Exploring the Meaning, Presentation and Assessment of Complexity in Mental Health NHS Dementia Inpatient Wards: An Interpretive Description Study.

A thesis submitted to the University of Manchester for the degree of Doctor of Philosophy in the Faculty of Biology, Medicine and Health

2018

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ABSTRACT

The University of Manchester: PhD in the Faculty of Biology Medicine and Health
Lesley Jones: September 2018

Exploring the meaning, presentation and assessment of complexity in mental health NHS dementia inpatient wards: An interpretive description study.

Background: The use of the terms complex and complexity alongside dementia is reflected in a number of policy documents. However, despite this, there is no accepted definition and there is a lack of evidence to support where the concept of complexity in dementia originated and how it is perceived, understood and experienced by people with dementia, their carers and clinicians working in the field. This lack of shared understanding is a concern as complexity is constantly referred to as one of the main reasons for admission into mental health NHS dementia inpatient wards.

Aims: Adopting an interpretive description methodology this thesis used mixed qualitative methods to explore the concept of complexity in dementia within the setting of mental health NHS dementia inpatient wards. Interpretive description is a methodological approach orientated toward clinical practice (Thorne et al., 1997). It allows phenomena that are identified from clinical practice to be explored and the findings of the research to be applied back to practice. The study was conducted over three phases; phase 1 was an online electronic survey of national dementia leaders; phase 2 comprised individual interviews and a focus group with dementia clinicians; and phase 3 involved case studies of four patients with dementia whom mental health NHS dementia inpatient staff identified as being complex.

Findings: The findings highlighted that complexity is constructed through a number of interconnected and interrelated domains; it is also not a static state but one that’s fluctuates in acuity. These findings have been developed into ‘The 3Fs Model of Complexity’. The 3Fs stand for Fundamental, Flexible and Fluctuating. The Fundamental domain consists of five components which are always present in complexity. The Flexible domain consists of 15 components and a person with dementia may experience any number of Flexible domain components at any time. Moreover, the components of complexity may interact with one another both within and across domains. The third F in the 3Fs Model of Complexity is Fluctuating and represents the fact that components in both the Fundamental and Flexible domains have the ability to fluctuate in their acuity and effect on the person. It is this fluctuation that reflects the dynamic, evolving and changing nature of complexity.

Conclusion: The research was inductively constructed and adopted a psychosocial approach to exploring complexity in dementia, in keeping with an interpretive description methodological approach. The 3Fs Model of Complexity may facilitate a more holistic view of a person with dementia than when ‘symptoms’ are viewed in isolation of each other, as often happens in practice and as observed in data collection. Going forward, and subject to further testing the 3Fs Model of Complexity could help guide the selection of tailored, personalised interventions.
DECLARATION

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DEDICATION

This thesis is dedicated to the people with dementia, their spouses and the clinicians who took part in this study and, also, to those people with dementia and clinical staff I have worked with over the years on mental health NHS dementia inpatient wards. Without the sharing of their time and experiences this study would not have been possible.

ACKNOWLEDGEMENTS

I would like to thank my supervisors, Professor John Keady and Professor Dame Nicky Cullum for their expert guidance during this project and for their unwavering support and confidence in my ability. I have learned so much from you both.

I am also grateful to Professor John Keady for all of his support during my clinical career, for seeing the ‘hidden researcher’ in me and for his guidance and advice in securing the funding on which the study is based.

This research was made possible by the National Institute for Health Research Clinical Doctoral Research Fellowship (CDRF–2012-03-033) and I would like to express my gratitude to them for this funding.

I would like to thank my work colleagues who have supported me in undertaking this journey and who, from the beginning have understood the importance of exploring complexity in dementia to further improve care, knowledge and practice. To Pat Lee and Gill Drummond thank you for being there and always believing in me, Michelle Aspinall you are an inspirational leader and I will never forget your support, ‘Doc Dykes’ thank you for listening and Carla Page thank you for always being able to making me laugh and for your commitment to dementia inpatient care.

I would also like to say a huge thank you to Jackie Kindell for her encouragement, guidance, sharing her experiences and answering my endless PhD questions.

To Vedo and Orzo, my canine companions, one of you has always been under my desk, keeping me company and being the perfect sounding board! Most importantly, I would like to thank my friend Sarah and my husband Colin, for without your love, support and understanding I would not have got through this study. Sarah, I think I may actually miss your daily motivational song lyrics! Colin you always believe in me and have quietly and happily made sacrifices over the years so I could fulfil my goals. You have been my rocks. Thank you both for being there, never once doubting my ability and keeping me going. You are the two people who truly know what it has taken for me to complete this work.

Finally to dad and Rochelle, you saw me start but sadly cannot see me finish. You both taught me so much and your memories continue to shape my life.
BACKGROUND TO THESIS

The Personal Context
I am standing looking at a lady who is in her eighties. She is making incoherent noises and, although she is looking straight at me, she offers no verbal or facial indication that she is aware of my presence. She is sat in a brown vinyl covered tall chair; which is on wheels. The chair is tilted backwards at a 45 degree angle and there is a tray fixed over her legs to stop her from getting out of it. I notice that her dress is pulled up to her waist and I can see her bare legs and hips. She is sat on some kind of pad. Her facial expression appears unhappy and her verbal utterances agitated. The chair she is sat on is in a large day room. All the chairs are positioned around the wall. They are all upright or tilted brown vinyl chairs. Older men and women are sat in the chairs: some asleep, some staring into space and some making repeatedly screaming-type noises.

I feel frightened and anxious and unsure of how to respond to these individuals. I want to reach out to the lady in the tilted chair. I want to comfort her, but I am unsure of how to do that. I am eight years old. The woman in the tilted chair (which I now know to be a ‘Buxton chair’ or a ‘geriatric chair’) is my grandmother (gran) and she is a patient on an mental health NHS dementia inpatient ward.

I had a very close relationship with my grandparents and would spend time with them every day. I can still recall my tears the day I realised that the changes we were seeing in my gran were more than her having ‘bad days’. I can remember helping to look after gran at home; sitting with her making sure she did not ‘wander’ out of the house, encouraging her to eat, reassuring her when she was frightened and responding to things I could not see or hear. I still recall gran’s agitation, sadness, despair, hallucinations and distress. I remember my family’s stress, worry and exhaustion in providing care for her around-the-clock when she was living at home. We did not understand what was happening.

Gran was eventually admitted into hospital as she had become doubly incontinent. She was resistant to personal care interventions, experiencing visual hallucinations and could quickly become very distressed, agitated and aggressive. As a family we could no longer
safely meet her needs at home. My granddad, parents and uncle were exhausted. Her admission to hospital was the first ‘intervention’ our family had received.

Even though I was only eight years old at the time, I still hold clear memories of gran’s journey into dementia. This was before the days of early diagnosis, or even diagnosis at all. Community support and services were non-existent. Dementia awareness and education was not available. Policy and guidance regarding dementia care had not been developed. The concept of living well with dementia and person centred care was unheard of. Most vividly of all though, I remember the mental health NHS dementia inpatient ward in which gran spent those last months of her life. It was an environment where gran spent her day in that ‘geriatric chair’ tipped back to stop her from moving. She received task orientated care; things were routinely done to her at set times. There was no concept that she was a person. In the late 1970’s this was dementia care. Gran died in this environment with memories of her as a hardworking, proud, opinionated lady long gone. A woman seen and not seen at all.

Fast forward to the present day; I have now been a mental health nurse for more than 30 years. For over 20 of these years I have specialised in the mental health care of older people, particularly those living with dementia. Within this speciality I have held a number of roles, for example: practice development nurse, ward sister, community psychiatric nurse, clinical leader and advanced practitioner in dementia care. I have also successfully completed a MA Gerontology, MSc (distinction) Advanced Practice and Independent Nurse Prescriber qualification.

I have seen many changes in psychiatry during my career. These have included the closure of large psychiatric asylums and the introduction of community care, increased access to a wider range of helping medications, greater awareness and understanding of mental health issues, a focus on psychosocial interventions and talking therapies, multidisciplinary team working, development of specialist nursing roles and the focus on person centred care as opposed to mechanistic, task driven routinised care giving. Perhaps the most significant recent change I have seen is the focus upon dementia. The last 10 years or so have seen a societal shift from dementia being hidden behind closed doors and a view that it is a normal part of ageing, to one where we have dementia strategies, dementia friends, dementia communities, television adverts about dementia and a focus on early diagnosis
and living well with the illness. As a dementia nurse I have gone from people looking embarrassed and changing the conversation when I tell them what I do for a living to them seeking me out and asking questions. I get asked to lecture and deliver conference presentations on the illness that was once never spoken about. A far change, one may argue, from the days of my gran’s dementia journey and her experience of being a patient in a mental health NHS dementia inpatient ward. But is it?

It is 2018. I am in a mental health NHS dementia inpatient ward and I am standing looking at a number of vinyl chairs arranged in a square around a television positioned on the wall. The remote control is not visible. There are men and women with dementia sitting in some of the chairs: a few are asleep, others stare straight ahead, one is crying, another is repeatedly shouting “help me, help me.” Three men with dementia are walking around, one keeps moving furniture, another keeps going down on his hands and knees and crawling around on the floor and then standing up and the third is pacing around and around trying all the door handles and mumbling utterances which are hard to make out. Looking closer, and sitting at dining tables located in the same area behind the chairs, are two sets of visitors; relatives of those on the ward. There is little conversation and they just look around the environment with pensive and tense facial expressions. One of the patients being visited looks asleep at the table but, every now and again, will shout out obscenities and then appear to go back to sleep and the other person, a lady, keeps standing up and lifting her skirt over her head and crying, asking to go home.

The television is on but no one appears to be watching it. A nursing assistant is sitting next to a lady with dementia and each time she stands up she asks her to sit down. Periodically, a nurse walks through this space. They do not stop but will say ‘hello’ or utter a few words to the individuals they pass. They then proceed to go into an office where other nurses and a doctor are sat. There is patient review underway in the office. The individual who is being discussed is being described as “challenging.” The nurses are discussing behaviour that is aggressive and violent; coupled with high levels of distress. There are also concerns that this person is physically unwell as they have a number of medical problems and that they are ‘complex’. There is a sense of helplessness as what to try next or how to proceed to be able to help this person.
The mental health NHS dementia inpatient ward I am describing is one of the wards where I have worked for the past 10 years as an advanced practitioner in dementia care. This is the contemporary equivalent to the 1970s dementia inpatient ward familiar to my gran and to my childhood self. Today, people with dementia continue to be admitted to mental health NHS dementia inpatient wards for assessment and treatment when there is no other safe option within the community. Those admitted to these environments usually have multiple needs and are often in hospital for months as opposed to weeks. It is not uncommon for staff working in these environments to have difficulty in ascertaining why a person is presenting in such a way, or why they are not responding to interventions or treatments.

As a registered mental health nurse I chose to spend most of my clinical career working with people with dementia in these inpatient environments. These wards hold the most vulnerable people with dementia but have received so little attention in the academic literature, and in national policy, over the years. Opening up this seldom-heard resident group and environment - just a little - is the focus of this PhD study.

**Introduction to the Study and Study Aims**

This study explores the how clinicians, people with dementia and their relatives construct and experience complexity in dementia within the setting of mental health NHS dementia inpatient wards. This is an area of interest which stemmed directly from my clinical practice. As an advanced practitioner working in mental health NHS dementia inpatient wards we would often receive for admission patients for assessment and treatment as their needs could not be safely met in community settings. These individuals would be referred to as ‘complex’ by the admitting clinical team, but there was no shared meaning or understanding as to what this means or how complexity uniformly presents. Similarly, there is an absence of literature and policy guidance in practice that exists in mental health NHS dementia inpatient wards (Pinner et al., 2011; National Institute for Health and Clinical Excellence/Social Care Institute for Excellence, 2006).

This thesis presents an early attempt at describing and identifying the factors which contribute to complexity in dementia. As the issue of complexity within dementia stemmed directly from clinical practice, I wanted to adopt a methodological approach that would
develop knowledge to inform practice. I also wanted to implement an approach that would embrace my clinical experience and support my working as both a clinician and researcher throughout the study. It is for these reasons I chose interpretive description as the methodological framework for this study (see: Thorne, 2014; Thorne, 2013; Thorne, 2008; Thorne et al., 2004; Thorne et al., 1997). Moreover, interpretive description was originally developed by nursing scholars Sally Thorne, Sheryl Reimer Kirkham and Janet Macdonald-Emes as a methodological framework that would meet specific needs within nursing research (Thorne et al., 2004). Indeed, Thorne (2008) suggests that:

“... the kinds of research question that nurses ask set the stage for the work that they will do to ameliorate human distress, to accommodate bodily frailty, to counter personal vulnerability and to make meaningful sense of the indignities that life has in store for our bodies and minds.” (p.15)

Whilst interpretive description is a relatively young methodological approach, its suitability to applied qualitative health related research appears to be growing in popularity and a structured search will identify a number of studies (see for example: Lasiuk et al., 2013; Hunt, 2009; Hayes, 2006; Giddings et al., 2006; Elmberger et al., 2002). There have also been a number of doctoral theses that have adopted interpretive description (see for example, Kortje, 2016; Draper, 2015; van Wissen, 2013; Burns, 2009; Hunt, 2008). Interestingly, the doctoral thesis undertaken by Burns (2009) concerned itself with the patterns of practice of art therapists working with people with dementia in the United Kingdom (UK).

Building on this foundation, this interpretive description study explores how clinicians, people with dementia and their relatives experience complexity in dementia within a much under-researched area, the mental health NHS dementia inpatient wards. Indeed, during the initial stages of developing this study, email communication was exchanged with Sally Thorne to ‘check out’ if this was the sort of clinically practiced research question which would lend itself to an interpretive descriptive methodology, which Sally Thorne was able to confirm that it was. I also had the opportunity to attend two conference presentations delivered by Sally Thorne on Interpretive Description in Canada (October 2014) which gave me further opportunity to discuss my study aims, questions and goals.
When designing an interpretive description study Thorne (2008) talks of scaffolding a study. Scaffolding is an important component of an interpretive description study and sets up the initial position from which the study design is built. Scaffolding a study consists of two essential elements: i) a literature review and ii) clarifying the theoretical forestructure. Thorne (2008) refers to the theoretical forestructure as the researchers “theoretical baggage” (p.54) or, in other words, the preconceived assumptions held by the researcher. Here, the researcher is encouraged to explore the theoretical and practical knowledge that they bring to the study. The combination of these two processes allows the researcher to be located “substantively, theoretically and within a disciplinary orientation” (Thorne, 2008, p.55) and provides a position from which to undertake the study. The literature component of the scaffolding review for this study is presented in Chapter 2 and my theoretical forestructure has been outlined in this current background to the thesis section (see pages 11-14).

This interpretive description study explores the concept of complexity in dementia and consists of three iterative phases of mixed methods qualitative data collection. This has resulted in a large volume of data. In discussion with my PhD supervisors, I have therefore had to make a number of informed choices regarding the presentation of this thesis. For example, in Chapter 3, due to the number of data collection methods used, it is not possible to provide a detailed discussion on each one and instead an overview as to why each method has been chosen is provided. Additionally, the layout of the thesis is also less ‘traditional’ than other completed works. It includes an applied element of the inductively developed practice theory in Chapter 6 in order to give an equal weighting in the discussion between theoretical development and clinical application, as the focus of interpretive description is to develop knowledge that can be applied to clinical practice (Thorne, 2008).

**Organisation of Thesis**

This thesis has seven chapters:

**Chapter 1** provides an overview of dementia, UK dementia policy and mental health NHS dementia services. This opening chapter will explore the prevalence of dementia; offer an overview of the different types of dementia and disease trajectory before moving to present
a summary of UK dementia policy. Finally, mental health NHS dementia inpatient wards will be introduced as this is the setting in which the study is located.

**Chapter 2** presents the literature review. This was undertaken using an interpretive description approach and provides the literature ‘scaffolding’ for the study. I will discuss the literature search strategy and illustrate how the literature was appraised and themed. The literature is presented and critically discussed in three categories. By presenting the evidence in this way I will outline what is known about complexity in dementia, what can be learned from complexity in health and social care in general and the current state of knowledge regarding mental health NHS dementia inpatient wards.

**Chapter 3** presents the methodology and methods used within this study. I will discuss the theoretical rationale for the study and provide an overview of the analytic framework. Issues of researcher reflexivity, rigour and ethical challenges will also be addressed. I will present the mixed methods study design and the three phases of data collection are outlined. I will also describe the approach to data analysis for each of the three phases of the study.

**Chapter 4** describes the findings from this study and it will highlight how complexity is constructed of a number of interconnected and interrelated domains and that it is not a static state but one that can fluctuate. The chapter will present the sequential data collection and analysis from the three phases of the study and will demonstrate the inductive and chronological nature of the study.

**Chapter 5** builds upon the findings from Chapter 4 and presents an integrated model of complexity, which I have termed the 3Fs Model of Complexity. The chapter commences with an overview as to the meaning and messages of complexity. I will then move onto explore the Fundamental, Flexible and Fluctuating components of complexity that comprise the 3Fs Model of Complexity.

**Chapter 6** in keeping with an interpretive description approach explores the practice application of the 3Fs Model of Complexity. This chapter describes how the 3Fs Model of Complexity was ‘piloted’ with two study participants from Jasmine ward by retrospectively applying the model to two of the case studies. The chapter demonstrates
that the 3Fs Model of Complexity has the potential to be used as a more comprehensive and holistic assessment tool for clinicians working in mental health NHS dementia inpatient wards.

Chapter 7 will conclude the thesis by reviewing the findings from the study. It considers how the 3Fs Model of Complexity contributes to current dementia theory and practice. The model will also be considered within the broader context of current initiatives within dementia care. Following this, issues of practitioner reflexivity will be revisited and emerging reflections on interpretive description explored. Study limitations and recommendations for practice, research, education and policy will be provided.

Definition of Terms and Writing Conventions Used

The following terms and conventions have been used:

- The thesis has been written in first person to allow for consideration of my role, my previous clinical experience and personal reflection within the study.
- The term patient is used on occasions throughout the study. This is in no way meant in a derogatory manner it is in fact a reflection of the clinical nature of the study and that it is a term that is used in day-to-day practice in a hospital setting.
- The term nursing assistant is used to describe the unqualified clinical staff on the mental health NHS dementia inpatient wards that assist the qualified nurses. Nursing assistant is used, as at the time of undertaking the study this was the job title for this group of people.
- The term ‘continuous observation’ is used to describe when a patient requires a member of staff to observe them at all times.
- With a few exceptions, numbers from one to nine are written in the text in full, with numbers 10 and above written in numerical form.
- I have used the Harvard style of referencing. Where there are two authors these are cited and where there are three or more ‘et al.’ has been used. Authors are presented in alphabetical order in the reference list and for each publication there is a full author list.
- Direct quotes from participants which are longer than 30 words have been indented, italicised and embedded in the text with double quotation marks. Shorter quotes are
embedded in the text using double quotation marks and are italicised. However, shorter quotes are sometimes also indented when a point is being made in the thesis.

- Job titles and job roles will be capitalised when it relates directly to a study participant. On all other occasions they will be written in lower case.
- The term ‘behaviour that challenges’ has been adopted in this thesis but other terms that are also commonly used are ‘challenging behaviour’, ‘behaviours that challenge’ and ‘behavioural and psychological symptoms of dementia’.
- Abbreviations used include:

  CPA = Care Program Approach.
  DH = Department of Health.
  NHS = National Health Service.
  PICU = Psychiatric Intensive Care Unit.
  RGN = Registered General Nurse.
  UK = United Kingdom.
  USA = United States of America.
  WHO = World Health Organisation.

I have used the descriptive term ‘mental health NHS dementia inpatient ward(s)’ throughout the thesis to refer to the study setting. I did this to differentiate the setting from ‘NHS dementia in patient assessment ward’, or ‘NHS dementia inpatient unit’, for example, as these latter descriptions could be applied to specialist acute hospital care. I acknowledge that the descriptive terminology I have used may require future refinement, but in the absence of any agreed terminology for the setting in which this study was conducted, I believe this differentiation is important to emphasise as it is the ‘dementia’ that has brought the person into mental health NHS service provision and assessment.

Please note this thesis does, at times, contain language that some people may find offensive, particularly in the case studies in Chapter 4. The swearwords are included as they are an authentic representation of what people with dementia consented into the study said and are not meant to shock or strip the person of their dignity. However, to soften their emphasis or not to include the swearwords at all would diminish the lived experience of those people with dementia and the family members exposed to such changes in presentation.
CHAPTER 1
An Overview of Dementia, UK Dementia Policy and Mental Health NHS Dementia Services

1.1 Introduction
The population of the world is increasing. Improvements over the last century in health care means people are living longer lives (WHO and Alzheimer’s Disease International, 2012) which, in turn, has resulted in more people living with dementia. Dementia is now reported to be one of the most important health and social care issues facing the world (NHS England, 2018) and has been referred to as a public health priority (WHO and Alzheimer’s Disease International, 2012). Dementia does not discriminate; it can affect anyone irrespective of their education, background or lifestyle (Alzheimer’s Research UK, 2016). Today, dementia seems to be a regular feature on the television, in the news or on social media and it appears that most people know someone with dementia or know of someone who knows someone with dementia (WHO and Alzheimer’s Disease International, 2012). Based on this context, this opening chapter will present current demographic data on dementia, provide an overview of the different types of dementia and disease trajectory and explore dementia from a policy context. Finally, mental health NHS dementia services and mental health NHS dementia inpatient wards will be introduced as this is the setting in which this study is located.

1.2 What is Dementia?
Dementia is not a normal part of ageing, but the risk of developing dementia does increase with age. Nor is it a disease in its own right (Alzheimer’s Research UK, 2016). Dementia is an umbrella term for a range of symptoms that occur when the brain is affected by conditions which cause brain cells to gradually die resulting in a progressive cognitive decline (Alzheimer’s Research UK, 2016). The speed of which cognitive decline progresses can vary from person to person and can, to a certain extent, depend on which type of dementia a person has been diagnosed with (Social Care Institute for Excellence, 2015). Although people with dementia may share some of the same general symptoms the manner and extent to which these affect the person will vary (Social Care Institute for Excellence, 2015).
The World Health Organisation (WHO, 2017, online factsheet) defines dementia in the following way:

“Dementia is a syndrome – usually of a chronic or progressive nature – in which there is deterioration in cognitive function (i.e. the ability to process thought) beyond what might be expected from normal ageing. It affects memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not affected. The impairment in cognitive function is commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation.”

Young onset dementia refers to people who develop dementia before the age of 65 and late onset refers to those who develop dementia after the age of 65 (National Institute for Health and Clinical Excellence/Social Care Institute for Excellence, 2006).

Dementia is a progressive condition which means that the symptoms will get worse over time (Alzheimer’s Society, 2017; NHS, 2017). There is no treatment currently available to ‘cure’ dementia or alter its progressive course (WHO, 2017). Globally, deaths due to dementia more than doubled between 2000 and 2016, making it the fifth leading cause of death in the world (WHO, 2018). In 2017, dementia was reported to have become the leading cause of death in the UK with more people dying with dementia than heart disease (Alzheimer’s Research UK, 2017).

As a dementia progresses, a person’s abilities will become affected and the rate of progression can vary. For some individuals, the illness will progress slowly over a number of years, whilst for others it will progress more rapidly over a period of months (Alzheimer’s Australia, 2005). Life expectancy is estimated at three to nine years after diagnosis (Xie et al., 2008); however, this is variable and in clinical practice I have seen people deteriorate and die within six months of diagnosis and others live in excess of 12 years.
1.3 Prevalence

In 2015 the number of people living with dementia worldwide was estimated to be 47 million (WHO, 2015) and this figure is predicted to increase to approximately 75 million in 2030 and to 135 million by 2050 (Alzheimer’s Disease International, 2013). In the UK there are currently around 850,000 people with dementia (Alzheimer’s Society, 2017), 42,000 of which are under the age of 65 (Alzheimer’s Society, 2017). The numbers for the total population of people with dementia is forecast to increase to over one million by 2025 and over two million by 2051 (Prince et al., 2014). The risk developing dementia increases exponentially with age rising from one in 14 over the age of 65 to one in six over the age of 80. The economic impact to the UK economy is costly. For example, the 2014 Dementia UK update report (Prince et al., 2014, p.xv) outlined that the overall economic impact of dementia in the UK is £26.3 billion, of which:

- £4.3 billion is spent on healthcare costs, of approximately £85 million is spent on diagnosis.
- £10.3 billion is spent on social care for people with dementia (publicly and privately funded).
- The cost of unpaid care for people with dementia is £11.6 billion, working out as 44% of the total cost of dementia.
- The total number of unpaid hours of care provided to people with dementia in the UK is worth £1.34 billion.

1.4 Types of Dementia

There are many different types of dementia. The most common ones being Alzheimer’s disease, vascular dementia, mixed dementia, Lewy body dementia, frontotemporal dementia and Parkinson’s dementia. The less common forms of dementia include corticobasal degeneration, Creutzfeldt-Jakob disease, Huntington’s disease and normal pressure hydrocephalus (Alzheimer’s Society 2015a, Prince et al., 2014). Table 1.1 (page 23) outlines the estimated percentage subtypes of dementia in the UK as per the data available in 2014.
Table 1.1 Estimated Percentage Subtypes of Dementia in the UK

<table>
<thead>
<tr>
<th>Dementia</th>
<th>Percentage Subtype</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alzheimer’s Disease</td>
<td>62%</td>
</tr>
<tr>
<td>Vascular Dementia</td>
<td>17%</td>
</tr>
<tr>
<td>Mixed Dementia</td>
<td>10%</td>
</tr>
<tr>
<td>Dementia with Lewy Bodies</td>
<td>4%</td>
</tr>
<tr>
<td>Frontotemporal</td>
<td>2%</td>
</tr>
<tr>
<td>Parkinson’s Dementia</td>
<td>2%</td>
</tr>
<tr>
<td>Other</td>
<td>3%</td>
</tr>
</tbody>
</table>

(Prince et al., 2014, p.xii)

I will now provide a brief overview of Alzheimer’s disease, vascular dementia, dementia with Lewy bodies and mixed dementia. I have chosen to highlight these four dementias as from my years of clinical practice these are the ones most frequently seen in mental health NHS dementia inpatient wards.

1.4.1 Alzheimer’s Disease

Alzheimer’s disease was named after Alois Alzheimer, a German physician who first identified this condition after undertaking a brain autopsy on one of his patients, Auguste Deter, in the early 1900’s. The autopsy identified shrinkage and abnormal deposits in and around the nerve cells in the brain. Today, the abnormal build-up of the proteins amyloid and tau are believed to have a role to play in the development of Alzheimer’s disease. Deposits of amyloid form plaques around the brain cells, whilst deposits of tau form tangles within the brain cells (Earlstein, 2016).

Although it is still not known exactly what causes this process to occur, scientists now know it begins years before symptoms of the disease appear (NHS Choices, 2018). Over time, there is also a decrease in neurotransmitters which are involved in sending messages between brain cells; brain cell connections are lost, cells begin to die and different areas of
the brain shrink (NHS Choices, 2018; Earlstein, 2016). Most people who develop Alzheimer’s disease will be over 65, but there is also a young onset Alzheimer’s disease which can affect people under the age of 65.

Alzheimer’s disease is progressive and gradually more parts of the brain become damaged. As the illness progresses, more symptoms occur and they can become more severe. There are some common symptoms of Alzheimer’s disease and these include: changes in memory; difficulty in recalling events; and learning new information (Alzheimer’s Society, 2014a). In the early stage of the illness, people may become lost in familiar places, experience problems with short term memory, repeat themselves and show signs of depression. As the illness progresses, they may experience: visuospatial problems; hallucinations and delusions; difficulty in planning and judgement; and start to require assistance with functional activities such as cooking, dressing and bathing. In the latter stages of the illness, a person may no longer recognise family and friends, they will have difficulty understanding events, speech production may be impaired and difficulty can be experienced eating and walking. At this stage a person will usually require assistance to meet all of their needs (Alzheimer’s Society, 2014a; Cayton et al., 2002).

How quickly Alzheimer’s disease progresses and the life expectancy of a person with it can vary greatly, making it very difficult to give accurate predictions to people regarding the disease trajectory (Thomas, 2008). Clinically I have seen some people live for over 15 years with a diagnosis of Alzheimer’s disease and others I have seen rapidly deteriorate from diagnosis to death in less than a year.

1.4.2 Vascular Dementia

Vascular dementia is reported to be the second most common form of dementia. It occurs when the blood flow to the brain becomes interrupted, due to diseased blood vessels within the brain (Alzheimer’s Research UK, 2016; Earlstein, 2016; Alzheimer’s Society, 2014b). Vascular dementia represents a group of conditions that include all dementia syndromes resulting from ischaemic, anoxic or hypoxic brain damage (Blossom and Brayne, 2008). However, out of these syndromes, the most common are stroke related dementia and subcortical vascular dementia (Alzheimer’s Research UK, 2016). Stroke related dementia refers to vascular dementia that occurs after a stroke, also known as post stroke dementia,
and dementia that occurs after a number of transient ischaemic attacks - which can sometimes be called multi infarct dementia. If a stroke causes memory loss and problems with attention then a person may be diagnosed with stroke related dementia (Alzheimer’s Research UK, 2016). Subcortical vascular dementia occurs when the very small blood vessels to the brain are damaged. This is also referred to as small vessel disease (Alzheimer’s Research UK, 2016). A person does not initially usually notice the changes occurring to the small vessels, but over time it can damage the parts of the brain that are responsible for memory, language function and attention (Alzheimer’s Research UK, 2016). As sub cortical dementia often affects the small vessels deep inside the brain, the symptoms can be different to that of stroke related dementia which usually affects different areas of the brain (Earlstein, 2016).

Signs and symptoms will vary depending on the part of the brain which is affected. Memory can be affected but, unlike in an Alzheimer’s disease, this is not often an early symptom (Earlstein, 2016). Signs and symptoms can include slower thought processing, difficulty in following simple chronological steps, difficulty concentrating and problem solving or decision making, depression, unsteady gait, language difficulties, urinary problems, mood changes and physical symptoms such as limb weakness (Alzheimer’s Research UK, 2016; Earlstein, 2016; Alzheimer’s Society, 2014b; Blossom and Brayne, 2008). Progression of vascular dementia can be variable with periods where things may appear stable and then periods where symptoms can rapidly get worse. How long a person will live with vascular dementia varies from person to person, but prognosis is usually three to five years and the person will often die from a stroke or heart attack (Earlstein, 2016; Alzheimer’s Society, 2014b).

1.4.3 Dementia with Lewy Bodies

Dementia with Lewy bodies shares some of the symptoms of both Alzheimer’s disease and Parkinson’s dementia (Alzheimer’s Research UK, 2018; Earlstein, 2016). In dementia with Lewy bodies, clumps of the protein alpha-synuclein build up inside the nerve cells in the brain. The clumps that are formed are called Lewy bodies. They are named after the German doctor who first identified them. These Lewy bodies damage the way the nerve cells work and communicate (Alzheimer’s Research UK, 2018; Earlstein, 2016).
Lewy bodies are also present in Parkinson’s disease, which may be why many of the symptoms experienced are comparable (Earlstein, 2016; McShane, 2008). Similar to Alzheimer’s disease, the initial symptoms of Lewy body dementia can be subtle and progression can, although not always, be gradual. Moreover, in dementia with Lewy bodies, the Lewy bodies affect the areas of the brain which are responsible for thinking, memory and movement. As seen in the reports by Alzheimer’s Research UK (2018), Earlstein (2016), Stubendorff et al. (2012) and McShane (2008) the core features of dementia with Lewy bodies include:

- Visual hallucinations typically of people and animals.
- Parkinson type symptoms such as slower movements, stiffness in the arms or legs. Facial masking and tremor can be experienced.
- Fluctuation in attention and cognition which can change hour to hour or day-to-day.
- Rapid Eye Movement (REM) sleep behaviour disorder presenting with vivid dreams, falling out of bed and acting out nightmares.
- Visuospatial difficulties.
- Delusional ideas often due to a combination of visual difficulties and visual hallucinations.
- Neuroleptic sensitivity.
- Autonomic dysfunction.

As dementia with Lewy body progresses the symptoms will get worse. It can affect men and women equally (Earlstein, 2016) and can be diagnosed in people aged over and under 65. The rate of progression is variable, but on average a person with dementia with Lewy body can live for five to eight years after symptoms appear (Earlstein, 2016). My clinical experience of individuals with dementia with Lewy Body in people under 65 who are admitted to mental health NHS dementia inpatient wards has been one of severe symptoms, which do not respond to treatments and rapid clinical decline.

1.4.4 Mixed Dementia

Mixed dementia is where a person is believed to have a combination of two or more kinds of dementia. It is reported to be the third most common form of dementia in the UK. The combination of dementias can include for example; Alzheimer’s disease and dementia with
Lewy bodies; Alzheimer’s disease, dementia with Lewy body and vascular dementia. However, the term is most commonly used where Alzheimer’s disease and vascular dementia are thought to coexist (Larson, et al., 2004). In a NHS Resource paper for General Practitioners regarding their role in dementia diagnosis and management, the authors (all of whom were doctors) reported that vascular dementia on its own is rare and is most often seen in conjunction with Alzheimer’s disease (Burns et al., 2015).

A firm diagnosis of mixed dementia can only occur after a brain autopsy. There have now been a number of studies that have identified the presence of multi dementia pathologies on autopsy particularly Alzheimer’s disease and vascular pathology (see for example: Bennett et al. (2012), Memory and Ageing Project and Medical Research Council (2001), Cognitive Function and Ageing Study). Symptoms that may be exhibited with a mixed dementia can vary depending on the areas of the brain affected and the types of dementia though to be involved.

1.5 Dementia Staging

In the acknowledgement that dementia is a progressive condition there are a number of dementia progression staging scales/tools in existence; for example, the Global Deterioration Scale for Assessment of Primary Degenerative Dementia (Reisberg, 1982) and the Functional Assessment Staging Tool (Reisberg, 1988). These scales/tools break dementia down into a series of stages and they use descriptive terminology such as ‘normal’, ‘early’, ‘mild’, ‘moderate’, ‘moderate severe’ and ‘severe’ to outline each stage. The Alzheimer’s Society advocate that looking at dementia as a series of stages can be helpful to understand the changes which can occur over time, however they use three stages with the terms ‘early’, ‘middle’ and ‘late’ (Alzheimer’s Society, 2015b). More recently, in an acknowledgement that many dementia staging scales focus on the losses of memory, cognition and function that an individual can experience, Teepa Snow (2018, online access) developed the Gems® Brain Change Model. This model uses gem stones to describe each stage and focuses upon remaining abilities which under the right conditions can shine. In this respect, the use of gemstones is trying to promote a more positive image of the progression of dementia and challenging professionals and carers to work with a person focusing upon their remaining strengths, as opposed to seeing loss and deterioration.
Within clinical practice it is common for dementia to be referred to by the stage of progression. My own clinical experience is that clinicians regularly focus upon the loss of an individual’s abilities and refer to people with dementia as being ‘mild’, ‘moderate’ or ‘severe’ within the illness trajectory. However, this is not supported by the use of an assessment scale and appears to be based on clinicians’ previous dementia knowledge and experience.

1.6 Dementia, Personhood and Person-Centred Care

Tom Kitwood was a UK-based social psychologist who questioned, in the late 1980s and early 1990s, and from within the then newly-established Bradford Dementia Group, the unchallenged medicalised view of dementia that saw decline and a loss of self as the inevitable consequence of a diagnosis (see for example: Kitwood and Bredin, 1992; Kitwood, 1993a). Instead, Kitwood argued that this focus failed to recognise the psychological needs that a person living with dementia will have and that addressing such needs, and the malignant social psychology that surrounded the person with dementia, could lead to ‘rementia’ and what, in today’s terms, could be seen as a recovery process (see for example: Kitwood, 1997, 1993a, 1993b; Kitwood and Bredin 1992). Today his work remains seminal in the field of dementia care.

