of Complexity.* Bordentown, New Jersey: Plexus Institut Press.

Wild D, Szczepura A, and Nelson S (2010). *Residential care home workforce development. The rhetoric and reality of meeting older resident's future care needs.* London: Joseph Rowntree Foundation. (Online) Available from: http://www.jrf.org.uk/publications/care-workforce-development (Accessed 30.7.10)

Wild D, Szczepura A, and Nelson S (2011). How social care staff working in residential homes perceive their professional status. *Nursing Older People*, 23(7):29-35.

Williams C, Zimmerman S, Sloane P, and Reed P (2005). Characteristics associated with pain in long-term care residents with dementia. *The Gerontologist*, 45 Spec No 1(1):68-73.

Worden A, Challis D, Hancock G, Woods R, and Orrell M (2008). Identifying need in care homes for people with dementia: The relationship between two standard assessment tools. *Aging & Mental Health*, 12(6):719-728.

Worth A (1999). *An ethnographic study of assessment of the needs of older people by district nurses and social workers.* Unpublished PhD Thesis, Glasgow Caledonian University.

Wright J (1998). *Health Needs Assessment in Practice*. London: BMJ.

Yin R (2009). *Case Study Research. Design and Methods.* 4th edn, Los Angeles: Sage.

Zimmerman S, Williams C, Reed P, Boustani M, Preisser J, Heck E, and Sloane P (2005). Attitudes, Stress and Satisfaction of Staff Who Care for Residents With Dementia. *The Gerontologist*, 45(1):96-105.

Zimmerman B (2009). *A Complexity Science Primer.* (Online) Available from: http://www.plexusinstitute.org/default.asp?page=exploring1&DGPCrSrt=&DGPCrPg=2 (Accessed 7.6.13)

Zucker D (2001). Using case study methodology in nursing research. *The Qualitative Report*, 6(2):1-9.

Zwakhalen S, Koopmans R, Geels P, Berger M, and Hamers J (2009). The prevalence of pain in nursing home residents with dementia measured using an observational pain scale. *European Journal of Pain*, 13(1):89-93.

APPENDICES

Appendix 1: Glossary of Terms

Care home: In the past in the UK the generic term 'care home' was used to define 'any home which provides accommodation together with nursing or personal care for any person who is or has been ill (including mental disorder), is disabled or infirm, or who has a past or present dependence on drugs or alcohol' (Office of Public Sector Information 2000).

Care homes were further divided into:
- Care homes (personal) previously known as residential homes, providing personal and social care, with nursing and medical care provided by primary care, mainly GPs and district nurses
- Care homes (nursing) previously known as nursing homes, providing personal, social and nursing care. With qualified nurses employed to provide nursing care and medical care provided through GPs
- Dual-registered care homes which are registered with both the Local Authority to provide residential care and with the Health Authority to provide nursing care (DOH 2000)

However, the terms have subsequently changed and the Care Quality Commission, the regulatory body of all health and adult social care services in England, uses the following terms:
- Care homes: for those providing accommodation and professional help with daily tasks such as washing, dressing and eating
- Care homes with nursing: for those providing 24-hour qualified nursing care as well as accommodation and personal care
- Dual-registered care homes no longer exist

A problem with these definitions is that there now appears to be no generic term which can be used when referring to all types of care home settings. So for pragmatic reasons and as much of the literature referred to in this thesis uses the previous terms the following terms will be used:
- Care homes: to refer generally to all types of care homes
- Residential care homes: to refer to those which provide personal care only
- Nursing homes: to refer to those which provide personal care together with nursing care

Ownership:
For-profit: Care homes commercially run for profit and typically owned by individuals, partnerships, limited companies, or commercial care home groups

Not-for-profit: Care homes that are not run for profit and are typically owned by charities, associations, societies or trusts

Local Authority: Care homes owned and run by Local Authorities

District Nurse: Refers to a senior nurse who usually holds a post-basic qualification and leads a team of primary care nurses and healthcare support workers.

Primary care nurse: Refers to a nurse working in the community who does not hold the post-basic qualification

Community nurses: Used as a collective term when referring to members of a district nursing team, both qualified and unqualified

Healthcare needs: A need that can benefit from healthcare, which includes health education, disease prevention, diagnosis, treatment, rehabilitation and terminal care (Wright 1998).

Appendix 2: Literature Review Protocol

Citation: Authors: _____

Title: _____

Journal: _____

Year: _____ Volume: _____ Issue: _____ Pages: _____

Type of Study: ☐ Quantitative ☐ Qualitative ☐ Mixed Method

Location/Setting: _____

Key Concepts/ Concepts _____

Variables: Intervention/Independent Variable: _____

Dependent Variable: _____

Controlled Variables: _____

Framework/Theory: _____

Design Type: ☐ Experimental ☐ Quasi-experimental ☐ Non-experimental

Specific Design: _____

Blinding? ☐None ☐Single: _____ ☐Double_____

Description of Intervention: _____

_____

Comparison group(s): _____

☐ Cross-sectional ☐ Longitudinal/prospective No. of data collection points: ___

Qual. Tradition: ☐ Grounded theory ☐ Phenomenology ☐ Ethnography ☐

Other: _____

Sample: Size: _____ Sampling method: _____

Sample characteristics: _____

_____

Data Sources: Type: ☐ Self-report ☐ Observational ☐ Biophysiologic ☐Other_____

Description of measures: _____

_____

_____

Data Quality: _____

_____

Statistical Tests: Bivariate: ☐ T-test ☐ ANOVA ☐ Chi-square ☐ Pearson's *r* ☐

Other: ____

Multivariate: ☐ Multiple regression ☐ MANOVA ☐ Logistic Regression ☐Other:

_____

Findings/ _____

Effect Sizes/ _____

Themes: _____

_____

_____

_____

Recommendations: _____

_____

Strengths: _____

_____

_____

Weaknesses: _____

_____

_____

(Polit and Tatano Beck 2008)

Appendix 3: Abbreviations used in the literature review matrices

AAS	Adjusted Activity Scale
ALEQS	Assisted Living Environmental Quality Scale
AMTS	Abbreviated Mental Test Score
Barthel Index	Barthel Activities of Daily Living Index
BAS	Brief Assessment Schedule
CAM	Confusion Assessment Method
CANE	Camberwell Assessment of Needs in Elderly
CAPE-BRS	Clifton Assessment Procedures for Elderly-Behaviour Rating Scale
CBS	Challenging Behaviour Scale
CCI	Charlson Comorbidity Index
CDR	Clinical Dementia Rating Scale
CI	Cognitive Impairment
CIRS-G	Cumulative Illness Rating Scale-Geriatric
CPS	Cognitive Performance Scale
Crichton Royal (Modified)	Crichton Royal Behaviour Rating Scale
CSDD	Cornell Scale for Depression in Dementia
DI	Delirium Index
DSM-III-R	Diagnostic and Statistical Manual, Third Edition, Revised
GMHR	General Medical Health Rating
GDS	Geriatric Depression Scale
GMSS	Geriatric Metal State Schedule
HDS	Hierarchic Dementia Scale
HONOS 65+	Health of the Nation Outcome Scale
ICD-10	International Classification of Diseases
ISI	Insomnia Severity Index
LQOLLP-R	Lancashire Quality of Life Profile-Residential
MBI	Maslach Burnout Inventory
MDS	Minimum Data Set
MDS-HC	Minimum Data Set-Home Care
MDS-NH	Minimum Data Set-Nursing Home
MDS/RAI	Minimum Data Set/ Resident Assessment Instrument
MEAP	Multiphasic Environmental Assessment Measure
MHCOP	Mental Health Care of Older People
MMSE	Mini Mental State Examination
MNA	Mini Nutritional Assessment
MOBID-2	Mobilization-Observation-Intensity-Dementia Pain Scale
MOSES	Multidimensional Observational Scale for Elderly Subjects
MQS	Medication Quantification Scale
NH	Nursing Home
NHBPS	Nursing Home Behaviour Problem Scale
NPI	Neuropsychiatric Inventory
NHP	Nottingham Health Profile (Pain)
NRS	0-10 Pain Numeric Rating Scale
NSS	Nursing Stress Scale
PACSLAC	Pain Assessment Checklist for Seniors with Limited Ability to Communicate
PAINAD	Pain Assessment in Advanced Dementia Scale
PFQ	Present Functioning Questionnaire
PGC-PIS	Philadelphia Geriatric Centre-Pain Intensity Scale
PGDRS	Psychogeriatric Dependency Ratings Scale
PPI	Present Pain Intensity Scale
QOL-AD	Quality of Life in Alzheimer's Disease
RAI	Resident Assessment Instrument-Assisted Living Facilities/Adult Care Home Assessment and Care Screening
RAID	Rating Anxiety in Dementia
RCH	Residential Care Home
SCES	Sheltered Care Environment Scale
SCUEQS	Special Care Unit Environmental Quality Scale
SIRS	Severe Impairment Rating Scale
SMAF	Functional Autonomy Measurement System
SMO	Structured Meal Observation
STAI	Spielberger State-Trait Anxiety Inventory