As part of his biopsychosocial theory of dementia, Kitwood (1993a) suggested that the clinical manifestations of a dementia could be more fully understood by recognising that it arose from the interaction of five factors, as opposed from it solely occurring as a result of a neurological impairment (i.e. the dementia itself). These five factors were identified as personality, biography, health status (physical), neurological impairment and social psychology. These five factors enable the person to emerge from within the mask of their dementia and was represented in his seminal book ‘Dementia Reconsidered: the person comes first’ (Kitwood, 1997), published one year before his untimely death, with the memorable phrase the ‘PERSON with dementia’, not ‘the person with Dementia.’ As a consequence, Kitwood was the first person to associate the terms personhood and person-centred care to dementia (see: Kitwood 1997).
Kitwood (1997) defined personhood in the following way:

“It is a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust. Both the according of personhood, and the failure to do so, have consequences that are empirically testable.” (p. 8)

In this respect, personhood and person-centred care recognises that there is much more to the person with dementia than their diagnosis. Developing this notion further, Kitwood (1997) identified six fundamental psychological needs that have to be met in order for a person to exist, flourish and maintain a sense of well-being. These needs were identified as love, comfort, identity, occupation, inclusion and attachment. These six needs were visually represented by Kitwood as a flower, with love being in the middle and the other five psychological needs being the petals. When caring for a person living with dementia, Kitwood (1997) advocated that caregivers need to be aware of these needs and take the time to fulfil them; failure to do so may well result in a state of ‘ill-being’ for the person with dementia.

At the turn of this century, the task of developing person-centred care was taken up by Professor Dawn Brooker who, at the time, was also working out of the Bradford Dementia Group in the UK. In a subsequent influential paper, Brooker (2004) developed the VIPS model of person-centred care that extended its reach on accounting for relationships, as follows:

- Value of all human lives;
- Individualised approach recognising uniqueness;
- seeing the world from the Perspective of the service user;
- Social environment that promotes wellbeing.

In a later text, Brooker and Latham (2015) advocated that the VIPSs should be used to enhance the culture of care home attitudes towards people with dementia in such settings and outlined the importance of ‘getting person-centred care into everyday practice’ (p.24). Indeed, in contemporary dementia care practice, person-centred care is heralded as the gold
standard of dementia care and is advocated in dementia related policy and guidance (DH, 2016) and it forms one of the guiding principles of today’s dementia care services (Manthorpe and Sansi, 2016).

### 1.7 Dementia and Behaviour that Challenges

Although usually synonymous with a decline in memory and cognitive function, dementia can also affect behaviour (Keady and Jones, 2010; Keady et al., 2009). This presentation of non-cognitive symptoms is often referred to as behaviour that challenges, behaviours that challenge or behavioural and psychological symptoms of dementia (James, 2011; Stokes, 2000). James and Jackman (2017) inform that the term behavioural and psychological symptoms of dementia can imply that the behaviours are purely as a result of the dementia, and this is not always the case, as many of the behaviours which can be seen are normal coping strategies used by the general population to deal with difficult situations (ibid.). Nonetheless this term continues to be used.

Behaviour that challenges has been defined as “*actions that detract from the well-being of individuals due to the physical or psychological distress they cause within the settings they are performed*” (James and Jackman, 2017, p.31). In essence, this means that behaviour that challenges are problematic behaviours that cause difficulties for the person or for the setting in which they occur. More recently Moniz-Cook et al. (2017) describe behaviour as challenging when it “*causes distress to the person, or the carer or others, thus threatening the quality of life of one or both parties*” (Moniz-Cook et al., 2017, p.2), hereby acknowledging the impact that a behaviour may have on others as well as the person with dementia.

The perception of what is challenging will differ between people and care settings and is therefore subjective and will be influenced by our beliefs and experiences (Bird and Moniz-Cook, 2008). Therefore, what may be perceived as challenging to one person or one care setting may not be to another person or in another care setting. It is for this reason that behaviour that challenges is seen as a “*social construct rather than a true clinical disorder which can be reliably measured*” (James, 2011, p.13). That notwithstanding behaviour that challenges is now recognised as a major component of a dementia syndrome (Robert et al., 2005; Stokes, 2000) and it is estimated that around 90% of people with dementia will
experience behavioural and psychological symptoms during their illness (Steinberg et al., 2003; O’Connor, 2000), particularly at the moderate and severe stages (Lyketsos et al., 2002).

Common examples of behaviour that challenges include hitting, screaming, apathy, sexual inappropriateness and violent and aggressive resistance towards help with personal care (James and Jackman, 2017; Moniz-Cook et al., 2017). There are often multiple interacting causes to the behaviour for example, physical, neurological and environmental (James and Jackman, 2017) and they often reflect some form of need that can be driven by an individual’s beliefs or related to their distress (James and Jackman, 2017; James et al., 2006; Cohen-Mansfield, 2000). These behaviours can be a cause of significant stress and distress for the individual and their carer, lead to a reduction in quality of life and be the reason for admission to: acute hospitals; mental health NHS dementia inpatient wards; and/or admission into supported living environments, such as care homes (Kales et al., 2014; Gilley et al., 2004; Moniz-Cook et al., 2000). They also play a major role in what makes a person with dementia complex (National Institute for Health and Care Excellence Dementia Quality Standard 2010; National Institute for Health And Clinical Excellence/Social Care Institute for Excellence, 2006).

1.7 UK Dementia Policy Context
In response to an ageing population, and the increasing incidence of dementia, there have been numerous dementia focused policy documents and drivers in an attempt to improve awareness, diagnosis, care, service provision and research studies. Examples of such documents include National Institute for Health and Care Excellence (2018), Prime Ministers Challenge on Dementia (DH, 2015; 2012), All-Party Parliamentary Group on Dementia (2016; 2012), Dementia Quality Standard (National Institute for Health and Care Excellence, 2010), National Dementia Strategy (DH, 2009) and National Institute for Health and Clinical Excellence/Social Care Institute for Excellence (2006). These policy documents have supported a drive to improve dementia diagnosis rates, support people to live with dementia within their own communities and improve the care and treatment that people with dementia receive when they are in a general hospital. From a nursing perspective, the Making a Difference in Dementia, Nursing Vision and Strategy (DH, 2016; 2013) was also developed to reinforce the integral role that nurses have in supporting
people with dementia through their illness trajectory across a range of settings. The use of the term complexity in conjunction with dementia is reflected within a number of these documents. For example, the National Institute for Health and Care Excellence Dementia Quality Standard (2010) reported that dementia is associated with “complex needs” (p.5) and the second Prime Minsters’ Challenge on Dementia (2015) reports that “the reality for many people with dementia is that they will have complex needs compounded by a range of comorbidities” (p.10). The first National Institute for Health and Clinical Excellence/Social Care Institute for Excellence (2006) guidance on dementia made reference to people with dementia being admitted to a mental health NHS dementia inpatient ward if a person is severely disturbed and where “assessment in a community setting is not possible for example where a person with dementia has complex physical and psychiatric problems” (p.100). However, the meaning of ‘complexity’ or ‘complex needs/problems’ are not explored, or defined, within this documentation. Arguably, this leads to significant uncertainty over its operationalisation in clinical practice and in organisational functioning.

1.8 Specialist NHS Dementia Services and Mental Health NHS Dementia Inpatient Wards

People with dementia may have contact with, and receive support from, numerous statutory and voluntary service providers, yet specialist dementia assessment and treatment within England is traditionally provided by mental health NHS trusts. These specialist dementia services usually consist of a memory assessment and treatment service, older adult community mental health teams and dementia inpatient wards. With the increased number of people experiencing dementia, and a national drive to improve diagnostic rates, primary care is also taking a greater role in the identification and initial assessment of people with dementia (National Institute for Health and Care Excellence, 2018; Robinson, 2015). Robinson (2015), in a paper published in the British Medical Journal, reports that secondary care have an important role in: defining dementia subtypes; identifying which patients with mild cognitive impairment are at greatest risk of developing dementia; and dealing with the more complex dementia cases. However, the authors do not expand on what constitutes a complex case. The Royal College of Psychiatrists Faculty of the Psychiatry of Old Age report (2015) elaborate slightly on complexity and they inform that:
“... the expertise of old age psychiatry services lies in the care and treatment of people with complex mixtures of psychological, cognitive, functional, behavioural, physical and social problems usually relating to ageing.” (ibid., p.1)

Yet, no further guidance is provided on how this complex mix may present in a person with dementia.

As a result of increased public awareness and a drive toward improving diagnosis rates (DH, 2015; All-Party Parliamentary Group on Dementia, 2012; DH, 2009), it can be argued that there is now increased recognition and awareness of memory assessment and treatment teams and the roles they play in supporting a person with dementia. However, this recognition and awareness has not extended to mental health NHS dementia inpatient wards and they remain an invisible component of mental health NHS dementia services with very little attention being paid to the demand for these beds (Tucker et al., 2015; Pinner et al., 2011). This is of concern as in a generic mental health context; the DH (2006) has recognised that mental health inpatient units provide care for those people who are “most acutely unwell, who experience high levels of distress and who cannot be cared for in their own home or other community settings” (p.40). The importance of separate inpatient provision for older people with dementia has been advocated as good practice now for a number of years (see Audit Commission, 2002; 2000). The Royal College of Psychiatrists recommend that bed numbers for the acute inpatient mental health care of older people should be 1-2 per 1000 older persons and the wards should be no larger than 20 beds (Royal College Psychiatrists, 2006).

As a result of changes to inpatient bed provision (focus on acute beds as opposed to continuing care beds), and the changing demographics of the ageing population, the Royal College of Psychiatrists (2006) informs that older people being managed in inpatient areas have become more complex in their presentation and are often high risk with increasingly significant comorbidities. They conclude that many admissions of older people to wards are as a result of significant risk, self-harm and self-neglect and that some patients will require compulsory admission and treatment under the Mental Health Act (DH, 1983) or admission and assessment under the auspices of the Mental Capacity Act (Pinner et al., 2011).
National data regarding the use of the Mental Health Act (DH, 1983) to compulsorily detain patients in hospital has demonstrated an increased use over the last twenty years, whilst nationally the number of mental health inpatient beds has been reduced (Care Quality Commission, 2018). One of the possible reasons given for the increase in the use of the Mental Health Act (DH, 1983) was that this is now being increasingly applied to people with dementia who would have previously been admitted as an informal patient (Care Quality Commission, 2018). In 2016/17 there were 9,533 people over 65 detained in hospital on a section of the Mental Health Act (DH, 1983); unfortunately, it has not been possible to identify out of this number how may had a diagnosis of dementia (NHS Digital, 2017).

The last decade has seen a national drive to improve the care and treatment of people with dementia in hospital (DH, 2009), but the focus has been on people with dementia receiving care and treatment in general hospitals (see for example: Young et al., 2011; Heath et al., 2010). This focus on general hospital care is evidenced, for instance, in the Alzheimer’s Society information sheet ‘Hospital Care’ as it has as its emphasis care of people with dementia in acute general hospital environments (Alzheimer’s Society, 2015c). There is no mention of people with dementia being admitted to mental health NHS dementia inpatient wards. A Mental Health Foundation report regarding the relationship between dementia and mental health problems (Regan, 2016), whilst referring to care and service provision, make no reference to the existence or role of mental health NHS dementia inpatient wards; instead, the reference points are shared care wards to meet physical and mental health needs, the role of hospital liaison and care homes.

The Alzheimer’s Society (2016) state that many people with dementia who live in care homes “have high levels of mental health needs as a result of the cognitive, psychological and behavioural symptoms of dementia and other mental health conditions such as depression” (p.27) and that they require access to good mental health services and support. However, as a result of mental health NHS dementia inpatient ward bed number reductions, on the occasions when these setting are required, it can mean the person with dementia being admitted to an environment many miles from home (ibid.).

When mental health NHS dementia inpatient wards do come to public attention sadly it is often as a result of reports of poor care and treatment. This was highlighted in Wales in
2015 when the Ockenden report (undertaken in 2014) came to public attention in response to reported concerns regarding care and treatment of patients with dementia on Tawel Fan ward Ablett Unit at Ysbyty Glan Clwyd in Bodelwyddan. The ward was closed, two further reports commissioned and the findings of the Ockenden report made headline news. Even within a mental health care setting the presence of mental health dementia inpatient wards is under recognised and could be considered as the ‘Cinderella’ of mental health inpatient services. Indeed, in a report commissioned by the Royal College of Psychiatrists in 2016 in recognition that urgent action was needed to improve acute psychiatric care for adult mental health patients, people with dementia and dementia wards were excluded from this report (Crisp et al., 2016).

Mental health NHS dementia inpatient wards have been missed in the current drive to increase research on all aspects of dementia from cause, cure to care. Individuals with dementia are admitted to these environments when there is nowhere else to meet their needs, and they are usually detained on a section of the Mental Health Act (DH, 1983). My experience of these environments is that they are very busy, always full and provide care and treatment for vulnerable people with high levels of need. Moreover, the presentation of the patient population in these environments is very different to other mental health inpatient wards due to the multiple overlapping conditions, high levels of physical care needs and impaired insight and capacity (Hilton, 2015).

Tinker et al. (2014) suggests that there are groups of older people who are “invisible” (p.187) to policy makers and practitioners in UK healthcare with that their needs are not recognised or addressed adequately. Tinker and colleagues highlight six underserved populations of older people who remain invisible within a health care sector; those with a physical disability, those with learning disabilities, those who are non-heterosexual, older prisoners, older people with chronic long term mental health problems and those who are homeless. It could be argued that this list should be extended to seven and include people with dementia who are patients on mental health NHS dementia inpatient wards.

This study therefore brings together two areas which have remained hidden from the current dementia lens; that of complexity in dementia within the setting of mental health NHS dementia inpatient wards.
1.9 Conclusion

This chapter has presented an overview of dementia, dementia policy and guidance and UK mental health NHS dementia inpatient wards. Information regarding what dementia is, economic impact, and prevalence have been discussed. An overview of the four most common types of dementia has been given along with brief commentary of the staging of dementia. A summary of recent policy initiatives has been presented before moving on to discuss mental health NHS dementia inpatient wards. I will now move onto present the literature review. In keeping with an interpretive description approach the literature review forms part of the scaffolding of the study (Thorne, 2008). In this context scaffolding is the framework and initial position from which you “build out your design plan” (p.53).
CHAPTER 2
Literature Review - ‘Scaffolding the Study’
Complexity and Dementia

2.1 Introduction
This chapter will commence by outlining an interpretive description approach to undertaking a literature review as part of ‘scaffolding the study’. Next, the aims of the literature review will be identified and following this, the literature search methodology will be explored and outlined. A discussion about how the identified literature was themed and appraised for the review will follow. The chapter will then present and critically discuss the findings from the review process. Due to the embryonic status of the concept of complexity in dementia, a variety of literature has been included in each section for example; qualitative studies, surveys, policy and practice guidance, all of which is in keeping with an interpretive description approach (Thorne, 2008). The literature will be presented in three categories and at the end of each category, a short conclusion will be offered. Finally, the chapter will conclude with a summary.

2.2 Scaffolding the Study
The methodological approach adopted for this study is interpretive description (Thorne, 2008). The reasons for this have already been outlined in the background to the thesis (pages 14-16). However, as a brief reminder, interpretive description was chosen as I needed a methodological approach that would allow an issue stemming directly from clinical practice to be explored and which would generate knowledge that could be applied back into practice.

Scaffolding the study is an important part of an interpretive description approach and sets up the initial position from which the study design is built. Scaffolding consists of two essential elements: firstly, a literature review and secondly, clarifying the theoretical forestructure. Within an interpretive description framework, the literature review enables one to draw conclusions about the “state of the science” in relation to the clinical problem of concern (Thorne, 2008, p.54). Thorne (2008) outlines that the literature review should; ground the study within the existing knowledge, offer critical reflection regarding what
does and does not exist and provide a discussion regarding the strengths and weaknesses within the overall body of knowledge. Literature is not just limited to research and the sourcing of relevant ‘grey literature’ is also advocated.

Thorne (2008) refers to the theoretical forestructure as the researchers “theoretical baggage” (p.54) or, in other words, the preconceived assumptions held by the researcher. The researcher is encouraged to explore the theoretical and practical knowledge that they bring to the study. My ‘theoretical forestructure’ has already been stated at the beginning of this thesis in ‘personal context’ section (pages 11-14), leaving the remainder of this chapter to focus upon the literature review to scaffold the study.

2.3 Literature Review: Aims
The research question that informs this study is based on my clinical understanding that the concept of complexity in dementia is not well-formed with regard to published studies, especially when applied to mental health NHS dementia inpatient wards. The aims of this review, therefore, are to map a terrain of literature to explore and ascertain:

a) How patient complexity, in general, is currently defined and represented.
b) The current state of knowledge regarding the concept of complexity in dementia.
c) The nature and number of publications about mental health NHS dementia inpatient wards.
d) The models/frameworks that are used in mental health NHS dementia inpatient wards for the assessment of patient complexity.

By exploring the literature to answer the above review aims, a theoretical backdrop will be provided which will perform two main functions. Firstly, to sensitise the areas that the research study will address; and secondly, to enable strengths and weakness of the literature to be commented upon and gaps in the research and knowledge base to be identified. I will now develop this further by outlining my literature search strategy.
2.4 Literature Search Strategy

The initial literature search was undertaken at the commencement of the PhD in September 2014 and updated in 2018. The initial search strategy undertaken at the start of the study encompassed a range of terms and concepts. The primary reason for this was that in order to scaffold the study, three areas required exploration, these being: complexity, dementia inpatient wards and complexity assessment. In addition, as there is no universally agreed term for mental health NHS dementia inpatient wards, a number of alternative terms were identified in an attempt to ensure that relevant literature was not missed.

A number of sources were utilised in developing the key words and concepts for the search. These included identifying key words and concepts from the research question and scanning related literature for key words. This process was undertaken to ensure that the most appropriate and relevant terms were identified. Advice was obtained from The University of Manchester library staff and within PhD supervision to ensure that the search terms were reflective of the research study focus. This process resulted in a number of amendments and modifications.

The search terms utilised are listed in Table 2.1, pages 40-41. Some of these terms were searched for in isolation and others were amalgamated in various combinations in order to ensure the retrieval of subject specific literature. An outline of the combinations used is located in Appendix 1. All searches were undertaken as key word searches. The literature review update that was undertaken at the beginning of 2018 used a refined and updated search criterion: see Table 2.2, pages 41-42. Table 2.3, page 42, identifies the databases which were searched on both the initial and updated review.

Grey literature was also searched. This included Department of Health and UK government publications, Royal College of Psychiatrists web site, Cochrane database for systematic reviews, University of Stirling Dementia Services Development Centre Website, Alzheimer’s Society and Alzheimer’s Disease International websites and EThOS theses database. A Google search was also undertaken to gain a feel for mental health NHS trusts’ service specifications for dementia inpatient environments and to attempt to ‘capture’ any further relevant information. References of relevant publications were also searched.
Table 2.1 Scaffolding Review Search Terms for Initial Literature Review

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<thead>
<tr>
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<tbody>
<tr>
<td>1</td>
<td>dementia OR senile OR senility OR “pre senile dementia” OR “early onset dementia” OR “vascular dementia” OR “multi infarct dementia” OR “frontotemporal dementia” OR “lewy body” OR “AIDS dementia”</td>
</tr>
<tr>
<td>2</td>
<td>Dementia AND “cog* impairment” NOT mild</td>
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<tr>
<td>3</td>
<td>Dementia AND “organic illness”</td>
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<td>4</td>
<td>“advanced dementia”</td>
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<tr>
<td>5</td>
<td>“severe dementia”</td>
</tr>
<tr>
<td>6</td>
<td>Dementia AND “co morbid*”</td>
</tr>
<tr>
<td>7</td>
<td>Complex* OR “rapid decline” OR “rapid deterioration” OR acuity OR acute OR “cognitive complexity”</td>
</tr>
<tr>
<td>8</td>
<td>vulnerab* OR frail*f</td>
</tr>
<tr>
<td>9</td>
<td>“challenging behavio<em>r</em>” OR “behavio<em>r</em> that challenge*”</td>
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<tr>
<td>10</td>
<td>“dementia in patient*” OR “dementia inpatient*”</td>
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<td>“dementia hospital” OR “dementia ward*” OR “dementia unit*”</td>
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<tr>
<td>13</td>
<td>“old* age psychiatr* ward*” OR “old* age psychiatrist* unit*” OR “old* age psychiatr* hospital”</td>
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<tr>
<td>14</td>
<td>“late* life psychiatr* ward*” OR “late* life psychiatrist* unit*” OR “late* life psychiatr* hospital”</td>
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<tr>
<td>15</td>
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<tr>
<td>16</td>
<td>“geropsychiatr* ward*” OR “geropsychiatr* unit*” OR “geropsychiatr* hospital”</td>
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<tr>
<td>17</td>
<td>“neuropsychiatr* ward*” OR “neuropsychiatry* hospital” OR “neuropsychiatry* unit*”</td>
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<tr>
<td>18</td>
<td>“psychogeriatric ward*” OR “psychogeriatric unit*” OR “psychogeriatric hospital”</td>
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Table 2.2 Scaffolding Review Search Terms for Literature Review Update

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<thead>
<tr>
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<tbody>
<tr>
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<td>Dementia AND Complex*</td>
</tr>
<tr>
<td>2</td>
<td>Complexity in dementia</td>
</tr>
<tr>
<td>3</td>
<td>“Defining patient complexity”</td>
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<td>4</td>
<td>“Patient complexity AND Assessment method*”</td>
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<td>7</td>
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<td>“psychiatric ward*” OR “psychiatric department*” OR “psychiatric unit*” AND dementia</td>
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<td>Search Terms</td>
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<tr>
<td>10</td>
<td>“late* life psychiatr* ward*” OR “late* life psychiatr* unit*” OR “late* life psychiatr* hospital”</td>
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<td>11</td>
<td>“special* dementia ward*” OR “special dementia unit*” OR “special dementia hospital”</td>
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<td>12</td>
<td>“geropsychiatr* ward*” OR “geropsychiatr* unit*” OR “geropsychiatr* hospital”</td>
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<tr>
<td>13</td>
<td>“neuropsychiatr* ward*” OR “neuropsychiatry* hospital” OR “neuropsychiatry* unit*”</td>
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<tr>
<td>14</td>
<td>“psychogeriatric ward*” OR “psychogeriatric unit*” OR “psychogeriatric hospital”</td>
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<tr>
<td>15</td>
<td>“geriatric ward*” OR “geriatric unit*” OR “geriatric hospital” AND dementia</td>
</tr>
<tr>
<td>16</td>
<td>“mental health ward*” OR “mental health unit*” OR “mental health hospital” AND dementia</td>
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### Table 2.3 Databases Searched for the Scaffolding Review

<table>
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<th>Databases</th>
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<tbody>
<tr>
<td>British Nursing Index</td>
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<tr>
<td>CINAHL</td>
</tr>
<tr>
<td>Ovid multiple data base search</td>
</tr>
<tr>
<td><em>(PsychARTICLES, Books@OVID, EBM reviews, AMED, Health &amp; Psychosocial Instruments, OVID medline, PsychBOOKS, PsychINFO)</em></td>
</tr>
<tr>
<td>Web of Science</td>
</tr>
</tbody>
</table>

### 2.5 Literature Inclusion and Exclusion Criteria

To be included the retrieved literature had to refer to work conducted in a health and social care context, with a focus upon dementia complexity, assessment of dementia complexity and mental health NHS dementia inpatient wards. However, early into the initial literature search, these criteria were widened to include literature which defined, or described,
patient complexity more generally within health or social care. This was in response to so little being published regarding ‘dementia complexity’.

Exclusion criteria included: papers not published in English, papers which addressed dementia complexity from a molecular pathophysiological perspective, dementia diagnosis, dementia aetiology, health care system complexity, assessment which focused on dementia diagnosis and inpatient care which referred to general hospitals and nursing homes.

Initially, no date restrictions were placed on the literature. However, in practice, literature sourced from before 1980 was rejected. This was because literature that predated this had a focus upon mental health ‘asylum’ type institutions and as these are no longer in existence, this literature was assessed as not being relevant.

On both the initial and updated searches the approach adopted resulted in the identification of a huge number of hits. However, by reading the abstracts, a large proportion of publications were immediately rejected as they met the identified exclusion criteria, leaving a much smaller number of publications for more detailed review. The most popular reasons for immediate exclusion were publications with a focus on dementia aetiology, dementia diagnosis assessment and general hospital care or nursing home care. Figure 2.1, page 44, identifies the number of initial hits after duplicates were removed and the screening and sorting process which led to the identifications of the papers included in this review.
2.6 Critically Appraising the Included Literature

At the stage of further review, an ‘organic’ process to organising, reviewing, and appraising of the literature evolved. In order to familiarise myself and understand the literature, I required a process whereby I could immerse myself in the literature. In reality, this consisted of a ‘hands on’ approach which included having paper copies of the literature and, by hand, annotating and highlighting literature, completing synopsis and quality appraisal forms. As the review aimed to map a terrain of literature in order to
sensitise readers to the main areas the research would seek to address (rather than undertaking a systematic review), this ‘organic’ process provided a suitable framework from which to review and appraise the literature.

All literature at this stage was read a number of times. A highlighter pen was used to mark relevant text or sections whilst reading, and text was also annotated. Synopsis forms were completed and stapled to each piece of literature and were adapted from the work of Wallace and Wray (2011). A copy of a hand-written synopsis form is located in Appendix 1. The re-reading of literature and completing of synopsis forms helped to initially organise the literature into broad categories and identify the degree of relevancy for the scaffolding of the study. From these categories, literature was then further organised into themes. The process of identifying themes consisted of reading through the literature and capturing key points/areas on ‘Post-it’ notes and then arranging ‘Post-it’ notes into themes. Additionally, these emerging themes were discussed in supervision. This hands on approach to reviewing the literature is in keeping with an interpretive description approach where the researcher is encouraged to familiarise themselves with the literature and use interpretation and reasoning in identifying what is explicitly known on the subject area (Thorne, 2008).

The literature also underwent a process of quality appraisal. Due to the differing types of literature reviewed, a number of tools and guidance were employed. These included, for example, the Critical Appraisal Skills Program [CASP] qualitative research checklist (2013), the nine step process to retrospective chart reviews (Gearing et al., 2006) and guidance regarding theoretical contributions (Whetten, 1989). In addition, the book by Greenhalgh (2010) on ‘how to read a paper’ was also consulted as necessary. A copy of a completed CASP qualitative research appraisal checklist for a study as included in the scaffolding review is located in Appendix 1 and Figure 2.2, page 46, outlines the categories the literature was divided into and the themes in each category.
Figure 2.2 Literature Categories and Themes

**Defining Patient Complexity**
- Health & Social Care
- Mental Health
- Dementia

**Mental Health NHS Dementia Inpatient Wards**
- Research Studies
- Policy / Guidance
- Reasons for Admission

**Complexity Assessment**
- Complexity Assessment Tools
- Dementia Inpatient Assessments

Complexity and Dementia
2.7 Defining Patient Complexity

The next section explores how patient complexity is currently defined from a general health and mental health perspective and then it will explore how complexity in dementia is represented.

2.7.1 Patient Complexity: A General Representation

Locating in the literature a widely accepted generic definition of patient complexity is difficult. Schaink et al. (2012) argue that there is a lack of common understanding regarding patient complexity. Similarly, Safford et al. (2007) report that although “complex patients are increasingly common within medicine” (p.382) the conceptualisation of patient complexity is only just emerging. This would therefore explain the limited degree of published literature in this area. Despite the view that conceptualisation of complexity is in its infancy, Peek et al. (2009) report that clinicians do sense or observe complexity in patients, but not “necessarily with a clear idea of exactly how the patient is complex or what to do about it” (p.288). Peek and colleagues (2009) also claim that conversations with stakeholders, including medical educators, struggle with patient complexity.

Wade (2011), when writing about complexity in the context of rehabilitation, informs that severity and complexity are different; a person may have a severe form of a condition, but that this in itself will not make them complex and that complexity is more related to uncertainty and unpredictability. Shippee et al. (2012), in acknowledging that complexity is inherently difficult to define, reports that “complexity is a dynamic state in which the personal, social and clinical aspects of the patients experience operate as complicating factors” (p.1041). They move on to state that “these factors appear and accumulate over time interacting with each other in emergent and even cyclical ways” (p.1041). This definition infers that patient complexity can have biographical, social and medical roots and that it is the interaction and recurring nature of the factors that can cause the complexity.

This interaction of multiple factors is also reflected in others attempts at defining complexity. When discussing self-management of patients with complex chronic illness, in
a paper providing an overview of the content at an American conference on managing complexity in chronic care, Weiss (2007, p.375) defines patient complexity as:

“... [A complex patient] is one for whom clinical decision making and required care processes are not routine or standard. For complex patients many recommendations from evidenced based medicine are unlikely to apply in a straightforward manner because of “exceptions” such as: multiple interacting chronic conditions, other co-morbid conditions that complicate the management of the focal chronic disease and socioeconomic factors such as homelessness or the absence of adequate family.”

The focus that complexity may be related to detraction from usual care processes is also reflected in the following definition of patient complexity provided by Peek and colleagues (2009): “The person specific factors that interfere with the delivery of usual care and decision making for whatever conditions the patient has”(p.291). The authors of this definition argue that there is a practical need for the establishment of a standard definition of patient complexity as this will guide clinicians to begin to incorporate interventions to address areas of complexity into care plans that are currently geared to the management of illness.

What is apparent from these definitions is that issues of patient complexity concern themselves with the presence of other factors in conjunction with the illness /disease being treated. Weiss’ definition explicitly makes reference to the fact that complexities may not just be related to other physical presentations, but may be socio-economic in cause. Somewhat more elusively, Peek and colleagues (2009) allude to ‘person specific factors’ in relation to complexity. These definitions lead one to begin to consider that issues of patient complexity may be unique to each patient and not be solely related to the illness for which they are being treated. Arguably, this stance has been adopted by Safford et al. (2007) who suggest that patient complexity is more than comorbidity of medical conditions and propose that socio-economic, cultural, behavioural and environmental factors also contribute towards complexity. However, these authors also highlight that such factors do not receive the same degree of attention as medical comorbidity.
In a cohort study aiming to define patient complexity from a primary care physician perspective in USA (Grant et al., 2011), the authors believed that patient complexity measures were predominantly based on the number of chronic conditions or medications prescribed, but that patient complexity was probably a multifaceted concept which was not being fully captured by recording the number or type of medical conditions or health care costs. In this study, 40 primary care physicians were asked to review a list of 120 of their own randomly selected patients and identify the patients they considered to be complex. The results indicated that within primary care, patient complexity reflected a wide range of medical, social and behavioural factors. Patients were identified as ‘complex’ on more than a count of comorbid conditions and many patients with multiple comorbidities were not classed as complex by their physician. Several factors were identified with complexity in younger patients but not in older patients; including alcohol related problems and drug misuse. Patient complexity was also associated with more clinic visits and complex patients were more likely to be uninsured, live in census blocks and have lower rates of income. Interestingly, the study demonstrates the range of multi-dimensional factors that can be associated with complexity, thereby taking the concept of complexity beyond medical comorbidity.

Rankin and Regan (2004) talk of complex needs as opposed to patient complexity. In a joint report undertaken with the Institute for Policy Research and Turning Point they address the meeting of complex needs from a social care perspective (Rankin and Regan, 2004). This report was based upon the findings of a literature review and qualitative interviews with a range of service users to explore the concept and presentation of complex needs. The report finds that too many health and social care services fail to recognise the interconnected nature of people’s needs and that meeting complex needs is at the “heart of two key government agendas: creating personalised services and combating social exclusion” (2004, p.E). The authors refute the concept of ‘generic’ complex care thereby inferring the individualised components of complexity. The report also discusses that ‘complex needs’ is a term used loosely by practitioners to describe those who have multiple problems, or as a shorthand term to describe those who are perceived the hardest to help such as people with substance misuse problems or those displaying challenging behaviour. Although it was reassuring to see that service users were involved in this report it is of concern to note that all participating service users were between the ages of 16 and 60. The authors acknowledge that the report does not explore the complex needs of older
people but does not explain why. Arguably, this is a significant limitation as increasing age is referenced as being a risk factor for having complex needs.

Rankin and Regan (2004) propose a framework, rather than a definition, as a way of representing complex needs. Two rationales are offered to support this. The first being that overly descriptive definitions are difficult to apply in practice and secondly, that by representing complex needs as a framework, it captures the fact that people respond in different ways and what may be complex for one person may not be for another. The premise of this framework is that complex needs have features of being multiple and interlocking and can span both health and social care issues. Consequently people’s complex needs can have a breadth (range of need) and/or depth (severity of need).

Three years on from the work of Rankin and Ragin (2004), Rosengard et al. (2007) undertook a literature review on multiple and complex needs. This review was undertaken on behalf of the Scottish Executive as part of a programme of works assessing the impact of multiple and complex needs and how services should respond. It is interesting that in this review the terms ‘multiple’ and ‘complex’ are utilised together thereby inferring that they are co-dependent upon each other and that complexity has a focus of multiplicity of need or presentation. In this review, the authors bring attention to the plethora of terms employed by various disciplines linked to the concept of multiple and complex needs. Examples given of such terms are: complex health needs, multiple and complex needs and dual diagnosis. The authors concluded that one of the reasons for a lack of definition, or agreed consensus to the meaning of complex and/or multiple needs, is that there is “an assumption that complex and or multiple needs are matter of fact and can be understood without definition” (Rosengard et al., 2007, p.6). They also believed that the terms complex and multiple are used interchangeably and that whether used singularly, or combined, they can be used to describe the “extreme end” (p.14) of a continuum of need.

Evidence of the assumption that complex needs can be understood as a matter of fact without definition is reflected in two papers examined for this review. Challis et al. (2010) in a published paper entitled Comprehensive Assessment of Older People with Complex Care Needs: the multi-disciplinarity of the Single Assessment Process in England, reported upon the findings of a survey regarding the prevalence and patterns of comprehensive assessment. Despite the title of the paper, the concept of complex care needs is neither
defined nor explored. It is difficult to derive from this how one can concur regarding the comprehensiveness on an assessment process if the areas it is assessing are not described. Similarly, the Kings Fund Sir Roger Bannister Health Summit in 2012 focused upon the care of frail older people with complex needs (Cornwell, 2012). However, considering complexity was one of the core themes of this summit, no definition is offered. Within NHS policy and guidance a similar theme is echoed. For example, Next Steps On the NHS Five Year Forward View (NHS, 2017) informs that the number and complexity of patients that NHS staff treat continues to increase; however, it does not make explicit what it means by complexity of patients. Similarly, the NHS Business Plan Putting Patients First 2013-14 to 2015-16 (NHS England, 2013) makes reference to complex care needs and older people with complex care needs, yet no definition or description is offered. Furthermore, the National Institute for Health and Care Excellence on older people with social care needs and multiple long term conditions (2015) talks about the complex nature of multiple long term conditions without describing what exactly this is.

2.7.2 Patient Complexity: In Mental Health

Within the UK, NHS dementia care falls under the remit of mental health services and therefore the literature has been examined to ascertain how patient complexity is represented within this specialty. In relation to a small volume of literature that focuses upon patient complexity from a general medicine/health perspective, there appears to be an even smaller volume that relates to patient complexity in mental health.

From Values to Action: The Chief Nursing Officer’s Review of Mental Health Nursing was published over a decade ago now (DH, 2006) and set the vision for mental health nursing for ten years. The report recognised mental health nurses to having the skills and experience to work with individuals who had the highest level of need in terms of severity, acuity or complexity. In the context of this report complexity is seen to arise from individuals having “additional needs for example substance misuse, physical healthcare problems or learning difficulties” (p.24). The report clearly identifies that the key clinical focus for mental health nursing should remain with those with higher levels of need, of which complexity is identified, as these are areas where mental health nursing can make the most difference. Despite these recommendations, the report does not outline what nursing skills are required to provide care for people with higher levels of need. Nor does
the report provide any further detail regarding complexity; it is left with the inference that complexity results from having a mental health problem and an additional need.

A year later, the concept of patient complexity is again made reference to in The New Ways of Working (DH, 2007) initiative. This initiative advocated that patients with the more complex needs are matched to the practitioners with greater experience and skills (p.10). In response to the acknowledgement that the term complexity is commonly utilised within policy and also in general NHS discourse and that “there is no clear widely accepted definition of what it means and approach to working with it” (DH, 2007, p.47), a working party was established to advise on the concept of complexity in mental health. The working party identified that there was a range of options in how complexity could be defined in clinical practice. These included:

- As a concept – identifying that the challenge of the more complex cases that do not fit into case conceptualisation or diagnostic categories.
- By multiplicity and or severity of needs including risk.
- By intervention – a complex case occurring as a patient’s needs are unlikely to be met by a standardised treatment package.
- By service – for example use of an enhanced Care Program Approach.

(DH, 2007, p.57.)

The New Ways of Working (DH, 2007) report also suggested that it may be more beneficial to focus upon variables that might contribute toward complexity, rather than seeking a specific definition. Suggested variables included: duration, severity and number of problems, level of functioning and level of risk/vulnerability (p.49). The document provides more in the way of exploring complexity than any other policy and guidance document considered in this scaffolding review. It also provides a useful starting point for examining complexity as a set of variables. However, there are a number of considerations to be taken into account. This was a report undertaken by an interim working group and no further work has been published or developed and as a result, there is no evidence as to the development of testing complexity as a set of variables.
The Care Program Approach (CPA) (DH, 2008) is the approach used in secondary mental health services from which to assess, coordinate and deliver care. Its aim is to provide care and support for people in contact with secondary mental health services who have “complex characteristics” (p.11). This guidance uses the term ‘clinical complexity’ as one of the characteristics to consider when assessing if an individual requires the support of CPA. Unfortunately, the document does not define complexity nor proffer any guidance as to how complexity should be recognised or assessed for.

2.7.3 Patient Complexity: In Dementia

The concept of complexity in dementia is frequently acknowledged within policy and guidance, but in keeping with other areas of health care, poorly defined and described. In England, the National Dementia Strategy (DH, 2009) reports that people with dementia can have complex needs. Similarly, The Case for Change (DH, 2011) states that people with more advanced dementia may have complex needs that fluctuate from day-to-day. Despite these acknowledgements of complex needs, again no further definitions are offered or guidance on how to assess for it. The National Institute for Health and Clinical Excellence/Social Care Institute for Excellence (2006) dementia guideline and Dementia Quality Standard (National Institute for Health and Care Excellence, 2010), whilst remaining consistent in a lack of definition regarding complexity, do offer examples of complexity. For example, the National Institute for Health and Clinical Excellence/Social Care Institute for Excellence (2006) makes reference to complexity in dementia being associated with the “coexistence of physical and psychiatric problems” (p.34), which may require assessment in a psychiatric inpatient environment. Interestingly, in the National Institute for Health and Care Excellence (2018), ‘Dementia: assessment, management and support for people living with dementia and their carers’ guideline, which replaced the earlier National Institute for Health and Clinical Excellence/Social Care Institute for Excellence (2006) guideline, this reference to complexity in dementia is dropped completely. Instead complexity is briefly referred to in the context of the provision of care and support being complex due to the number of people living with dementia and the variation in symptoms each person faces (National Institute for Health and Care Excellence, 2018). However, that is the only reference to complexity.
The Dementia Quality Standard (National Institute for Health and Care Excellence, 2010) talks of dementia being associated with complex needs and:

“as the condition progresses, people with dementia can present carers and social care staff with complex problems including aggressive behaviour, restlessness and wandering, eating problems, incontinence, delusions and hallucinations, and mobility difficulties that can lead to falls and fractures.” (p.5)

More recently the All-Party Parliamentary Group (2016) inquiry into dementia and comorbidities informs:

“Although dementia is a health condition the nature of the condition means that people with dementia need significant support from social care services. As dementia progresses a person’s needs will become more complex, especially if they are living with long term conditions.” (p.12)

Although complexity is not defined there is a clear intimation that it is related to the progression/severity of a person’s dementia and the co-existence of other health conditions.

The Royal College of Old Age Psychiatrists (Pinner et al., 2011) published a Faculty report on inpatient care for older people within mental health services. It covers inpatient services for older people with dementia and functional mental illness. The report informed that mental health inpatient care for older people is “highly specialised, focused on the most vulnerable, those with the greatest need and complexity” (p.6). It is, therefore, surprising and somewhat perplexing that this statement is neither extended upon nor explored in any detail, and the meaning of complexity remains without description or definition. This is even more concerning when considering that this report is making reference to complexity being a factor to warrant an inpatient admission. However, a later Royal College of Psychiatry (2015) report outlining the criteria for old age psychiatry services does offer a greater insight as it outlines that the expertise of old age psychiatry “lies in the care and treatment of people with complex mixtures of psychological, cognitive, functional, behavioural, physical and social problems usually relating to ageing” (p.1).
The lack of definition of complexity within dementia is also reflected when one turns to the research literature. This is highlighted in a qualitative research study exploring nursing students’ experiences of caring for people with advanced dementia where the authors report that advanced dementia is “profoundly complex” (Watts and Davies, 2014, p.1149), yet they do not expand on this to inform how or in what way advanced dementia is profoundly complex. Indeed, only two studies were identified which focused upon patient complexity within dementia. The first, a case study, was part of a Kings Fund research project (Sonola et al., 2013) which examined UK based models of care coordination in the management of age-related chronic and complex medical conditions. The case study describes the work of the Oxleas Advanced Dementia Service. A mixed methods approach to the case study was used and consisted of semi-structured interviews with team members and stakeholders, observation of a team meeting and a content analysis of key documents, presentations and impact data. The service provides care coordination, palliative care and support to patients with advanced dementia living at home. Whilst the report does not define patient complexity in dementia, it does describe the presentation of complexity within this patient population. The Oxleas Advanced Dementia Service work with people who have a diagnosis of moderately severe or severe dementia complicated by complex mental and physical comorbidities who require a palliative approach to care. Examples of these complex comorbidities are given as: recurrent infections, significant weight loss and poor nutrition, severe physical frailty, severe persistent distress (mental or physical) or another condition such as comorbid cancer. As this report is focused more on care coordination than complexity, it does not give any further insight into the severity or degree of the complex comorbidities, but it does provide a valuable insight into the possible components of patient complexity in dementia. This interpretation of complexity suggests that complexity is a combination of dementia and at least one other physical or mental comorbidity. This could be viewed as a ‘medical’ model view of complexity as the relevance of personal and social components are not referenced.

The second located study was a doctoral thesis, which focused upon exploring the concept of age-related complexity within secondary mental health services (McGeorge, 2010). This doctoral study used a constructivist grounded theory approach and collected data from 13 registered nurses working with older people in a mental health NHS trust. The study identified a number of components that contribute to complexity in older people, including the biological, psychological and social. Nurses appeared to construct age-related
complexity as a “bio-psycho-social phenomenon” (p.68). The author split the components of complexity into two domains: internal and external. Examples of internal components were: physical illness, mental illness, willingness to accept help or engage, challenging or risk behaviour. Examples of external components were: bereavement/losses, family carer support, living environment, beliefs and attitudes of others. In this study, complexity was not necessarily correlated with long term conditions or frailty. Complex needs were identified as a result of complexity which consists of both multiplicity of needs and the interactions between them. Complexity was also discussed as a dynamic state from which there could be recovery (McGeorge, 2010).

One of the findings reported from McGeorge’s study was that complexity also seems to have abstract properties which include unpredictability, instability, intangibility and invisibility. As a result of these abstract properties it becomes impossible to measure complexity. McGeorge (2010) concluded that these abstract properties make it hard for nurses to discuss complexity as there is a lack of vocabulary and terminology to assist with this practice. This doctoral study by McGeorge has been the only study located which has explored complexity within older people’s mental health services. Out of the 13 nurses interviewed five worked in wards, six in the community and two in liaison psychiatry. Unfortunately, the study does not identify how many of these staff worked in mental health NHS dementia inpatient wards. The study findings are correlated across the service and not differentiated in accordance to where the staff worked i.e. dementia or functional care. The findings from this study were also published as a journal article a year later (McGeorge, 2011).

2.7.4 Summary
This section has concluded that the concept of patient complexity is currently in its infancy across health in general. Despite this, the terms ‘complex’ and ‘complex needs’ are regularly used in relation to dementia and are represented within dementia policy and guidance. To-date, there is no commonly accepted definition of complexity in dementia. Despite this lack of a definition, it is possible to begin to draw (from the small body of work to-date) tentative thoughts about the presentation of complexity in dementia. The literature infers that complexity occurs as a result of properties interrelating with each other and that their origin can be biological, psychological, personal, social, or
environmental/economic. There is also the suggestion that complexity is individualised, so the components which present as complex in one individual may not be complex in another. This emerging picture of complexity is more than a presentation or sum of comorbid conditions and perhaps this picture challenges a medical model view of illness and reminds us of the need to look holistically at people. Within dementia it is widely accepted that there are high levels of physical comorbidity (All-Party Parliamentary Group on Dementia, 2016; Hewer and Stark, 2010; Adamis and Ball 2000; Sanderson et al., 2002), yet this in itself may not necessarily result in complexity.

McGeorge’s PhD work (2011; 2010) has greatly contributed to this emerging body of knowledge regarding complexity within older peoples’ mental health services. However, this work did not specifically focus upon complexity in dementia and her focus was upon age-related complexity. Also, the small number of studies to-date generally which have explored patient complexity have used methods such as obtaining data from electronic records and interviewing staff; no studies were located which observed complexity from the perspective of the individual experiencing it.

2.8 Mental Health NHS Dementia Inpatient Wards

As the study is focused upon exploring the concept of complexity within mental health NHS dementia inpatient wards it is appropriate that the state of knowledge around these environments is considered in this scaffolding review. Chapter 1 has provided an insight into the purpose of these environments. This section will therefore provide an overview as to types of research and publications that have been undertaken in recent years within mental health NHS dementia inpatient wards. Studies that have encompassed reasons for admission will also be reviewed. By presenting the literature in this way it provides an insight into the state of knowledge (Thorne, 2008) about these areas and will give an understanding as to the types of presentations that lead to admission, thereby further contributing to the scaffolding of the study.

2.8.1 Mental Health NHS Dementia Inpatient Wards: The State of Knowledge

There is a paucity of studies which have been conducted within mental health NHS inpatient dementia wards (Tucker et al., 2017). The literature search located only 25
publications of 11 studies/developments since 1980 where mental health NHS dementia inpatient wards had featured (see: Scales et al., 2017; Tucker et al., 2017, 2015 and 2008; Gridley et al., 2016; McPherson et al., 2016; Revolta, 2016; Wilson et al., 2015; Dawson, 2014; Murphy et al., 2013; Lloyd et al., 2011; McGeorge 2011, McKeown et al., 2010; Schneider, 2010; Schneider et al., 2010; Dinshaw, 2006; Stevenson et al., 2009, 2006, 2005; Ball et al., 2004; Adamis and Ball, 2000; Neville et al., 1999; Riordan and Mockler, 1996; Perry et al., 1995; Wattis et al., 1994). It is worth noting that 11 of the 24 publications have occurred in the last five years thereby perhaps suggestive that there may be a growing interest in this much neglected area.

These publications focus upon a variety of differing themes including: the use of life story work in improving care (Gridley et al., 2016; McKeown et al., 2010), medication audits (Wilson et al., 2015; Dawson, 2014), duration of stay (Ball et al., 2004), outcomes of admission (Wattis et al., 1994), physical morbidity (Adamis and Ball, 2000; Perry et al., 1995) and psychological consultation (Murphy et al., 2013). Ten of the of the publications did not solely focus upon mental health NHS dementia inpatient wards, but also included functional mental health wards for older people. (see for example; Tucker et al., 2017, 2015 and 2008; Revolta, 2011; Murphy et al., 2013; Adamis and Ball, 2000; Dinshaw, 2006; Riordan and Mockler, 1996; Perry et al., 1995; Wattis et al., 1994). One study which explored the feasibility of life story work as a mechanism for improving care for people with dementia also included care homes (Gridley et al., 2016).

Two PhD theses were also located. One of which explored how inpatient psychiatric nurses made sense of and responded to behaviours in dementia (Vidya, 2017, unpublished doctorate in clinical psychology thesis). This study was undertaken in one mental health NHS trust and consisted of eight inpatient nurses from two mental health NHS dementia inpatient wards. There is little description of the wards offered other than they were busy and mixed sex. The second was McGeorge’s (2010, unpublished PhD thesis) and this was a constructivist grounded theory study of nurses’ construction of age-related complexity. Whilst undertaken with nurses working in NHS older peoples mental health services, it does not differentiate findings that originate from staff working within mental health NHS dementia inpatient wards to those of functional or community origins.
There were no studies located which primarily concerned themselves with exploring complexity in dementia within this environment. However, it has been possible to begin to gain an understanding of how patients present within a mental health NHS dementia environment from two studies. Interestingly, in the first study, this insight is not the central focus of the study. The aim of the National Institute for Health Research funded ethnographic observational study was to understand the experiences of staff working directly with older people with dementia (Schneider et al., 2010). The study was undertaken in a mental health NHS trust and focused upon health care assistants. For six months, three researchers worked as part time supernumerary health care assistants in three mental health NHS dementia inpatient wards within the trust. This study provides insights into life on wards from the perspective of healthcare assistants in regard to the process of caring and the rewards and impacts of caring (Schneider, 2010). This paper commences with a preface in which some of the initial experiences of the researchers’ early days in the field (the dementia wards) are shared. The accounts are anonymised transcripts of their field notes. One account tells of a female patient who was presenting with distressed and disturbed behaviour. The researcher’s field notes recorded:

“... a lady who had been moved from a nursing home for aggressive behaviour and confusion, suddenly got extremely upset and angry. .... From the day room we could hear her down the corridor shouting and hitting various doors and walls with her walking frame.’ (p.7-8)

In response to this experience, the researcher’s field note also recorded her own thoughts of “I could not imagine there being a ‘worse’ case than this. I had never heard anything like it before and would be quite happy if I never heard it again” (p.7-8). Another captures the severity of the illness presentation that can lead to an admission “… during handover one of the qualified spoke of a new patient who had become increasingly aggressive at home and had threatened to kill her neighbours and their families.” (p.11)

These accounts offer an honest and raw insight into the acuity and severity of the presentation of dementia within mental health NHS dementia inpatient wards and the affect that can have on people experiencing this for the first time.
Further insights into the severity of presentation of people with dementia within inpatient wards were obtained from publications detailing a psychiatric intensive care unit (PICU) in the Fife region of Scotland (Stevenson et al., 2009, 2006, 2005). PICUs are secure units for people with mental health problems and associated severe behavioural disturbances (Stevenson et al., 2006) who cannot be safely cared for within a mental health acute assessment ward. They are more commonly associated with adult patient populations as opposed to people with dementia. The publications detail how a 12 bedded male PICU for patients with dementia was established in response to local need due to a small number of people with dementia being admitted with severe behavioural disturbances and whose presentations and subsequent management was proving difficult for the dementia assessment wards. Examples of reasons for transfer to this environment are given as: persistent verbal abuse, severe and persistent agitation, repeat absconding, persistent physical aggression and resistive behaviours (Stevenson et al., 2009, 2006). Dementia PICUs are not a regular feature in mental health NHS dementia care services and it is possible that the presentation of severity and aggression highlighted is ‘specific’ to this area of Scotland. This possibility is also acknowledged by the authors and possible reasons for this explored for example the reduction in NHS continuing care beds contributing to a concentration of behaviourally disturbed men with dementia.

From a guidance perspective, psychological interest in mental health NHS older adult inpatient wards from both a functional and organic perspective seems to be growing and 2017 saw the publication of psychological best practice guidance for this area (see for example: The British Psychological Society, 2017). This may be in part as a result of the Royal College of Psychiatrists recommending minimum standards for psychology input to each older adult ward as part of the accreditation standards for older adult inpatient mental health Services (Royal College of Psychiatrists, 2017). These standards intend to provide staff with a clear and comprehensive benchmark of ‘best practice’ in inpatient care for older adults with mental health problems. The standards are written for both dementia and older peoples functional wards. There are three types of standards ranging from: type 1 fundamental standards of care which all inpatient areas should meet; type 2 standards that wards would be expected to meet; and type 3 standards that are desirable. Older adult mental health inpatient areas participating in this accreditation process are externally assessed and have to provide evidence against the standards. There is also a cost
implication in applying for accreditation so this may prevent some inpatients areas from working toward this accreditation process.

2.8.2 Reasons for Admission

Mental health NHS dementia inpatient wards featured in three research papers which examined service provision for older people with mental health problems within a given geographical area in the North West of England (Tucker et al., 2017, 2015 and 2008). However reasons for admission were only detailed in the 2015 publication which explored alternatives to admission to mental health older adult NHS inpatient beds. Data was collected from two neighbouring mental health NHS trusts across three geographical areas in 2010/11 about people admitted to the older adult mental health wards for a six month cohort of people over the age of 65. In total this was 216 admissions, 82 of which had a primary diagnosis of organic impairment - the authors acknowledge was most commonly a dementia. The most prevalent reason for admission for people with dementia was reported to be due to presentation of behaviour that challenges followed by risk of harm to others.

The third paper published by Tucker et al. (2017) reported on the factors affecting length of stay, delayed discharge and discharge destinations for the same 2016 admissions which the 2015 publication focused upon. Higher levels of dependency, cognitive impairment and the presentation of behaviour that challenges were reported to be associated with longer lengths of stay because the provision of appropriate care is complicated by the multiple and complex needs of this group of people. The authors suggest that there is a need for more research that focuses upon direct care and treatment provide to people in mental health inpatient settings.

Behaviour that challenges as being a reason for admission was also reflected in a descriptive survey undertaken in 1999 examining the reasons people are admitted to mental health NHS dementia inpatient wards (Neville et al., 1999). The survey was conducted over a six month period in one health district in England across three sites and the survey reported findings on 224 admissions. Only 25 out of the 224 admissions had a single reason for admission identified and the remaining 199 admissions had between two and six reasons for admission given. Aggression, severe agitation and inappropriate sexual behaviour were all listed as common reasons for admission, which today would be classed
as behaviour that challenges. Other reasons for admission also included the presence of psychotic features, self-neglect and poor appetite. Even though this survey is now dated, it provides an insight into the multiplicity of problems experienced by a person with dementia that can lead to an inpatient admission that is still reflected in clinical practice today.

2.8.3 Summary
This section has explored the state of knowledge regarding UK mental health NHS dementia inpatient wards. As the review has identified, relatively few research studies have been undertaken within these environments. This lack of research attention may be a reflection that this area of dementia care remains ‘hidden’ within the dementia spotlight; with the current focus being on cause, cure and early diagnosis. It could also be argued that the lack of research attention also contributes to the area of mental health NHS dementia inpatient wards remaining hidden as there are few publications to promote and publicise these environments.

However, even from the small amount of literature available, it is possible to begin to draw a picture that these environments are for people with dementia who are experiencing behaviour that challenges, presenting with high levels of risk and may be a danger to themselves or someone else. This is powerfully reflected in the Schneider et al. (2010) study in the researchers’ field notes that capture insights into patient’s presentations within these environments. I will now move onto present complexity assessments.

2.9 Patient Complexity Assessment
As this literature review has ascertained to-date, there have been no published studies defining complexity in dementia and information regarding mental health NHS dementia inpatient wards is scant. It is therefore, of no surprise that it has not been possible to locate research/publications which focus upon a model for assessing complexity in dementia or guidance as to areas to address. Additionally, locating studies/publications which explore assessment models/frameworks utilised in dementia assessment wards within the UK, are rare. This section will commence by initially exploring more broadly patient complexity assessments in order to facilitate an understanding of how these are represented generally
in health and social care. A number of patient complexity assessments will be discussed and questions raised as to the possible transferability to being utilised with people with dementia. I will then look at assessment in dementia and attempt to draw and reflect from the literature the way assessment in complexity in dementia is represented.

2.9.1 Patient Complexity Assessment Models

A small number of tools for the assessment of patient complexity have been developed though none has been identified that is specific for dementia, nor is there evidence to show they have been ‘tested’ with people with dementia or their use adopted within dementia-focused clinical practice. Examples of such tools are: INTERMED (Huyse et al., 1999; De Jonge et al., 2001; Stitching INTERMED Foundation, accessed on line 10th February 2014;); COMPRI (Huyse et al., 2001); Minnesota Complexity Assessment Method (Peek at al., 2009, Baird and Peek 2008); Vector Model of Complexity (Safford et al., 2007); Pearce Case Complexity Scale (Pearce, 1996, p.60-61); and Oxford Case Complexity Measure (Troigros et al., 2014). I will now explore and discuss in more detail a number of these assessments models.

The INTERMED (Stitching INTERMED Foundation) originates in the Netherlands. The INTERMED is currently being used in several European countries, America and Canada (Thurber et al., 2017). The Stitching INTERMED Foundation informs that the tool is suitable for use in clinical practice and for research purposes. The tool was designed for complex medically ill people, examples of which are given as frail elderly, chronically medically ill with psychiatric disorders, substance misuse and pain with unexplained medical complaints (Stitching INTERMED Foundation, online). There is observer rated and self-administered versions of the INTERMED. The self-administered version was developed in response to the fact the observed rated INTERMED requires training before clinicians can use it and the assessment itself can be time consuming for practitioners (van Reedt Dortland et al., 2017). In both versions there are four domains for assessment of complexity identified; biological, psychological, social and health care. A number of tick box statements are attached to each domain and the participant has to identify which ones are most representative of their presentation. The assessment of complexity is by a scoring system and higher scores are representative of increased complexity. The original tool is nine pages long but there is also a shorter four page self-assessment version designed for
older people. De Jonge et al. (2001) report, that the applications of this tool in patient populations with somatic and psychosocial comorbidities have demonstrated its utility. As the tool relies upon a patient being able to identify how their current presentation impacts upon them, how long it has been present for and how long they expect it to continue, it raises questions about how this would fare in a population of people with more advanced dementia whose history reporting ability and insight into their condition may be impaired. Completion is this instance would only be possible if someone who knew the person well was involved.

The INTERMED has subsequently been utilised as the foundation for the development of two further assessments. The COMPRI (Huyse et al., 2001), which is a shorter version of the INTERMED and was developed to predict complex needs in patients admitted to general hospitals (Huyse et al., 2001). Then leaving the Netherlands and moving to the USA, the INTERMED was used as the foundation for the development of the Minnesota Complexity Assessment Method (Peek at al., 2009). Unlike the INTERMED the Minnesota Complexity Assessment Method offers further advice to clinicians regarding actions to take if complexity is identified and provides guidance towards care planning requirements, including documenting a plan of action. Within the UK the Minnesota Complexity Assessment method has been further developed into the Minnesota Edinburgh Complexity Assessment Method (MECAM) for use by nurses in Scotland who were undertaking the keep well health checks (Maxwell et al., 2011). The ‘keep well health check’ is an anticipatory care approach targeted at geographical communities of greatest need. Conclusions from the development and validation of the MECAM reported that the tool was acceptable to practitioners. There was agreement that it encouraged a more holistic assessment of patient needs. The MECAM was subsequently further adapted and its name changed to PCAM (patient centred assessment method) following feedback from nurses who wanted to emphasise the patient centeredness of the assessment rather than focus on the word complexity (Pratt et al., 2015).

The Vector Model of Complexity (Safford et al., 2007) originates from the USA. This model uses the principles of vector physics and complexity is represented utilising a multi axis model which represents the determinants of health. The identified axes are: socio economics, culture, biological/genetic and behaviour. Each of the axes are tied into each other and when diagrammatically represented, the model begins to look like a web. The
authors demonstrated its use by two case examples. Although the authors of this publication make an interesting argument for the presentation of patient complexity and its representation via a vector model, there is no evidence to support the model has moved beyond conceptualisation and is being used in clinical practice (Corazza, 2017).

The Pearce Complexity Scale is a scale for rating case complexity and was developed within the UK for use within child and adolescent psychiatry. It is underpinned by the assumption that the more complex the case the “greater the therapeutic effort required to produce a satisfactory outcome” (Pearce, 1996, p.60). This rating scale asks raters to assess an individual in six domains: co morbidity, psychosocial problems, legal issues, other agencies involved, unsuccessful professional treatment for same disorder, disability. Raters are asked to score each section from 0-2 with zero being no problem and 2 representing two or more problems in the category. On first examination this assessment scale appears to be very brief and quick to administer. It also enables a ‘score’ to be captured. However, the tool lacks the provision to add the specific details as to which individual components of each area have contributed to the scores, how this affects the person and how they interrelated with each other. For these reasons its transferability to a population of those living with dementia appears limited.

2.9.2 Assessment of Complexity in Dementia

Currently, there does not appear to be any universally adopted tools for assessing complexity in dementia in any setting: inpatient or community. Overviews of assessment processes were retrieved from a small number of publications. The first was a publication by Ball et al. (2004) examining the factors that influenced duration of stay and discharge outcomes on an mental health NHS dementia inpatient ward. This publication makes reference to an integrated inpatient dementia pathway from admission to discharge. Components of this pathway were the completion of a number of measures for all patients which included a cognitive assessment, functional ability assessment, behaviour assessment and physical health assessment. However, this paper falls short of offering further exploration of how the results of these measures were used to affect patient care and guide interventions.
The Chief Nursing Officer’s review of mental health nursing (DH, 2006) outlines the importance of good assessment in the provision of excellent person centred care. It advocates that mental health nurses when undertaking assessments should see “whole people” with interrelated psychological, social, physical and spiritual needs (DH, 2006, p.4). This is initially a reassuring statement, particularly as this report outlines that mental health nurses should be caring for those with the highest levels of needs, in terms of severity, acuity or complexity. Indeed in the appendix there is further information detailing the process of assessment and giving guidance as to what areas should be covered. Areas suggested for assessment are: social, physical, spiritual, risk substance misuse and carers. Taking into account, the emphasis on nursing those with the highest level of need and seeing ‘whole people’ with interrelated needs the assessment information feels almost one dimensional. It fails to offer any guidance regarding the interrelatedness of any of the areas being assessment or of the subsequent impact this interrelatedness can have on an individual. This report initiates a dialogue regarding mental health nurses role in caring for people with high levels of needs and the importance of holistic assessment, yet it falls short of providing the guidance that mental health nurses need to be able to deliver this level of care.

Oxleas Advanced Dementia Service provides support and care for people with dementia with complex presentations at home (Sonola et al., 2013). Assessment provided by this team seeks to identify mental, physical and social needs. These needs are identified by history taking covering areas such as: personal and social background, medical and psychiatric history, medications, existing care and support, spiritual needs and wishes. Assessment and examination is also undertaken to identify for example current mental state, functional ability and sleep pattern. The assessment findings are then presented and discussed at the multidisciplinary team meeting and a personalised care plan produced. Delivery and monitoring of care plan is then overseen by care coordinator. This approach to assessment does appear to be more holistic and reference is made to team discussions about care and care planning. Yet is misses an important discussion regarding the impact of the areas of assessment on each other and the individual. It would be further strengthened by information regarding how the interrelatedness of needs are assessed and subsequently cared for.
Over recent years there has been a growing awareness of the prevalence of the behavioural and psychological symptoms of dementia, which are often referred to as behaviours that challenge or behaviour that challenges. Indeed, this review has highlighted that it is these symptoms of dementia which can ‘trigger’ admission into a mental health NHS dementia inpatient ward. In response to these presentations, a multifactorial assessment to behaviour has been advocated (see Bird and Moniz-Cook, 2008; National Institute for Health and Clinical Excellence/Social Care Institute for Excellence, 2006) and models have been developed that examine and assess people’s behaviour in terms of need or unmet need. The underpinning theory being that the behaviour being demonstrated is a manifestation of a need or unmet need (James and Jackman, 2017; Cohen-Mansfield, 2000; Stokes, 2000). Models of assessment and examination of such behaviour are all similar in construct and use two types of information. Background information; for example, personal history, physical health, cognition, pre morbid personality coupled with an in-depth description of the behaviour (see: James and Jackman, 2017; Bird and Moniz-Cook, 2008; James and Stephenson, 2007). This information is then used to develop a formulation which is a hypothesis about the cause and nature of the issues and needs, from there, interventions and care plans are agreed (Rainforth and Laurenson, 2014).

The Newcastle model is an example of an approach that uses a multifactorial approach to assessment of behaviour that challenges in a person with dementia. From the gathering of biopsychosocial information, a formulation is developed and interventions and approaches are identified (James and Jackman, 2017; Jackman and Beatty, 2015; James and Stephenson, 2007; James et al., 2006). Although the approach is now widely published and disseminated at dementia related conferences, locating publications or research studies which demonstrate the use of the Newcastle model - or other similar formulation led models within mental health NHS dementia inpatient wards - was difficult. Only one publication was located which explored a needs led approach to assessment within a mental health NHS dementia inpatient ward. This paper utilised a case study needs led formulation approach to demonstrate the exploration of behaviour in a patient who was admitted to a mental health NHS dementia inpatient ward (see Keady and Jones, 2010).

Finally, a ‘Google’ search was undertaken in an attempt to see if further information about assessments undertaken within mental health NHS dementia inpatient wards could be obtained directly from mental health NHS trust websites and service information.
Unfortunately, information obtained did not give any further insight into ‘how’ people are assessed although claims of ‘provide a person centre assessment’ and ‘highly specialised assessment and treatment’ were frequently made.

2.9.3 Summary
This section has demonstrated that assessments of patient complexity do exist but they have not been specifically developed for dementia nor do they seem to have been adopted within dementia practice. The review was not able to identify any universally adopted assessment frameworks that are used in mental health NHS dementia inpatient wards. Due to the prevalence of the behavioural and psychological symptoms of dementia, there is growing evidence of the applicability of needs led approaches to the assessment of these behaviours. Yet, to-date, studies exploring such approaches have tended to be undertaken in community and care home settings. As these models utilise a multifaceted approach, the question arises as to whether they have the flexibility to also be adapted to assess complexity? Arguably, until the concept of complexity in dementia is described and components of complexity identified, it will be extremely challenging to clarify what an assessment framework should look like.

2.10 Conclusion
The literature review has revealed that the concept of patient complexity is under-developed within and across health and social care, and particularly within dementia. As a result, there is no universally adopted definition or description. However, there is evidence that this is an evolving concept and the work that has been undertaken to-date indicates that complexity consists of a number of components and is more than the sum of comorbid conditions. There is also suggestion that it is dynamic and degrees of complexity can change. From a dementia perspective, the review has demonstrated that the term complexity is used in policy, guidance and publications when referring to patients’ presentation and needs. At times is it utilised in association with behaviour or physical comorbidity. Yet there is no research which has explored why or how behaviour or comorbidity can result in complexity. Both behaviour and physical comorbidity are common presentations in dementia, but the review would suggest that there is more to complexity than the existence of these two properties.
Complexity is also referred to as a reason for admission into a mental health NHS dementia inpatient wards, but the review has demonstrated that studies focussed on such settings are scarce and none could be found that involved interviewing people with dementia in such a setting, for example. As a result of the lack of definition/description of complexity in dementia, and a paucity of research focusing upon inpatients who are undergoing assessment, it is of no surprise that locating assessments for complexity in this population is sub-optimal and in need of development. It is to this area that the thesis will now turn.
CHAPTER 3
Interpretive Description: Methodological Approach and Study Design

3.1 Introduction
This chapter begins by stating the aims and objectives of the study. The theoretical rationale for the study will then be presented and following this an overview of interpretive description as a methodological approach is offered. Issues of practitioner-researcher reflexivity are discussed. This study presented considerable ethical challenges and these are outlined in this chapter. Methods of data collection and analysis are discussed including a description of an advisory group which was established to provide advice and guidance throughout the study. For each phase of data collection, a rationale for the chosen method/s, the strategy for study recruitment and eligibility and the practical aspects of data collection will be presented. Similarly, the approach to data analysis for each of the three phases of study is discussed. Finally, issues of rigour and credibility are explored.

3.2 Study Aims and Objectives
Following the scaffolding review, conducted in the preceding chapter, it was clear that there is an under development of the literature regarding the concept of complexity in dementia. This finding augmented my clinical experience and observations. Drawing on both these resources, the primary aim of this study is to explore the concept of complexity in dementia within the setting of mental health NHS dementia inpatient wards. This aim is supported by the following objectives:

- To explore with various stakeholders in dementia care and clinical staff how they construct and recognise complexity in dementia.
- To explore the perspectives and views of complexity by people with dementia who are patients on mental health NHS dementia inpatient wards and to gain a similar understanding from their relative/friend.
- To describe the key components of complexity in dementia.
- To describe key components of the assessment of individuals with dementia who are perceived as being complex.
3.3 Theoretical Rationale for the Study

This is an applied qualitative research study conducted through three applied and empirical phases. Qualitative research is suited to exploring phenomenon about which little is known (Polit and Hungler, 1985). It is inductive and naturalistic (Padgett, 1998) and can yield rich detailed descriptions of a phenomenon (Welford et al., 2012) as it attempts to describe, explain and understand (Barbour, 2000). As Morse (1997) succinctly writes, qualitative methods are for understanding “what is going on” (p.1) and applied research is concerned with “using the knowledge gained through research to contribute directly to the understanding of a contemporary issue” (Ritchie and Ormston, 2014, p.45). Thorne (2008, p.44) informs that the requirement for qualitative research is best justified when: themes and patterns within a phenomenon have not been well documented; where there are subjective or experiential elements of the phenomenon which have not yet been fully reported; and what is being studied has relevance and utility to the discipline in which it originated.

As the scaffolding of the study has identified in Chapter 2, the concept of complexity in dementia is underdeveloped, as is the state of knowledge regarding mental health NHS dementia inpatient wards. This is supported by evidence from my own clinical practice that complexity in dementia is a concept that clinicians in the inpatient environment are regularly faced with and is an issue of which there is no shared understanding or meaning. Therefore, an applied approach is best suited to the study as it seeks to explore, describe and interpret in an attempt to further develop the understanding of the concept of complexity in dementia.

3.4 Interpretive Description

Interpretive description was developed as a way of exploring the clinical questions that are relevant to nurses, but which are not readily answered by the more traditional methodologies and where the generation of “useable knowledge” (Thorne, 2008, p.16) is required. This will now be developed further as I provide an overview of interpretive description as a methodological approach.
3.4.1 Analytic Framework

Interpretive description is grounded in an “interpretive orientation that acknowledges the constructed and contextual nature of much of the health-illness experience yet allows for shared realities” (Thorne et al., 1997, p.172). The authors ascertain that an interpretive description approach is a way of applying qualitative inquiry into human health and illness experiences for the purpose of developing knowledge. In other words, interpretive description is presented as a methodological framework that can address the multifaceted experiential questions arising from practice and develop clinical understanding. Thorne et al. (2004, 1997) originally referred to interpretive description as a non-categorical method of research. In this respect, the term ‘non-categorical’ was used to signify a qualitative research method that does not fit with an established approach. Thorne (2008) defines interpretive description as:

“A qualitative research approach that requires an integrity of purpose deriving from two sources; 1) an actual practice goal and 2) an understanding an understanding of what we do and don’t know on the basis of the available empirical evidence (from all sources).” (p.35)

Defining interpretive description in this way enables the researcher to be best placed to decide the context of the research. It will include, for example, what is known theoretically and clinically about the current situation and the breadth and depth of the phenomenon to be studied (Thorne, 2014).

Interpretive description has a philosophical alignment of an interpretive naturalistic orientation. It acknowledges the constructed and contextual nature of human experience, whilst at the same time allowing for shared realities to emerge (Thorne et al., 1997). The philosophical underpinnings for research design are mirrored on those described by Lincoln and Guba (1985) and include: multiple constructed realities that can only be studied holistically; the inquirer and object of inquiry interact to influence one another; and no prior theory could encompass the multiple realities that are likely to be encountered (Thorne, 2008).
Researchers using interpretive description will investigate a phenomenon of clinical interest with the aim of capturing themes and patterns within the phenomenon under study. However, even in this search for applied commonalities, the researcher using an interpretive description methodology is also looking out for and accounting for variation between individuals (Thorne, 2014; Hunt, 2009). The purpose of interpretive description is to produce a logical, conceptual description based on the commonalities found in the phenomenon whilst also accounting for the variations found within them. The end product should have application potential within clinical practice. In this sense clinicians should see the sense in the findings and they should support the assessment, planning, intervention and evaluation of care approaches (Thorne et al., 2004). Here, the products of interpretive description are a “tentative truth claim” (Thorne et al., 2004, p.7) about what is common within a clinical phenomenon. I will return to this area in more detail in the final chapter of this thesis.

An important aspect of interpretive description is that it is not singularly responsible for method and it borrows from, and adapts, aspects of ethnography, phenomenology and grounded theory if they have the potential for exploring and solving the problems of practice (Thorne, 2013; Thorne et al., 2004). It is the search for “a coherent logic model that serves the discipline” (Thorne, 2013, p.297) that becomes the goal of the approach and the use of methodology and methods. The trick in interpretive description is to give a clear and credible explanation of the processes that the practitioner-researcher has followed.