Appendix 4: Literature review matrix - Quantitative studies (UK)

Authors	Purpose of study	Country	Specific healthcare need studied	Sample size and type	Study design	Instruments used	Results	Conclusions	Additional Comments
Barry et al (2015)	To determine pain frequency, analgesic use and views of relatives	UK	Pain	42 residents, 16 staff, 35 relatives. 9 dementia nursing and residential care homes across Northern Ireland. Convenience sample	Cross-sectional study	Interviews, Severe impairment battery, CSSD, medical history, visual analogue scale, functional assessment rating, NPI-SD	85.7% had severe to moderate dementia. 88.1% prescribed mild to moderate analgesia, usually PRN. High use of antipsychotics	Pain common. Difficulties assessing and managing pain as evidenced by use of PRN analgesia and antipsychotics	Small sample size. Poor participation rate amongst residents (27.6%)
Benbow et al (1997)	To examine the patterns of care and levels of complication for diabetic residents	UK	Diabetes	109 residents, 45 Nursing and residential care homes in the catchment area of 1 hospital in North West England. Random sample	Cross-sectional study	Interviews, physical examination	Incidence of diabetes 9.9%. Little evidence of regular diabetic monitoring. Those in EMI homes significantly less likely to receive any formal diabetic care	Provision of care inadequate for this group. Improved staff training and closer co-operation between primary and secondary care is needed	Small sample size. Although reported all the results it was a very short paper with minimal detail
Gordon et al (2014b)	To describe the health status and healthcare resource use of UK care home residents	UK		227 residents, 5 nursing and 6 residential care homes nearby one UK city. Convenience sample of care homes	Longitudinal	Barthel index, MMSE, NPI, Mini-nutritional index, EuroQoL-5D, General health questionnaire-12 item, medical notes	High levels of CI (75%), co-morbidities (mean 6.2) and polypharmacy. 30% malnourished and 66% had behavioural disturbances. Had contact with NHS once/month on average	Residents in care homes have high levels of dependency, CI and multiple morbidity. They are frequent users of both primary and secondary care and those using secondary care do so intensively	Convenience sample of care homes from a small area in the UK

Hancock et al (2006)	To assess the met and unmet needs of older people with dementia in residential care homes	UK	Dementia	238 residents, 24 residential care homes across the UK Convenience sample of care homes. Random sample of residents	Cross-sectional study	CANE, CAPE-BRS, Barthel scale, CBS, CSDD, RAID, CDR, MMSE	Only 37% had dementia diagnosis recorded. Environmental and physical health needs met. Sensory and physical disability (incontinence and mobility), mental health and social needs often unmet. If needs unmet leads to increased levels of anxiety and depression	Those caring for these individuals need training and support to be able to identify and meet more complex needs.	Study concerned with exploring situation in residential care homes Method of identifying residents with dementia may not have picked up all those at an early stage. So this group may have been under represented
Kinley et al (2014)	To identify care provided to residents dying in nursing homes	UK	End-of-life care	2,444 residents 38 NH across SE England. Convenience sample	Cross-sectional study	Survey of notes	Incidence of dementia 79%. 56% died within 1 year of admission. Supported by a range of healthcare professional. 34% admitted to hospital in last month of life, 58% were inappropriate admissions. Most common was a slow dwindling death	Significant numbers die within a year of admission. Support by healthcare professional needs to be proactive to support staff and prevent inappropriate admissions	Large resident sample size Only one region in England
Macdonald and Carpenter (2003)	To estimate the nursing staff's recognition of dementia in non-specialist NH residents	UK	Dementia	445 residents, 135 nurses, 157 non EMI NH in South East England. Random sample.	Prospective survey	MMSE, CSDD, Barthel Index, Behave-AD	Nurses only correctly identified 34% of residents as having dementia. Dementia identified in 5 residents, who actually had other major psychiatric conditions. Recognition not associated with training or duration of employment	Whilst formal recognition of dementia not a pre-requisite to providing good care, it may be a start	Probability sample drawn up, but only 58% of these actually visited, so may not be a representative sample No details given about staff who took part

Mann et al (2000)	To investigate the response of residential care homes to 4 specific health problems and the relationship of the quality of this response to rates of depression	UK		309 residents, 17 residential care homes across the UK. Convenience sample	Post hoc analysis of data from a cross sectional survey.	MEAP, SCES, BAS, CAPE, Barthel Index	79% of residents had some degree of dementia. 40% classified as depressed. Low recognition of depression by key workers The 4 health problems were common in all residents. Quality of response to these variable.	Residential care homes are caring for a very disabled population. There is a need for better training of staff. Need for more involvement by GPs and community healthcare staff	The care homes selected to take part were felt to provide excellent or standard quality care, so may not be truly reflective of the sector
Martin et al (2002)	To compare needs and levels of dependency in residential and nursing home settings	UK		74 residents, 1 residential care home and 2 nursing care settings, 1 continuing care ward and 1 NH in NW Essex. Convenience sample	Cross sectional study	CANE, CAPE-BRS, MMSE	89% of residents had dementia. Those in RCH had significantly less CI. Both care home types had similar levels of met and unmet needs. Those in RCH appear to be more dependent than in the past	There were a wide range of needs in both populations, but most residents had their needs met. RCH had more difficulty meeting more specialist needs e.g. behavioural or memory problems	Small sample size in one part of a county so may not be representative
Mozley et al (2004)	To identify the factors determining quality of life of older people who have moved into care homes	UK		308 residents and 440 care staff 35 nursing or residential care homes across UK. Convenience sample	Longitudinal study	MMSE, AMTS, GDS, Barthel, Crichton Royal, HONOS 65+, LQOLP-R, Spitzer Uniscale, GMSS, MEAP, SCES, non-participant observation, General Health Questionnaire, Job Satisfaction Scale	Those newly admitted were more cognitively impaired. Good physical health related to good mental health. High levels of depression or loneliness. Activity or occupation important for QOL. 59% of staff had no job related qualifications. Training for staff limited, especially in psychiatric, or psychological issues	Dementia widespread across the care home sector. Good physical health related to good mental health and other positive outcomes. Effective care is needed for residents with mental health problems. Staff need training in a variety of areas	Residents were followed up over a year Poor response rate to staff questionnaires 37%, although varied greatly between homes from 6-84%

Sinclair et al (1997)	To document the prevalence of known diabetes and quantity of diabetes care in long term institutional settings	UK	Diabetes	109 diabetic and 106 non diabetic residents, 31 nursing/dual registered homes, 88 residential homes in South Wales. Random sample.	Cross-sectional study	MMSE, Diabetic Knowledge Index, Barthel Index, Behavioural rating scale, Semi-structured interview with residents, postal questionnaire care home managers	45% of those with diabetes also had dementia. Diabetic residents had significantly higher levels of disability and dementia. Overall diabetic care to care homes relatively unstructured. Knowledge of care home staff poor, especially in RCH.	The high levels of CI and disability indicate that this group is vulnerable and as such they require detailed planning and assessment of their needs and care	Small sample size, resulting in issues of generalisability
Stewart et al (2014)	To describe prevalence and severity of dementia, depression and behavioural problems in care homes	UK	Dementia	301 residents, 4NH, 5 RCH, 5EMI, 1 Dual registered 4 boroughs in SE London. Random samples	Cross-sectional study	Clinical dementia rating scale, CDDS, NPI	Prevalence of dementia 75.1%. 26.3% were depressed. 87.3% experienced 1+ behavioural problem.	High levels of morbidity in EMI setting. High levels of severe dementia in non-EMI setting. High incidence of depression and behavioural problems suggest possibility of unmet needs	Small sample size

Appendix 5: Literature review matrix - Quantitative studies (International)

Authors	Purpose of study	Country	Specific healthcare need studied	Sample size and type	Study design	Instruments used	Results	Conclusions	Additional Comments
Aminzadeh et al (2004)	To examine health/functional profile, patterns of service use and medical/care needs of a sample of older adults in residential care facilities in Ottawa	Canada		178 residents, 9 residential care facilities in Ottawa Random sample of residential facilities	Cross-sectional study	Perceived health compared to peers, MDS, SMAF, Get up and go test, MMSE, GSS	On average 6.3 medical diagnoses. For those that needed further assessment most common reason was CI / dementia. 39.9% of residents had dementia and 32.6% had had a diagnosis of depression. Polypharmacy common. Those in special care units had higher levels of need.	There appears to be considerable overlap in long term care residents in terms of levels of functional and mental disabilities. Although high levels of need recorded they do appear to being met. High levels of care increasingly related to dementia.	Whilst the sample was random, it may not be representative as it was from one French speaking Canadian city Although carried out in residential care facilities there was a registered nursing presence in these care homes
Black et al (2006)	To describe the health problems and comorbid illnesses of NH residents with advanced dementia	USA	Pain	123 residents 3 NH in 1 US state Convenience sample	Prospective study	SIRS, review of medical notes	Most prevalent conditions were: skin problems (95%), nutrition/hydration (85%), psychiatric and behavioural (85%), GI (81%), Infections (80%). Pain common (63%) and associated with a number of conditions. Those with recognised pain had better cognitive function	High levels of recognised medical and physical comorbidity in residents with dementia near end of life suggesting that healthcare needs in those with advanced dementia are often very complex	Results may not be generalisable as small sample only
Di Giulio et al (2008)	To describe the last months of life of residents with severe dementia	Italy	End-of-life care	141 residents 7 LTC facilities in Northern Italy	Retrospective study	Clinical records	Month before death 88% experienced severe symptoms e.g. fever, dyspnoea,	Suggests that treatment at end-of-life for those with dementia is	Relies on medical records for data so not able to understand clinical decisions

	in LTC and clinical decisions in the management of end-of-life events			Convenience sample			pain, pressure sores. Use of life sustaining treatment noted with IV therapy, tube feeding and antibiotics common in last 48 hours. Also common use of physical restraint	aggressive rather than palliative in nature	made. Care faculties not typical as have medical staff on site including geriatricians
Donini et al (2013)	To determine the prevalence of malnutrition, perceived quality of food and nutritional care	Italy	Nutrition	100 residents 1 NH in Rome Random sample	Cross-sectional study	Mini nutritional assessment, anthropometric data, muscle strength, dietary recall, dental health, medical history, SPMSQ, GDS, functional abilities, lab tests	Prevalence of malnutrition 36%, with 46% at risk. High prevalence associated with severe CI (66.7%). Also associated with depression, pain, dental and GI problems. Little attention paid to nutritional status by medical staff or nurses	Greater attention needs to be paid to nutritional needs, including need for tasty and nutritious food, especially by medical and nursing staff	Small sample size from a specialised nursing home in one Italian city
Ferrell et al (1995)	To describe the pain experienced by residents in NH which have a high prevalence of CI	USA	Pain	325 residents, 10 nursing homes in 1 US city Random sample	Cross-sectional study	MMSE, Katz Activities of daily living scale, questionnaires, PPI, 5 pain scales	62% reported pain. No resident's pain regularly assessed on an on-going basis. Analgesia used sparingly. Other strategies rarely used. 86% with CI could complete at least one pain tool. 21% unable to make their needs known	Those residents with CI need their pain to be constantly and frequently assessed	108 residents excluded from final report for various reasons such as unresponsive or non-English speaking. Results were of a descriptive nature only Carried out in 1 US city
Fuchs-Lacelle et al (2008)	To determine if systematic pain assessment leads to improved pain management practices	Canada	Pain	181 patients, 61 carers, 12 long term care facilities, either nursing homes or units in rehabilitation	Comparative longitudinal study Quasi-experimental design	PFQ, PACSLAC used in experimental group, activity log in control group, MQS,	High levels of severe CI present. Regular use of tool increased use of PRN medication and reduced levels of burnout and stress	Highlights the role of systematic, routine pain assessment in those with severe CI	Some carers had difficulty completing the pain assessment. Results exploring staff stress may not be representative as few completed these tools

				hospital Convenience sample		NSS, and MBI used to measure staff burnout and levels of stress	amongst carers		
Gruber-Baldini et al (2005)	To assess the prevalence of depression in , residents with dementia and staff and facility characteristics associated with depression	USA	Depression	347 residents, 10 NH and 35 ALFs 4 US states Random sample.	Cross-sectional study	CSDD. Interviews with care supervisor	High levels of depression in all types of care facility. Low involvement of mental health professionals. Those with depression more likely to be severely cognitively impaired. Over half those depressed not detected by staff.	Undetected depression high in all types of care facilities. May benefit from improved training and greater involvement of mental health professionals	4 states selected were chosen as they had differences in structuring and financing of ALFs. CSDD is a measure of depressive symptoms and not a clinical diagnosis and so may well be an underestimation of the problem
Horgas and Tsai (1998)	To explore the relationship between CI and analgesic drug use in NH residents	USA	Pain	339 residents in 4 NH in 1 US state Convenience sample	Cross-sectional study	MOSES, Clinical records	45% diagnosed as having a cognitive disorder. 55% had a diagnosis which would result in chronic pain. 88% prescribed analgesia, 47% given analgesic during study period. Those with CI prescribed and given significantly fewer pain meds and lower doses	Those with CI are less likely to be prescribed or given pain medication	Based only on presence of painful conditions and not of direct assessment of pain severity Sample may not be representative as only 4 NH in one area in one US state
Koch et al (2005)	To determine the prevalence of uncorrected visual disorders in residents with AD and whether staff take corrective measures	USA	Sight loss	85 residents, 2 NH in 1 US county Convenience sample	Retrospective cohort study	MMSE, resident interviews, chart reviews	94% of residents prescribed glasses. 31% didn't wear them as they were damaged, lost or the wrong prescription. No resident had had an eye examination in the past year. Poor vision known to	Ensure residents have glasses when needed. To have at least yearly eye examinations	Results may not be generalisable as small sample carried out in only 2 NH

255

							be a common cause of low MMSE, independent of level of dementia		
Kopetz et al (2000)	To describe the clinical characteristics and outcomes of residents in a specialised dementia ALF	USA		144 residents in 1 ALF in 1 US state, compared to 737 patients with dementia in other ALFs, NHs or at home Convenience sample	Longitudinal study	Range of neuro-psychiatric evaluations: including MMSE, CDR, CSDD, PGDRS and GMHR. MMSE, CSDD and PGDRS reassessed every 6 months	Residents in ALF had an intermediate level of dementia and moderate care needs when compared to those in NHs. Those in this specialised dementia care unit had no clinical differences from those in a general ALF. High incidence of depression in all settings	Building a clearer picture of the population with dementia, living in ALFs	May not be generalisable as small sample i.e. 1 ALF, which was also not typical as had a close association with a local teaching hospital
Leong and Nuo (2007)	To determine the prevalence of pain and its impact on residents with different levels of CI	Singapore	Pain	358 residents from 3 NH Convenience sample	Cross sectional study	Self-reporting, PAINAD, GDS, CSDD, AMT, STAI, AAS	Prevalence of pain around 51-57%. Acute pain was more prevalent in those with CI. Large numbers had significant mood complaints due to pain	Need to assess both pain and mood, as they are interrelated. The use of proxy measures may not be as accurate as self-reporting	No data given about the nursing homes who took part in the study, unable to decide if representative
Lou et al (2007)	To determine changes in BMI and health outcomes and associated factors in residents with dementia.	Taiwan	Nutrition	55 residents, 2 long term care facilities in Taiwan Convenience sample	Cross sectional study	Weight, BMI, Barthel Index, adverse health events recorded	18% of residents undernourished. There was a trend over the 3 months for BMI to decrease. Increased adverse health events were associated with the need for more assistance in feeding or the presence of an NG tube.	Need to identify those at risk of malnutrition and poor health outcomes and plan care accordingly	Small sample size. Only 42 residents completed the study
Martin-Garcia et al (2013)	To analyse the relationship between	Spain	Dementia	525 residents with dementia and 234 without	Cross-sectional study	SPMSQ, Barthel index, EQ-5D,	Residents with dementia had worse health status, QOL	Residents with dementia reportedly had the	Small sample size using a convenience sample. Significant

	comorbidity, health status, QOL and dementia			14 care homes across Spain Convenience sample		cumulative illness rating scale for geriatrics, EQ-visual analogue scale	and higher functional dependence. 96.8% had at least 2 medical conditions	most compromised health status, especially those with sight, oral and GU problems	differences between the 2 groups in terms of characteristics
Mitchell et al (2004a)	To describe and compare the end of life experiences of persons dying with advanced dementia in NH and home care settings	USA	End-of-life care	2730 NH residents, 290 home care recipients Patients who died within a year of admission to NH or home care in 1 US state. Convenience sample	Retrospective cohort study	MDS-NH, MDS-HC	Palliative care suboptimal in both groups. Potentially treatable symptoms common amongst those who were dying. Hospital admissions common just before death.	Poor recognition when a person with advance dementia is dying. Highlights the need for better palliative care for this group	Relied on data from MDS only on which to base results so only gives a picture of what measured by MDS 12% of admissions had to be excluded as no full data set available and so may not be a true representation of the situation
Mitchell et al (2004b)	To describe the end-of-life experiences of NH residents with advanced dementia	USA	End-of-life care	1609 residents with dementia 643 NH in New York State USA Comparison group 883 with cancer	Retrospective study	MDS	Those with dementia not recognised as having a terminal condition, yet 71% died within 6 months. Use of non-palliative treatments common in those with dementia e.g. IV therapy, tube feeding, restraints. Distressing symptoms included pressure sores, pneumonia, chewing/swallowing problems	Residents with advanced dementia not perceived to have a terminal illness. As a result care is often not of a palliative nature	Relied on data from MDS collected between 1994-1997 so relying on accuracy of data that had been collected by others Residents from one US state only
Moss et al (2002)	To examine how NH administrators describe care of terminally ill residents with dementia	USA	End-of-life care	400 NH from across USA Random sample	Survey	Questionnaire, 50 qualitative telephone interviews	Many residents end their lives in hospital. Symptom control often poor, especially pain control. Staff training	NH staff report difficulty predicting if a resident is dying. Suggests that staff need specific training	Response rate only 29%. Questionnaire shortened half way through study. Paper only reports on those who completed longer