3.4.2 Sampling and Data Collection

There are no fixed design elements in an interpretive description study. Sampling may be convenient, theoretical or purposive. Thorne (2008) acknowledges that within sampling the idea of representation is complicated and that a study can never represent anything other than what it is. Thorne (2008) therefore urges researchers to accept that although the sample will not be meaningfully representative it will, however, reflect a “certain kind of perspective built from an auditable set of angles of vision whose nature and boundaries we can acknowledge and address” (p.89). Understanding the sample, the limitations of the sampling procedure and the implications this holds for the research findings shapes the integrity and credibility of the study. Interpretive description can be conducted on samples...
of any size although it is particularly suited to smaller scale qualitative investigations (Thorne et al., 2004).

There are no limitations to data sources that may be used. Whilst acknowledging that interviews, participant observation and focus groups are popular with nurses, Thorne (2013, 2018) indicates that it is important not to neglect other alternative data sources such as patient records, published testimonials and policy documents, all of which may provide valuable insights into areas of professional practice or health experience. Qualitative mixed methods approaches are supported to avoid an over emphasis on one data source (Thorne et al., 2004), to help further develop insights that emerge during data analysis (Thorne et al., 1997) and to contribute towards the trustworthiness of the findings (Hunt, 2009; Thorne et al., 1997).

3.4.3 Data Analysis

There is no prescriptive recipe provided for analysing data within an interpretive description methodology. Researchers are required to use inductive analytical approaches that allow structure and meaning to be given to the data so that new understandings and insights can be developed (Thorne, 2014, 2000; Thorne et al., 1997). Data collection and analysis occur concurrently with the researcher constantly reflecting and asking questions such as: ‘why is this here?’, ‘why not something else?’, ‘what does this mean?’ (Thorne, 2013; Thorne et al., 2004). The researcher is encouraged to manually work with the data by reflecting, pondering and challenging it until they can form the data into parts that tell us something that was not known about the phenomenon previously. The use of qualitative software systems at the beginning of data analysis is not recommended as it can overwhelm with detail and prevent inductive interpretation (Thorne, 2013; Thorne et al., 1997).

Thorne (2008) advises caution against premature coding and sorting as, once you begin to code, particularly using software systems, she argues that it may be too late to reverse the process and premature coding can overshadow the use of “reason, intelligence and inductive thinking” (p.144). Instead, Thorne advocates the use of broader based coding and not to be too precise in early coding, and to consider bringing together data into groups that might be thematically related. The use of jotting down memos, highlighting data with
colours to reflect possible thematic similarities are advocated, as is the use of analytic notes, so that questions about the analysis can be raised with other team members and/or research supervisors (Thorne, 2008).

Drawing inspiration from other qualitative data analysis techniques is permissible, such as constant comparative analysis that is seen in grounded theory, as this approach is suited to studies which want to find commonalities and patterns (Thorne, 2008). However, Thorne advises that, if such approaches are borrowed, they should not be used in a manner which is entirely faithful to the original tradition or applied uncritically. Moreover, the researcher needs to remain aware of the need to account for the relationship between the analysis technique and the underling approach of interpretive description whose aim is to develop knowledge that can be used in practice (Thorne, 2008). As a result of its reliance upon interpretation, interpretive description does not produce ‘facts’ but instead produces constructed truths (Thorne, 2008; Thorne et al., 2004).

3.4.4 Rigour and Credibility
In the promotion of rigour and credibility Thorne (2008) makes a number of suggestions. Similarly to other qualitative research studies, Thorne (ibid.) maintains that for the findings to be credible, the research process must have a research question which is consistent with the epistemological view and an interpretation of data and interpretive approaches which sensibly stem from the question. The need for representative credibility is also recommended in the theoretical claims that are made as they need to be consistent with the manner in which the phenomenon was studied (Thorne, 2008). To promote the constructed perception of an event, or process, the use of triangulation of data sources is recommended.

The provision of an audit trail is suggested as a way of providing a path which can be followed by another researcher as a way of outlining the analytic logic that has been employed throughout the research. Reflective journals and reflective memos are also recommended, as is the notion of returning conceptualisations representing the entire sample back to individual participants for critical consideration. The concept of the “thoughtful clinician test” is also introduced by Thorne (2004, p.8) as a marker of validity. This is when those with expert knowledge of the phenomenon find that the outcomes of the research confirm their “clinical hunches” and that the research brings new understandings
and relationships within the phenomenon, thereby providing “disciplinar
relevance” (Thorne, 2014, p.110). I will now move onto to discuss issues of researcher reflexivity.

3.5 Researcher Reflexivity

Throughout this study an important issue has been my role as a practitioner-researcher. Clinically, I was an advanced practitioner in dementia undertaking research into areas of my own practice. Reed and Procter (1995) talk about practitioner-researchers “being part of the world that they are researching in a way that an academic researcher cannot be” (p.5). This practitioner-researcher role has been likened to that of a double agent by Yanos and Ziedonis (2006). Whilst acknowledging that the role brings distinct advantages, for example a practitioner who is involved in both research and clinical practice is able to facilitate an “interactive flow of ideas” (Yanos and Ziedonis, 2006, p.250) between the two domains, they also highlight the risk of ethical conflict.

Both Reed and Proctor (1995) and Thorne (2008) have developed this further and talk about insiders and outsiders. Insiders being practitioner-researchers who undertake research in a clinical setting to which they are familiar, and outsiders referring to undertaking research within an area that a practitioner-researcher is not familiar with. As well as the obvious benefits that being an insider brings, Thorne (2008) cautions that people may find it difficult to ‘step out of role’ and for example find themselves drawn into clinical practice. There is also the risk that insider practitioner-researchers may “absorb untested assumptions about how things are done” (Thorne, 2008, p.118) and that study participants may shape their stories or avoid raising certain issues as the researcher is known to them.

The dual role of practitioner and researcher had advantages and disadvantages throughout the research. Whilst word limitations prevent me from discussing this at length, there are some key points worth exploring. This research study stemmed from issues arising from clinical practice and was undertaken in the ‘real world’ of clinical practice. From the very start, my practitioner experience has influenced all aspects of the study. One of the reasons I adopted interpretive description as the research methodology was it allows the practitioner to be ‘seen’ throughout the study as long as this presence is accounted for.
A number of the phases of the study were undertaken in clinical settings in which I was familiar and known as a colleague and advanced practitioner, thereby making me the ‘insider’ practitioner-researcher. Given these circumstances it was essential that I was aware of this status and that I worked reflexively throughout. I have been aware of how my own experiences, thoughts and history have been brought to the study, from articulating the research question through to designing the data collection methods, engaging with study participants, interpreting the data and writing the thesis. These issues were a regular feature within supervision and reflective journals that were kept throughout the study.

My decision to include people in this study with advanced dementia and who were detained on the mental health NHS inpatient dementia ward(s) under sections of the Mental Health Act (DH, 1983), and who lacked capacity to consent to involvement in the study, was heavily influenced by my previous experience of involving people with moderate to advanced dementia in aspects of service delivery and development. It did not feel balanced to undertake a study exploring the concept of complexity in dementia without involving the very people who are being explored. The issues of assessing capacity and working within the remit of the Mental Capacity Act (2005) were not something I was anxious about because I could draw on my clinical skills. I was fully conversant with the Mental Capacity Act (2005) and assessing decision specific capacity; however, translating this clinical experience into a research ethics submission proved to be a lengthy and quite arduous journey.

When I commenced my PhD in 2014 I stopped working clinically on the wards. This was in order to let the staff get used to my not being around as the advanced practitioner so that when I returned as the researcher they would find this easier to adapt to. In addition, it ensured that clinically I was not involved with any patients who may become research participants. Removing myself from these environments prior to data collection taking place also helped to reduce the risk that I may make untested assumptions about how things are done. Despite these plans there were still occasions where I experienced tensions in my role as a practitioner-researcher. Reed and Proctor (1995), whilst acknowledging these tensions, promote the importance of recognising and resolving them. There were times when I would, for example, overhear clinical conversations about patients and I would have to restrain myself from proffering an opinion or becoming clinically involved in the case. There were other occasions during periods of observation where the role of the
practitioner-researcher became a ‘delicate balancing act’ (Thorne, 2008, p.121). One example is when I noticed a patient physically deteriorating, whilst I was on the ward undertaking a period of observation. I alerted nursing staff and suggested that the patient concerned needed an immediate medical review. On this occasion the registered nurse in me came to the fore as I recognised the acuity of the patient’s presentation. For all other times, the use of a reflective note book and supervision discussions helped to maintain the filter that I needed to keep to ensure that these tensions were appropriately managed.

During interviews I needed to establish a rapport with study participants and put them at ease. This is where my clinical background was beneficial as I found study participants were able to identify with me and it seemed to help that they knew that I had worked in mental health NHS dementia inpatient wards for a number of years. However, I had to remember that I was not the ‘seasoned clinician undertaking a clinical interview’; instead, I was a researcher wanting to know others thoughts and experiences on the phenomenon. Thorne (2008) refers to this as “learning not to lead” (p.110) and in order to ensure that I did not default to the clinician’s stance of interviewing, I adopted a number of actions. During my first few interviews I attached a reminder on top of my notes page that I was the researcher not the practitioner. I also had a number of questions or statements I would use to try and find out a little more information; for example, ‘can you please tell me a little more about how that looked?’ This helped to prevent me from making assumptions. I also listened back to all the interviews immediately after I had undertaken them as I found this to be a helpful way of checking that the clinician in me had not taken over.

3.6 Ethical Approval

Before I move onto discuss the phases and methods of this study I want to discuss the ethics approval process at this point as it was an important feature in this study. As a clinician it was important that the study was undertaken in the clinical environments in which the research question arose and that people with dementia who were patients on the ward were involved in the study. The process of preparing for ethical approval was therefore a lengthy one (approximately eight months) as time needed to be spent considering and accounting for all the ethical issues that may be encountered. Due to the limitations of words I will focus on the two ethical issues I consider to be the most significant. These are issues of consent and undertaking observations of patients within the
mental health NHS dementia inpatient wards. A full list of all the ethical issues considered for the study can be located in Appendix 2 in the format which was submitted as part of the ethics application.

My clinical experience had prepared me for the fact that patients who were to be recruited into the study would be either detained on a section of the Mental Health Act (DH, 1983) or they would be in hospital on a Deprivation of Liberty Safeguard (2008) and their capacity to consent to participating in research would be impaired as a result of the progression of their dementia. However, I believed that it was important for these individuals to have the opportunity to participate as I was exploring a concept of dementia that they were living and experiencing within an environment where they were legally detained. To facilitate the participation of individuals who did not have the capacity to consent, the Mental Capacity Act (The British Psychological Society, 2008; Mental Capacity Act, 2005) guidance was strictly adhered to and a detailed consent procedure was written, which served as a step-by-step guide. A pictorial information sheet was also developed for those patients who had capacity to consent, but required information presenting to them in a format which was easier to understand and process. Personal consultees were sought for patients who did not have capacity and this accounted for all four of the patients who were recruited to the study (as will shortly be explained under phase 3 of the study design) with their spouses acting as personal consultee. A copy of the consent procedure is located in Appendix 2, and a copy of the pictorial patient information sheet, and personal consultee information sheet, are located in Appendix 3.

The other ethical issue of note was the undertaking of patient observations within the mental health NHS dementia inpatient ward environment. As a clinician I knew that these environments could be busy, noisy and, at times, disturbed. I wanted to undertake observations in a way that was minimally disruptive but which would enable an insight to be gained into how the patient presents, and acts, within the ward environment. In order to protect all patients’ privacy and dignity, a decision was made not to undertake observations during the provision of direct care which requires privacy (for example washing, dressing, bathing, and using the toilet). In addition, prior to undertaking periods of observation, I would check with the care team and the patient’s personal consultee that this was acceptable. An observation protocol was developed and all staff were made aware during
study awareness raising sessions what the observations would entail in an attempt to reassure them. Please see Appendix 3 for a copy of the observation protocol.

Ethical approval for this study was obtained from the Integrated Research Approval System from North West Haydock NHS Research Ethics Committee on 10th February 2015. This was a committee which had been designated to consider studies involving people who may not have the capacity to consent, as was the case in phase 3 of this study (as will be described shortly). A substantive amendment was also submitted to this committee outlining the need to use handouts as part of the awareness raising with clinicians in the study. This was approved on 12th May 2015. Research governance approval was received from a local mental health NHS trust (please see Appendix 2 for copies of these ethics approvals). The study was also adopted onto the National Institute for Health Research Clinical Network for Dementias and Neurodegeneration portfolio.

3.7 Study Design: A Mixed Methods Approach

The study design used a mixed methods approach to explore the meaning presentation and assessment of complexity within mental health NHS dementia inpatient wards. The study was iterative in nature and consisted of three phases of data collection. The same three areas were explored at each phase of data collection. These areas were: 1) reasons for admission to mental health NHS dementia inpatient wards; 2) exploring what the term complexity in dementia means; and 3) views of how people with dementia who are receiving care and treatment on mental health NHS dementia inpatient wards should be assessed.

The three phases were explored using qualitative mixed methods data collection comprising of an electronic online survey (phase 1), individual and focus group interviews (phase 2), and case studies (phase 3). This mixed methods approach to data collection is in keeping with an interpretive description methodology as the researcher is encouraged to think about using a combination of approaches in order to enable a comprehensive understanding of the phenomenon being studied and reduce the risk of over-reliance and the limitations of one data collection approach (Thorne, 2014). Figure 3.1, page 81, provides a summary of these iterative and sequential phases including the methods and approaches used.
I will now move onto discuss each phase on the study. I will provide a rationale for the methods chosen before moving onto to discuss issues of recruitment and sampling.

### 3.8 Study Advisory Group
An independent advisory group for the project was established in February 2014. This group consisted of two registered mental health nurses with experience of mental health NHS dementia inpatient wards, a clinical psychologist, two old age consultant psychiatrists, a person with dementia, a previous carer who has cared for her husband and father-in-law with dementia and a volunteer coordinator with extensive experience of
supporting people with dementia to become involved in developments and research. The members of the advisory group were invited to comment on the study design and were involved in the development of the pictorial patient information sheet. In addition a number of the advisory group also tested the electronic online survey and piloted interview questions. The advisory group met periodically through the duration of the study so updates could be provided and comments and feedback received regarding progression and emergent themes.

3.9 Phase 1: Electronic Online Survey
The primary aim of phase 1 was to explore how complexity in dementia within mental health NHS dementia inpatient wards is constructed and understood by a number of key stakeholders within the UK. The stakeholders of interest were those with policy, education, academic and practice perspectives who held leadership roles in the dementia field, including those with dementia. For the remainder of this thesis, this stakeholder group will be referred to as ‘national dementia leaders’.

As the scaffolding review in Chapter 2 identified, although the term complexity is used in dementia it is not used in a uniform way, resulting in a lack of meaning and understanding about its use and application. Phase 1 addressed this identified knowledge deficit and explored the views of national dementia leaders regarding their understanding and experience of complexity in dementia. An electronic qualitative survey was used as it enabled this type of exploratory information to be captured from a range of individuals across a wide geographical area. Whilst surveys have been traditionally related to quantitative research, Jansen (2010) argues that when used qualitatively, surveys study diversity rather than distribution in a population. Fink (2003) also informs that qualitative surveys can be used to collect information on the meanings that people attach to their experiences and the way these are expressed.

3.9.1 Electronic Online Survey Development
The internet web survey platform used to develop the survey was SelectSurvey. SelectSurvey was chosen as it was The University of Manchester’s preferred internet survey database as it met (at the time) the European Union legislation on data protection.
The web server that the survey software is hosted on and the database server that the survey data is stored in are managed by the University’s Windows Infrastructure Team in Information Technology Services. The database is also firewalled to ensure that it can only be accessed by the system administrators/developers and by the web server. All survey responses were stored in a dedicated database so only the administrators of that database have direct access to the data stored in it.

Over approximately an eight week period (January 2015 – February 2015) the survey was developed. The background survey development work was undertaken whilst I was waiting for ethical permission to undertake the study. As The University of Manchester computer technicians were familiar with SelectSurvey, they were able to provide assistance and guidance during this time. I also frequently liaised with a Professor from the Division of Nursing Midwifery and Social Work at the University of Manchester, who specialised in survey design to ensure that the developed survey would meet the research requirements.

Survey questions were developed to mirror the research aim and objectives. Questions were discussed in supervision, with members of The University of Manchester ‘Dementia Ageing and Research Team’ and members of the study advisory group. This process enabled questions to redefined and clarified to ensure they were unambiguous and clear. The final survey consisted of three sections:

- Section 1 background information which contained 5 questions about demographics and previous experience.
- Section 2 had four questions that explored complexity.
- Section 3 asked if the participant would like a summary of the research findings once the study had been completed.

A copy of the survey is located in Appendix 4. Section 1 consisted of a mix questions with a drop down box selection of predetermined answers where participants had to choose the most appropriate answer and input some short free text responses. All four questions in Section 2 required free text answers and there was no limit to the amount of free text which could be used. Section 3 is self-explanatory.
The survey was developed so that it would be easy to access and take no longer than 30 minutes to complete, thereby minimising the response burden (Denscombe, 2014). The rationale for this was based upon my belief that participants would have busy workloads so it needed to be quick and easy to undertake to increase the likelihood of completion. The anticipated length of time of completion was outlined in emails sent to participants. Providing information to participants regarding the length of survey and time it may take to complete is recommended as a way of increasing a good response rate (Denscombe, 2014). Prior to use the survey was ‘tested’ by four individuals, who were members of either, Dementia and Ageing Research Team or the study advisory group. This was to ensure that the systems for accessing the survey worked, that the accompanying information was clear and unambiguous, that the survey format was easy to use, the questions understandable and that it was possible to complete within 30 minutes. This was the case, although one individual asked about the option of being able to part complete the form and return to it later. This was discussed with web design team at The University of Manchester but I was advised that it was not a viable option. Therefore, the email information that was sent to potential participants made this ‘once only’ input clear.

3.9.2 Recruitment and Sample Size

As the study was exploring the meaning and presentation of complexity of dementia within mental health NHS dementia inpatient wards, a decision was made to limit participant recruitment to those who worked within the UK as those who work outside of the UK may not be able to identify with these environments.

The following inclusion criteria were used:

- Individuals who were leading clinicians, policy developers or thinkers in dementia within the UK.
- Individuals had to meet at least one of the following criteria:
  - An academic (university based health role).
  - A lead dementia role in a care organisation (this may be the NHS or nursing homes).
  - A dementia advisory position that influences (or has influenced) policy and guidance.
o Be widely published on the topic of dementia care.
o Be a person with dementia who does public facing work on dementia and who has experience of working in healthcare.

- Individual roles to include doctors, nurses, psychologist, government policy advisors.
- Individuals with an accessible email address and in the public domain.
- Individuals with ability to read and write in English.

The process of identifying potential participants was discussed in supervision to ensure that the process was fair, transparent and that the individuals identified met the inclusion criteria. This discussion and checking was particularly important as this seemed to be the first time that a national sample of dementia leaders for the purpose of exploring complexity within mental health NHS dementia inpatient wards had been undertaken.

A purposeful sample of national dementia leaders were identified using a variety of mechanisms. This included:

- A search of Google and LinkedIn.
- Reviewing relevant websites for example Alzheimer’s Society and Dementia UK, reviewing contributors list for dementia guidance.
- Reviewing recent copies of dementia journals and their editorial boards to identify relevant authors.
- Reviewing dementia related websites.

Appendix 4 provides a comprehensive outline of the search mechanisms used to identify the sample.

The search strategy produced an initial list of 67 names. The list was then further refined to ensure that: it was representative of the participant inclusion criteria, multi-professional, geographically diverse and there was a publicly available email address for potential participants. This process reduced the list of names to 46. Unfortunately, I could only locate an email address for one person with dementia who fitted the inclusion criteria. This final list of 46 names was then discussed with my primary supervisor (during supervision
in February 2015) to ensure that I had considered all relevant options and had a rationale for the names included.

The survey was launched on 3rd March 2015. Of the initial emails sent, a number were immediately removed due to email addresses registering as ‘unknown’ or having an ‘out of office’ return email in situ for the duration of this phase of the study. This left 31 potential participants who were asked to respond within three weeks of receiving the email. The time period was decided upon taking into account participants’ workloads and the possibility of participants being on annual leave balanced with the timescales of the study. Reminder emails were sent each week. Sending email prompts has been demonstrated to also increase responses for online questionnaires and surveys (Densombe, 2014; King and Horrocks, 2010; Nulty, 2008; Shih and Fan, 2008) and this was reflected in the survey as further responses were received after each reminder. In total nineteen surveys were returned. After completion, a ‘thank you’ email was sent. All emails were sent individually so as to protect the identity of fellow participants. Copies of the sent emails are located in Appendix 4.

3.9.3 Demographic Profile of National Dementia Leaders

Of the 19 returned surveys, participants answered all the questions. The length of time participants took to complete the survey varied with the longest being 1 hour and 46 minutes and the shortest six minutes. The average time for completion was 25 minutes.

Section 1 asked national dementia leaders the following: what is your job title, what is your professional qualification (choice from drop down menu), to identify where their current role sits (choice from drop down menu), what is their experience of mental health NHS dementia inpatient wards, and how many years’ experience of dementia care do they have. A copy of the survey is located in Appendix 4.

The range of job titles reported included nurse consultant, dementia quality lead, professor of dementia, lecturer, consultant geriatrician, professor of dementia and honorary old age psychiatrist and clinical psychologist. The range of professional qualifications given is listed in Table 3.1, page 87.
<table>
<thead>
<tr>
<th>Qualification</th>
<th>Number of Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>General Practitioner</td>
<td>1</td>
</tr>
<tr>
<td>Geriatrician</td>
<td>4</td>
</tr>
<tr>
<td>Occupational Therapist</td>
<td>1</td>
</tr>
<tr>
<td>Psychiatrist</td>
<td>2</td>
</tr>
<tr>
<td>Psychologist</td>
<td>1</td>
</tr>
<tr>
<td>Registered Mental Nurse</td>
<td>4</td>
</tr>
<tr>
<td>Registered Mental Nurse and Registered General Nurse</td>
<td>2</td>
</tr>
<tr>
<td>Social Worker</td>
<td>1</td>
</tr>
<tr>
<td>Speech and Language Therapist</td>
<td>1</td>
</tr>
<tr>
<td>Other (1 academic dementia qualifications listed and 1 from a medical background)</td>
<td>2</td>
</tr>
</tbody>
</table>

Participants were also asked to identify from a list of domains where their role sat. Table 3.2, page 88, outlines the participant responses.
A large proportion of the sample (84%) indicated that they had been working in dementia care for more than 16 years. Figure 3.2 demonstrates the breakdown in more detail.

**Figure 3.2 National Dementia Leaders’ Years in Dementia Care**
With regard to experience of mental health NHS dementia inpatient wards, 15 of the 19 (79%) participants indicated they had had some clinical experience of these environments. Experience included: working on the wards as a nurse, nurse consultant, consultant psychiatrist, visiting wards to assess aspects of patient management (e.g. behaviour, medical liaison) or arranging admissions for clients. The remaining four participants indicated that although they had not had clinical experience in these environments they were aware of their existence.

From the demographic information a sample frame of survey participants was developed. This framework identifies participants’ roles, professional qualifications, which role domains and the number of years they have worked in dementia care. In Chapter 4, which explores the analysis of section 2 of the phase 1 survey, participants will be identified by their role as outlined in the sample frame below. Table 3.3, page 90 demonstrates the sampling framework.

In keeping with the iterative nature of interpretive description the findings from this part of the study were used to shape the next component of the study which focuses on obtaining the views of dementia clinicians from mental health NHS dementia inpatient wards and from clinicians working in an older adult community mental health team. I will now move onto discuss phase 2 methods, recruitment and sample.
<table>
<thead>
<tr>
<th>Participants Role and Participant Coding</th>
<th>Professional Qualification</th>
<th>Role Domains</th>
<th>Years’ Experience</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consultant Nurse 1</td>
<td>RMN</td>
<td>Clinical</td>
<td>6-10</td>
</tr>
<tr>
<td>Consultant Nurse 2</td>
<td>RMN</td>
<td>Clinical/Research/Education/Policy &amp; Guidance</td>
<td>20 +</td>
</tr>
<tr>
<td>Consultant Nurse 3</td>
<td>RMN &amp; RGN</td>
<td>Clinical/Education/Strategic</td>
<td>20+</td>
</tr>
<tr>
<td>Consultant Nurse 4</td>
<td>RMN</td>
<td>Clinical/Education/Policy &amp; Guidance</td>
<td>20+</td>
</tr>
<tr>
<td>Professor 1</td>
<td>GP</td>
<td>Research/Education</td>
<td>16-20</td>
</tr>
<tr>
<td>Professor 2</td>
<td>Psychiatrist</td>
<td>Clinical/Research/Education/Policy &amp; Guidance</td>
<td>20 +</td>
</tr>
<tr>
<td>Professor 3</td>
<td>Geriatrician</td>
<td>Research</td>
<td>20+</td>
</tr>
<tr>
<td>Professor 4</td>
<td>Occupational Therapist</td>
<td>Research</td>
<td>20+</td>
</tr>
<tr>
<td>Consultant Geriatrician 1</td>
<td>Geriatrician</td>
<td>Clinical/Education</td>
<td>11-15</td>
</tr>
<tr>
<td>Consultant Geriatrician 2</td>
<td>Geriatrician</td>
<td>Service Provision &amp; Development</td>
<td>20+</td>
</tr>
<tr>
<td>Professor / Consultant Psychiatrist</td>
<td>Psychiatrist</td>
<td>Clinical/Research</td>
<td>20+</td>
</tr>
<tr>
<td>Consultant Physician / Honorary Professor</td>
<td>Geriatrician</td>
<td>Clinical/Research/Education/Policy &amp; Guidance</td>
<td>16-20</td>
</tr>
<tr>
<td>Clinical Psychologist</td>
<td>Psychologist</td>
<td>Clinical</td>
<td>16-20</td>
</tr>
<tr>
<td>Speech and Language Therapist</td>
<td>Speech and Language</td>
<td>Clinical/Research</td>
<td>20+</td>
</tr>
<tr>
<td>Dementia Lead</td>
<td>RMN</td>
<td>Clinical/Education/Policy &amp; Guidance</td>
<td>16-20</td>
</tr>
<tr>
<td>Development Lead</td>
<td>Academic Qualifications</td>
<td>Service Development/Strategy/Research/Education</td>
<td>20+</td>
</tr>
<tr>
<td>Reader</td>
<td>RMN &amp; RGN</td>
<td>Research/Education</td>
<td>16-20</td>
</tr>
<tr>
<td>Lecturer</td>
<td>Social Worker</td>
<td>Education</td>
<td>16-20</td>
</tr>
<tr>
<td>Person Living with Dementia</td>
<td>Medical Background</td>
<td>Education</td>
<td>6-10</td>
</tr>
</tbody>
</table>
3.10 Phase 2: Individual and Focus Group Interviews

Phase 2 consisted of individual interviews with clinical staff who worked in mental health NHS dementia inpatient wards and a focus group with clinicians who were members of an older adult community mental health team. Phase 2 was shaped by the data received from phase 1. The aim of this phase of the study was to explore how complexity is perceived and understood from individuals who are working clinically in mental health NHS dementia inpatient wards, or who work in an older adult community mental health team as care coordinators for individuals who are admitted to these environments. Interviews and focus groups are commonly associated with qualitative research (Creswell, 2007; Polit and Hungler, 1985) and suit the methodological approach of interpretive description (Thorne, 2008). As the nature of this study was to explore the concept of complexity in dementia, it was important that participants were able to explain their ideas, viewpoints and experiences of this phenomenon.

3.10.1 Rationale for Individual Interviews and a Focus Group

Interviews were used in phase 2 for the clinical staff working on the mental health NHS dementia inpatient wards. For the rest of this thesis the clinical staff will be referred to as dementia clinicians.

Interpretive description recognises interviews as a “useful core for the development of knowledge in relation to clinical issues encountered” (Thorne 2008, p.79). Denscombe (2014) reports that interviews are best used when the aim of the research is to understand opinions and experiences in depth or when the research is focusing on multifaceted issues that call for a detailed understanding of how things relate or are interconnected or when there is the opportunity to speak with key people who can give insights and thoughts based on their experience or wisdom. This summary supports why I chose to undertake interviews at this phase of the study. Caution has been raised as to the over-reliance of interviews as a research method in qualitative studies (Yeo et al., 2014; Thorne, 2008). However, within this study, they were being used as part of a mixed methods approach thereby reducing the risk of over-reliance.

Individual face-to-face semi-structured interviews were used which allowed participants to be asked questions within a flexible framework and be encouraged to talk about their
experiences through the use of open ended questions (Dearnley, 2005). The use of semi-structured interviews also allowed for the interviews to develop over the duration of the project in response to information given in previous interviews and to allow for new lines of enquiry to be followed up (Denscombe, 2014).

A focus group was chosen as the method of data collection for the older adult community mental health team. The clinical staff working in this team act as care coordinators for people receiving care and treatment in the community and for those individuals who are admitted to mental health NHS dementia inpatient wards. For the rest of this thesis the clinical staff from the community team will be referred to as community clinicians. The older adult community mental health team was from the same mental health NHS trust as the participating mental health NHS dementia inpatient wards so the community clinicians were familiar with these environments. The purpose of the focus group was to explore with the community clinicians their understanding of complexity and reasons why they would refer an individual for admission.

A focus group brings people together to explore attitudes, feelings and experiences about a specific subject and its use in applied healthcare research has increased dramatically in recent years (Kamberelis and Dimitradis, 2014). One of the strengths of a focus group over individual interviews is the effect of the group dynamic and the interaction of group members in stimulating discussion and eliciting information (Denscombe, 2014; King and Horrocks, 2014). The researcher’s role is to facilitate discussion on a specific subject rather than lead it (Denscombe, 2014). Participants are encouraged to discuss the topic amongst themselves whilst the researcher looks to understand the reasoning behind the views and opinions that are shared (Denscombe, 2014). It can be helpful to have an observer whose role it is to take notes during the discussion, pick-up on key issues and non-verbal communication which can be used in the analysis (King and Horrocks, 2014).

3.10.2 Recruitment and Sample Size
Phase 2 data collection had initially been planned to occur within two NHS mental health trusts in the North of England. However, as a result of initial access problems and incurred time delays, in the end only one mental health NHS trust participated. The participating mental health NHS trust was the one that I worked in as an advanced practitioner.
Permission to undertake research was granted from the mental health NHS trust local ethics committee (see Appendix 2).

Dementia clinicians from two mental health NHS dementia inpatient wards participated. For the purpose of this study these wards have been given the pseudonyms of Daisy ward and Jasmine ward. These wards were in geographically different locations and admitted people from different parts of the county. Initially, it was planned that a focus group would be held with the older adult community mental health teams attached to Daisy and Jasmine wards. However, due to the pressures of the community teams and time restraints of the study, this was not possible and instead one slightly larger focus group was held with the older adult community mental health team attached to Daisy ward. Although the older adult community mental health team were attached to Daisy ward, the focus group members were also familiar with Jasmine ward as approximately 18 months earlier, and for a short period of time, both wards had been amalgamated.

Prior to participant recruitment a number of awareness raising processes were undertaken. This commenced with meeting senior managers, consultants, team leaders and ward managers to outline the study. Ward managers and team leaders were given notices about the study to leave in the clinical areas to start to raise awareness with staff. Following this, a period of awareness raising was undertaken in the participating clinical areas. Numerous visits were made to Daisy and Jasmine wards as during this time (March 2015–June 2015) both environments were particularly busy and it was not possible to speak to the staff as a group. Instead, sessions had to be taken with one or two staff at a time. In response to this a substantive amendment was submitted to the ethics committee and granted which allowed me to also give the staff handouts to support the information I was telling them verbally. Awareness raising with the older adult community mental health team proved an easier process as I was invited to their team meeting. Appendix 2 has copies of substantive amendment and Appendix 5 shares copies of the awareness raising notices for staff and the study information handout for staff.

Awareness raising for phase 2 commenced at the end of March 2015 and the individual interviews and the focus group were held between June–August 2015. Participant recruitment commenced initially on Daisy and then on Jasmine ward. The ward managers sent all eligible members of staff a participant information leaflet and study consent form
along with a stamped self-addressed envelope so completed forms could be posted back to me at The University of Manchester. This process was mirrored in the older adult community mental health team a short while later. Located in Appendix 3 are examples of a participant information leaflet and consent form for the inpatient dementia clinicians and the community clinicians.

Inclusion and exclusion criteria for phase 2 were as follows:

**Inclusion Criteria:**
- Dementia clinicians are staff working in a clinical role on the ward or the older adult community mental health team. This will include registered nurses, social workers, psychologists, allied health professionals.
- Nursing assistants/support workers.
- Participants must be currently working clinically in Daisy or Jasmine wards or older adult community mental health team and be able to communicate in English, verbally and written.

**Exclusion Criteria:**
- Clinicians who are not working in in Daisy or Jasmine wards or older adult community mental health team or an individual who is not working in these environments in clinical role.

### 3.10.3 Individual Interviews and the Focus Group
To help facilitate the semi-structured individual interviews an interview guide was developed (Creswell, 2007). It was envisaged that interviews would last approximately 60-90 minutes. The questions in the interview guide built on the data from phase 1. Question areas were discussed in my PhD supervision and they were also piloted prior to use with a member of the study advisory group who had had many years of experience of working in mental health NHS dementia inpatients ward. Questions were reviewed after each interview and during the course of this phase of data collection a number of refinements were made. Copies of the initial interview guide and final interview guide are located in Appendix 6. All interviews with clinical staff from Daisy and Jasmine wards were
undertaken within the hospital building but off the ward. This was in an attempt to minimise disruption and provide a private interview space.

An interview guide was also developed for the focus group (see Appendix 6). This had similar question areas on it, but also sought to explore from a community perspective the reasons why a person is referred to inpatients and community staff expectations of an admission. As in the individual interviews, the interview guide was discussed in my PhD supervision. Originally, a focus group was planned to be held after the individual interviews had been undertaken; in part, this was so it could be used as a forum to seek further clarification or explore themes that had emerged for the semi-structured interviews (Thorne, 2008). However, the reality of practice meant that I had to work to the availability of the older adult community mental health team so the focus group was held before the semi-structured interviews were over (1st July 2015). At the request of the community team, the focus group was held in a meeting room in their base. As I was aware I would be facilitating the session I also had a note taker. This was an individual from The University of Manchester who had had previous experience of undertaking this role. The focus group followed five stages: scene setting and ground rules, introductions, opening the topic, discussion and drawing to a close (Finch et al., 2014). From a personal perspective, my previous group facilitation skills and experience were of great benefit in this group as, at times, I needed to keep the session on track and I also had to ensure that all members of the group had a voice. This was important as on at least one occasion there was a risk that the session would have been dominated by one or two more powerful voices.

Interviews and the focus group was audio recorded. I also jotted notes and memos to myself as thoughts occurred. This tended to be a mix of areas that I wanted a person to expand upon or that I needed more clarification on or a thought for me to reflect upon after the interview. Immediately after interview I also took time to reflect and note down any thoughts or ideas. Examples of these interview notes and reflections are located on Appendix 6.

Over a three month period (June–August 2015) 20 interviews took place with dementia clinicians from Daisy and Jasmine wards. Study participants were from across the multidisciplinary team and consisted of consultant psychiatrists, mental health nurses, nursing assistants, psychologists, occupational therapist and physiotherapy. As can be seen
in the participant sample frame (Table 3.4, page 97-98), occupational therapy and physiotherapists have collectively been referred to as allied health care professions. This was in response to a request from a participant that due to smaller numbers of these roles in the study, it may increase the risk of individual people being identified. All other participants who took part in phase 2 interviews consented to be referred to in the study by their occupation or role. The focus group consisted of nine community clinicians from a nursing, social work and occupational therapy backgrounds all of whom consented to be referred to in the study by their occupation or role.

As can be seen in the dementia clinicians sampling frame (Table 3.4, page 97-98) the number of participants from Daisy and Jasmine wards is evenly split. However, all the nursing assistants are from Daisy ward; the reasons for this are unknown. No nursing assistants volunteered to participate on Jasmine ward despite awareness raising sessions being undertaken. There was also only one psychologist recruited and this is due to the fact that at the time of recruitment Daisy ward did not have a psychologist in post. In addition, the dementia clinicians were asked to outline what training they had received in dementia. Surprisingly, the most consistent training the staff had received was the mental health NHS trust delivered dementia level 1 and 2 awareness training. A small number of participants had attended conferences or other in-house training/presentations.