257

							in terminal care for those with dementia poor	survey (n=201)
Nygaard and Jarland (2005)	To examine pain assessment and treatment in relation to mental state, patient's and nurse's opinion of pain and diagnostic information	Norway	Pain	125 residents, 3 nursing homes in 1 city Convenience sample	Cross sectional study	AMT, Barthel, medical records, Patient and nurse interviews	83% had CI or dementia, but 29% had no dementia diagnosis. 44% who were considered to be in pain received no treatment and 45% who complained of pain received no treatment. Those with a dementia diagnosis received less PRN medication.	Residents with a dementia diagnosis at increased risk of receiving inadequate PRN treatment for pain as compared to those who have dementia, but in whom there is no diagnosis.	Small sample size, with small numbers in each group i.e. cognitively intact, CI and dementia May not be representative as conducted in only one city
Payne et al (2002)	To estimate the incidence, prevalence and outcomes of depression in NH residents with dementia	USA	Depression	201 residents, 1 long term facility Purposive sample	Longitudinal study	CSDD, Neurological examination, MMSE, blood tests, scan if necessary	19.9% had depression on admission. 40% of these had a prior history of depression. Incidence decreased whilst in the facility	Those with a history of depression at increased risk. As a large number were depressed on admission appropriate assessment needed	May not be generalisable as study carried out in a specialised nursing home, which had psychiatric staff on site
Proctor and Hirdes (2001)	To examine the prevalence of pain in residents with dementia	Canada	Pain	3195 residents in 8 + NH across 3 states	Cross-sectional study	MDS, CPS	31.6% residents had severe dementia. 49.7% had pain and 23.7% experienced pain daily. Prevalence of pain decreased with degree of CI.	Pain less well identified in those with CI, but not due to differences between the prevalence of conditions likely to cause pain	The 3 states differed culturally which may have had an effect on the results Unclear the total number of NH which were involved
Quinn et al (1999)	To explore the health characteristics of elderly personal care home residents	USA		80 elderly residents, convenience sample 21 Personal care homes in 1 US state	Cross-sectional study Exploratory descriptive study	RAI, Short Orientation-Memory-Concentration Test of CI, MNA	60% of residents had CI. Needed assistance with many ADLs. Combination of functional deficits and CI indicates that	May be a role for registered nurses to visit this type of home regularly for health assessment or case management	Small sample, resulting in issues of generalisability

				Convenience sample			may have unmet needs. May be at risk from preventable health problems		
Quinn et al (2003)	To compare the health characteristics of elderly residents without dementia, with possible early dementia and those with dementia	USA		80 elderly residents, 21 Personal care homes in 1 US state Convenience sample	Cross-sectional study Exploratory descriptive study	RAI, Short Orientation-Memory-Concentration Test of CI, MNA	The 3 groups have different service needs. Many physical health characteristics were not significantly different between 3 groups. But those with dementia had problems with decision making, some ADLs and medication management	People with possible dementia, but without a diagnosis are found in these care homes. There may be a role for monitoring by nurses to help these residents avoid complications from co-morbid conditions	Small sample, resulting in issues of generalisability
Reed et al (2005)	To assess characteristics associated with low food and fluid intake in residents with dementia.	USA	Nutrition	421 residents 10 NH and 35 ALFs Random sample care homes Purposive sample 4 US states	Cross-sectional study	SMO, MMSE, MDS	Over 50% of residents had severe dementia. Low food (54%) and low fluid (51%) intake observed. Large differences between observed and reported difficulties. Those in ALFs less likely to be assessed for eating difficulties.	Identified characteristics which can improve intake in these residents, such as monitoring by staff, meals taken in public dining room	The 4 states selected were chosen as they have differences in the structuring and financing of their ALFs Only recorded one meal so difficult to generalise
Reynolds et al (2008)	To test the association between residents CI and pain management practices.	USA	Pain	551 residents, 6 nursing homes in 1 US state Random sample	Cross-sectional study	MDS	Documentation of pain decreased in linear fashion as CI increased. Only 56% of those with CI received pain medication. Non-drug therapies used in only 7% residents.	CI associated with lower reports of pain and less treatment being given. Use of PRN medication questioned in those with moderate to severe CI	Lower levels of pain in these residents may be a result of under identification by the MDS Residents from one US state only
Sloane et al (2005)	To compare health and functional outcomes and	USA		1,252 residents, 166 ALFs and 40 NH	Longitudinal cohort study	MDS, Cohen-Mansfield Agitation	Those in ALFs were less cognitively impaired, had fewer	Whilst no significant difference	The 4 states selected were chosen as they had a well-developed

				Random sample care homes Purposive sample 4 US states		Inventory, CSDD, Multi-dimensional Observation Scale for Elderly Subjects	co-morbid conditions and fewer impairments in ADLs. However after 1 year nearly 25% of residents had been discharged to a NH. Hospitalisation rates significantly higher for ALF residents with mild dementia	between either type of care home in terms of mortality and incidence of new or worsening conditions, hospitalisation rates were much higher in ALFs, suggesting they have a problem with caring for a resident if they develop a significant medical or nursing need	ALF sector but may not be representative of other states Although care homes randomly selected high refusal rate (41%) so there may be some bias
health care utilisation of persons with dementia living in ALFs and NH									
Sloane et al (2008)	To better understand the experiences and possible unmet needs of people who are dying in LTC	USA	End-of-life care	581 interviews with care staff who had cared for 422 residents with dementia and 159 who were cognitively intact. 293 interviews with family members Random sample of care homes Purposive sample 4 US states	Cross-sectional study	Interviews with staff and family members	No differences between those with and without dementia in terms of pain, psychological status, family involvement, advanced care planning, most life prolonging interventions and hospice use. There were differences between care for those with and without dementia and also between type of care facility e.g. those with dementia more likely to be restrained and in ALFs to have pressure sores and poor hygiene	Quality of palliative care not affected by dementia status, or place of care. However specific areas such as use of restraints and sedatives could be improved	Relied on staff reporting care given so may not be a true reflection Small response rate from family members who were interested in being involved and so may not be representative
Suominen et al (2004)	To determine nutrient content and intake and	Finland	Nutrition	23 residents, 1 NH	Cross-sectional study	MMSE, Mini Nutritional Assessment	All residents either malnourished (13%), or at risk (87%) of	Need to identify those who are malnourished, or	Very small sample size, resulting in issues of

	nutritional status of residents with dementia			Convenience sample.		Test, energy and nutrient content of food, energy and nutrient intake	malnourishment. Energy content and nutritional content sufficient. The residents were eating much less than they needed.	at risk of malnourishment and to provide care tailored to their needs as soon as is possible	generalisability
Voyer et al (2008)	To determine detection rates of delirium by nurses among elderly residents with dementia	Canada	Delirium	156 residents, 40 nurses, 4 Long term care facilities in Quebec Convenience sample.	Prospective study	CAM, 6 items of MDS-2, DI, HDS, DOLOPLUS-II, CSDD, CCI, NHBPS, SMAF, ISI	Over 95% of residents had severe CI. Nurses under recognised delirium. High rate present in residents (70%), yet only recognised in 13-18% of cases.	The poor detection rate by the nurses highlights the need for education and training in the recognition of delirium	Small sample size, resulting in issues of generalisability
Wallace Williams et al (2005)	To describe the characteristics associated with limited mobility in long term residents with dementia	USA	Mobility	343 residents, 10 NH and 35 ALFs Random sample care homes Purposive sample 4 US states	Cross-sectional study	MMSE, MDS, Cohen-Mansfield Agitation Inventory, CSDD, Philadelphia Geriatric Pain Intensity Scale, Structured meal observation, SCUEQS, ALFQS, interviews with staff and family	89% of residents had some level of mobility limitation. Levels did not vary between home types, yet NH residents supposedly have higher levels of functional limitation. Those in ALFs less likely to receive assessment and treatment for mobility difficulties	Poor levels of assessment and treatment indicate the need for more attention to this group of residents	The 4 states selected were chosen as they have differences in the structuring and financing of their ALFs Residents weren't interviewed in the study, just observed.
Williams et al (2005)	To assess the prevalence, assessment and treatment of pain in residents with dementia	USA	Pain	331 residents, 10 NH and 35 ALFs Random sample care homes Purposive sample 4 US states	Cross-sectional study	PGC-PIS, NRS, MMSE, MDS, interview with care supervisor	Prevalence of pain between 20% (supervisors) to 39% (self-reporting). 90% of care supervisors felt adequately trained, yet around 40% of residents with pain received no pain medication and 25% had not been assessed.	Prevalence of pain lower than other studies, Used the cut-off point as 2.0 for pain, rather than 'any' pain. If this is used then prevalence is between 62-76%	Proxy reporting was primary pain measure, considered to be less accurate than self-reporting

Zimmerman et al (2005)	To explore dementia related attitudes of staff together with their levels of stress and satisfaction	USA		154 direct care givers, 10 NH and 35 ALFs, Random sample care homes Purposive sample 4 US states	Cross-sectional study	Approaches to dementia, work stress inventory and staff experience working with demented residents	Lower levels of stress associated with being older, better trained and working in a smaller home. Also if staff felt better trained in dementia they had more person-centred attitudes and were more satisfied. More stress if had been working for between 6-18 months and if in a specialised dementia unit.	Paying attention to the welfare and training of staff will result in staff who are less stressed and who are more willing to embrace a person-centred approach to care provision	Relied on self-reporting of care given and so may not be an accurate reflection of care provided
Zwakhalen et al (2009)	To explore pain prevalence in residents with dementia using an observational tool and to identify the association of pain with resident characteristics	Netherlands	Pain	117 residents, Convenience sample. 3 nursing homes across the country	Cross-sectional observational study	PACSLAC-D, MMSE, medical notes	Majority of residents severely impaired. Pain prevalence 47%. 40% who experienced pain received no pain medication. Those receiving regular medication were still experiencing pain.	The use of an observational tool has a place as one step in the assessment of pain	Small sample size, resulting in issues of generalisability No self-reporting of pain, relied on observational tool

Appendix 6: Literature review matrix - Qualitative Studies

Authors	Purpose of study	Country	Specific healthcare need studied	Sample size and type	Study design	Instruments used	Results	Conclusions	Additional Comments
Chang et al (2009)	To explore the challenges for providers of care for people with advanced dementia living in aged care facilities	Australia	End-of-life care	5 focus groups (n=24), 4 GPs, 12 RNs, 6 volunteers, 1 social worker, 1 assistant in nursing (AIN) 20 interviews, 2 directors of nursing, 3 RNs, 2 ENs, 4 AINs, 2 therapists, 7 key providers 10 NHs, Sydney	Action research	Interviews	Main challenges were in terms of knowledge and skills around care provision, dementia and palliative care e.g. accurate assessment especially of pain, managing physical and behavioural symptoms and communicating with families	Highlights the difficulties experienced in meeting the needs of residents with advanced dementia and the need for better knowledge and skills around assessment, symptom management and ethical issues	Small sample only from one city which may not be representative
Kaasalainen et al (2007)	To explore nurse's perceptions around providing palliative care for LTC residents with dementia	Canada	End-of-life care	34 participants, 7 RNs, 14 registered practical nurses, I nurse practitioner and 14 personal support workers, 3 LTC facilities in Ontario	Qualitative study	Focus groups	Difficulty judging if a person was dying from dementia. Caring for the family is important and they need education in to what is happening. Lack of staff repeatedly mentioned as an obstacle to effective palliative care	Training is needed for healthcare providers regarding end of life care for those with dementia. The family needs to deal with someone who is well educated in end of life care	Incentives offered to attend the focus group Sample made up only of nurses so may not represent views of all those who care for these patients
Livingston et al (2011)	To examine barriers and facilitators to care homes staff delivering improved end-of-life care for residents with dementia	UK	End-of-life care	58 staff, 20 RNs, 8 senior carers, 30, care workers, 1 NH in London	Qualitative study	Interviews	Staff felt they were skilled in recognising when a person was reaching the end of their life and how to care for them. A number of barriers were identified which included poor communication with relatives about	There is a need to implement interventions to improve care and tackle barriers to good end-of-life care, to allow residents to remain in the home rather than be sent to hospital, to avoid	May not be representative as study conducted in 1 NH based in a large city, providing care only for a single religious group. Majority of staff were non UK born and care home was receptive to research

							approaching death, worries over blame, lack of knowledge about advanced decisions, staff feeling emotionally unsupported	possible blame	
Tilly and Fok (2008)	To identify key elements of good end of life care for residents with dementia and perceived policy barriers to preventing this care being delivered	USA	End-of-life care	49 experts, both researchers and providers including physicians, nurses, social workers, counsellors	Qualitative study	Telephone interviews	Identified a number of key areas, including good communication, advanced care planning and symptom control. Staff also need to be adequately trained and have necessary knowledge specific to the needs of the person with dementia	The key characteristics of good end of life care include communication, advanced care planning and person centred approaches to care provision	No specific details given about the experts who took part

Policy barriers related to the American system of funding healthcare provision so not generalisable outside the USA |

Appendix 7: Literature review matrix - Literature reviews

Authors	Purpose of study	Specific healthcare need studied	Study design	Results	Conclusions	Additional Comments
Chalmers and Pearson (2005)	Oral hygiene care for residents with dementia in residential aged care facilities	Oral health	Literature review	Dental pain and problems under detected. Poor oral health affects QOL. Staff can be trained to carry out assessments. Identification of factors which may prevent oral care being carried out in residential care	Staff need to use screening tools and preventative oral hygiene practices	306 articles reviewed. Majority of studies were narrative.
Cowan et al (2003)	Assessment and management of pain in older people in care homes	Pain	Literature review	Neglected area in the UK. In US incidence between 49-83%. CI makes assessment more difficult. Analgesics under used. Nurses in care homes receive little training or support from specialists.	Need to conduct more research in this field in the UK setting. Need to address the barriers to effective treatment	Unclear how many studies reviewed or included
Goodman et al (2009)	A review of the evidence for end of life care for community dwelling older people with dementia, including those in care homes	End-of-life care	Integrated literature review	The majority of older people with dementia spend their last months or years at home or in care homes. Little research had focused on the experiences of those with dementia or has considered what supports or inhibits the provision of good quality end of life care at home or in settings that have intermittent access to specialist palliative care.	Research on end of life care for older people with dementia is fragmented and largely descriptive	68 papers included, of these 64% had been undertaken in care homes
Jones and Trigg (2007)	Review of people who have both dementia and serious sight loss	Sight loss	Literature review	Conservative estimates are that 2.5% of those over 75 have both dementia and serious sight loss. Levels believed to be higher in residential care. Sight loss and CI may lead to agitation	A dearth of data on the situation in the UK. Eyesight needs to be checked regularly in this group.	70 articles reviewed

Appendix 8: Letter of invitation to care home staff

CITY UNIVERSITY
LONDON

Research study: Meeting the healthcare needs of people with dementia in care homes

I am a PhD student at City University, with the Care of the Older People Team and a District Nurse, based at XXXX Health Centre. For my research study I am proposing to explore how the healthcare needs of older people with dementia are being met within residential care homes and the issues and challenges that staff, both in care homes and primary care, are experiencing in trying to meet the needs of this group of residents.

I have recruited one care home within XXXXX to take part in this study. As you work in this care home I am writing to you to introduce myself and to see if you would consider becoming involved. By showing interest you are not signing up to anything at the present time. What I would do if you are interested, is to meet with you and to explain in greater depth what I hope to achieve from this study and what taking part would involve. I would then give you time and space to decide if you would be interested. If you are interested in taking part then please let me know next time I visit your care home.

All research which is undertaken in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and approved by The Joint South London and Maudsley Research Ethics Committee.

If you require any further information I can be contacted at:

or my mobile number is

Regards

Jenny Dudman
District Nurse Team Leader
PhD Student

Appendix 9: Care home Staff Information Sheet

CITY UNIVERSITY LONDON

Participant Information Sheet

Meeting the healthcare needs of people with dementia in care homes

You are being invited to take part in this study through which it is hoped to improve how health and social care staff work together to meet the healthcare needs of people with dementia in residential care homes. Before you decide to take part it is important that you understand why this study is being done and what it will involve. Please take time to read the following information and to discuss it with others if you wish. Please ask the researcher anything that is not clear to you, or if you would like more information. Take time to decide if you wish to take part.