In the individual interviews, as part of the background information, participants were asked to identify how long they had been qualified (if appropriate) and how many years’ experience they had had working with people with dementia. Similarly, the focus group participants were asked how many years they had been working in older adult community teams and how many years’ experience of dementia they had. As indicated earlier the participant sample frame for details of this information is located in Table 3.4, page 97-98. During the interviews for phase 2 a number of participants outlined why they enjoyed working in dementia care and this information can be located in Appendix 6.

Table 3.4, page 97-98, contains details of the participant sample frame for phase 2 dementia clinicians and Table 3.5, page 98, contains details of the participant sample frame for phase 2 community clinicians. These tables identify the role and the participant identification that will be used throughout the rest of this thesis, along with how many
years they have been qualified and their length of experience in working with people with dementia.

**Table 3.4 Phase 2 Participant Sample and Coding Frame Dementia Clinicians**

<table>
<thead>
<tr>
<th>Participants Role and Study Code</th>
<th>Ward</th>
<th>Years Qualified</th>
<th>Time in Dementia Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consultant Psychiatrist 1</td>
<td>Daisy</td>
<td>Consultant for 11 years</td>
<td>14 years</td>
</tr>
<tr>
<td>Consultant Psychiatrist 2</td>
<td>Jasmine</td>
<td>Consultant for 4 years</td>
<td>8 years</td>
</tr>
<tr>
<td>Ward Manager 1</td>
<td>Daisy</td>
<td>6 years</td>
<td>6 years</td>
</tr>
<tr>
<td>Ward Manager 2</td>
<td>Jasmine</td>
<td>32 years</td>
<td>5 months</td>
</tr>
<tr>
<td>Deputy Ward Manager 1</td>
<td>Daisy</td>
<td>3 years</td>
<td>12 year</td>
</tr>
<tr>
<td>Deputy Ward Manager 2</td>
<td>Jasmine</td>
<td>32 years</td>
<td>5 months</td>
</tr>
<tr>
<td>Staff Nurse 1</td>
<td>Daisy</td>
<td>6 months</td>
<td>6 months</td>
</tr>
<tr>
<td>Staff Nurse 2</td>
<td>Daisy</td>
<td>12 years</td>
<td>14 years</td>
</tr>
<tr>
<td>Staff Nurse 3</td>
<td>Jasmine</td>
<td>2 years</td>
<td>18 years</td>
</tr>
<tr>
<td>Staff Nurse 4</td>
<td>Jasmine</td>
<td>10 years</td>
<td>20 years</td>
</tr>
<tr>
<td>Nursing Assistant 1</td>
<td>Daisy</td>
<td>16 years</td>
<td>16 years</td>
</tr>
<tr>
<td>Nursing Assistant 2</td>
<td>Daisy</td>
<td>N/A</td>
<td>14 years</td>
</tr>
<tr>
<td>Nursing Assistant 3</td>
<td>Daisy</td>
<td>N/A</td>
<td>21 years</td>
</tr>
<tr>
<td>Nursing Assistant 4</td>
<td>Daisy</td>
<td>N/A</td>
<td>2 years</td>
</tr>
<tr>
<td>Senior Nursing Practitioner 1</td>
<td>Jasmine</td>
<td>32 years</td>
<td>30 years</td>
</tr>
<tr>
<td>Registered General Nurse</td>
<td>Jasmine</td>
<td>38 years</td>
<td>7 years</td>
</tr>
</tbody>
</table>
Table 3.5 Phase 2 Participant Sample and Coding Frame Community Clinicians

<table>
<thead>
<tr>
<th>Community Clinicians</th>
<th>Participants Role and Study Code</th>
<th>Years in Community Team</th>
<th>Years In Dementia Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community Psychiatric Nurse 1</td>
<td>9</td>
<td>30</td>
<td></td>
</tr>
<tr>
<td>Community Psychiatric Nurse 2</td>
<td>10</td>
<td>10+</td>
<td></td>
</tr>
<tr>
<td>Community Psychiatric Nurse 3</td>
<td>17</td>
<td>30+</td>
<td></td>
</tr>
<tr>
<td>Community Psychiatric Nurse 4</td>
<td>6</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Community Psychiatric Nurse 5</td>
<td>1</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>Community Psychiatric Nurse 6</td>
<td>7</td>
<td>7+</td>
<td></td>
</tr>
<tr>
<td>Occupational Therapist</td>
<td>13</td>
<td>13</td>
<td></td>
</tr>
<tr>
<td>Social Worker</td>
<td>10</td>
<td>Did not say</td>
<td></td>
</tr>
<tr>
<td>Social Worker</td>
<td>Since they were developed</td>
<td>30+</td>
<td></td>
</tr>
</tbody>
</table>

3.11 Phase 3: Case Studies

In keeping with an interpretive description approach (Thorne, 2008) a case study approach was assimilated into the overall study design. This allowed for an in-depth account of experiences to be generated by focusing and illustrating why and how things are occurring (Denscombe, 2014; Richards and Morse, 2013). Yin (2014) describes a case study research as:
“An empirical inquiry that investigates a contemporary phenomenon in depth and within its real life context, especially when boundaries between phenomenon and context may not be clearly evident.” (p.16)

Using a case study approach in phase 3 allowed me to begin to explore how someone with dementia may experience complexity within the setting of a mental health NHS dementia inpatient ward. It facilitated an “holistic view” (Denscombe, 2014, p.56) of the person and enabled an exploration of how the themes and components from phases 1 and 2 are not just experienced, but also how they affect and interact with each other. Yin (2014) informs that case study research is appropriate when a ‘how?’ or ‘why?’ question is being asked about a contemporary set of events of which the researcher has little or no control. Adopting a case study approach in phase 3 therefore allowed a detailed exploration of how complexity may present in a person with dementia within the real world setting of a mental health NHS dementia inpatient ward. In the sampling structure a decision was made that anyone admitted to the mental health NHS dementia inpatient wards participating in the study was deemed to be complex by the fact they required an admission for assessment and treatment.

Phase 3 consisted of four case studies. In keeping with both a case study and interpretive description approach, multiple methods of data collection were used (Denscombe, 2014; Yin, 2014; Thorne, 2008). These included: interviews, observations and a care record review. I will now discuss recruitment, sample and data collection methods for this phase in more detail and then move onto describe the mixed methods data collection that was used.

3.11.1 Recruitment and Sample Size

Phase 3 was undertaken with the same mental health NHS trust that phase 2 had occurred and therefore I already had access to the mental health NHS dementia inpatient wards. As phase 2 data collection was drawing to an end, I spent time on both Daisy and Jasmine wards undertaking awareness raising sessions with the clinical team regarding this phase of data collection (September 2015). As this phase relied on the ward nurses approaching patients and their relatives to initially make them aware of the study, I wanted to ensure that staff were familiar with the process. In addition, I was mindful that during this phase I
would be spending time on the ward undertaking non-participant observations and it was important that staff understood my role during this time. Notices were also developed to inform staff and patients and their relatives about this phase of the study (see Appendix 5).

For patients and their relatives to be approached about possible participation in the study, they had to have been a patient on the ward for a minimum of five days in order for them to have had a period of time to adjust to the environment and for the care team to have commenced their assessment and care interventions. The role of the named nurse was to make the patient and their relative aware that the ward was participating in a research study and to give them an information leaflet about the study. As a result of my clinical experiences of working on these types of wards, I was aware that most patients admitted were in the moderate to advanced stages of their dementia and there was a high probability that they would not have the capacity to consent to participate in a research study. Therefore, a consent protocol was developed for recruiting patients into the study. A copy of this is located in Appendix 2.

For patients to be eligible for the study they needed to:

- Have a diagnosis of dementia.
- Currently be an inpatient on the mental health NHS dementia ward.
- Have been a patient on the ward for a minimum of five days.
- Be able to give informed consent or their personal consultee or nominated consultee able to give assent.
- The person giving informed consent to have sufficient English to understand the study information and interview questions.

Patients were excluded if:

- They did not have a diagnosis of dementia.
- They had been a patient for less than five days.
- There was a likelihood of planned discharge within the next 7 days.
- They were not an inpatient on a mental health NHS dementia ward.
- Patients who indicate verbally or non-verbally that they do not wish to participate.
Patients who have previously been on the caseload of the researcher.

Four case studies were recruited into phase 3 of the study. Although the awareness raising regarding this phase of the study occurred on both Daisy and Jasmine wards, all the cases came from Jasmine ward. In all likelihood, this was because staff on Jasmine ward were more active at making patients and their relatives aware of the study.

3.11.2 Mixed Methods of Data Collection

Mixed methods of qualitative data collection were used for the case studies. This approach to data collection is not only in keeping with a case study methodology, but is also in keeping with an interpretive description methodology (Thorne, 2008). The methods used in this study were interviews, observations and a care record review.

Interviews

The merits of using interviews as part of qualitative data collection have already been discussed earlier in this chapter so will not be repeated here, other than to state that they can be considered one of the most importance sources of case study evidence (Yin, 2014). The interviews were semi-structured in nature and were offered to the person with dementia, their relative and a member of the care team who was closely involved in their care and treatment. The interviews sought to explore how complexity presented in the patient, from the perspective of the patient, their relative and a member of the care team. As in phase 2, interview guides were prepared to help facilitate these interviews and these guides were discussed with my supervisors prior to use (see Appendix 6 for copies of these guides).

I attempted to interview the four people with dementia who were recruited as case studies. However, as a result of the progression of their dementia none of the individuals were able to give any verbal information regarding their illness or how it affected them. As in phase 2, interviews with the person’s spouse and member of the ward care team were digitally recorded and professionally transcribed following the same data management processes.
Observations
Observations also feature in case studies (Simons, 2014; Yin, 2014) and within interpretive description (Thorne, 2008). Observations were chosen as they allow close up “descriptions of events, activities and incidents that detail what happened in a particular context” (Simmons, 2014, p.462). Observations offer a rich description of what it is like to experience a situation. As the four cases could not verbally explain to me how their dementia affected them, observation was one way of exploring this phenomenon. For the purposes of this phase of the study, I decided that I would conduct non-participant observations. The rationale for this was that I wanted to ‘blend into the background of the ward’ and absorb myself in observing the person within that environment. As a result of my clinical background, I felt that if I undertook a participant-observer role I may become distracted from observing the person and start to help clinically within the ward and staff may experience role confusion. As part of the awareness raising with the clinical teams, my role as an observer was discussed. I also placed notices in the ward environment when I was observing so people were aware (see Appendix 5 for a copy). An observation protocol was also developed which outlined how observations would occur and situations when an observation would be stopped (see Appendix 6 for the developed protocol).

Documentary Analysis
Documentary analysis is also a feature in case studies and can be part of an interpretive description study (Thorne, 2008). Documentary analysis in this phase of the study took the form of a care record review for each of the four cases. The care records were held on an electronic patient record system. As a clinician I was familiar with this system which proved helpful when I was undertaking the review, as the system often presents as fragmented and difficult to negotiate and locate documents. The aim of this review was to explore how complexity is captured and documented in the records. I wanted to see how issues of complexity were described and how a person’s assessment process and interventions are recorded. A template was developed to ensure that I reviewed each cases record in the same manner and searched for the same information. A copy of this is located in Appendix 7.
3.11.3 The Cases

The four cases are presented in the order they were recruited and are discussed in detail in Chapter 4. None of the cases were assessed as having the capacity to consent to participating in the study; therefore, as per the requirements of the Mental Capacity Act (2005), their spouses were approached as per the studies consent protocol (see Appendix 2) and they agreed to act as personal consultees. Appendix 3 also shares a copy of the personal consultee information sheet. In each of the four cases an interview was also undertaken with an immediate member of the care team and the patient’s spouse. Observations of differing lengths of time were undertaken with all of the four cases. Finally, a review of the care records for each case was undertaken. The participant sample frame for each of the cases is provided in Table 3.6, page 104. All attributed names are pseudonyms.

This section has outlined the phases of the study and the mixed methods approach that was used for data collection. I will now more onto discuss how the data was managed and analysed.
<table>
<thead>
<tr>
<th>Case</th>
<th>Diagnosis</th>
<th>Age</th>
<th>Legal Status</th>
<th>Personal Consultee</th>
<th>Interviews</th>
<th>Periods of Observation</th>
<th>Care Record Review</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brian</td>
<td>Alzheimer’s disease</td>
<td>80</td>
<td>Section 3 Mental Health Act</td>
<td>Wife Gloria</td>
<td>Wife Gloria</td>
<td>11</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Deputy Ward Manager Joan</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eric</td>
<td>Vascular dementia</td>
<td>78</td>
<td>Section 3 Mental Health Act</td>
<td>Wife Anna</td>
<td>Wife Anna</td>
<td>2</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Consultant Psychiatrist</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Charlotte</td>
<td>Young onset Alzheimer’s disease</td>
<td>71</td>
<td>Section 3 Mental Health Act</td>
<td>Husband Harry</td>
<td>Husband Harry</td>
<td>8</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Named Nurse Linda</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Celia</td>
<td>Probable mixed vascular dementia/Alzheimer’s disease</td>
<td>82</td>
<td>Section 3 Mental Health Act</td>
<td>Husband George</td>
<td>Husband George</td>
<td>7</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>with psychosis</td>
<td></td>
<td></td>
<td></td>
<td>Occupational Therapist Lucy</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
3.12 Managing the Data

The study had evidence from the following sources:

- Electronic online survey responses from phase 1.
- Audio recordings of interviews, associated transcripts and interview notes/memos from phases 2 and 3.
- Audio recording of the focus group and associated transcripts from phase 2.
- Field notes of observations and clinical reflections from phase 3.
- Care record review notes from phase 3.
- Reflective journal kept throughout the study.

All interviews and the focus group were digitally recorded, using an encrypted machine. Due to the volume of data that was generated a transcription service, that was approved by The University of Manchester was used. Processes were in place to ensure the safe and confidential transfer and transcription of data. Observation field notes and the care record review data were self-transcribed. All data that was held on a computer was in password protected documents and stored in an encrypted computer at The University of Manchester. Paper copies of information were stored in a locked filing cabinet in a locked office in a designated research office at The University of Manchester.

3.13 Analysing the Data

Thorne (2008) informs that analysing the data to develop new insights is “the most painfully difficult and yet the most essential element in what constitutes a credible interpretive description study” (p.141). To attain such insights, a descriptive content analysis approach was adopted when analysing the data from phase 1 and a thematic content approach was adapted for phases 2 and 3. Thematic analysis can be described as a “method for identifying, analysing and reporting patterns (themes) within data” (Braun and Clarke, 2006, p.79). This approach “discovers, interprets and reports patterns and clusters of meaning within the data” (Spencer et al., 2014, p.271) and thematic analysis is not tied to any particular discipline (Spencer et al., 2014; Braun and Clarke, 2006). Thematic analysis has been widely utilised as a data analysis approach in nursing research (Vaismoradi et al., 2013) and it has the potential to provide “a rich and detailed, yet complex account of data” (Braun and Clarke, 2006, p.78). Thematic analysis is a method
dependent upon the constant comparative analysis processes to develop and create knowledge that is descriptive and interpretive (Thorne, 2000) and this process can be adopted to guide analysis in order to offer description and interpretation.

In keeping with an interpretive description approach the data analysis for this study was undertaken manually. Whilst this proved to be a time consuming process, I wanted to be able to familiarise myself with the data and have the opportunity to work with it in a hands on manner and to be able to ask myself: ‘what am I seeing?’, ‘why is this here?’, ‘what is happening?’ (Thorne et al., 2004, 1997). By undertaking this approach I slowly moved from broad codes to themes and from themes to interpretation. A software system was used (NVIVO 10) for storage of data. All stages of data analysis were discussed in supervision. I will now outline in more detail the data analysis process for each phase of the study.

### 3.13.1 Phase 1: Analysis of Online Electronic Survey

As each survey response was received I familiarised myself with by printing it off and reading it three times. Any thoughts and ideas that arose were jotted down and any similarities/overlap of question responses were also noted. Coloured pens were used to highlight similarities.

Once all 19 responses were returned, I then began the process of comparing the responses as a whole and per survey question. I read all the responses as a whole a number of times and continued to jot down thoughts and make notes as to any areas that were related. I then copied all the responses for each question onto one document to facilitate comparison between responses. This was printed out and re-read a number of times to familiarise myself with it as a whole question response. I checked for similarities in responses and any standalone comments.

Following this, for each question, all the areas that had been highlighted in different coloured pen were written down on Post it’ notes and placed in related descriptive groups on a wallchart. Any responses that had not been highlighted were also written on a ‘Post-it’ note and placed together. Doing this gave me the opportunity to stand back from the data and view it as groups of similarities and as whole question responses. I found this process really helpful and it facilitated the questions of ‘what is going on here?’, ‘what am I
seeing?’, ‘what am I looking at?’ I was also able to move the ‘post-it’ notes around to try responses in different places. Mind maps were also developed to highlight the descriptive themes and supporting evidence for each. From this final themes were identified. An illustration of the process is shown in Appendix 8.

3.13.2 Phase 2: Analysis of Individual Interviews and Focus Group

Phase 2 analysis was undertaken in a similar way to phase 1. During the interviews I would jot down any thoughts or questions which occurred and immediately after each interview I wrote down my reflections (Appendix 8 contains salient examples). Each recorded interview was listened to prior to being sent for transcription. There were two main reasons for this. One was to make sure that the recording quality was acceptable for transcription. Secondly while the interview was still fresh in my mind, I wanted to listen to it so I could make further notes on; for example, the reason for any silences, the emphasis of any points or any further impressions of the interview (Thorne, 2008). I also found this process useful for personal reflection on my skills as a research interviewer.

Familiarisation continued once the transcript was returned. I listened to the recording again whilst simultaneously reading the transcript. This gave me the opportunity to ensure that the transcript was correct and again re-familiarise myself with the piece of data. I then highlighted my questions on the transcript in blue so they stood out from the participant’s responses and each line was numbered to assist with analysis. Transcriptions were printed off and read through twice more. As I was reading I would add notes, points or any questions which arose. The research aims were also printed off and kept with the transcripts; I found this helpful in keeping on track when I was reading lots of data and it was helpful in the initial grouping stage.

As in phase 1, coloured pens were then used to start to create broad codes. From here, hand-written notes were made, capturing all the parts of the data that fell under these broad codes. Following this, these notes and accompanying extract from the data were typed up and further refinements made. Once this process had been undertaken for all 20 interviews, each broad code was brought together and compared across the data set. This consisted of re-reading each one a number of times and then printing off each section and comparing all the responses within it. Next, thematically related group were developed. Mind maps were
also developed to capture all the concepts within each theme, identify any further associations or connections and make any further refinements. This enabled themes to be defined and sub headings developed. I also reviewed the outstanding data to see if there were similarities between quotes.

Throughout this process the research aims were kept to hand to help keep a focus and the data was interrogated with my constant asking of ‘what am I seeing?’, ‘what is going on here?’, ‘what is happening?’, ‘why is this here?’ (Thorne et al., 2004, 1997). As well as constantly comparing the data for similarities, I was also mindful of looking for differences and exploring if these were significant. Reflective journals, note books and memos were also reviewed. Finally, the themes were reviewed a number of times together to see if they cohesively gelled and were representative of the data findings. This final reviewing occurred over a period of days, and in reality consisted of mind maps, themes and extracts from data being stuck on a wall so I could visually see it and move it around. I also found it helpful to keep having breaks and then returning to the data. Analysis, themes and concepts were also regularly discussed in supervision. An illustration of this process is seen in Appendix 8.

3.13.3 Phase 3: Analysis of Case Studies
Initially, each of the four cases were analysed individually. The themes from phases 1 and 2 were used as a base from which to build the analysis. The aim of analysis in phase 3 was to see how complexity was experienced and represented in a person with dementia who was on a mental health NHS dementia inpatient ward and who was viewed as complex by the care team. I wanted to explore how the themes from phases 1 and 2 were represented in the case studies and if there were any additional themes and concepts about complexity that had not been identified in the previous two phases. The analysis of phase 3 took time as it was important for the four case study stories to evolve and be told. As there were a number of methods involved in the data collection for phase 3 I will summarise below how each method was analysed.

The interviews which occurred in phase 3 were analysed as in phase 2. For each case there were two interviews: their spouse and a member of the care team. As these interviews focused upon one person’s experience of complexity in dementia, the analysis sought to
explore how this related to the themes from phases 1 and 2 and was there anything different which had not previously been considered.

When I undertook the observations of the cases approximately every five minutes, I recorded what was happening. As I left the ward at the end of the observation period, I would spend time making notes on my reflection of the period of observation. These handwritten notes were then transcribed and I chose to undertake this transcription myself for a number of reasons. For example, as I had hand-written the initial observations, I needed to ensure my hand-writing and my own abbreviations could be translated. Also, by typing the observations I found that I was able to mentally visualise and re-visit the period of observation and I could in a note book add any thoughts, ideas or connections as they further occurred. For each observation I repeated the ‘what am I seeing?’ set of questions and I was especially looking to see if any of the themes outlined from the interviews in phase 3 were evident, when I was observing the patient in the ward environment. A copy of a post observation reflection is located in Appendix 8.

The analysis of the care record review looked to see if the records captured how and in what way a person’s complexity had been recorded, how it had been assessed, what care plans were in place that outlined the interventions a person required and how clinical staff recorded a person’s complexity on a day-to-day basis. I also wanted to identify if the care records mirrored the description of the person I had been given from interviews and if the records mirrored the data I was seeing during observations. A copy of a completed record review is located in Appendix 8.

Finally, all four case studies were compared, to identify similar themes and patterns and to clarify if there were any standalone issues that were worthy of further analysis. As per phases 1 and 2 analysis, phase 3 analysis and its findings were discussed in supervision.

3.14 Rigour
As Thorne (2008) states in the promotion of rigour and credibility, within an interpretive description design four evaluative criteria are to be established, these being: i) epistemological integrity, ii) representative credibility, iii) analytic logic and iv) interpretive authority. I will briefly address each in turn in relation to my study:
i) Epistemological integrity has been achieved through ensuring that all stages of this study have been designed and conducted in a manner consistent to the beliefs and principles of an interpretive description methodology. Initially, at the start of the study, time was spent liaising with Sally Thorne via email and in person, to ensure that the question and methods chosen were compatible to an interpretive description approach. My experiences and theoretical forestructure about 'what I bring’ to the study (Thorne, 2008) have been recognised and acknowledged throughout the work. The research design and adoption of qualitative mixed methods ensured that the three phases of data collection have aligned with the epistemological principles of an interpretive description study. Data collection and analysis have also occurred concurrently for each phase of the study, and the phases have informed and connected with each other. Analysis was also undertaken manually to enable me to immerse myself in the data and reduce the risk of premature coding (Thorne, 2008).

ii) Representative credibility focuses on the need for studies to show that the theoretical claims they make are consistent with the manner in which the phenomenon was sampled (Thorne, 2008). In this study, the participants were selected through the use of purposive sampling and carefully selected inclusion and exclusion criteria ensured that the sample in each of the three phases were representative of those intended in the design of the study. The study design also ensured that a variety of participants were included, for example nurses, allied health care professionals, people with dementia and their spouses. This ensured that the participant sample was substantive and varied and the study also employed triangulation of data sources (Thorne, 2008).

iii) Analytic logic was achieved through a number of processes. Notes were made after each interview and period of observation, including my own clinical reflections. In addition, a reflective journal was kept which outlined personal thoughts, questions and decisions throughout the whole research project. Supervision notes were also kept. Each method of data collection was undertaken using the same process to promote consistency. There was also a consistent process in place for analysing data. The consistency of both the data collection and analysis helps ensure analytic consistency and credibility.
iv) Interpretive authority provides the assurance that the interpretations of the study are trustworthy and they illustrate some truth external to the researcher’s bias or experience (Thorne, 2008). A number of steps in the research were undertaken to assure this. This included ensuring that as data collection and analysis developed, clarifying questions were developed from the transcripts rather than my own curiosity to further explore aspects of developing themes. This further exploration was sought using open non-leading questions. As the researcher, I was aware never to use my clinical experience to assume that I knew what participants were saying and I sought every opportunity to ensure clarity and confirmation were achieved. In addition, the inclusion of people with dementia and their spouses added an additional layer of interpretive authority, as the concept of complexity in dementia was explored from their personal subjective experiences in addition to the views and experiences of professionals.

3.15 Chapter Summary
An overview of the methodologies and methods used in this study has been presented in this chapter. The study has presented with practical challenges. Undertaking a mixed methods study over three phases took a considerable amount of time. In addition, the decision to undertake a manual approach to data analysis was again time-consuming but it presented me with an opportunity to immerse myself in the data and the concept of complexity in dementia. Theoretically, the lack of previous research in the field of complexity in dementia and within mental health NHS dementia inpatient wards meant that there was no previous work or guidance from which to base this study. Therefore, research decisions were carefully considered and drew on research knowledge, clinical knowledge and exploring issues in supervision. The use of interpretive description as a methodological approach is at this time still not widely used with in the UK, thereby reducing access to methodological expertise. In the next chapter I will present the study findings in sequence with the three iterative phases of the study.
CHAPTER 4
Study Findings

“Complexity is a tangled ball of wool”

(Registered General Nurse).

4.1 Introduction
This chapter presents the sequential data collection and analysis of the three phases of the study which took place between 2014 and 2016. Each of the three study phases helped to inform the development and implementation/analysis of the next. The chapter, therefore, also represents the inductive and chronological nature of the study and is lengthy in order to do justice to the clinical application of the methodology. The chapter commences with a descriptive account of the findings from phase 1, the online electronic survey of national dementia leaders. It then presents the findings from phase 2, interviews with participants working in mental health NHS dementia inpatient wards and a focus group with an older adult community mental health team. Finally, phase 3, case study findings are presented along with critical reflection points for each case. The findings presented in his chapter will highlight that complexity is constructed through a number of interconnected and interrelated domains; it is also not a static state but one that fluctuates in acuity.

4.2 Phase 1: Online Electronic Survey
This opening section provides a descriptive account of the findings of phase 1 which used an electronic survey to explore a representation sample (n=19) of UK national dementia leaders’ views about complexity in dementia. Further information about the rationale and representativeness of the sample can be located in the preceding chapter and in Table 3.3, page 90. However, in summary, the UK dementia leaders comprised: consultant nurses, psychiatrists, geriatricians, dementia leads, academics, psychology, speech and language therapy and a person living with dementia. Through the research design and online electronic survey, respondents were asked four questions:

i) What are the reasons people with dementia are admitted to mental health NHS dementia inpatient wards?

ii) What is your understanding of the term complexity in the context of dementia?
iii) What factors, or components, do you feel contribute to complexity in dementia?

iv) How should people with a complex presentation of dementia be assessed?

A copy of the survey is located in Appendix 4.

The responses to the four survey questions will now be described in more detail to provide a sensitising context for phases 2 and 3. Participants provided their responses in a free text boxes to the questions meaning they were not limited to wordage.

4.2.1. Online Electronic Survey Responses

Question 1: What are the reasons people with dementia are admitted to mental health NHS dementia inpatient wards?

Descriptive content analysis of the responses revealed four main views and routes to admission:

i) ‘Deterioration’ in the presentation of the person with dementia, in the environment in which they are living.

From the data, examples of the type of reasons why a person may experience a ‘deterioration’ included: behaviour that challenges (for example, violence, aggression, sleep disturbance, wandering); psychiatric/psychological problems (for example, presence of affective and psychotic symptoms in conjunction with dementia); and physical comorbidity (for example, presence of acute or chronic physical illness in conjunction with dementia). However, for this change, or deterioration, to warrant an admission to a mental health NHS dementia inpatient ward, the event also needed to be coupled with what participants described as ‘severe and complex needs and/or high levels of risk’. This important linkage is best illustrated through the following three extracts from the survey data:

“Generally for assessment and treatment where needs are complex and may be challenging to others, and meeting these needs in community or other care settings by formal and informal carers has not been possible.” (Lecturer)
“Severe and complex problems that are not manageable in the community. Risk of harm to self or others.” (Professor 2)

“Usually due to risk issues, fear of harm to health or others or for a mental health assessment.” (Consultant Nurse 3)

ii) Events outside of the actions of the person with dementia
Here, the primary reason for such an outside event was described as ‘relative/carer stress and the breakdown of caring relationships at home’, a situation best summarised by one respondent who simply said “intolerable caregiver burden” (Consultant Nurse 2). The degree of stress and burden which can be experienced by caregivers was illustrated by Consultant Geriatrician (2) who cited caregiver strain as a reason for admission due to the “physical and mental stress of caring for a loved one who requires care 24/7.”

iii) Lack of community care services
The third route to admission was grounded in the perceived lack of community care services to meet the person with dementia’s needs at home “lack of community resources” being a typical response. One study participant also described this as “the inability for care services to assess and manage in the community” (Professor 3).

iv) Not understanding how dementia can affect a person
The fourth route to admission was a little more opaque, but nevertheless an important feature of the data set. It concerned services and individuals not understanding how dementia can affect a person and impact upon their subsequent needs. Indeed, a person with dementia him/herself reinforced this lack of awareness stating that admissions happen because “sometimes families, carers and GPs do not understand dementia.” This response demonstrates how the lack of understanding of others as to how dementia may affect an individual can impact upon that person’s presentation and, for some, result in an admission to a mental health NHS dementia inpatient ward for assessment.

Question 2: What is your understanding of the term complexity in the context of dementia?
Whilst complexity is a crucial part of everyday working practices, part of the lexicon of dementia care and a significant reason for admission to a mental health NHS dementia
inpatient wards, no respondent in the survey was able to share a definition about it. Perhaps this lack of specificity is unsurprising given that complexity is used in UK dementia policy and evidence-based guidance without a definition, as outlined previously in the thesis in Chapter 2. That said, two respondents did share their own uncertainty about complexity expressing the views that “the word can have some ambiguity” (Lecturer) and “it is difficult to define and is very subjective” (Dementia Lead).

Whilst participants were unable to provide a definition about complexity, they were able to discuss their understanding about what complexity meant to them. In doing so, a more rounded and consistent picture of complexity emerged, as illustrated below:

“The term complexity, as I understand it, refers to the depth and breadth of needs as presented by many people with dementia. Usually, the term includes needs which are physical, psychological, emotional and social. Complex needs are multifactorial and require a range input from a variety of health and social care professionals and agencies. In my experience, the complexity of need is closely related to the progression of the condition.” (Reader)

and

“Complexity, to me, is generally related to multiple issues experienced by someone with dementia which makes their needs more difficult to support in the average home or care home environment. This might be the result of the particular disease causing their dementia, or due to more than one disease process impacting the person’s cognition. But it can also be someone for whom it is difficult to understand and meet the needs they are expressing through behaviour. There are times in which some people may be deemed complex due to the nature of their behaviour making it difficult to live in community with others.” (Development Lead)

This multiplicity and interconnectedness is suggestive of the appraisal that, on their own, individual factors may not result in a person with dementia being perceived as complex, but, instead, is more to do with the effect that multiple factors can have on each other and the person. Therefore, to look at factors in isolation may not help meet, or fully appreciate,
the person’s needs. A focus on the importance of the multiplicity and interconnectedness of factors and how they can affect the person with dementia is supported in this data provided by a Speech and Language Therapist:

“... this would be something about the sum of the factors, multiple factors, not adding up to the whole, so about the way in which factors are not just adding to but interact with each other to create a complex picture of physical, cognitive, mental health, personality and social needs. This means when you isolate each factor for assessment it is useful, but it may not fully explain the constellation of symptoms.”

Indeed, when referring to multiple and interconnected factors, respondents wrote about concurrent comorbidities, multiple symptoms and types of dementia; for example “multiple symptomatology and concurrent comorbidities” (Professor 3) and “sub-type of dementia and physical health/multi-morbidity” (Consultant Geriatrician 1). Interestingly, reference was also made in passing to complexity being about the ‘intensity of symptoms’ and ‘severity of needs’, points taken up in more detail when analysing the data present in the third and fourth questions of the online electronic survey.

Part of providing care to people with dementia within the setting of mental health NHS dementia inpatient wards, is the identification and delivery of care interventions to meet the person’s needs. Within the data there is a suggestion that this is ‘challenging’ thereby indicating that the identification, and delivery, of the intervention itself can, at times, be complex. This difficulty in finding and identifying interventions was represented in one response which described complexity as “a challenging presentation that does not have a simple solution” (Professor 3), thus implying that there are no straightforward interventions that will meet the persons’ needs. likewise, another participant reported that complexity is “used to represent a person’s needs that are difficult to clearly identify and meet” (Lecturer).

Furthermore, the data revealed that even when interventions have been identified as potentially suitable, choosing the most appropriate one can require complex decision-making. This scenario was highlighted in the analysis with illustrations about pharmacological interventions and the management of comorbid conditions: for example, when taking into consideration cardiac function, a Consultant Geriatrician talked about the
“complexity of whether to use drugs such as Donepezil” (Consultant Geriatrician 1). Similarly, when a survey participant, who is living with dementia, was describing factors contributing to complexity in dementia, they discussed ‘medications’ and that “there can be complex problems and these side-effects can cause worsening of dementia.”

**Question 3: What factors, or components, do you feel contribute to complexity in dementia?**

On the one hand, responses to this question were, at times, verbose and it was clear that the question struck a chord with those completing the survey. The analysis also identified that certain sub-types of dementia, and the presence of behaviour that challenges, were seen to contribute to complexity. This is highlighted in these two extracts from the data “complexity with regard to the subtype of dementia and the symptoms – such as Lewy body (Consultant Geriatrician 1) and “behaviours such as shouting, screaming, throwing self on floor, refusal of care” (Nurse Consultant 1). On the other hand, analysis of the data appertaining to this question fell into three broad domains: i) individual factors/needs; ii) degree of intensity and severity of needs; and iii) high levels of risk/severe distress. Each of these domains will be further developed below:

**Domain i) Individual factors/needs**

This was seen to break down to the following components and some have been highlighted previously in this section:

**Physical:** this included the presence of other co-morbid conditions, both acute and chronic, and the occurrence of pain. The multiplicity and interconnectedness of these factors can be seen when participants talked about physical health in the context of a dementia as a “mix of physical health problems of later life with dementia” (Professor 4, for example).

**Psychological:** Psychological factors also included co-existing depression and psychosis and the impact the individuals personality/life history is having on the current situation. One participant reported that “I think it is often that people’s defence mechanisms, which have served them well throughout their earlier lives, become problematic when it comes to their needing care” (Consultant Nurse 4).
**Functional:** were concerned with an individual’s needs about, for example, self-care, nutrition and mobility.

**Environmental:** The effect of unfamiliar surroundings, heat, noise light.

**Social factors:** family dynamics and social support. Life history also featured and the resurgence of previous distressing life events. Interestingly, reference was also made to the role of the family and how this may contribute to someone being perceived as being complex. This is highlighted in the response made by a lecturer who talks about complex living arrangements in the context of the family:

> “Complexity can also be used to describe complex care/living arrangements where, for example, there might be complexity in family dynamics/networks or complex situations in which there are risks e.g. of abuse or neglect.” (Lecturer)

Similarly, the family situation and the impact this can have on a perception of complexity was reflected in another participant’s response:

> “Support, or lack of it, from family, complex family dynamics impacting on problem or particularly disagreements about management and care options.” (Speech and Language Therapist)

**Domain ii) Degree of intensity and severity of needs**

This second domain concerned itself with the intensity and severity of need that an individual is experiencing. This intensity or severity of need can result from the effect of the dementia itself or as a result of the interaction of a number of factors/components. The following extracts from the data highlights such a scenario:

> “This involves the quantity and severity of a range of cognitive, functional, psychological and behavioural symptoms in the dynamic relationship with the person's social milieu.” (Consultant Physician/ Professor)

and
“Someone who has more intense needs or multiple needs/ requirements.”
(Consultant Nurse 3)

The data also indicated that this level of need could be difficult to meet, or that it did not lend itself to a simple solution. This inference is reflected in the following two responses “a person's needs that are difficult to clearly identify and difficult to meet” (Lecturer) and “challenging presentation that does not have a simple solution” (Professor 3).

Domain iii) High levels of risk/severe distress.
This alignment of complexity to risk was demonstrated in the following response “usually a multitude of needs that impact upon levels of risk and ability to maintain safety” (Dementia Lead). These levels of risk [or distress] can result from the intensity/severity of a person’s needs as a result of multiple needs interacting with one another. Moreover, a person’s level of insight into their presentation and capacity to communicate needs and make decisions were also important features, for instance “lack of insight on the part of the person and discrepancy between what he person wants to happen and what the team feel is in their best interest” (Consultant Nurse 1).