What is the purpose of the study?
The study hopes to gather information from a number of different sources by interviewing residents, care homes staff, healthcare staff and relatives/friends to discover whether the healthcare needs of residents with dementia are being fully met. To explore what is stopping needs from being met and if there are better ways that health and social care staff could work together to meet these needs. The findings of the study can then be used to identify how service provision could be improved to residential care homes.

Why have I been invited?
You have been invited to take part as you are one of the care staff who works in this care home, which has agreed to take part in the study.

Do I have to take part?
You do not have to take part if you do not wish to do so. If you do decide to take part then you will be given this information sheet and be asked to sign a consent form.

If you decide to take part then you are still free to withdraw at any time and without having to give any reason. This includes your right to stop during an interview. Any decision to withdraw, or not to take part will have no effect on the healthcare services given to the care home.

What do I have to do?
If you are interested in taking part then you can let the person who gave you this written information know when she next visits the care home. She will then arrange a date that is convenient for you for an interview to take place at the care home. Any questions that you may have can be discussed with her.

During the interview you will be asked to talk about your experiences of identifying health problems in residents with dementia, any difficulties or challenges you have had in meeting health problems and any ideas of how these challenges could be overcome.

The interview could be carried out as either a one-to-one interview with the researcher, or you could be part of a focus group, where there will be other members of the care staff with you. Each interview should take no longer than an hour and each focus group no longer than 90 minutes. You will only be asked to take part in one interview during the time the researcher spends at your care home

What happens to the information I give at the interview?
The interview or focus group will be tape recorded so the interviewer can listen to what you have to say without the need to take notes. Following the interview it will be typed up from the tape recording.

Your personal details and any names or people you mention will remain confidential. The tapes will then be destroyed once the study is finished. A written report will be produced at the end of the researcher's time in your care home, which will be shared with others, so they can better understand what is happening in trying to meet the needs of the residents with dementia and how provision of services could be improved. Whilst the report may contain quotes of what has been said during interviews, these quotes will be anonymised and so no one will be able to identify who said what, this will include your employers.

What happens if poor care is identified?
If something is heard that suggests unacceptable or unsafe practice then the interviewer will have to report this practice locally. In the unlikely situation of this happening, the interviewer will discuss this with you and will explain what will happen. This is designed to safeguard patients. All NHS staff are required to report anything they hear that might suggest poor practice.

What will happen if I don't want to carry on with the study?
If you do decide to withdraw from the study and have taken part in an interview then you can decide if you wish for your data to continue to be included or not in the analysis and final report.

What happens if there is a problem?
If you have a concern about any part of the study you should ask to speak to the researcher who will do her best to answer your questions. Her contact number is ▇▇▇▇ ▇▇▇▇▇ If you remain unhappy and wish to complain formally, you can do this through Professor J Meyer at City University. Her contact number is ▇▇▇▇▇▇▇

What will happen to the results of the study?
The results of the study will be used to help improve healthcare provision at a local and national level. The findings and possible service improvements will be published in a number of ways, for example at a local workshop event, shared on the *My Home Life* website, in journal articles and through guidance on improving health services to care homes.

Who is organising and funding the study?
This study is being carried out as part of a PhD which the researcher is undertaking at City University. Professor Julienne Meyer is the supervisor and is overseeing the study.

Who has approved the study?
All research which is undertaken in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and approved by the south London and Maudsley Research Ethics Committee.

Contact for further information
Jenny Dudman
District Nurse Team Leader

Appendix 10: Consent form

CITY UNIVERSITY LONDON

Study number ………………………………………………….

Name of the participant …………………………………….

Consent Form

Meeting the healthcare needs of people with dementia in care homes

Name of Researcher …………………………………………..

Please put your initials next to each point that you have read and agree with and then sign the form at the end

- I agree to take part in the above study. I have read the information sheet which is attached to the form. I understand what my role will be in this research and all my questions have been answered to my satisfaction

  ……..

- I understand that any information I give is confidential and that no information that could lead to the identification of any individual will be disclosed in any reports of the study. No identifiable personal data will be published and that identifiable data will not be shared with any other organisation   …….

- I understand that I am free to ask any questions at any time before and during the study   ……..

- I have been provided with a copy of this form and the Participant Information Sheet   ……..

- I agree to be interviewed and that taped recordings will be made. I understand that these will be destroyed at the end of the study   ……..

- I understand that I am free to withdraw from the study at any time, for any reason and without being disadvantaged in anyway   ……..

Name of participant (print) ……………….. Signed ………….. Date ……….

You will be given a copy of this form to keep

Appendix 11: Community Nurses Information Sheet

CITY UNIVERSITY LONDON

Participant Information Sheet

Meeting the healthcare needs of people with dementia in care homes

You are being invited to take part in this study through which it is hoped to improve how health and social care staff work together to meet the healthcare needs of people with dementia in residential care homes. Before you decide to take part it is important that you understand why this study is being done and what it will involve. Please take time to read the following information and to discuss it with others if you wish. Please ask the researcher anything that is not clear to you, or if you would like more information. Take time to decide if you wish to take part.

What is the purpose of the study?
The study hopes to gather information from a number of different sources by interviewing residents, care homes staff, healthcare staff and relatives/friends to discover whether the healthcare needs of residents with dementia are being fully met. To explore what is stopping needs from being met and if there are better ways that health and social care staff could work together to meet these needs. The findings of the study can then be used to identify how service provision could be improved to residential care homes.

Why have I been invited?
You have been invited to take part as you are a healthcare professional who is involved in providing healthcare services to this care home, which has agreed to take part in the study.

Do I have to take part?
You do not have to take part if you do not wish to do so. If you do decide to take part then you will be given this information sheet and be asked to sign a consent form.

If you decide to take part then you are still free to withdraw at any time and without having to give any reason. This includes your right to stop during an interview.

What do I have to do?
If you are interested in taking part then you can let the person who gave you this written information know when she next contacts your health centre. She will then arrange a date and place that is convenient for you for an interview to take place. Any questions that you may have can be discussed with her.

During the interview you will be asked to talk about your experiences of identifying health problems in residents with dementia, any difficulties or challenges you have had in meeting health problems and any ideas of how these challenges could be overcome.

The interview could be carried out as either a one-to-one interview with the researcher, or you could be part of a focus group, where there will be other members of your healthcare team with you. Each interview should take no longer than an hour and each focus group no longer than 90 minutes. You will only be asked to take part in one interview during the time the researcher spends in the care home

What happens to the information I give at the interview?
The interview or focus group will be tape recorded so the interviewer can listen to what you have to say without the need to take notes. Following the interview it will be typed up from the tape recording.

Your personal details and any names or people you mention will remain confidential. The tapes will then be destroyed once the study is completed. A written report will be produced at the end of the researcher's time in the care home, which will be shared with others, so they can better understand what is happening in trying to meet the needs of the residents with dementia and how provision of services could be improved. Whilst the report may contain quotes of what has been said during interviews, these quotes will be anonymised and so no one will be able to identify who said what, this will include your employers.

What happens if poor care is identified?
If something is heard that suggests unacceptable or unsafe practice then the interviewer will have to report this practice locally. In the unlikely situation of this happening, the interviewer will discuss this with you and will explain what will happen. This is designed to safeguard patients. All NHS staff are required to report anything they hear that might suggest poor practice.

What will happen if I don't want to carry on with the study?
If you do decide to withdraw from the study and have taken part in an interview then you can decide if you wish for your data to continue to be included, or no, in the analysis and final report.

What happens If there is a problem?
If you have a concern about any part of the study you should ask to speak to the researcher who will do her best to answer your questions. Her contact number is ▮▮▮▮ ▮▮▮▮▮ If you remain unhappy and wish to complain formally, you can do this through Professor J Meyer at City University. Her contact number is ▮▮▮▮▮▮▮▮

What will happen to the results of the study?
The results of the study will be used to help improve healthcare provision at a local and national level. The findings and possible service improvements will be published in a number of ways, for example at a local workshop event, shared on the *My Home Life* website, in journal articles and through guidance on improving health services to care homes.

Who is organising and funding the study?
This study is being carried out as part of a PhD which the researcher is undertaking at City University. Professor Julienne Meyer is the supervisor and is overseeing the study.

Who has approved the study?
All research which is undertaken in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and approved by the Joint South London and Maudsley Research Ethics Committee.

Contact for further information
Jenny Dudman
District Nurse Team Leader

Appendix 12: Interview schedule (Care home staff)

Background questions: Tell me a little about yourself:

Your age

Your ethnicity

How long have you worked in social care?