From a mental health NHS dementia inpatient ward perspective, this high level of risk and lack of insight also acts as indictors for use of a number of legal framework such as the Mental Health Act (DH, 1983), Mental Capacity Act (2005) and Deprivation of Liberty Safeguards (2008). The use of these legal frameworks in the provision of care and treatment within a mental health NHS dementia inpatient setting was highlighted by one participant, a Professor/Psychiatrist, who referred to this as “legal complexities” and that “most patients will lack capacity to consent to an informal admission and therefore fall under the rubric of the Mental Health Act and or the Mental Capacity Act.”

Importantly, it seems to be the interaction of factors within each domain and between domains that provides an indication as to the degree of complexity being experienced. This will be returned to again in the next chapter when considering the practice applications of the findings.
Question 4: How should people with a complex presentation of dementia be assessed?

When discussing the assessment of people with dementia who are believed to be complex, study participants identified that the assessment should be undertaken using the skills of a multidisciplinary team. As one participant reported “carefully, clinically using the skills of a multidisciplinary team” (Professor 2). Early assessment and identification of needs was considered to be important. Emphasis was also placed on gaining a collateral history from family members/relevant others in order to obtain a full picture. Acknowledgement of the person’s life story and personality and the impact this has on their current presentation were also considered to be important factors in assessment. This was highlighted by one of the participants living with dementia when they shared “we need to know their past patterns so we can engage them in their reality and speak their language.” The effect of the environment in which the assessment was being conducted, and the relationship with the ward staff, was also considered important considerations in the assessment process. This can be seen in the following two extracts from the data:

“the impact of life within the inpatient unit itself will play a contributing factor in a person’s behaviour/wellbeing.” (Lecturer)

and

“In ward settings too little attention is paid to the poor communication and interaction strategies of staff.” (Clinical Psychologist)

Participants also indicated that the assessment should be used to facilitate a review, care plan and discharge plans. A number of assessment frameworks were suggested. These included: Comprehensive Geriatric Assessment, which will assess all aspects of frailty, physical function and mental health; and the Newcastle model (James, 2011; James and Stephenson, 2007; James et al., 2006) which undertakes an assessment based on needs led approaches to understanding behaviour. Interestingly, this was the first time that frailty had been mentioned in the survey responses. Other types of assessment that were suggested were holistic assessment, person-centred assessment and risk assessment. Building on this platform other areas that should be incorporated into an holistic assessment included strengths and weaknesses, cognition, function, and environmental factors. One participant also recommended that “validated assessment tools especially developed for use in
dementia” (Reader) can contribute to the assessment process; however, there were no such examples suggested to support the assertion although the limitations of the data collection method must be recalled at this point.

Finally, none of the survey participants highlighted the use of any specific tools developed for assessment of people with a complex presentation of dementia or any general assessment tools that could identify complexity. There was a suggestion that it may be helpful for local pathways for complexity to be developed and that “teams should have a framework to assess complexity so this can guide their discussions to deliberately consider multiple factors” (Speech and Language Therapist). However, as before, any evidence beyond the aspirational was lacking.

4.2.2 Phase 1: Summary

With the lack of a formal definition of complexity, it would appear from this descriptive analysis of the four open-ended questions that multiplicity and interconnectedness are important domains in attempting to understand complexity and the working practices involved. In particular, the following domains were extracted from the data to be further explored in phase 2 of the study: i) individual factors/needs; ii) the intensity of severity of symptoms or needs; and iii) the presence of high degrees of distress and/or risk. It was evident from the survey that it was these domains - and sometimes the interaction of factors within a single domain - that could lead to a person with dementia being perceived as being complex. In addition, the role of the family and care providers in making decisions about the complexity of interventions was also an important bridge to understanding. However, the data also revealed that there was some consensus as to the reasons why people with dementia are admitted to mental health NHS dementia wards but no consensus as to what constituted an assessment of people with a complex presentation of dementia. The data also suggested that participants’ were not aware of any specific ‘complexity’ assessment frameworks, models or general assessment tools that would help in everyday practice.

Moreover, the findings demonstrate that although there was no consistent definition of complexity in dementia, there was consistency in participants’ views that complexity in dementia consists of multiple needs or factors which interconnect with, and affect, each
other. It is this multiplicity and interconnectedness which is perceived as complexity in dementia and will be further explored in phase 2 of the study.

4.3 Phase 2: Individual and Focus Group Interviews

4.3.1 Context

Building on the phase 1 data analysis, and as described more fully in the preceding chapter, this second phase of the research design comprised of interviews with 20 participants working in mental health NHS dementia inpatient wards. Data collection was conducted through semi-structured interviews. This data set was supplemented through the conduct of one focus group involving nine members of a local older adult community mental health team, who had responsibility for admitting people to the mental health NHS dementia inpatient wards and facilitating their discharge from these environments in their role as care coordinators. Thematic content analysis was used as a bridge across these two methods of data collection to draw out the four theme headings, namely: 1) Getting Admitted to the Ward; 2) Adjusting to Admission; 3) Interpreting Complexity on the Ward; and 4) Stabilising Complexity for Discharge. The four theme headings are numbered in this section, not as a hierarchy but as a structural guide for the reader. A more detailed sample and participant coding frame for this phase of the study can be found in Table 3.4, page 97-98, and Table 3.5, page 98.

4.3.2 Theme 1: Getting Admitted to the Ward

There was a consensus amongst study participants that getting admitted to a mental health NHS dementia inpatient ward should be seen as a last resort after all other community based options had been explored and exhausted. This view of admission being a last resort was demonstrated by a social worker in the older adult community mental health team focus group: “usually everything’s been tried already and this is like the last thing, they come on the ward” (Social Worker 1). Examples given by the older adult community mental health team of things which can be tried in the community to prevent inpatient ward hospital admission included: home care, day care, respite care, telecare and dementia crisis prevention teams. However, there was no discussion on the efficacy of such service suggestions.
Similarly, the view that prior to an admission ‘everything possible’ had been tried by the older adult community mental health teams to stabilise the person and keep them at home was also reflected by study participants who were working in mental health NHS dementia inpatient wards. The following data extract from an interview with an Allied Health Professional reflect this position:

“Everything’s been tried by the community teams to try and support and that it has failed to a point where the person is not able to be looked after in that situation and assessment is needed for their needs to stabilise or to look at future care whatever.” (Allied Health Professional 2)

In a similar vein, when talking about the circumstances leading to admission, a Consultant Psychiatrist shared that “we only admit them when everything else out here [in the community] has failed” (Consultant Psychiatrist 1). The following data extract reflects this position:

“People are admitted when everything out there is not adequate enough to deal with the person including the dementia crisis team. Things have got that severe.” (Consultant Psychiatrist 1)

There was also acknowledgement amongst study participants that by the time people were admitted the situation had often reached a crisis point, as the following two quotes reveal:

“I think community teams have got so good now at keeping people out for hospital for longer, then we do really only get patients that come in at crisis point.” (Allied Health Professional 1)

and

“Everything has got to a point where it is kind of a crisis situation. It seems to me that every admission there been a … [pause] … it’s a crisis point that been reached.” (Staff Nurse 1)
Whilst there was an acknowledgement that admission into a mental health NHS dementia inpatient ward was in response to a crisis that could no longer be managed in the community, the reasons why a crisis had occurred in the first place were strikingly similar to those outlined in phase 1 of the study. For instance, the data revealed that getting admitted to a mental health NHS dementia inpatient ward was due to one, or a combination of, the following factors:

i) Deterioration in the person with dementia’s presentation

The similarity with the phase 1 data findings continued as the three main reasons shared for such deterioration were: the presence of behaviour that challenges; psychiatric/psychological problems; and physical co-morbidity. However, in contrast to the brief written responses from phase 1, study participants in this second phase gave much greater emphasis to the presence of behaviour that challenges at home as a reason for admission, rather than the latter two. Drawing on my own clinical experience, as well as the information contained in the data, this may be because the most common reason for referral for admission to a mental health NHS dementia inpatient ward was the presence of behaviour that challenges. As shared in the data, examples of behaviour that challenges that could result in an admission included: aggression, agitation, wandering, medication refusal and resistance to care interventions (in clinical practice this is commonly referred to as resistiveness to care). The following data extracts from across the multidisciplinary team reinforce this standpoint:

- “Agitation, aggression and people not being able to cope with it” (Social Worker 1).
- “Increased deterioration in behaviour, they could have been hitting out, they could have been aggressive to other residents” (Staff Nurse 3).
- “Not taking medication” (Nursing Assistant 1).
- “It’s everything happening in conjunction with each other and you’ve kind of got the patient in the middle, but you can’t put any of these in silos, you can’t just look at one of these areas” (Allied Health Professional 3).

Less frequently mentioned as factors leading to admission but nevertheless evident in the data were psychotic features such as paranoia, hallucinations and delusions. This was
reflected when a Consultant Psychiatrist said “hallucinations and delusions, saying that the spouse or their partner is seeing other people and trying to murder them...” (Consultant Psychiatrist 2). Not only does this highlight the severity of psychosis the individual is experiencing, but also the risk of potential harm to others in the community (and also the ward of course) associated with such a presentation. Likewise, a Nursing Assistant, when talking about the reasons people are admitted, gave a similar example:

“If they no longer see their partner any more, if they look at her and they remember their partner being 50 years younger and who’s this imposter?”
(Nursing Assistant 3)

As in the phase 1 study findings, participants in phase 2 acknowledged that the presence of a physical comorbidity frequently accompanied dementia, particularly when the dementia is in the more advanced stages. There was also overall acknowledgement that people are admitted with physical as well as mental health (the dementia) issues. A Deputy Ward Manager shared that “a lot of people will come in with their mental health issues and with physical health issues” (Deputy Ward Manager 1), a position supported by a member of the physical health care team “it would be abnormal if people came in with no physical [illness]” (Registered General Nurse).

The data also indicated that study participants understood that the presence of a physical illness can cause someone’s presentation of dementia to deteriorate. This was seen in the data when a Ward Manager was discussing reasons for admission “they will come in because of increased confusion and when we have done a urine test it’s an infection, raging infection” (Ward Manager 1). However, if the person was considered to be acutely physically unwell, and in need of urgent physical health treatment despite the impact this was having on the person with dementia, then admission under these circumstances was not considered appropriate. This practice dilemma was highlighted in an extract from a Deputy Ward Manager who was talking about recent admissions to the mental health NHS dementia inpatient ward after being transferred in from an acute NHS trust:

“...we seem to be getting patients from across other trusts and they are not physically fit when they arrive ... [pause] ... quite often they arrive and we’ve done
bloods and they are so physically unwell they end up getting shipped straight back across [to the acute trust].” (Deputy Ward Manager 1)

This is suggestive of the fact that even though it is accepted that physical illness can affect a person’s behaviour, a person with dementia needs to be medically stable before being admitted into a mental health NHS dementia inpatient ward.

The data also indicated that it is common for people to be admitted for a number of reasons which have become interrelated and the resulting effect is a deterioration in the presentation of their dementia. The following data extracts highlight how both behaviours and physical illness are interlinked and the effect of multiple behaviours on an individual’s ‘complex’ presentation:

“Initially when they come in they’re really aggressive, possibly because they have not been taking medication at home, people who are physically unwell, people with pressure sores, people who have been refusing care at home, so people come in in like really dishevelled states.” (Deputy Ward Manager 1)

and

“I think it’s usually mix of behaviours. So you know not one, more than one, there’d be usually a mix of say agitation, aggression, getting lost outside or definitely wanting to get out and destroying sort of ... furniture whatever that sort of aggression to that or aggression to people but can’t be sort of looked after in that situation.” (Allied Health Professional 2)

Clearly, the data here suggests that a skilled practitioner in both physical and mental health [dementia] is needed to give optimal care.

ii) Increased risk /severity of symptoms

Again, the findings for phase 2 of the study were similar to those of phase 1 in that in order to trigger an admission to a mental health NHS dementia inpatient ward, the deterioration in presentation of dementia was accompanied by either a level of risk which could not be safely managed in the community and/or by a marked severity - or acuity - of symptoms.
The following data extract from an interview with a Staff Nurse who was talking about the presentation of people being admitted highlights this increased severity and risk; “yes severe and yes acute and yes aggression, or it’s got to a really unmanageable point” (Staff Nurse 1). This indicates that in order to get to the mental health NHS dementia inpatient ward an individual’s presentation would have had to have reached a point where it was simply not possible to safely meet their needs in the community. However, this situation can become even more complicated as Deputy Ward Manager 2 explained:

“More recently we’ve had people in that are quite complex because their families have kept them as home for so long, so by the time they come to us, they are pretty much high needs and high risk.”

The spotlight on risk featured significantly in the older adult community mental health team focus group when they were discussing reasons for admission. This is perhaps not surprising as the community clinicians working in the older adult community mental health teams are the professionals who will assess and care coordinate people with dementia in their own homes and in nursing and residential homes. They are also the professionals who make recommendations for admission into mental health NHS dementia inpatient wards. To take but one example from the data, one of the focus group participants, a Social Worker who is also an Approved Mental Health Professional, talked about when they are assessing someone for admission under a legal framework, such as the Mental Health Act (DH, 1983), the focus is on risk management “so there we are looking mainly at risk. You know, you’re looking at risk to self, risk to others, risk to health” (Social Worker 2).

Severity of presentation also featured when study participants spoke of reasons why people were admitted to mental health NHS dementia inpatient wards. The data indicated that an individual’s presentation, or symptoms, had to be severe enough for an admission to be warranted. Finding where this threshold lay, however, was a little more complicated to explain as this Senior Practitioner informed:

“I think within this environment at the minute the people that are being admitted are the people with the most difficult to manage illnesses, irrespective of whether that’s behaviour or that’s because they’re just so complicated with their co-morbidity or whatever.”
This severity was also reflected in the following data extract from a Consultant Psychiatrist talking about the presentation of patients of the ward “we tend to get the more severely unwell patients in their dementia basically and with other conditions and problems as well” (Consultant Psychiatrist 2). Interesting, along with the word ‘severity’ the phrase ‘acute’ was also used in a comparable manner.

iii) Breakdown of home or community care
Breakdown of care in the community was also given as a reason for admission. This scenario included when the person with dementia was living at home and care was being provided by a family member, partner or friend or when the care being received was provided by a nursing or residential home. A number of reasons were given for this breakdown of care. Again, perhaps reassuringly, these reasons broadly mirrored those given by the dementia leader study participants in phase 1. For instance, one of the reasons for breakdown in care was associated with changes in the person’s presentation, usually behaviour that challenges leaving the carer unable to meet the person’s needs or viewing the level of risk as being too high to be safely met in their present environment. This is reflected in the following data extract where a Deputy Ward Manager is discussing admissions to the mental health NHS dementia inpatient ward:

“Quite a lot of them just lately are actually coming from other care homes. They have been in care homes, they can no longer manage them because they are attacking other patients in the care homes, they’re attacking staff, sort of banging on the windows and things, throwing food.” (Deputy Ward Manager 2)

Carer stress and burn out also featured as a factor which could result in a person being admitted. This was seen in the following data extract from a Staff Nurse:

“We’re literally now getting very, very complex patients that tend to be at the end of their illness, where their families just can’t cope anymore, they’re just at the end of their tether.” (Staff Nurse 3)

Additionally, there was also an acknowledgment that care in the community can breakdown due to a carer’s (paid or otherwise) lack of knowledge about how to care for, or meet a need for, the person with dementia. Interestingly, staff at the mental health NHS
dementia inpatient wards were often sceptical of the assessments that were received on the admission of people with dementia from the care home sector, as this quotation from a Nursing Assistant illustrates “they’ve come in and we’ve not seen any of that, none of it, and I think a lot of the time it’s how you handle somebody” (Nursing Assistant 1). Similarly, a Staff Nurse shared that “there is not always the same amount of knowledge skills and training in a lot of nursing homes EMI [Elderly Mentally Ill] homes” (Staff Nurse 3). Being seen as an expert, or being positioned as an expert practitioner in dementia care, appeared an important professional attribute for staff taking part in this phase of the study.

4.3.3 Theme 2: Adjusting to Admission

Once admission to a mental health NHS dementia inpatient ward had taken place, the data revealed a consensus amongst study participants of its consequences, for the person with dementia, the family, the ward staff and themselves as clinicians. For example, for the person with dementia, it was taken-for-granted that all individuals admitted to the mental health NHS dementia inpatient wards were admitted under the legal frameworks of the Mental Capacity Act (2005) using a Deprivation of Liberty Safeguards (2008) standard or the Mental Health Act (DH, 1983). There was also acknowledgement that it was more common to admit under the Mental Health Act (DH, 1983) and that informal admissions into these environments were virtually non-existent. The need to admit individuals under the Mental Health Act (DH, 1983) was explained by a Consultant Psychiatrist in the following way:

“As a result of the dementia severity they do not understand that they have an illness, they do not understand that they need to come into hospital for treatment and assessment at all” and they “all meet the criteria for detention under the Mental Health Act.” (Consultant Psychiatrist 1)

Study participants informed that admissions were normally people whose dementia had progressed to a moderate or advanced stage of the illness trajectory. Indeed, an experienced inpatient ward manager, when comparing people with dementia admitted today as compared to those from a number of years ago, put this position succinctly “I think they are much further along that journey by the time they come to this ward” (Ward
Manager 2). Similarly, one Consultant Psychiatrist shared that “the acute dementia ward hosts the more moderate to severe [stage of the illness]” (Consultant Psychiatrist 2) and another Consultant Psychiatrist reported that “inpatients should be the severest end of the complexity” (Consultant Psychiatrist 1).

This belief that the mental health NHS dementia inpatient ward dealt with those people with dementia furthest along the diagnostic trajectory also had consequences for the meaning and construction of complexity as seen across the data set and across all grades of clinical staff, as these slices of data suggest:

- “From my point of view working on an inpatient assessment ward we are seeing people further down the line with more advanced dementia where there is definitely more complexity” (Allied Health Professional 2).
- “They are definitely more complex [than patients used to be years ago]” (Staff Nurse 3).
- “Now the complexity of patients has increased so much and we really do get the people with the most advanced dementias” (Allied Health Professional 3).
- “They wouldn’t be in this environment [mental health NHS dementia inpatient ward] if they didn’t have complex needs” (Nursing Assistant 3).

Moreover, study participants [mainly nursing staff] who had worked on the mental health NHS dementia inpatient wards for a number of years indicated those patients in the more advanced stages of dementia had consequences for the amount, regularity and necessity of ‘hands on care’ that was provided on a daily basis. For instance, Staff Nurse 3 shared that “a good 80 percent of the patients need full assistance with diet and fluids, washing and dressing and bathing.” A worthwhile reminder of the high level of physical care needs [as well as the specialist cognitive and dementia assessment work] that is necessary for people with dementia admitted to such environments and the demands such attention places on care staff.

When participants were invited in interview to ‘talk about the type of people who are admitted,’ study participants attributed, unprompted, the word complex to today’s admissions. The data revealed a professional discourse about complexity and complex
presentations that was a coherent narrative from the point of identification through to admission onto the mental health NHS dementia inpatient ward, and onwards. It is this ongoing discourse around complexity as experienced and understood on the mental health NHS dementia inpatient ward that is explored more fully in the next theme heading as it appeared to underpin much clinical decision-making and associated professional identity.

4.3.4 Theme 3: Interpreting Complexity on the Ward

Despite participants in phase 2 indicating that the people being admitted to the mental health NHS dementia inpatient wards were more complex than a number of years ago, study participants, similar to the phase 1 respondents, were unable to provide a unified definition of the term complexity in dementia. This struggle in providing a definition of complexity in dementia was acknowledged by a Consultant Psychiatrist:

“When it comes to actually defining what it means so that everyone in your little ... in your team or geographical area or, what you call it, the region you work in, the country you work in, and even more internationally, will know exactly what you mean. It’s very, very difficult, yes.” (Consultant Psychiatrist 1)

The data indicated that some of the difficulty in defining complexity in dementia may be as a result of the perceived subjectivity of the term. This notion that it was a subjective term was reflected in the data across a range of professional backgrounds. The following data extracts highlight this analysis:

- “It’s a loaded term. It means different things to different people...” (Consultant Psychiatrist 1).
- “So I think it is people’s perception of what they consider to be challenging or complex isn’t it? Everybody has their own perception on it don’t they” (Nursing Assistant 2).
- “I think it’s down to perception really...what one person might class as being complex another one may not” (Staff Nurse 3).

Similarly, clinicians in the older adult community mental health team focus group acknowledged that the term complexity in dementia was a “currency” and a “language we
all use” (Community Psychiatric Nurse 5). Yet, despite these affirmations, there was also ambiguity as to the meaning and definition of the term as this Community Psychiatric Nurse identified:

“I think what it means to the patient and their carer or their relatives could be different to what it means to us or ward staff or to anybody else that's involved in any aspect of their lives. So it does mean different things to different people.” (Community Psychiatric Nurse 4)

Despite participants experiencing difficulty in providing a definition of complexity in dementia, they were able to provide descriptions of their personal understanding and perception of complexity in dementia. For example, a Consultant Psychiatrist shared that “it’s probably not your average patient” and went on to explain that “a complex person is someone who is above average in their presentation within the diagnostic category” (Consultant Psychiatrist 1). This telling observation positions complexity outside of what you would ‘expect’ in a person with dementia at that particular stage of their dementia. This understanding is also reflected in the following extract from a staff nurse, with many years of nursing on mental health NHS dementia inpatient wards: “it means they present in a way that is out of the context of the normal expected presentation within their diagnosis” (Staff Nurse 2). Similarly a Psychologist talked about their perception of complexity being about the presentation of behaviours that “aren’t predictable or can’t be understood easily” thereby suggesting that complexity is about something different than you would normally expect to see.

Study participants also talked about complexity in dementia as being related to the presence of a number of factors which interact and affect the individual’s presentation. This multiplicity and interaction of factors was very similar to those descriptions of complexity provided in phase 1 data collection from dementia leaders. Examples of this from study participants in phase 2 are shared below:

- “Complexity to me is somebody who may have the same challenging behaviours but have all other things going on as well” (Staff Nurse 4).
• "I think a lot of it is, for me, around just the multiple different needs that the person may have, so it’s not just about their dementia” (Allied Health Professional 3).
• "I would see them as having multiple needs, so I think there’s lots of kind of facets to the person that perhaps needs addressing” (Allied Health Professional 1).
• "I guess the standard thing would be where there are other issues just other than memory impairment, such as behaviour or other mental disorders or difficulties, challenges in meeting a person’s needs, sorts of things where there might be issues about safety, there might be issues about agitation or aggression” (Social Worker 2).

These factors were referred to by a Consultant Psychiatrist as “layers of complexity” (Consultant Psychiatrist 1). So, in this instance, an individual may not be your ‘average’ patient so the person is above average in their presentation and there are a number of factors or layers which can contribute to this, for example intensity of behaviour, profound sensory impairments, unpredictability and risk.

This interaction of factors as a description of complexity in dementia is nicely demonstrated when a member of the physical health team was describing what the term complexity in dementia means as the individual provided the following example:

“With regards to behaviour and behaviours that make it harder to get to grips, to get to help that person, so if you’re diabetic, for instance, and you need your blood sugars taken by a finger prick test but you have no insight at all into that disease of why it is that I am trying to hurt you on a daily basis, that would make it complex for me.” (Registered General Nurse)

This study participant likened complexity to a “tangled ball of wool” (Registered General Nurse) which needs to be unravelled, thereby inferring the interrelatedness of factors and how they affect each other and the person. It is also the quotation shared at the start of this chapter.

The analysis of the phase 2 data also indicates that when study participants were describing complexity they frequently discussed it in terms of difficulties in solutions and
interventions. Study participants talked about presentations or symptoms that are not easily managed, or the amount of interventions required in meeting an individual’s needs and the difficulties in providing care for the person with dementia. The following three extracts from the data provide examples of this where study participants are describing complexity in terms of solutions and interventions:

“I think it’s perhaps the severity of symptoms and the mix of symptoms that are not easily managed. Perhaps not easily managed in other settings if we talk about complexity, to need admission to us.” (Allied Health Professional 1)

“For me complexity would be in the amount of interventions we have to do … for that person to remain alive. For example if we didn’t feed them, get them out of their bed, change them when they’re soaking wet or doubly incontinent.” Ward Manager (Ward Manager 2)

“So for me I think that a lot of complexity is that’s it’s difficult to care for people at that essential sort of level.” (Staff Nurse 1)

“[long pause] their inability to understand their own basic needs [pause] about eating, going to the toilet, erm just the general things that we class as everyday things in life. They can’t do it themselves they need help and support to be able to function...” (Nursing Assistant 4)

From a Nursing Assistant perspective, there was a view that the notion of complexity derived from impaired communication due to the person’s dementia. This understanding that complexity stems from impaired communication was only talked about from this staff group although, in other professions, when impaired communication was mentioned, it was more of a factor of complexity rather than the cause. The following extracts from interviews with Nursing Assistants demonstrate this view of complexity deriving from impaired communication:

“Complex to me is some...[pause]...is the communication because I think if they can’t communicate.” (Nursing Assistant 1)
“I think the biggest thing I have seen in my personal life and on the ward is communication. I think a lot of what people term complexity sort of derives from that [communication].” (Nursing Assistant 3)

Interestingly, participants did not view complexity as a static fixed state where people were either complex or not complex. Instead, study participants described complexity as being a concept which was dynamic and movable with different degrees of severity of complexity as Consultant Psychiatrist 1 indicated: “complexity is not static at all it’s fluid.” The data also identified that people with dementia could move in both directions along this continuum thereby inferring that complexity could increase or decrease. Study participants also identified that changes in the degree of complexity would be in response to a change in the factors that were causing the complexity and also the interventions/treatments required to meet an individual’s complex needs.

An Allied Health Professional visualised complexity as a graph with those admitted to the mental health NHS dementia inpatient wards were at its higher end because “they have multiple needs, they wouldn’t have capacity, there’s lots of risk and therefore things have started breaking down in the community” (Allied Health Professional 3). In this portrayal of complexity it was the assessments and interventions which would help to reduce an individual’s complexity. There was also a view amongst study participants that once a person is complex this complexity will never completely go but they can become “less complex” (Consultant Psychiatrist 1). This belief that complexity never completely goes away is reflected in the following data extract from an Allied Health Professional, and is also reflected in the final theme heading:

“I think it’s one of those areas where I can’t think of any better terminology than not to take your eye off the ball. I don’t think that you can suddenly say the complexity gone. I don’t think that the complexity would ever go.” (Allied Health Professional 3)

Study participants also concurred that complexity can increase in line with the progression of a dementia, but, conversely, when a dementia reached a very advanced stage for some people, the complexity may lessen as factors which have caused the complexity may have changed for example “behaviours which challenge may have diminished” (Deputy Ward
Manager 1) or as a result of “illness progression the individual has deteriorated physically” (Allied Health Professional 2). This is evidenced in the following data extract “I would say it can change and it can stabilise and also with the decline in the dementia” (Deputy Ward Manager 1). There was also agreement that the people being admitted to the dementia wards should be at the higher end of the complexity continuum, but with interventions and treatments this complexity should lessen and pave the way for being discharged from mental health NHS dementia inpatient wards.

4.3.5 Theme 4: Stabilising Complexity for Discharge

Although there is no predetermined maximum length of stay on a mental health NHS dementia inpatient ward, there is an expectation that people with dementia are assessed, appropriate interventions and treatments identified and provided and that they are discharged as soon as they are stable. Mental health NHS dementia inpatient wards are assessment wards and, drawing on my own clinical experience of these areas, discharge planning begins on admission and there are pressures to discharge patients as soon as they are ‘stable’. Both participating wards in this study were usually functioning at full patient occupancy and it was not uncommon for there to be a waiting list for admission. This was reflected in Staff Nurses’ interviews who informed that the “ward is normally full...if one person gets discharged there is usually another waiting to come in” (Staff Nurse 3) and “we have 18 beds and are normally full” (Staff Nurse 4). So, in essence, staff were always working towards stabilising complexity enough for the person to be discharged and for their needs to be met in a less restrictive setting. This dynamic was neatly summarised by a Consultant Psychiatrist who said that the aim of admission is to “define what complexity is, manage it, know your management plan works and then discharge the patient with a plan” (Consultant Psychiatrist 1).

There was also an acknowledgement amongst study participants that once admitted to a mental health NHS dementia inpatient ward then the likelihood was that, when the person was ready for discharge, they would be discharged into 24-hour care. This is evidenced in the following extract from the data when a Social Worker is talking about influencing factors in admitting a person with dementia to the ward:
“In making the decision [to admit] very often you are very aware that if you admit this person to hospital chances are you know they're not going home again in the majority of cases with people with dementia...[pause]. The reality is once they leave their home familiar environment they end up in hospital. The likelihood is they end up going into 24-hour care which is a massive change for that person and their family.” (Social Worker 1)

Similarly, a Consultant Psychiatrist reported that “rarely do people go home after coming into hospital. We now keep people at home for much longer hence 24-hour care [on discharge]” (Consultant Psychiatrist 1). The pivot to move from admission to discharge was stability in complexity. The view that assessment and intervention can help reach this state was seen across the data set and typified in the following statements from two Consultant Psychiatrists: “complexity can plateaux [pause] a plateaux is about continuing interventions and tasks to keep the patient on a plateaux” (Consultant Psychiatrist 2) and “if you treat one thing it can make the complexity go down really” (Consultant Psychiatrist 1). Moreover, there was a view that “assessments and interventions have to be done to prevent relapse” (Allied Health Professional 3).

Despite the acknowledgement of the importance of assessment in the role of reducing complexity and preventing relapse, study participants were not able to articulate a clear assessment pathway, or model, with which they work in order to assess and then stabilise complexity. This practice uncertainty was reflected in the following statement from a Deputy Ward Manager who said that there is no approach or model “for exploring a patients presentation except for discussing it in ward rounds and handover” (Deputy Ward Manager 2) and from a Staff Nurse “no approach or model of assessment” (Staff Nurse 3).

Even though study participants were unable to articulate a model of assessment, they were able to identify the components of what they felt should be in an assessment model and talk about what one should look like. Examples of assessment components included information regarding activities of daily living skills, a collateral history from family, an exploration of previous coping mechanisms and a physical health assessment. With regards to a model of assessment, a needs led or formulation led model was frequently cited as being the best approach. This can be evidenced in the following extracts from the data:
“I’m going to advocate the Newcastle model as the best way of pulling everything together for everyone to understand. Newcastle model as a needs led model has breadth to pull it all together.” (Psychologist)

“Formulations are good for patients we have come to the end of the road with and we need help to know what to do. Formulation included breaking down feedback from lots of people, looking across everything and agreeing interventions to try” (Deputy Ward Manager 2)

Reference to the ‘Newcastle model’ was also seen in the phase 1 data - and reported earlier in this chapter - and perhaps is consistent with the view that a multidisciplinary team approach to assessment is essential in order to assess and reduce complexity. Developing this position further an Allied Health Professional reported that:

“The multidisciplinary team break down complexities and try to distinguish what might make a person complex. The multidisciplinary team approach to assessment is essential as different professionals pick up different things.” (Allied Health Professional 1)

Similarly, a Consultant Psychiatrist, when talking about assessing what makes someone complex, reported that:

“You need a meeting where you can sit down and talk about what makes a person complex. Try to understand the person and approach and life history. I have experienced this approach before and staff were surprised at the things they found out about the person. This approach keeps the person as a person as opposed to a separate entity.” (Consultant Psychiatrist 2)

When study participants talked in terms of interventions to help reduce or manage the complexity, there was a view that flexibility and adaptability should underpin any intervention. An Allied Health Professional referred to this as the necessity to have a “bucket load [of interventions] as no one-size-fits-all and it is very tailored to what a person needs” (Allied Health Professionals 3). This flexibility was further evidenced when a Consultant Psychiatrist talked about “trying different approaches to see what works”
(Consultant Psychiatrist 2). Adaptability was highlighted by a number of participants who talked about the need for stepped approaches or stepped interventions. In this context, participants were advocating starting care interventions with a number of staff and increasing or decreasing as necessary depending upon how the patient responds. This is highlighted in the following data extracts “stepped interventions....start with three staff and if not needed back down...fluctuation and escalation can be rapid” (Staff Nurse 3) and “stepped approaches, so start with two staff, for example, and increase as necessary” (Senior Practitioner).

Coupled with the need for flexibility and adaptability was the importance of staff approach and communication in order to facilitate an intervention. There was a recognition that if the staff’s approach was not right it could actually contribute to making the situation worse. For the Nursing Assistants who participated in this phase of data collection, the importance of establishing a rapport and the appropriate use of touch in order to facilitate interventions was highly valued, for instance “It’s how you approach someone...rapport and respect, the use of a hug, kind words and time” (Nursing Assistant 3) and “rapport is really important, it helps the anxious feel safe helps when preventing someone from doing something” (Nursing Assistant 2).

The importance of communication included both verbal and nonverbal communications. As a dementia progresses it can affect an individual’s ability to verbally communicate. Therefore, the importance of assessing and observing nonverbal communication, either before undertaking an intervention or as an indication for what type of intervention may be required, is paramount. The following extract from a Ward Manager indicates how the observation of nonverbal communication can be used to identify a need “observing facial expression and body language for example for pain” (Ward Manager 2). The importance of observing nonverbal communication to judge when to undertake an intervention and when to try again later was highlighted in this data extract from a Staff Nurse “observing body language and knowing when to go in and when to back off” (Staff Nurse 1).

With regard to interventions and treatments that may be implemented with an individual to stabilise their complexity, study participants were able to discuss a range of options. These included social engagement based activities, for instance baking, quiz, beauty session; therapeutic interventions, e.g. Singing for the Brain, reminiscence, sensory doll therapy,
medication treatments, functional assistance, e.g. mobility aids, communication aids and personal care interventions which included washing, dressing, physically giving food and fluids and assisting with continence needs. Life story work, continuous observations and, controversially, physical restraint in order to promote safety or provide care and treatment, also featured as interventions. Further developing the first point of this analysis, the use of an individual’s life story seemed to serve a number of purposes which included “life story work as a therapeutic activity” (Allied Health Professional 3), “using life story information to identify interventions” (Psychologist) and “life story work used as a distraction” (Allied Health Professional 1). However, how such life story work was documented and evaluated as successful in such contexts was not described.

The use of continuous observations as an intervention was frequently referred to with study participants who were from a nursing background. This level of observation was used in an attempt to minimise risk and increase safety. Reasons that were frequently cited for the use of continuous observations as an intervention were risk of falls, aggression, agitation, intrusiveness and poor spatial awareness. Within Daisy ward and Jasmine ward, it appeared a frequently used intervention as demonstrated in the following data extract “usually always someone on 1:1, sometimes two people” (Ward Manager 1).

Perhaps the most contentious finding was the use of restraint as an intervention to help stabilise complexity. Again this featured within a nursing discourse and it could be argued that this approach is not something that is first thought about when interventions to reduce, or stabilise, complexity are considered. In this context restraint was identified as an intervention which was used to deliver personal care when a person with dementia no longer had the ‘insight’ into such self-care needs and if left without an intervention would not wash, or change their clothes, and would continue to be incontinent. Indeed, a Senior Practitioner reported that between “three to five staff” were required for personal care and restraint. For such patients, staff reported, perhaps unsurprisingly given the numbers involved in such a personal intervention, that they were are often met with restiveness, aggression and violence by the person with dementia. The line between a helping intervention [by staff] and a perception of this act being misinterpreted as one of a personal assault [by the person with dementia] is a fine one indeed and magnified by the environment in which care is taking place as it is not in an environment familiar to, or in the control of, the person with dementia. Stabilising complexity in such situations is not an
easy task and perhaps helps to account for the uncertainty over a patient’s length of stay in the mental health NHS dementia inpatient ward.

On the other hand, one of the most interesting concepts put forward for stabilising complexity in the mental health NHS dementia inpatient ward was not one of skilled practice but one of the ‘passage of time’. For some people with dementia, their complexity decreased and stabilised due simply to their time on the ward and the subsequent progression of their illness. This is highlighted in the following two extracts from the data:

“People can become less complex when dementia deteriorates as mobility may deteriorate or food and fluids and they are not as strong as they were which can lessen some of the behaviour.” (Staff Nurse 4)

“People at a further stage can become more complex and then they get to a stage where they are less complex as the challenging behaviour has diminished.” (Deputy Ward Manager 1)

I will now briefly summarise phase 2 findings before moving on to present phase 3 findings.

4.3.6 Summary
Phase 2 has built on phase 1 analysis and four themes have been explored: 1) Getting Admitted to the Ward; 2) Adjusting to Admission; 3) Interpreting Complexity on the Ward; and 4) Stabilising Complexity for Discharge. The intersecting and interactional processes involved in these themes and in the findings from phase 1, will now be ‘tested’ against detailed case study ethnographic observations of four people with dementia on a mental health NHS dementia inpatient ward and a summary report on each patient’s care records during their time on the ward. All participants in phase 3 of the study design and data collection were detained under the Mental Health Act (DH, 1983) and seen by the staff to be complex. To the best of the author’s knowledge, this is one of the first times that such a patient population has formed part of a research study and the ethical hurdles that needed to be overcome were significant. However, phase 3 was a necessary step for the
triangulation of qualitative methodologies and methods to authentically represent all stakeholders who took part in the study.

4.4 Phase 3: Case Study Observations

4.4.1 Introduction
In phase 3 four people with dementia admitted to the mental health NHS dementia inpatient ward were recruited into the study. In line with the study design, their inclusion is presented as a set of individual case studies that allow a more descriptive and detailed narrative of lived experience to emerge. The four case studies will be presented in the order in which they were recruited into the study. As explained in the preceding chapter, none of the four participants with dementia had the capacity to consent so, in line with the study protocol and the requirements of the Mental Capacity Act (2005), the next of kin (as personal consultee) was approached. In all four cases their next of kin and a member of the ward care team were also interviewed. In addition, each person’s case records were reviewed and all cases were observed in the ward environment on multiple occasions. The participant sample frame for phase 3 can be seen in Table 3.6, page 104.

The aim of recruiting case studies for this phase of data collection was to explore how complexity in dementia is represented in people who are currently resident as inpatients. This stage allowed for explorations of how the themes identified in the previous stages were present, or otherwise, in the naturalistic practice observations. Each of the four participants with dementia [Brian; Eric; Charlotte; Celia] are presented with the same structure [Background Details; Care Record Review; Observations on the Ward; Clinical Reflection Points] which allows for within and between case analysis in the development of the practice model of complexity presented in the next chapter. However, as the four case studies were all recruited from Jasmine ward, I will start this phase outline by describing the ward environment - and staffing team - where the observations took place.

4.4.2 Setting the Scene – Jasmine Ward
Jasmine ward is located in a community hospital which provides assessment, care and treatment for people with dementia and older people with mental health problems. The hospital is part of a large mental health NHS trust and Jasmine ward is a mental health
NHS dementia inpatient ward. At the time of the study there were two inpatient wards and a memory assessment and treatment service; a third ward was in the process of being built. Access to Jasmine ward is via the main reception and the wards are located at the end of a long straight corridor. This corridor has three reminiscence seating pods located on it. On the walls are pictures of the local area and at the end of the corridor where the wards are located, there is a display of artwork undertaken by a local man living with dementia.

At the time of data collection Jasmine ward was an 18-bedded mixed sex ward for people with dementia requiring assessment. Jasmine ward accepts patients from two localities within a defined geographical area. The four participants in this phase of the study were recruited from these localities. Jasmine ward is entered by ringing a bell and the staff inside the ward unlock the door to allow admission. Initially, you step into a vestibule. Located on one side of the vestibule is the housekeeper’s storeroom and on the other side is a small meeting room. From within this vestibule there is another set of locked doors with glass panels that allow you to see into the ward area. These doors cannot open until the first doors have closed in effect, creating an ‘airlock’. Staff on Jasmine ward control access to opening and closing these inner doors. Once this set of inner doors are opened you then step into a large day area.

The day area consists of a dining area and a sitting area. The sitting area has a large television on the wall, armchairs and two sofas. The dining area comprises of a number of round tables with dining chairs. This day area appears light with daylight coming in from the windows to the right where the main ward garden is located. A number of other doors with glass panels line the walls of the day area. These doors are to the administrator’s office, clinic room, ward kitchen, therapy kitchen and ward managers’ office. There is also an office for the multidisciplinary team which has glass windows all the way around allowing people to (theoretically) see in and out; however, there are a lot of notices pinned to the glass inside the office thereby obscuring the view. The rooms located in this day area are only accessible using a key or a staff swipe card. It is/was not uncommon to see patients trying to get in these rooms by trying the handles or knocking on the glass panels.

The day area also has a toilet for the male patients. There is a menu board and orientation board located on the wall in the dining area and there are a number of other signs and leaflets dotted around all the walls. One of the walls hosts a large clock and under the
television there is a wooden unit. There are also a couple of smaller lower tables dotted around the space. The flooring is a wood effect vinyl and the chairs are different shades of burgundy. Leading off from the sitting area is a short connecting T-shaped corridor with two doors. This leads to another glassed office, which is usually staffed by occupational therapists, a bedroom with a small lounge area and a private garden (originally designed for end-of-life care) and another toilet. At each end of the T-shape is another set of connecting doors with glass panels in. These connecting doors, when closed, can only be opened using a staff swipe card. The left door leads to the male bedrooms, bathroom, male lounge and garden and the right door leads to the female bedrooms, bathrooms, female lounge and garden. Located in the ‘female side’ are also an examination room and the sluice room.

All the bedrooms are single rooms and they consist of a single bed, sink, small wardrobe fixed to the wall and a small chest of drawers. Some rooms also have a chair in them similar to those which are located in the dining room. Bedrooms can be different sizes, with the bigger rooms usually being allocated to people who need assistance with mobility and lifting aids. Both bedroom corridors turn at the end leaving a number of bedrooms with a feeling of isolation as these are not visible from the main bedroom corridor.

Periodically around the ward on the walls are small boxes which resemble a small house alarm setting box. These are what staff call the ‘pin points’ and when a staff alarm goes off, staff go to these boxes and see what area of the ward the person is in. When the staff alarm goes off, this sets off a loud noise on the ward until deactivated. The telephone is on an extension so it can be heard in the dayroom along with the ward door bell. The main garden off the day area has a number of plants in raised beds, outside lighting, flat paths where patients can walk around and interact with the plants and numerous seating areas. There is also all weather artwork located on the walls and an outside open shed for activities such as potting plants.

The ward team is multidisciplinary and consists of a ward manager, two deputy ward managers, staff nurses, nursing assistants, occupational therapist and an occupational therapy assistant. There are two consultant psychiatrists and their junior doctors. At the time of data collection there was also a senior nurse practitioner, physical health nurse,
assistant practitioner, physiotherapist, physiotherapy assistants and some psychology input which was divided across the three inpatient areas. The wards were overseen by a matron.

Throughout phase 3 of data collection the ward usually ran at maximum capacity. If a bed became empty it was usually filled within the next 24 hours. There were also a number of patients who required continuous observations (a member of staff with them all the time), one in 10 minute or one in 15 minute observations (a member of staff checks the person at the stipulated time) as they were either at high risk of falls, were spontaneously aggressive to others or were intrusive into other people’s space and, as such, were at risk of being assaulted by other patients. This resulted in a number of ‘bank’ and ‘agency staff’ being used each shift in addition to the regular staff. Depending on numbers of patients and acuity of the ward staff numbers ranged from six to nine in a morning and four to eight in an afternoon and night.

Figure 4.1, page 146, reveals a drawing of Jasmine ward day area.
Figure 4.1 Drawing of Jasmine Ward Day Area
4.4.3 Case Study 1: Brian

Main Storyline: ‘Complexity is more than the eye can see.’

Case Study Overview
The case of Brian demonstrates how complexity can be more than the eye can see. In this case Brian’s wife, Gloria, and the Deputy Ward Manager Joan, (who was also his named nurse) talk of his complexity stemming from a mix of factors. However, on observation, and in reviewing his care records, these factors are not overt. Instead, Brian portrays a picture of a man who looks bewildered and lost and who is constantly trying to problem-solve where he is and why he is there.

The data collected for Brian comprised an interview with Gloria, an interview with the Deputy Ward Manager, a review of Brian’s care records and multiple periods of observation.

A summary of the periods of observation is detailed below in Table 4.1.

Table 4.1 Summary of Periods of Observation for Brian

<table>
<thead>
<tr>
<th>Date Range</th>
<th>Periods of Observation</th>
<th>Locations</th>
<th>Longest Observation</th>
<th>Shortest Observation</th>
<th>Total Hours</th>
</tr>
</thead>
<tbody>
<tr>
<td>October – December 2015</td>
<td>11</td>
<td>Day area, corridor leading to bedrooms and male lounge</td>
<td>2 hours</td>
<td>15 minutes</td>
<td>11hrs 55mins</td>
</tr>
</tbody>
</table>

Background Details
Brian is 80 years old, married and has two daughters. Brian was diagnosed with Alzheimer’s disease 6 years ago. He was admitted to Jasmine ward from a nursing home registered to look after people with dementia, during an afternoon in August 2015. This was an emergency admission as over recent weeks, there had been a deterioration in his behaviour. Brian’s admission was a compulsory one and he was detained under the Mental Health Act (DH, 1983). On the ward he was allocated his own bedroom in the male
sleeping area. Brian had a selection of his own clothes and toiletries with him on admission but no other personal possessions.

As well as having Alzheimer’s disease, Brian had a number of comorbid physical conditions which included long-standing depression, osteoarthritis, retinitis and an inguinal hernia. As a result of falls, Brian also had three previous head injuries. He wore hearing aids in both ears.

Brian was prescribed a number of regular, and when required (PRN), medications. These are detailed below in Table 4.2.

**Table 4.2 List of Prescribed Medications for Brian**

<table>
<thead>
<tr>
<th>Medication</th>
<th>Route</th>
<th>Dose</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lorazepam</td>
<td>Orally</td>
<td>500mcg</td>
<td>PRN</td>
</tr>
<tr>
<td>Lorazepam</td>
<td>Intramuscular</td>
<td>500mcg-1gm</td>
<td>PRN</td>
</tr>
<tr>
<td>Olive oil</td>
<td>Topically both ears</td>
<td>Not recorded</td>
<td>PRN</td>
</tr>
<tr>
<td>Aripiprazole</td>
<td>Orally</td>
<td>2.5mg</td>
<td>Mané</td>
</tr>
<tr>
<td>Venlafaxine M/R</td>
<td>Orally</td>
<td>225mg</td>
<td>Mané</td>
</tr>
<tr>
<td>QV cream</td>
<td>Topically</td>
<td>Not recorded</td>
<td>QDS</td>
</tr>
<tr>
<td>Paracetamol</td>
<td>Orally</td>
<td>1gm</td>
<td>QDS</td>
</tr>
<tr>
<td>Capasal shampoo</td>
<td>Topically</td>
<td>Not recorded</td>
<td>When washing hair</td>
</tr>
<tr>
<td>Lactulose</td>
<td>Orally</td>
<td>10ml</td>
<td>22.00hrs</td>
</tr>
<tr>
<td>Fortisip Compact</td>
<td>Orally</td>
<td>one</td>
<td>Daily</td>
</tr>
<tr>
<td>Betcap</td>
<td>Topically</td>
<td>Not recorded</td>
<td>Daily</td>
</tr>
</tbody>
</table>
Whilst Brian was on the ward his wife would visit him six days a week and on the other
day, he would be visited by an old work colleague. His daughters would also visit when
they could.

Brian’s admission to hospital came as a relief to Gloria as she shared “I came home and
for the first time [since he had been admitted to the nursing home] I could go to bed, I
could go to sleep and I knew he were safe.” Gloria talks of Brian in terms of the man she
has known since she has been a young woman. To Gloria her husband is a man who has
always led his own life, doing the things he liked and enjoyed with his own set of friends; a
man who seemed to like to control even the smallest of decisions and choices. Gloria
informed me “I’ve never been able to understand him thoroughly. So, to me, I think he’s
always been a complex person.” Gloria believes that Brian’s personality has continued into
his dementia and that the illness has taken from him the control he used to have on his life
“... he’s always been his own man.... and that’s where the frustration comes in.”

The purpose of Brian’s admission was outlined by the Deputy Ward Manager as “to
explore the aggression” that he had been reported to have been displaying in the nursing
home. She described Brian’s dementia as being “...moderate to severe, but not quite at the
severe, I’d say more the back end of moderate.” When the Deputy Ward Manager talked
about Brian, her perception of him was embedded within the “here and now” and in the
context of his dementia, as opposed to the biographical view taken by his wife:

“I’d say he is quite a complex person because he’s not just got dementia he’s also
got his depression and he’s got his behaviour stuff, he’s got his hearing problems.”

This was Brian’s second admission to this type of inpatient environment. His first
admission was for a period of assessment after he had attacked his wife and tried to stab
her in their home. On discharge from the ward he had moved to a nursing home registered
to look after people with dementia which he had continued to reside in until this admission.

**Care Record Review**

Brian’s care records detail his reasons for admission. They paint a picture of a man who, in
the nursing home, was displaying a high degree of violent behaviour: “he has become
agitated and aggressive during care interventions. Knocked a member of staff’s teeth out and bit another member of staff.” His care records reported that the “risk to others [in the nursing home] high and risk of retaliation from others. Psychotropic medication recently been used but behaviour remains challenging” and that there was “no option but to admit.” The use of the statement ‘no option but to admit’ conjures up the image of admission being as a last resort where there are no other options available in the community that can safely meet Brian’s needs.

However, Brian’s care plan gave no indication of Brian’s needs, the care interventions he may need or any sense of him as a person. If I was a qualified nurse caring for Brian for the first time, his inpatient care plan would give me no indication of how to help Brian. For example, in the section of the care plan about needs, it was written that Brian has a diagnosis of dementia. This is a statement not a need and there was no further information as to how Brian’s dementia affects him or what needs may arise as a result of him having this illness. The only information written under the interventions section stated that “his mood will be assessed and medication will be administered as prescribed.” There was a risk assessment in place; however, the risk management plan was not dissimilar to the nursing care plan in that, as opposed to recording risk factors and risk management interventions, there was a series of statements such as “admitted on a section 3 from a nursing home, can be aggressive has used a weapon in the past causing staff injury.’

I was unable to locate, or get a sense of, any assessment model or process that was in place for Brian. There was evidence of specific assessments being undertaken for example dietary assessment and a moving and handling assessment but these seemed to be situated in isolation and not tied into care plans, risk assessments, day-to-day caregiving or an overall approach or direction. I could find no assessments that explored the possible causes of Brian’s behaviours or any guidance on the most appropriate interventions and responses. Additionally, I was unable to locate any life story information. It was as if Brian’s life commenced the day he walked onto the ward and who he was before this day had no bearing on the person he is now or who he may become. I was unable to get a sense of how Brian’s assessment was actually being undertaken.

Yet, when the Deputy Ward Manager talked about Brian as shared earlier in this case study, her conversation revealed that, from her perspective, Brian’s complexity was as a
result of a combination of factors which included his mood, behaviour, hearing and communication issues and impaired insight. Yet this interconnectedness of factors, and how it affects Brian, was not reflected within his care records. The most detailed assessment I was able to locate was the specialist healthcare assessment. This is a document which is usually completed by nursing staff as part of a discharge process. It is one of the core documents which is presented when a patient’s case goes to funding panel for nursing and residential care. In Brian’s case it had been completed to support the clinical team decision that on discharge Brian needed to receive care and treatment in a specialist unit for people with dementia and challenging behaviour. The document broke Brian’s behaviours down into inappropriate toileting, extreme restlessness/agitation, aggressive behaviours, severe communication difficulties, disturbed sleep pattern, danger of absconding, and restiveness to care. There was also a completed continuing healthcare screen where the rationale for the screen was documented as “complex and challenging needs.”

On inspection, the progress notes demonstrated that each week Brian was reviewed and discussed in the multidisciplinary team meeting. However, the recording of these meetings is brief with little evidence to support how his behaviours are being assessed and explored. In my clinical experience, as a minimum on each shift, an entry should be made in the ‘progress notes’ section of Brian’s care records to reflect how he has presented, and anything that has happened that day relevant to his assessment, care and treatment. Each shift the nurses had written a short entry as to how Brian had presented. Again, these notes tended to be brief and problem orientated for example “unsettled this evening”, “difficult night time interventions taking 4 staff”, “irritable and confrontational toward staff”, “wandersome this evening with long unsettled periods moving chairs and tables” and “tearful and demanding at the start of the shift however settled.”

Words frequently occurring in the daily progress notes included: unsettled, settled, wandersome, aggressive, mithersome and tearful. There was nothing in the progress notes that demonstrated how staff was exploring the possible reasons why Brian was displaying certain behaviours or any evidence of any non-pharmacological interventions being deployed. There were no care plans relating to these recorded presentations or behaviours.
Observations on the Ward

During my periods of observation (see Table 4.1, page 147 for a summary of the periods of observation), I did not witness the aggressive and violent man that had been painted in his admission notes. According to the Deputy Ward Manager this presentation was usually displayed during personal care interventions and more often at night “it’s usually two staff that go in, but when they say they’re having a bad night it’s three, two need to hold in restraints while the other person gets him ready” because if not “he head butts, spits, kicks, tries to trip staff up.” However, my observation protocol did not allow me to observe during personal care interventions where privacy may be compromised; therefore I cannot bear personal witness to these actions. The following is a selection of reporting’s from my observation of the Brian that I saw within the ward environment.

Tuesday in October 2015 11.40hrs: There are 13 patients in the day area and three staff. Two of the staff are sitting with patients and the third is sitting in a chair not engaging with anyone. The radio is playing. A fourth member of staff starts to serve hot drinks. I am sat near the ward office doorway. All the patients except Brian are sitting in the lounge area. Brian is walking round asking to go home. No one answers him. The female nursing assistant serving the drinks tells him to sit down and have a cup of tea, she reassures him that his wife is coming later and then walks off. Brian follows still trying to engage but the nursing assistant is now seeing to another patient. She tells Brian to sit down pointing to the chair he is to sit in. The nursing assistant then goes and sits at a dining table and Brian stands looking at her questioningly. Brian then goes to the occupational therapist who has just entered the day area. She talks to him briefly and leaves. Brian stands and watches her. I remain seated in the same place watching Brian and he seems unaware of my presence. However, I find it hard not to get up and go to him. Staff appear unaware of his anxiety or that he is seeking them out.

Tuesday in October 2015 14.00hrs: There are 14 patients and three staff in the day area. Two members of staff are sitting with three patients at a dining table and the other staff member is sitting in the lounge area. There are three male patients and one female patient walking around the dining area. Seven of the patients who are sitting in arm chairs are asleep. The radio is still playing and other than that, the noise level on the ward is quiet. For the afternoon shift that day there are eight staff on duty, two qualified nurses and six
nursing assistants. I position myself in the far corner of the dining room. At the beginning of my observations Brian is sitting in the chair in the lounge but almost immediately he gets up and starts walking around the day area. His walking is slow and he is constantly looking at the environment in which he is in. Facialy, he looks puzzled as if he is trying to work out why he is there.

14.05: The female nursing assistant, who is sitting in the lounge, starts dancing with a male patient. Brian sees this and smiles, and he walks towards them. He stops near them and stands and watches the other four patients who are walking around the day area. Brian moves towards a female nursing assistant seeking contact with her. He asks her where she is going. The nursing assistant responds that she does not know where she is going. Brian says to her “I think I am going around the bend”. The nursing assistant does not respond to Brian and goes to see to another patient. Brian is left standing there alone looking and watching.

Tuesday in October 2015 11.30hrs: There are currently 16 patients on the ward. Of these 16 patients one is continuous observations; three are on one in every ten minute observations and two on one in every 15 minute observations. There are six staff on duty, two of whom are qualified nurses. I sit at the dining table in the corner. There are 10 patients in the lounge area. There are two nursing assistants in the lounge, one of whom is observing a lady on continuous observations. Three patients are in the rehabilitation kitchen baking jam tarts. They are accompanied by an occupational therapy assistant, nursing assistant and a student occupational therapist. The radio is playing and the atmosphere feels calm. Brian is sat in the lounge in a chair under the window and is watching the staff in the lounge.

11.35: Brian gets up and walks around the dining room, he makes his way to the rehabilitation kitchen; he stops at the open door and looks in. He does not speak. He then walks to the ward door and looks through the glass into the ‘airlock’. He cannot access this space.

11:40: Brian walks out of the lounge toward the bedroom corridor area, then back to the lounge. He goes to the lounge window and looks out at the garden. The physical health nurse walks through the dayroom greeting all the patients she sees by name. Brian moves
to the garden door and looks out at the garden. Brian notices me sitting at the table. He walks towards me and asks me how I am. I tell him ‘I’m good thank you; how are you?’ He replies ‘dreadlington’, smiles at me and then walks off back around the lounge area and then toward the bedroom corridor. Even though he smiles at me, he looks anxious and sad.

**Friday in December 2015 11.00hrs:** The ward is full, there are 18 patients. The morning shift has seven staff on duty; one of these is a qualified nurse. There is one patient on continuous observation and two patients on one in every ten minute observations. I sit in the ward office doorway. There are 10 patients in the day area, three of whom are walking around. There are two nursing assistants who are not regular staff. The radio is on. Brian is one of the three patients walking around. Each time he comes to a window he stops and looks out at the ward garden. Another nursing assistant comes into the day area and generally asks the patients ‘are they okay?’ Brian keeps walking from window to window and looking out. He then walks around the day area. His gait is a little stooped, his steps are shuffling and he keeps stopping and looking around.

11.10: Brian slowly walks around the day area looking and watching those who are in it, he then makes his way toward the male bedroom area and walks into the male bedroom corridor. In the day area there is a sudden flurry of activity as three qualified staff arrive on the ward at the same time as two doctors. Only one of these staff engages with the patients in the day area, all the others disappear into various offices. There is a male patient pushing lounge chairs and dining chairs across the floor. The chairs are making loud screeching noises on the floor. A nursing assistant intervenes and tells the patient to ‘stop’ but she does not give him anything else to do instead.

11.20: Brian returns into the day area and continues to walk around. He moves around the walls of the ward, looking out of windows or stopping and looking at every notice, sign or picture on the wall. Every now and again he just stops and looks around at people in the day area. He looks puzzled by his surroundings like he is trying to make sense of it all. No staff members have engaged with him during this entire period of observation.

**Monday in December 2015 14.30hrs:** There are 18 patients on the ward; it is full. There is one patient on continuous observations and four on one in 10 minute observations; three of which change to continuous observation when the individual is mobilising. There are
seven staff on duty, three of whom are qualified. I sit in a corner in the dining room. ‘Singing for Brains’ has set up in the lounge area. It consists of a keyboard player, a singer and a number of volunteers. In the lounge area are 14 patients, six staff and six ‘Singing for Brains’ volunteers. The only patient who is walking about is a lady on continuous observations and her visitor who is walking with her. I notice that all the male patients who are usually walking around are sat in the singing group. Copies of the songs are handed out to patients and staff. Staff and ‘Singing for Brains’ volunteers situate themselves with patients so they can assist. Brian is sat in the group.

14.40: The singing commences; today it is a mixture of Christmas songs from the 1940s, 50s and 60s. All the patients in the group are joining in some way either singing, or looking at the song sheet or tapping feet with the exception of Brian who is sat staring ahead. He does not appear upset but his expression is difficult to read. The ward seems full with the patients, relatives, volunteers. Now there are three patients walking around. An occupational therapy assistant is dancing with one of the male patients.

14.50: Brian is still sat in the group but has not indicated any signs of participating. A ‘Singing for Brains’ volunteer comes and sits next to Brian. She holds his hand while she is singing ‘jingle bells’. She moves his hands in time to the music. Brian still does not sing. He looks at the volunteer, he does not pull his hands away but he makes no attempt to move them to the music himself.

14.55: Brian is now playing with his hands. The volunteer is still sat next to him. I notice that Brian’s face has a number of red patches on it and I wonder if it is psoriasis.

15.00: ‘Singing for Brains’ starts to wind down. They finish with a calm relaxing song and a staff member goes to make a drink. Brian is still sat in the chair. His head is looking down at his thigh. He appears tense and distressed.

15.10: Brian is still sat in the same chair. His distress continues. He is crying and covering his face with his handkerchief. Two ‘Singing for Brains’ volunteers try to comfort him but he continues to cry. Hot drinks are being given out by a nursing assistant. Music is now playing in the background. The ward is noisy with talking and occasional laughter. A male patient is walking around the day area. There is now one volunteer trying to comfort Brian.
She is rubbing his arm; she looks uncomfortable and at a loss as to what to say. There are nursing staff in the day area but they do not come over.

15:15: Brian still looks upset and distressed. He gets up out of the chair and walks away from the volunteer. He walks across the lounge towards the Christmas tree. He stands near the tree and looks through the window out to the garden. He stays like this for a minute or so. He looks sad and wistful. He turns and moves to the sofa next to a male patient who was asleep. Brian sits on the edge of the sofa. His chin is resting on his hand and he is staring ahead. He looks sad and lost.

15.20: Brian has got up and is now walking around. He continues to appear distressed. He is crying again. A volunteer comes and hugs him but he does not respond. The volunteer gets the attention of a nursing assistant and passes Brian to him, and the volunteer moves away as ‘Singing for Brains’ group is getting ready to leave the ward. Brian says to the nursing assistant “I am going to die”. In response to this statement the nursing assistant offers Brian a drink. Brian takes the drink and sits in the chair. The nursing assistant has moved away. Brian is left sitting in the chair alone with his drink looking sad and distressed. The patients and staff on the ward continue without connecting with Brian. He is left to his distress, in a busy ward, alone.

Clinical Reflection Points
Observing Brian within the ward environment made me realise that complexity is not always overt and can often be ‘more than the eye can see’. Brian’s admission notes painted an image of a violent and aggressive man and these behaviours were also reflected when the Deputy Ward Manager discussed his presentation on personal care interventions. However, whilst I am not disputing that that behaviour occurred, my observations led me see other facets to Brian’s presentation. These are detailed below and are a synthesis of my period of time with Brian and note-taking.

- **Watching and Sense Making**: My observations enabled me to see a man who seemed to be constantly looking, observing and trying to make sense of his environment and where he was. He would spend hours constantly walking around the day area stopping and reading every notice, looking through office windows, looking out of the window to the garden or just standing and looking at other
patients on the ward. He often had a quizzical look on his face as if he was trying to make sense of where he was and why he was there. It was as if he knew he was not in a familiar environment and could not be at ease there.

- **Seeking and Yet Alone:** Brian made no attempt to interact or engage with any of the other patients on the ward. However, he would frequently approach the staff to try and engage with them. On these occasions it was not unusual for the staff to engage with Brian briefly and then tell him to ‘sit down’ or they would go about their business and leave him. At this point though it would be as if Brian did not want to disconnect and his gaze would follow them, or he would get up and move toward them again. Yet staff never seemed to see this or sense his need for connection. Brian never approached other patients suggesting he was able to differentiate between staff and patients. On a number of occasions I wondered if staff were actually aware of his level of internal distress, or if they just become accustomed to it, or if it is the patients who are louder and more outwardly disturbed that get (all) the attention.

- **Listening but Not Hearing, Seeing but not Seeing:** On a number of occasions Brian looked facially distressed or would be tearful and yet staff did not seem to recognise this or make the first connection with Brian. He frequently appeared anxious and, more often than not, distressed. He seemed to know he was not at home. I often heard him make statements like ‘I want to die’ or asking ‘to go home’ or asking ‘where is my wife?’ On one occasion, when he told a staff member he wanted to die they responded by offering him a drink. It was as if they saw him but did not really see the emotions he was experiencing. Staff heard his voice yet did not listen to the words he was saying or hear/feel the emotionally charged silences.

### 4.4.4 Case Study 2: Eric

**Main Storyline:** *The changing faces of complexity.*

**Case Study Overview**

The second case study demonstrates how complexity for some individuals is not a static state, but is, instead, a dynamic one where the many faces of complexity change and evolve over time. In this case, Eric’s wife, Anna, and his Consultant Psychiatrist, talk
about how, since admission, Eric’s complexity changed in its presentation to another state altogether, that of a terminal stage of dementia. For Eric, therefore, this changing face of complexity developed in tandem with the progression of his dementia and demonstrates that even when an individual’s behaviour stabilises they still present as being complex.

The data collected for Eric comprised an interview with Anna, an interview with the Consultant Psychiatrist, a review of his care records and a limited number of periods of observation. As Eric’s condition rapidly deteriorated at the time I recruited Eric into the study, my observations of him are limited. This is because he was actually discharged soon after on continuing care fast track funding to a nursing home for end-of-life care. An outline of the periods of observation is detailed below in Table 4.3

### Table 4.3 Summary of Periods of Observations for Eric

<table>
<thead>
<tr>
<th>Date Range</th>
<th>Periods of Observation</th>
<th>Locations</th>
<th>Longest Observation</th>
<th>Shortest Observation</th>
<th>Total Hours</th>
</tr>
</thead>
<tbody>
<tr>
<td>October 2015</td>
<td>2</td>
<td>Day area Bedroom</td>
<td>30mins</td>
<td>30mins</td>
<td>1hour</td>
</tr>
</tbody>
</table>

**Background Details**

Eric is 78 years old, married and has a son and a daughter. Eric was diagnosed with vascular dementia approximately four years ago. He was admitted to Jasmine ward during the afternoon in March 2015 from a general nursing home where he had been admitted for a period of respite care. He had been there for approximately six weeks. Prior to this, Eric had been living at home with his wife. This was an emergency admission as the nursing home staff were unable to manage his behaviour as he was reported to be ‘aggressive on personal care’ and there had been reported incidents of ‘impulsive aggression’. Eric’s admission was a compulsory one and he was detained under the Mental Health Act (DH, 1983). On the ward he was allocated his own bedroom in the male sleeping area. Eric had a selection of his own clothes and toiletries and a couple of framed family photographs.

As well as having vascular dementia Eric had a number of comorbid physical conditions which included a previous spontaneous pneumothorax, varicose veins, osteoarthritis, stroke when he was in his 40’s and a history of constipation. Although he had been prescribed a
number of medications since his admission, at the time Eric was recruited into the research study these had been reduced to just essential items. These are detailed in Table 4.4.

Table 4.4 List of Prescribed Medications for Eric

<table>
<thead>
<tr>
<th>Medication</th>
<th>Route</th>
<th>Dose</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Buprenorphine</td>
<td>Transdermal patch</td>
<td>10ug/h</td>
<td>Weekly</td>
</tr>
<tr>
<td>Sodium Valproate</td>
<td>Orally</td>
<td>50mg</td>
<td>BD</td>
</tr>
<tr>
<td>Ibuprofen</td>
<td>Orally</td>
<td>400mg</td>
<td>TDS</td>
</tr>
</tbody>
</table>

Whilst Eric was on the ward his wife would visit him daily and his children would also visit him when they could.

Eric’s compulsory admission into a mental health NHS dementia inpatient ward and the reasons for the admission seemed to come as a surprise to Anna. Anna had never observed the aggression and agitation Eric was displaying in the nursing home which led to his emergency admission into hospital. She shared “funnily enough it was never in front of me and I was quite surprised when they did tell me what was going on [nursing home staff].” When talking about Eric’s admission Anna indicated that she knew his admission was for ‘an assessment.’ Whilst she knew his illness could not be cured she hoped that a medication could be found that would help stop his agitation and he would become calmer. Ideally, Anna wished that Eric would be able to return home to live. Little did Anna know at the point of admission that Eric would rapidly deteriorate with a range of changing and evolving presentations and reach end-of-life.

Not dissimilarly, Eric’s Consultant Psychiatrist, whilst acknowledging that dementia isn’t a curable condition, informed me that the aim of admission was to “stabilise him, stabilise his mental health.” However, for Eric, this aim of stability proved to be an ongoing challenge as his presentation was forever changing. For example, initially, after admission, Eric’s presentation of agitated and aggressive behaviour increased in intensity and severity. Anna informed that he was like a “Jekyll and Hyde” and he would be extremely aggressive towards her when she visited. He would lash out at her and swear at her. She
told me that Eric would look at her and his facial expression would change and the look on his face would “frighten her.” This agitated and aggressive behaviour was also seen by the clinical team. Eric’s Consultant Psychiatrist informed that he could be “very restless on personal care interventions.” Eric’s awareness of risk had also deteriorated which required staff to intervene for his safety: this would then cause Eric to become increasingly aggressive or resistive as he did not understand what was happening. At the same time, Eric also began to experience symptoms of psychosis and he was experiencing visual hallucinations which were causing him distress.

From this point onwards it seems that Eric’s presentation, and needs, never reached a point of stability. In fact, his presentation was one of constant deterioration. The changes discussed by both Anna and his Consultant Psychiatrist included refusing medication, extreme sensitivity to medication, refusing food and fluids, swallowing problems, weight loss, changes to mobility and having falls and becoming immobile. Eric also experienced numerous physical health concerns and these included urinary tract infections, transient ischemic attacks, myoclonic jerks and pain in his right side following a dense stroke a number of years ago. Coupled with these changes was the fact that Eric was not able to verbally communicate his needs and would become frustrated when he could not say what he wanted to say and that, as a result of his dementia, the clinical team believed he did not have the capacity to understand his needs or required interventions.

Both Anna and Eric’s Consultant Psychiatrist tell a story of Eric’s complexity consisting of a mix of behaviour, cognitive, physical, medication and impaired insight problems which, despite numerous interventions, continue to evolve and deepen. When they talked about Eric, a picture emerged of a man with numerous health needs and, as one area started to stabilise, another area would become unstable. Indeed, as Eric’s Consultant Psychiatrist explained, in his last few weeks on the ward, Eric’s complexity had moved to “the physical side of things.”

When Eric was admitted to the mental health NHS inpatient dementia ward, his Consultant Psychiatrist believed that, at that time, his dementia was in the ‘moderate stages’, but, due to his progressive deterioration during admission, his dementia advanced to ‘severe’. Eric’s presentation had deteriorated to the point where the clinical team believed he was rapidly approaching end-of-life. This, in itself, presented with yet another layer of complexity as,
because Eric had become more physically frail and less mobile, he was now at risk from other patients on Jasmine ward whose behaviours included severe intrusiveness and impulsive and unpredictable actions. This was the reason Eric’s discharge was being planned so his end-of-life care needs could be met in a more suitable environment.

When talking about Eric’s illness and deterioration which has occurred during his admission, Anna shared that the hardest part for her has been the changes in personality that the illness had brought about for her husband, and the fact that she knows she is going to lose him.

**Care Record Review**

Eric’s care records reported his admission in the following way: “staff in the nursing home are unable to cope with Eric’s agitation and aggression. There had been injury to staff other residents and property”. His presentation on admission to the ward was summarised as being “restless and non-compliant, he was refusing medication and required covert medication”. Eric’s behaviour was also described as consisting of “unpredictable aggression and agitation.”

The risk assessment at the time of admission reported that Eric was: very challenging, would “hit out” at staff and family that he was refusing all medication, his mobility was poor and that he had a urinary tract infection which was believed to be causing increased aggression. Some of these documented risks correlated to the complexities which were discussed by his Consultant Psychiatrist. At the time of his care record review, his most current risk assessment captured how Eric’s presentation had changed since his admission. The risks were identified as he still required covert medication to be administered, and that he could still be resistive to care interventions, his diet and fluid intake was poor but due to a decline in his physical health he had been placed on an end-of-life care plan.

When the two risk assessments are compared it was evident that, over the course of his admission, Eric’s complexity had changed. The presentation of behaviour that he was admitted with had reduced in frequency and severity, but in turn this had been replaced symptoms which indicated a rapid decline in his physical presentation. Eric’s care plan, although lacking in the detail of interventions, did give an insight into the number of needs
that he had at the time of the care record review. These were identified as full assistance with diet and fluids, risk of falls, can be aggressive, assistance required with personal care, pain, constipation, risk of developing pressure ulcers and in the event of a cardiac arrest a ‘do not attempt resuscitation’ care plan. The interventions detailed in each care plan were brief but included statements such as: “provide pressure area care, undertake a pain assessment, requires 3 staff on interventions, refer to dietician, requires 1:1 observations.” These care plans and statements again reflect that changing presentation of Eric to one where meeting his physical health care need is the priority.