What did you do before?

What qualifications do you have? (e.g. NVQs)

How long have you worked in this care home?

What is your job title?

What sort of health problems do your residents suffer with?

Do you think that there are health problems which are going unmet?

Do you have problems getting all the information that you need in terms of previous health needs?

What do you think is your role in managing the healthcare needs of residents?

Does dementia have an effect on a resident's health problems?

How do you meet healthcare needs?

Who do you approach to help you meet these needs?

How do you access their support?

Do you know what type of help/support they are able to provide?

What do you think is their role?

Do they have skills/experience in caring for people with dementia?

If not does this ever present any problems?

What training have you received?

Have you had any training around dementia care?

How has this helped you?

Have you had any training around managing any healthcare problems?

What training do you think has helped you to meet healthcare needs?

What training do you think may help you to meet these needs?

How do you work with primary care staff to manage a residents healthcare needs?

What has been your experience in getting the support that you need?

Could you give an example of how this went?

Is it always like this / is it always this difficult?

Is there any sort of support that you would value?

Do you feel that primary care staff understand your role in managing healthcare problems?

Do they know what you are able to do and what you can't do?

Looking to the future

What do you think could be better done to improve healthcare provision for residents with dementia?

Have you any ideas, from your own experiences, what could be done to improve how staff from different disciplines work together?

Is there anything else we haven't covered that you would like to say?

Appendix 13: Interview schedule (Community Nurses)

Background questions: Tell me a little about yourself:

How long have you been qualified?

Do you have a district nursing qualification?

How long have you been working in the community?

Where did you work before this?

How many residential care homes does your team cover?

What does the term 'healthcare needs' mean to you?
- Physical
- Mental Health

Accessing the district nursing service?

Who is referring residents to your service?

For what type of health problems would you typically be visiting?

Do you think this accurately reflects the health needs of this group of residents? (Given degree of frailty and that they need ongoing 24-hour care)

If you aren't addressing these other needs who do you think might be assessing and meeting them?

How do you assess the healthcare needs of residents in care homes?

Is there any difference in the assessment if they have some degree of cognitive impairment or dementia?

What assessment tools do you use to help you assess the healthcare needs of these residents? Do you have any difficulties in identifying healthcare needs in these residents?

What information do you have access to which could help in assessing healthcare needs?

Are there any other factors which might affect how you are able to carry out an assessment?

How do you meet the healthcare needs which you identify?

What has your experience been in providing care to meet the healthcare needs of a resident with dementia?

Could you give an example of how you this went?

- Is it always like this / is it always this difficult

- How does this make you feel?

- How is your experience if it doesn't work like this?

Who else might you approach to meet these needs if you were having problems meeting the health problems of residents?

- Yourself – do you feel able to meet them?
- Internal – who can you approach?
- External – who can you approach?
- How would you access their support?

What training have you received around caring for a person with dementia?

Have you had any training around dementia care?

If so has this had any impact on the care you now provide this group?

Have you had any specific training around healthcare needs of residents with dementia?

What training do you think has helped you to meet healthcare needs in residents with dementia?

What training do you think may have helped you to meet these needs?

Is there any previous experience you have had which helped you to care for a resident with dementia?

What are the roles of health and social care staff in meeting healthcare needs?

What type of support do you receive from the care home in managing a residents healthcare needs?

What do you think is your role in addressing the healthcare needs of residents in care homes?

What do you think is the role of care home staff in addressing the healthcare needs of residents in care homes?

Given the difficulties that care staff may have in meeting many health issues, e.g. limited knowledge or training, do you believe that we are working collaboratively together to meet the needs of residents?

Can you give an example of how we are/are not working together?

Is there any other support you think would be helpful?

5. Looking to the future

What do you think could be better done to improve healthcare provision for residents with dementia?

Have you any ideas, from your own experiences, what could be done to improve how staff from different disciplines work together?
Internal
External

Is there anything else we haven't covered that you would like to say?

Appendix 15: NVivo coding used

Tree node Level 1	Tree node Level 2	Tree node Level 3
A lack of understanding		
Advice not followed		
Ageism		
Assessment practices (DNs)		
	Concentrate on physical needs	
	Continual assessment	
	Dementia specific tools	
	Difficulties in assessing	
	DN notes	
	From resident	
	Holistic assessment	
	Lack of time	
	Rely on carers	
	Same assessment used	
	Use of tools	
Assessment practices (CH)		
Assume		
Attitudes of Care home staff		
	Defensive	
	Disinterest	
	Hostility	
	Lack confidence	
	No stake	
	Positive attitudes	
	Proactive carers	
Attitude of nurses towards care homes and carers		
	Critical	
	DNs visiting care homes	
	General attitudes re staff	
	How attitudes change	
Care home manager		
	Experience	
	Role	
	Skills	
	What it is like	
Care home staff		
	Challenges they face	
	Complex skills needed	
	Lack of knowledge/skills	
	Limited support	
	Lowest of the low	
	Skills needed	
	Skills they possess	
	Vulnerable	
Care homes		
	Activities	
	Admitted to hospital	
	Attitudes of c/h providers	
	Attitudes to staff	
	Care home type	
	Complex needs of residents	
	Concerns of managers	
	Dependency	
	Environment	
	External support	
		Difficulty in accessing
	Fees	
	GPs	
	Health problems	
	Home from home	
	Inappropriate referral	

	Money	
	Needs changing	
	Pressures	
	Staff	
	Staffing levels	
	Vacancies	
Care needs to change		
Care provided to care home by DNs		
	Care missing	
	Differences in care given	
	Importance of good care	
	Less control	
	Limited	
	Not taking on extra	
	Tasks	
	Unclear of responsibilities	
Care given to residents by care home staff		
	Care given	
	Care missing	
	Getting information	
Care rationed		
Caring		
Case histories		
	Problems encountered	
		Accessing external support
		Behaviour
		Different priorities
		Lack of knowledge
		Resident unable to express themselves
		Time
	Story	
Change role of DN		
Complex needs		
	Change in residents	
		Care at home
	Complex needs	
	Dementia	
	High levels of need	
	Move on	
	Needs changing	
Culture		
Definition of healthcare needs		
	Care home manager	
	Care home staff	
	DNs	
Delegate work appropriately		
Demands on DN service		
Dementia training		
	Benefits	
	Carers need training	
	Training received	
	Gaps in general training	
	In care homes	
	Not needed	
	Possible training	
	Preventing uptake	
	Rely on experience	
	Theories	
Differences in care given		
	24-hour care	
	Are faceless	
	Become detached	

	Care differs	
	Degree of complexity	
	Get them done	
	Less control	
	Needs being met already	
	Not focusing on other things	
	Seen as a simple dressing only	
	Shouldn't differ	
	Someone else to rely on	
	Support not given	
Different care provided in care homes		
DNs		
	Attitudes voiced	
	Team size	
Evidence of lack of care skills		
Experience of caring for person with dementia		
	Access to outside services	
	Admitted later	
	Care can't be given	
	Care homes can't cope	
	Care homes providing good care	
	Care staff	
		Advocate
		Behaviour
		Continuity
		Knowing the resident
		Lack of training or skills
		Needs changing
		Non-compliance
		Not knowing them
		Skills needed
	Dementia impacting care	
	Dementia overlooked	
	DNs and CNS	
		Behaviour
		Can't tell what is wrong
		Care planning/notes
		Communication difficulties
		Compliance
		Ethical issues
		General trained
		Impact on caseload
		It's depressing
		It's hard
		Know the patient
		Lack of continuity
		Left alone
		Needs more complex
		No life history
		Previous experience
		Relying on carers
		Strange face
		Time
		Try to manage yourself
		Work around it
	Family	
	HCPs lack skills	
	Lack of information	
	Lack of training	
	Little support from other professionals	
	Mental health training	

	Specialist nurses	
	Specialist role in care home	
	Support from healthcare professionals	
	Units	
Factors impacting care provision		
	Care homes	
		Care staff busy
		Different priorities
		Difficulty accessing support
		Fear
		Healthcare professionals
		Lack of knowledge and skills
		Lack of staff
		No plans
		Pay and conditions
		Poor communication skills
		Poor support for staff
		Reactive care
		See as DN role
		Training issues
		Unsuitable for care homes
	DNs	
		Care differs
		Continuity
		Critical
		Episodic care practices
		External factors
		External support
		Lack of information
		Lack of knowledge
		Mixed messages
		Need to be diligent
		Not having necessary supplies
		Not knowing the resident
		Not willing to take on extra
		Physical care only
		Poor care planning
		Resources
		Task orientated
		Time
		Unsure of their role
	Lack of continuity	
	Not working	
	Other people	
	Silo working	
Financial factors		
Fitting in with care home		
Forgotten population		
Good care practices		
	Activity	
	By care homes	
	Continuity of care provider	
	Knowing the person	
	Music	
	Proactive care	
	Take time	
	Talking	
Healthcare professionals		
	Benefits of external support	
	Challenges	
	GPs	
		Good practice
		Regular visits
	Need for external support	

	Specialist nurses	
Improving collaborative working		
Improving care		
	Regular reviews	
Improving dementia care		
	Better communication	
	Better joint working	
	Knowing more	
	Time	
	Tools	
	Training	
Inappropriate care practices		
Information		
	Importance of information	
	Lack of information	
	Life history	
	Social care focused	
	What information available	
	Who provides information	
Joint working		
	Encouraging joint working	
		Approachable
		Attitude of DN
		Communication
		Dementia
		Followed prescribed care
		Insight into limitations
		Interested
		Joint care
		Rapport
		Support
		Trust
		Valued
	Examples	
	Preventing joint working	
		Attitudes nurses
		Carer workload
		No joined up service
Just dementia		
Not asking for help		
Nurse and carer relationship		
Person centred care		
Physical care		
Poor support of care home staff by DNs		
Previous experience		
	Care home manager	
	Care staff	
	DNs	
Proactive care		
Referral to DN service		
	Difficulties created by referral service	
	Missing problem	
	Only what is referred	
	Reasons for referrals	
		Advice
		Catheter care
		Constipation
		Diabetes
		Equipment
		Injections
		Leg ulcers
		Palliative care
		Pressure sores

		Wounds
	Specific things	
	Taking on more	
	What staff don't do	
	When referring	
	Who is referring	
Regular medical support		
Rely on the carers		
Residents feelings		
Respite		
	Challenges	
Responsibility		
Risk		
	Care given because of risk	
	Safe environment/24-hour care	
	To cover themselves	
Role for senior staff (DNs)		
Role of carers in meeting healthcare needs		
	Asking a lot	
	Carers role	
	Could do more	
	Limited understanding	
	Missing problems	
	Need monitoring	
	Need support in the role	
	Need to know the resident	
	Role is unclear	
	Unable to manage	
Role of DN		
Role of HCSW		
Role of the family		
Sharing care		
Skills of DN staff		
Specialist nurses		
	Assessment	
	Dementia training	
	Difficulty in accessing info	
	Rely on the carers	
	Role	
		As a clinical lead
		Conflict
		Support
		Training
	Time to offer	
	Training needs	
	Who referring	
	Why referring	
Time		
Trained nurses in care homes		
	Nurse as a manager	
	Role for qualified staff in care homes	
Training in care homes		
	Attitude of manager	
	Attitude of staff	
	Benefits of training	
	Fed back	
	Lack of training	
	More than just training	
	Preventing	
	Possible training	
	Responsibility	
	Training provided	
Unclear roles		

	Carers unsure of nurses roles	
	Carers unsure of their role	
	Duplicating care	
	Nurses unsure of care home role	
	Nurses unsure of own role	
	Others unsure of role	
	What carers can or can't do	
Unrealistic expectations		
What changes needed		
What support valued		
Working with care home staff		
	Can't just pop in	
	Difficulties experienced	
		Attitudes of staff
		Care not followed
		Doesn't fit with their regime
		Kept waiting
		Left to it
		Losing things
		Mistrustful
		No more training
		Not knowing due to be seen
		Not picking up problems
		Poor communication
		Poor relationship
		Unnecessary referrals
	Fit with them	
	Give clear instructions	
	Judgemental	
	Limited need for them	
	Need supervision	
	Need support	
	Now your responsibility	
	Positive experiences	
	Staff accompany nurse	
	Time pressures	
	What it is like	
Working with community matron		
	Difficulties	
	Reasons to refer	
	Relationship	
	What they offer	
Working with nurses		
	Critical	
	Difficulties	
		Attitudes towards care home
		Mixed messages
		Not a priority
		Not aware of carers role
		Poor communication
		Referring
		Resident shouldn't be there
		Time factors
	Good experiences	
	Just a carer	
	Lack skills/knowledge	
	Provide support	
	Recognise carers skills	
	Reluctant to criticise	
	Role of the nurse	
	Task not person centred	
	Use the carers	

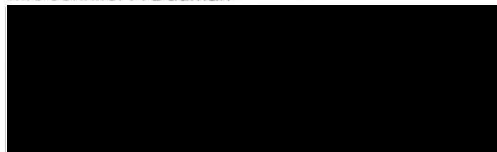# Appendix 16: Approval letter from ethics committee

NHS

National Research Ethics Service

The Joint South London and Maudsley and The Institute of Psychiatry NHS
Research Ethics Committee

South London REC Office (2)
1st Floor, Camberwell Building
94 Denmark Hill
London
SE5 9RS

Telephone: 020 3299 5033
Facsimile: 020 3299 5085

04 March 2010

Mrs Jennifer A Dudman

███████████████████████

Dear Mrs Dudman

Study Title:	Seeking Solutions: Exploring Better Ways of Meeting the Healthcare Needs of Older People with Dementia in Care Homes (Residential)
REC reference number:	10/H0807/7
Protocol number:	1

Thank you for your letter of 17 February 2010, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

The Committee has not yet been notified of the outcome of any site-specific assessment (SSA) for the non-NHS research site(s) taking part in this study. The favourable opinion does not therefore apply to any non-NHS site at present. I will write to you again as soon as one Research Ethics Committee has notified the outcome of a SSA. In the meantime no study procedures should be initiated at non-NHS sites.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

This Research Ethics Committee is an advisory committee to London Strategic Health Authority

The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England

297

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk. *Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.*

Sponsors are not required to notify the Committee of approvals from host organisations.

Clinical trial authorisation must be obtained from the Medicines and Healthcare products Regulatory Agency (MHRA).

The sponsor is asked to provide the Committee with a copy of the notice from the MHRA, either confirming clinical trial authorisation or giving grounds for non-acceptance, as soon as this is available.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Covering Letter		09 December 2009
REC application		14 December 2009
Protocol	1	08 December 2009
Investigator CV		08 December 2009
CV of Prof Julienne Meyer	1	08 December 2009
GP/Consultant Information Sheets	1	08 December 2009
Letter of invitation resident	1	08 December 2009
Letter of invitation to relative to be interviewed	1	08 December 2009
Letter of invitation to primary care staff	1	08 December 2009
Letter of invitation to care home staff	1	08 December 2009
Letter of invitation to care home provider	1	08 December 2009
letter of invitation to care home manager	1	08 December 2009
Participant Consent Form: Adult with capacity	1	08 December 2009
Participant Consent Form: Resident unable to consent	1	08 December 2009
Evidence of insurance or indemnity		28 October 2009
Letter to relative/representative for assent	1	08 December 2009
Relative information sheet/Assent form	1	08 December 2009
Participant Consent Form: Consent of relative/consultee to approach resident	1	08 December 2009
Review by Prof J Meyer		
Review by Dr R Elosworapu		

Email Review by Wendy Moyle		
Review by Prof E Lekalokolo-mokgek		
External peer review assessment form		
Summary/Synopsis	1	08 December 2009
Interview questions (care home staff)	1	08 December 2009
Interview questions (care home manager)	1	08 December 2009
Interview questions (primary care staff)	1	08 December 2009
Interview questions (relative)	1	08 December 2009
Email confirming Sponsor		11 December 2009
Covering Letter		17 February 2010
Participant Information Sheet: Healthcare staff	2	17 February 2010
Participant Information Sheet: Care home Staff	2	17 February 2010
Participant Information Sheet: Relative/Representative	2	17 February 2010
Participant Information Sheet: Resident	2	17 February 2010
Participant Information Sheet: Personal Consultee General	2	17 February 2010
Participant Consent Form: Personal Consultee	2	17 February 2010
Email from Jennifer Dudman		17 February 2010
Response to Ethics Committee		17 February 2010
Response to Request for Further Information		
Participant Information Sheet: Personal Consultee	2	17 February 2010

Statement of compliance

This Committee is recognised by the United Kingdom Ethics Committee Authority under the Medicines for Human Use (Clinical Trials) Regulations 2004, and is authorised to carry out the ethical review of clinical trials of investigational medicinal products.

The Committee is fully compliant with the Regulations as they relate to ethics committees and the conditions and principles of good clinical practice.

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

10/H0807/7	Please quote this number on all correspondence

Yours sincerely

███████

Chair

Email: ██████████

Enclosures:	"After ethical review – guidance for researchers" [SL-AR1 for CTIMPs, SL- AR2 for other studies]
Copy to:	Professor Ros Bryar, School of Community and Health Sciences, City University, Sponsor