The care records demonstrated that Eric had been reviewed by the medical team on numerous occasions. Reasons for these reviews seemed to concentrate on changes to his physical health, for example: “he appeared unwell, his overall presentation had deteriorated and he had developed twitches/ jerks, he had fallen.” This frequency of medical review is perhaps indicative of Eric’s changing complex needs and rapid physical decline. The notes documented that Eric’s discharge was being planned. As opposed to a discharge being planned because an individual’s condition has stabilised, Eric’s care records indicated that, from admission, his presentation had been forever changing. A fast-track application for continuing healthcare funding had been made as the care team believed Eric to have a rapidly deteriorating condition which was entering the terminal phase. In essence, the care team believed that Eric was now in the dying phase and was being discharged to a nursing home to receive end-of-life care.

Words frequently occurring in the daily progress notes included: “unsettled”, “restless”, “resistive to personal care”, “slept well”, “difficult”, “frustrated”, “agitated”, “deteriorating”, “less aggressive”, “mobility deteriorated”. Some of the progress notes reflected issues that were documented in his care plans, but the progress notes did not make specific reference to these care plans. There was nothing in the progress notes that demonstrated that staff were exploring the possible reasons why Eric was displaying certain behaviours, or any evidence of any non-pharmacological interventions being deployed.
Observations on the Ward

Due to the rapid deterioration in Eric’s condition, I only had the opportunity to observe him on two occasions in the ward environment before he was transferred to a nursing home. One was in the lounge area and one was in his room. The observation in his room was at his wife’s invitation as she was visiting with him and asked me to sit with them both for a while and undertake the observation in his room. The ward manager also agreed at the time that this was acceptable. These observations are detailed below.

Thursday in October 2015 12.00hrs: The ward is full with 18 male patients. There is seven staff working an early shift, three of whom are qualified. There is one patient on continuous observations and two patients on one in every fifteen minute observations. I sit in the dining area so that I can observe the whole ward. Eric is dressed in trousers, slippers, a shirt and a jumper and he is sat in a straight back arm chair which is situated under the window in the lounge area. He is asleep. The radio is playing. There are two nursing assistants in the day area and three housekeepers are sitting at a dining room table having a break. Along with Eric there are eight other patients in the day area, three of whom are walking around. One of the female patients sitting in the lounge area is shouting at staff for getting her out of bed. Compared with the other patients in the day area, Eric looks frailer and somehow more vulnerable.

12:05: Eric is awake and his eyes are open. The noise level on the ward is quiet. There are two nursing assistants in the day area. They are standing together, talking. Eric is aware of their presence as he is watching them. They are talking socially and their conversation is not work related. They are unaware that he is watching them and make no attempt to engage with him.

12:10: The noise level on the ward has increased. A female patient is shouting “shut up! shut up!” and another female patient has repeatedly shouted for a cup of tea. Eric remains in the same position in the chair, with his posture supported by two pillows. He has made no attempt to move. I am not even sure if he can move without any assistance. On observation he does not appear to be in discomfort or any distress. His eyes are open and his head is leaning to the left. A nursing assistant has placed herself in the empty chair next
to him, but she has not made any visual, verbal or physical contact with Eric. I want to ask her to engage with Eric and to see if he is comfortable.

12.15: More patients now enter the day area. They have just come out of a baking group with the occupational therapist. A staff nurse comes into the lounge area and discusses breaks with two nursing assistants. Eric’s eyes are closed as if he is asleep. His head remains leaning to the left. I want to get up and readjust his head as I am sure the position he is in will result in him getting neck pain and stiffness.

12.15 – 12.30: Eric remains in the chair in the same position with his eyes closed looking like he is asleep. A female patient is sitting close to Eric and is repeatedly shouting out a female nursing assistant. He gives no indication that the noise of the ward is disturbing him. In the last half an hour his position in the chair has not altered once. None of the staff have made any verbal visual or physical contact with him during this timeframe.

Wednesday in October 2015 14.00hrs: When I arrive on the ward to undertake observation, nursing staff tell me that Eric is in bed. I am informed that he had physically deteriorated and that the clinical team feel he may be approaching end-of-life. I am further informed that his consultant psychiatrist had made a fast-track application for continuing care to enable him to be quickly moved into a nursing home where his palliative and end-of-life care needs could be met. I thank the staff for updating me and, as I walk out of the nursing office, Anna, Eric’s wife, is walking towards me from the bedroom area of the ward. Anna asked me if I would like to observe Eric in his room. I explain that I do not expect this as I do not wish to intrude upon her time with him. She informs me that she would like me to. In line with the research protocol I check that this is permissible with the ward manager, who agrees.

Anna and I walk together towards Eric’s bedroom. His room is situated to on the left bedroom corridor from the day area and it is the first bedroom you come to. To get access to the bedrooms you have to go through a set of double doors which can only be accessed by a swipe card which the staff have access to. We are let through the double doors by a nursing assistant. Compared with the day area, the bedroom corridor feels quiet and still. I notice that there is a button that can be pressed enabling the double doors to open allowing us to exit the bedroom corridor without needing a member of staff. Notwithstanding this
opportunity to exit, this corridor and the doors give the feeling of a sense of isolation away from the busy day area.

The door to Eric’s bedroom has a glass panel in it. This panel has a small curtain pulled across preventing anyone from looking into the room. His door is closed but Anna opens it, walks in and invites me to enter Eric’s room. The room has a bed located against the wall and there is also a small draw unit, a wardrobe, a sink and two chairs. I notice a couple of family photographs standing on the chest of drawers. There is a window in the room and the curtains had been pulled across; I assume that this is to give a sense of privacy as the room currently looks out onto what used to be a car park, but at the time, was being developed into another ward. Anna sits in a chair and asks me to sit with her. As I do so I quietly greet Eric. He is lying in bed in a right lateral recumbent position with his face to the wall. He gives no verbal or non-verbal indication that he is aware of my presence; he appears to be sleeping. He looks peaceful and not in any pain or distress. I become aware of a ‘hissing noise’ in the room and realise that Eric is in a profiling bed and lay on a pressure relieving air mattress. The hissing noise is the sound of the pump as air is circulated within the mattress.

Anna seems to take some comfort in having someone sit in the room with her. She tells me how, even though she knew Eric was deteriorating, this further decline has come as such a shock to her. She looks upset and uncertain, as if she is trying to make sense of the change of events. Anna is also concerned that Eric has to move to another facility as it’s another change to make and exposure to yet more people who don’t know them. I let her talk and then we sit in a comfortable silence. Every now and again she reassures Eric verbally or gets up and strokes his head.

14:20: After about 20 minutes Eric starts to move in the bed. I stand and I can see that he is now awake. He eyes are open and I can see his mouth opening and closing as if he is trying to speak, but no words are coming out. He appears restless, his legs keep moving but he seems unable to alter his own position. Anna is stroking the back of his head and verbally reassuring him but he cannot see her. I wonder if this restlessness is because he recognises her voice but cannot see her. With Anna’s permission I leave the room and approach the ward staff. I ask if they could see to Eric and I share with them that I wondered if some of this current restlessness was distress based in that he was lay in bed
facing the wall and could not see his wife but could hear her. The qualified nurse informs me that they will go and attend to Eric. I go back and tell Anna and then I say my goodbyes and leave as the nursing staff arrive.

Clinical Reflection Points
Interviewing Eric’s wife and Consultant Psychiatrist enabled me see a real picture of the changing faces of complexity. It is not a static entity but a state which for some is forever changing and evolving and as one area stabilises another becomes complex. My clinical reflections from the interviews, review of the care records and my brief observations of Eric are detailed below.

- **Always Changing Never Stabilising**: Conversations with Anna and Eric’s Consultant Psychiatrist revealed that they both concurred that Eric had been admitted for a period for assessment to stabilise him. However, sadly for Eric, that envisaged stabilisation did not occur. Instead, his admission marked the start of a rapid decline both mentally and physically. Despite numerous interventions, Eric did not reach an overall level of stability. As one symptom or presentation seemed to become less complex, or stabilise, another appeared to take its place. How must this have been for Anna, who was forever waiting and watching for her husband to stabilise enough so she can have him home, and for a care team who, for all intent and purposes, were unable to stabilise the rapid decline which was occurring. This also leads one to question the effect that this type of presentation also has on the family and the care team. As a care team you aim is to treat symptoms and help an individual’s presentation stabilise and, ideally, improve. Yet, in the case of Eric, despite all the interventions and best intentions, he continued to deteriorate with a range of symptoms.

- **When Medication Makes it Worse … Not Better**: The interview with Eric’s Consultant Psychiatrist identified that, sometimes, healthcare interventions can inadvertently cause other symptoms to occur which then further contribute towards the complexity and deterioration. In Eric’s case, this was demonstrated when he was prescribed antipsychotic medication in an attempt to help reduce his agitation and treat the visual hallucinations he was experiencing. Unfortunately, for Eric, he experienced sensitivity to the medication and his Consultant Psychiatrist informed
Eric experienced “severe extrapyramidal side effects and there was an issue with his blood pressure.” Even when the medication was changed to a different antipsychotic, his sensitivity continued and he started falling. This resulted in this medication being discontinued as it was further contributing to his complexity.

- **The Layers of Complexity:** Eric’s case highlights the range of complexity that can be experienced by an individual and the skills needed by clinical staff to meet these needs. In Eric’s case this range started with his mental health needs and his behaviour and stemmed into numerous physical health care needs as his condition further deteriorated. He was in an environment where his needs were being met predominantly by mental health staff. Eric’s case highlights that in order to provide care for people with complex presentations of dementia, care staffs’ knowledge and skills need to transcend mental health skills and also embrace physical health knowledge and skills. These two domains, in the case of dementia, are inextricably linked.

- **The Vulnerability of End-of-Life:** My observations of Eric showed me a man who appeared reliant upon staff for all aspects of his existence and care. He was unable to independently mobilise, feed himself, see to his personal needs and verbally articulate his thoughts and feelings. He was not even able to re-adjust his position when in bed or in the chair. Despite nursing many people over the years who had similarities with Eric, observing him made me fully realise just how vulnerable this state must be. Eric was in a mental health NHS dementia inpatient ward and was believed to be at the end-of-life and reliant upon others to meet all of his needs for him. He was surrounded by patients who were in many ways much more robust in their presentations. Although he had walked into the ward as one of these seemingly robust individuals, he was at the end of his life a few weeks later, and robbed of a stable care environment as he no longer met the criteria for being on a mental health NHS dementia inpatient ward. This, in turn, necessitated a further move to yet another care environment that was not his home. For Anna, this was another transition she had to face and deal with as her husband was dying. The told and untold story here is that Anna lost the familiarity of the nurses with whom, over the preceding months, she had got to know and establish a relationship with. At the very least, organisational and environmental planning for relationship continuity in complexity seemed lacking.
4.4.5 Case Study 3: Charlotte

Main Storyline: “Only my family can help.”

Case Study Overview
The third case demonstrates how, for some patients, complexity is not just the number and severity of need, but also about the emotional state of the individual and who they connect with to allow care interventions. In this case, Charlotte has multiple needs of which she was dependent upon others to meet and she is only willing for her family to provide this support. In addition, Charlotte can spend protracted periods of time distressed, perplexed and agitated where she will be shouting and swearing. This complexity is further compounded as Charlotte is currently receiving care and treatment in a mental health NHS dementia inpatient ward and is reliant upon staff to meet all of her needs. The difficulty is that she is not willing to allow staff to undertake these interventions and refuses to accept diet, fluids and medication off anyone other than her close family. The data collected for Charlotte consisted of an interview with Harry her husband, an interview with her Named Nurse Linda, a review of her health care records and a number of periods of observation. An outline of the periods of observations is detailed below in Table 4.5

Table 4.5 Summary of Periods of Observations for Charlotte

<table>
<thead>
<tr>
<th>Date Range</th>
<th>Periods of Observation</th>
<th>Locations</th>
<th>Longest Observation</th>
<th>Shortest Observation</th>
<th>Total Hours</th>
</tr>
</thead>
<tbody>
<tr>
<td>November – December 2015</td>
<td>8</td>
<td>Day area</td>
<td>1 hr 5 mins</td>
<td>30 mins</td>
<td>7 hrs 55mins</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Female lounge</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Background Details
Charlotte is 71 years old, married and has a son. She was diagnosed with young onset Alzheimer’s disease when she was 64 years old. Charlotte was admitted to Jasmine ward during an afternoon in July 2015. She had been transferred to the ward from the local acute general hospital where she had been a patient for a couple of weeks. Charlotte had initially been admitted to the general hospital as she had had an adverse reaction to a medication
and had stopped mobilising. Prior to this, Charlotte had been living at home with Harry, her husband, and he was her main carer. Charlotte’s admission was a compulsory one and she was detained under the Mental Health Act (DH, 1983). Charlotte had a selection of her own clothes with her and some toiletries but no other personal possessions.

Charlotte appeared to be in good physical health. She was a previous smoker, having stopped smoking three years prior to her admission. A recent blood test had identified that she had raised calcium but this did not require treatment. Charlotte was prescribed a number of regular and when required (PRN) medications. These are detailed below in Table 4.6.

Whilst on the ward Charlotte would be visited by her husband, son, brother and uncle. Between them they ensured that she was visited twice a day every day.

<table>
<thead>
<tr>
<th>Medication</th>
<th>Route</th>
<th>Dose</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lorazepam</td>
<td>Orally</td>
<td>500mcg</td>
<td>PRN</td>
</tr>
<tr>
<td>Zopiclone</td>
<td>Orally</td>
<td>7.5mg</td>
<td>PRN</td>
</tr>
<tr>
<td>Fortisip Compact</td>
<td>Orally</td>
<td>one</td>
<td>BD</td>
</tr>
<tr>
<td>Clonazepam</td>
<td>Orally</td>
<td>250mcg</td>
<td>12.00hrs</td>
</tr>
<tr>
<td>Rivastigmine transdermal patch</td>
<td>Transdermal</td>
<td>9.5mg /24hrs</td>
<td>Daily</td>
</tr>
<tr>
<td>Trazodone</td>
<td>Orally</td>
<td>100mg</td>
<td>Daily</td>
</tr>
<tr>
<td>Cinicalcet</td>
<td>Orally</td>
<td>30mg</td>
<td>Daily</td>
</tr>
</tbody>
</table>

When Charlotte was in the general hospital, Harry was made aware that she was going to be transferred to Jasmine ward as the staff experienced difficulty in caring for Charlotte. This was because of Charlotte’s behaviour, as Harry shared:
“When she was on [general ward’s name] she really kicked off and they were having a time to control her. When I went to visit from walking, you know, 100 yards away from the ward I could hear her. She had really, really kicked off.”

As a result of her presentation, Harry was in agreement with the transfer to Jasmine ward for further assessment. On Jasmine ward Harry informed me that Charlotte resists all interventions/staff attempts at help, such as “changing her pad or dressing her or feeding her” and for the first month of Charlotte’s admission, Harry visited daily as he was having to feed, give drinks and medication to his wife. As Harry shared, this was because she “wouldn’t allow anyone else to do it” and, when staff tried, Charlotte “moved their hand out of the way, she would give of a lot of bad language, swearing and pushing.”

When Harry was caring for Charlotte at home he had developed his own approach to caring for her when she became angry and agitated and this consisted of “waiting for her to settle down before I can even look her directly in the eye and talk to her.” Finding opportunities for Charlotte to have a bit of space and calm down were crucial as if the timing is wrong, Harry described the changes in his wife’s behaviour as like “knocking a switch on and off.” Once Charlotte’s assessment was complete, Harry wanted her to return home as he was concerned that a nursing home would not be able to meet her needs. Harry shared “[the] only way I can be sure that she’s ok is if I can have her with me; but I know that I would need help.”

When Harry talks about the affect dementia has had on Charlotte he says that the hardest thing to deal with is the change that the illness has brought to his wife. He shared a story of Charlotte being nick-named “Encyclopaedia Britannica” such was the level of her general knowledge. He moved on to say that:

“Now when you see the way she is, I mean, I’m looking at Charlotte, talking to Charlotte, but she is not the Charlotte I’ve been married to all these years, but I’m looking at her and I love her just as much now as I did then.”

It was clear that the instability in Charlotte’s presentation in recent months caused her husband significant distress. Harry talks about his feelings when he leaves the ward after visiting in the following way:
“I’ve gone home and I’ve, sort of, felt so dejected by the stuff. Because of what it is, thinking that the person that matters more to me than anyone ever has, has got this damned awful disease and there’s not a thing I can do about it. Because in the past, when there’s ever been anything, I’ve done things with her and she’s always been able to rely on me and in a funny kind of way, I, kind of, feel that I’ve let her down or she might think…I’m thinking she might think I’ve let her down, because I’m not there for her. But I know that’s not the case, because she can’t think like that.”

The sense of helplessness, loss and guilt that Harry is feeling when he is talking with me is palpable.

Charlotte’s Named Nurse, Linda, believed that by the time Charlotte was admitted to Jasmine ward she was “probably, sort of, fairly advanced in her dementia” and as a result of this she was not able to make any choices “regarding attending to her own personal care and recognising her own needs.” This meant that if she was left she on her own she would not recognise that she needed to change her clothes, take herself to the toilet, get up and dressed, or ask for a drink or food. Linda feels that Charlotte’s admission to the ward for an assessment was appropriate and, if anything, she “could have done with being admitted a little bit sooner” because of the high degree of anger and aggression Harry had been dealing with when she was at home. When she was admitted, Linda recalls that Charlotte presented as being “really angry, very angry all the time.” From Linda’s perspective as Charlotte’s Named Nurse, the purpose of admission was:

“... to try and reduce this agitation, to try to get her used to accepting assistance with her personal care and for her to take regular diet and fluids, and we thought, at that time, that maybe the use of appropriate medication would help this.”

Charlotte’s refusal to accept food, fluids and medication from staff has been present since admission and it has remained unchanged despite ongoing attempts from nursing staff. When Linda talks about this you can see the worry and concern on her face. She acknowledges that, in the main, Charlotte’s anger has reduced in intensity and her periods of shouting and swearing have lessened, and although she still refuses personal care interventions, her anger and restiveness has abated somewhat. However, Charlotte’s
refusal to accept diet fluids and medication from staff has not changed at all. Linda tells me:

“It’s so difficult really. She persists in not taking much diet from us at all. She will take some things. She’ll have the occasional biscuit, a bit of a banana maybe. She might have a little bit of dessert now and again but it’s not that consistent that it would meet her needs really.”

Consequently, Harry and close family come to the ward twice a day to undertake this intervention with Charlotte. Linda acknowledges that if the family were not able to do this then they would really struggle and Charlotte would become “a lot more complex because we wouldn’t have an identified intervention that worked”. When reflecting upon Charlotte, Linda describes her as being “one of the most challenging people that I have ever had to look after.”

Care Record Review
Charlotte’s care records reported that she was “transferred [to the ward] from the general hospital where she had been admitted following a fall” and that she “had also had haloperidol at home and could not move the day after”. They furthermore made reference as to why she was admitted to the mental health NHS dementia inpatient ward Charlotte’s “behaviour was difficult to manage on the general ward and admission on a Section 2 was arranged for assessment”. On the general ward, Charlotte was displaying behaviour that challenges and was non-compliant with medication and diets. Her immediate presentation on admission to Jasmine ward was summarised as “presenting as very agitated, shouting and swearing.”

Both Charlotte’s risk assessment and care plan provided an insight into Charlotte’s multiple risks, needs and required interventions. Factors reported on the risk assessment included that Charlotte could be abusive to staff and fellow patients, she was resistive to personal care interventions and treatments, she could be violent to staff, she was very sensitive to medication, was at increased risk of falls and would only accept medication, food and fluid from her family. Her risk management plan included interventions such as: monitoring diet and fluids to ensure adequate hydration and fluid; and to use a skilled
approach during personal care to ensure the safety of Charlotte and staff and to reduce any distress. However, it did not specify what constitutes a skilled approach.

The results of a number of nursing assessments were located in Charlotte’s care records and included falls assessments, depression assessment, nutrition assessment, continuing health care assessment and specialist health needs assessment. The specialist health needs assessment was by far the most detailed assessment located in Charlotte’s health care record. This is an assessment which is undertaken by an individual’s care coordinator to support discharge planning from hospital and is presented to health and social care funding panels to support applications for discharge funding. The aim of the document is to identify an individual’s needs and the level of care they require. In Charlotte’s case, this assessment informed of factors such as Charlotte being unable to make informed choices, that she requires full assistance with personal care, she is resistive during personal care and will spit scratch scream and shout, refuses diet and fluid from staff and relies on family to support her to eat, is doubly incontinent, shouts and swears at other patients, can become increasingly agitated if the ward is unsettled and, when staff offer her food, she will often shout and swear at them.

Charlotte’s care records demonstrated that she was regularly reviewed by the multidisciplinary team. These reviews demonstrated that Charlotte's capacity was regularly revisited and the consistent view was that she lacked capacity to consent to treatment admission and medication; she required three staff in care interventions due to her level of restiveness and that diet and fluid were provided by her family. Words and phrases frequently appearing in Charlotte’s progress notes included: “verbally aggressive”, “refused diet and fluids until husband visited”, “refused diet and fluids”, “assisted to wash and dress but was resistive throughout”, “assisted to wash and dress by three members of staff, shouting and spitting during care interventions.” The most frequent of entries were ones which were concerned with Charlotte consistently refusing all offers of diet and fluids from staff, her restiveness to personal care interventions and of being unsettled in the ward environment and shouting and swearing at staff and patients.
Observations on the Ward

The following is a selection of reporting’s from my observation of the Charlotte that I saw within the ward environment.

Monday in November 2015 13.55hrs: There are 16 patients on the ward. Three of these are on continuous observations; two as they are at high risk of falls and one because they are aggressive. There are seven staff on the afternoon shift, three of which are qualified nurses. The day area appears busy and noisy. The ‘Singing for Brains’ people have arrived, along with some visitors. Charlotte is sat on the sofa, she is quiet. All the time she is watching and looking around. She appears calm, but I notice her fingers are moving and rubbing together. Her facial expression is hard to quantify but she looks almost perplexed.

14:04: The doorbell to the ward rings. A member of staff lets in some visitors; it is Harry and Charlotte’s brother. Charlotte recognises them immediately and she gets up and walks toward them. She has a big smile as they are moving toward each other. Harry hugs her and they walk out of the day area towards the ladies lounge holding hands.

14:15: Charlotte is in the female lounge with her family. I have given them some time alone before I re-commenced my observations. The female lounge is a much smaller space and is situated near the female bedroom area of the ward. It seats approximately six people. There is a window and a door which leads to a small garden. The door is kept locked. On the wall there is a television housed in a wooden box; it is quite high and the wooden box makes it more difficult to see. There is also a small stereo system but, again, this is located high on the wall and out of reach. The lounge resembles a small waiting room.

To access the female lounge it is necessary to enter the start of the female bedroom corridor which has double doors at the beginning. If these doors are shut, a member of staff has to be approached to let you in via their swipe card. Once in the female lounge there is a button you can press which unlocks the doors allowing entry back into the main ward area. However, I feel that if I sit inside this lounge I will intrude, so instead I choose to locate myself outside so I can observe unobtrusively. The only people in the female lounge are Charlotte and her family. Charlotte is sat in one of the armchairs and her brother is in another one. Harry has pulled up a chair and is sat on it directly in front of Charlotte. He is
very close to her and his legs are positioned either side of her legs. Charlotte appears calm and is smiling at Harry. Harry opens a small flask and takes out a bag with a pie in it. He breaks off a piece of pie and puts it to her mouth. He tells Charlotte to take a bite. He also rubs her cheek and calls her ‘chuck’. Charlotte accepts the piece of pie and starts chewing slowly. All the while her gaze has not left Harry’s face.

When she has eaten the piece of pie, Charlotte starts to verbally communicate to Harry. As opposed to recognisable words she uses sounds and neologisms, but the pace and rhythm of it feel very much like social chit chat. I notice that, seemingly without thinking, Harry mirrors this communication pattern matching her speech volume, rhythm and cadence. In the background the ‘Singing for the Brain’ session can be heard.

14:25: Charlotte remains in the female lounge with Harry and her brother. Harry and Charlotte remain in the same position. Her gaze continues to remain on him. Very slowly she is eating the pie and is accepting a drink from a flask cup. Harry continues to stroke Charlotte’s face and use his own words of endearment with her. She looks relaxed and facially appears happy. The 1950s rock and roll song ‘great balls of fire’ can be heard in the background as this is being sung in the ‘Singing for the Brain’ session.

14:30-15:00hrs: Charlotte, Harry and her brother remain in the female lounge. Harry has remained in the same position and, very slowly, Charlotte has accepted a pie and a hot drink from him. She continues to look relaxed and content in their company. Every now and again Harry and Charlotte’s brother chat and they always include Charlotte in this. Periodically, Charlotte will look at her brother and smile. Whenever Charlotte verbally interacts, Harry immediately responds with a word or to touch her face, stroke her hair, kiss her face or use a pet name for her. I leave feeling humbled to have been privy to this observation.

Monday in November 2015 11:00: There are six staff on duty, two of whom are qualified. The ward is full with 18 patients, two patients are on continuous observations due to being at high risk of falls and another one is on one in 10 minute observations due to being a risk of falls. I sit in a corner of the lounge area. There are 11 patients in the day area two of whom are walking around and three are in an occupational therapy group activity. Christmas carols are playing. Three occupational therapy staff and two
physiotherapy staff are in the day area but there is no nursing staff present. Charlotte is wearing a skirt, t-shirt and slippers and she is sitting in a chair in the lounge. Occasionally, she will speak out loud. It is usually one or two words and they are difficult to make out. On the table next to her is a cup of tea. It is not her drink and I do not know how long it has been there. Charlotte picks up the drink but she does not put the cup to her mouth and, instead, puts it straight down again. She looks at me and smiles. Charlotte continues to look around the ward, watching.

11:15: The ward doorbell rings and two paramedics, a nurse and a female patient in a wheelchair turn up. It is a new admission. The staff nurse and physiotherapist greet the new patient and help her sit in a chair in the lounge. They offer her a drink. The new admission sits in a chair opposite Charlotte. Charlotte is intently watching the staff talking to the new admission and suddenly she laughs out loudly and noisily. Charlotte continues to laugh loudly and I am unsure what is making her laugh. She is still watching the new admission. The lounge area now feels busy with lots of people talking.

11:20: Charlotte is still sitting in the same chair. She is now looking around the day area and laughing out loud. I ask her if she is ‘okay’ as I am still sitting next to her. Charlotte replies “yes.” She is now alternating between laughing out loud and rubbing her hands together and looking worried and apprehensive.

11:25: Charlotte leans forward and stretches her arm out to pick up a cup of tea which is near her. It is not hers. It was left there untouched by another patient a while ago. I wonder if it is still warm. The agency nursing assistant hands it to her and Charlotte takes the cup from him. The nursing assistant tries to guide the cup to Charlotte’s mouth, but she moves away by leaning back in the chair. The nursing assistant asks her what she has been doing this morning. Charlotte does not answer.

11:27: Christmas carols are now being played. A female nursing assistant, who has come into the day area, jokes with Charlotte and asks if she has a feather. Charlotte responds by saying “I have no medal”. The nursing assistant has a file and is writing in it. I make an assumption, based on my clinical experience, that the nursing assistant is completing the checks where staff have to sign to say they have seen all patients on the ward each hour.
The nursing assistant tells Charlotte that she is doing the register. Charlotte repeats the word register out loud.

11:30: The female nursing assistant brings Charlotte a biscuit. She breaks a piece off and offers it to her to taste. Charlotte says to her “don’t be daft”; the nursing assistant responds “if I taste it will you”? Charlotte responds by saying “I’m not that daft” the nursing assistant says “your Jack sent it”, Charlotte laughs out loud but she does not take the biscuit. The nursing assistant leaves the biscuit near her but she makes no attempt to take it. Charlotte pushes the biscuit away from her.

11:35: Charlotte watches the physiotherapy team walk past her and then laughs loudly. Charlotte mutters to herself but I cannot hear what she is saying. She then reaches for the cup of tea which is still near her and then changes her mind. She points to the physiotherapist who is walking past her with another patient and laughs out loud whilst muttering to herself. I wonder if this is in response to a member of staff saying they will get a patient a Vimto [a concentrated drink].

11:45: A female staff nurse, who has come into the day area, tries to get Charlotte to eat the biscuit that the nursing assistant left but she does not succeed. The staff nurse walks back to the office. Charlotte remains sitting in the chair watching. She moves the biscuit away from her.

Thursday in December 2015 16:28hrs: There are 17 patients on the ward and one on leave. There are six staff on the afternoon shift, three of whom are qualified. There is one patient on continuous observation when awake and three on once every ten minute observations, one of which is increased to continuous observations when awake and mobilising. All these observations are as a result of these individuals being at high risk of falls. There are 11 patients in the lounge area and one visitor. There are no staff in this area. A male patient is walking around trying all the door handles; his manner seems restless and angry. Two staff are with a patient in the toilet and I think another is on her break. I don’t know where the remaining staff are. The atmosphere in the lounge feels tense and busy. Charlotte is sat in the chair. She says “fuck off”. This does not appear to be directed at anyone. The female patient who is sat across from Charlotte responds by saying “stupid bitch”. Charlotte looks around and swears. She seems to be repeating words
she is hearing elsewhere in the day area; for example “tired, tired, tired”. This word had just been used as part of a sentence in the day area.

Charlotte then shouts “daft bastard, stupid bastard”. It is unclear what this is in response to. Facialy she looks angry and her body appears tense. She is still sat in the chair on the edge of the seat leaning forward slightly. The male staff nurse comes out of the ward office and walks directly towards Charlotte. He leans towards her and, without saying a word; he gets hold of her arms and goes to stand her up. Charlotte stands and is saying to him “you are nasty, nasty”. He walks her out of the day area into the bedroom corridor. Shortly after the same staff nurse and nursing assistant come back in to the day area with Charlotte. They are walking either side of her with their hand on her elbow. Charlotte looks distressed and angry. She is shouting “dirty bastard, shut up, shut up, don’t touch me, I don’t like you”. They sit Charlotte on a chair and disengage. The nursing assistant stays in the day area and the staff nurse goes back in to the office. Charlotte sits looking tense and upset rubbing her hands shouting “Christ, Christ, Christ, Christ”. I am assuming that the two staff had taken Charlotte to the toilet.

16:35: Charlotte is still sat in the same chair. She now has her head in her hands. Her voice is very loud, her pitch angry and cadence quick. She is saying “fucking hell, fucking hell, blah, blah, it’s not yours, fuck off, fuck off and don’t go in” I wonder if the last three words have been triggered by an nursing assistant on the ward that she had overheard saying the same thing elsewhere in the day area. Charlotte is now looking around. She shouts “fuck off”. This is quickly followed by “don’t come near me”, “get on, get on”, “I’ll tell you, you know”, “twitter, twitter”, “tonight, tonight” “oh yes we will”. This again is said very loudly. I wonder if it is in response to a patient walking past or is it the emotion connected to her going with the male staff nurse to what I assume was the bathroom remaining with her, or possibly a little of both.

16:40: There are 11 patients in the day area, two of whom are male patients who are constantly wandering round. There are two nursing assistants, one of which is on continuous observations, and there is also a relative still visiting a patient. There is no qualified staff present in the day area. I can see two staff nurses in the office with a doctor. Charlotte starts to shout “get out, get out, get out, get out, you dirty bastard”. I am not sure if this is now in response to a male patient who is in her vicinity, still the emotion from
earlier or if she is hallucinating. However, my instinct wants to go with the fact that Charlotte is still left with the emotion attached to an event she did not enjoy even if she can now no longer recall what that event was. A female staff nurse comes out of the office but she does not stay in the day area - she walks through it and leaves the ward. Charlotte watches her.

A female nursing assistant is now walking around the day area asking patients if they would like to go to the toilet. This is the first time this afternoon that I have seen this happen. Charlotte starts to shout “shut up, shut up, shut up”, “there is nothing in it”, “do you a jags”, “do I a dag”, “get it out”. She is quiet for a few moments and then even louder shouts “shut up you stupid twat”. I wonder if this last statement is in response to a noise she has heard behind her. This noise is actually a male patient kicking a door.

Charlotte is now stood up and is shouting “shut up you stupid twat”. Her fists are clenched at her sides and her face is distorted with anger and distress. A female patient who is sat in a chair across from her mimics her tone of voice and says “sit down sit down”. This same patient continues to hold an out loud running commentary about how she believes that Charlotte is doing this on purpose. Charlotte continues to shout “shut up, shut up”. There are two nursing assistants in the day area and one visitor. Up to now neither of the nursing assistants has approached Charlotte. Two staff nurses remain in the office.

16:45: Charlotte is now sitting but continues to shout. It is a mixture of swear words, shut up, get off and neologisms. There are now three nursing assistants in the day area. They are talking. Their conversation is about Charlotte and whether her shouting is because she needs the toilet; I know this as I can hear them. They decide to try to take her. Two of the nursing assistants approach Charlotte and ask her to go to the toilet. They lean in to her and get her up. She stands for them but continues to swear. They walk either side of her linking their arms with hers and take her through to the bedroom area where the ladies toilet is situated. Even though she has moved out of the main day area and into the bedroom part of the ward I can still hear Charlotte shouting. The female patient in the lounge once again says out loud about Charlotte “she is making it up.”

16:50: Charlotte remains in the toilet with the nursing assistants. I can still hear her shouting even though she is not in the day area. The shouting gets louder and this is
because Charlotte is on her way back to the day area. She is near the nursing office. A nursing assistant is linking her at each side and Charlotte is shouting “get out”, “shit out”, “I am not coming”. One of the nursing assistants says to her “the tea is here” to which Charlotte shouts “I am not having ‘owl.” Charlotte then starts shouting “shut up, shut up”, “get off me”, “get out.”

16:55: Charlotte is now in the lounge area. The two nursing assistants sit her in a chair and move on to start tea as the tea trolley has arrived. Charlotte continues to look angry and upset; she is also looking tired. I think this tiredness is perhaps as a result of the stress and distress she has constantly been under for the last couple of hours. The nursing assistants are inviting patients to the table for their tea. Charlotte begins to shout “bagstall, bagstall, bagstall”, “fuck off”, “fuck over it”. The ward feels noisy and busy with the tea activity.

There are three nursing assistants standing in the dining area talking about a plan for Charlotte should she start shouting when the other patients are having tea. They agree that if this occurs the student nurse will take her into the female lounge away from the day area. I did not even realise that there was a student nurse working that afternoon as I had not seen them. Charlotte has been quiet for the last few minutes. She is sat in the lounge and is looking over to the dining area. The nursing assistants are going around the patients offering them a choice of meals. There are 14 patients now in the day area, some sat at tables, four sat in chairs and two male patients walking around the ward. Charlotte starts to laugh loudly. The female patient sitting next to her tells her to shut up.

17:05: Charlotte gets up and starts walking around the day area. She stands in the lounge and starts shouting “ba, ba, ba, ba, ba, ba.” She walks out of the lounge area and toward the bedroom corridor. She does not return.

17:15: Charlotte is in the ladies lounge. The door is open and a student nurse is standing just outside the door. Charlotte is alone in the lounge. There is a television and a music system but they are not turned on. The curtains are open but it is dark outside so the garden cannot be seen. Charlotte is sat on the edge of a chair. She is quiet; she looks bewildered and exhausted.
Clinical Reflection Points

Interviewing Charlotte’s Named Nurse and observing Charlotte in the ward environment enabled me to gain a much greater understanding as to the full extent of Charlotte only accepting care from family members. My clinical reflections from the interviews, review of the care records and my observations of Charlotte are detailed below.

- **Where is the dementia?:** Although Charlotte’s care plan identified multiple needs and was more detailed than Brian and Eric’s, there was actually no mention of Charlotte having a dementia. It went straight into listing her needs without really explaining why some of these may have occurred. It made me question if is this because everyone of the ward has dementia and the nursing staff assume that everyone knows this and therefore it does not need to be mentioned in a care plan.

- **Forgotten event but lasting emotion:** On a number of occasions I saw Charlotte appear distressed, agitated and angry. Frequently this followed an intervention which she may, or may not, have wanted to happen; for example, taking her to the toilet, changing her clothes as she had been incontinent or changing her transdermal patch. I wondered if the emotions Charlotte was experiencing and displaying were the lasting emotional response to an event that she may no longer be able to recall. In this sense the feeling connected to the event remains and continues to affect the individual but the recall of the actual event is lost.

- **Caring with eyes and ears closed?:** There were many occasions during my observations where Charlotte appeared lost and bewildered. There were also times where she looked distressed. Yet, on these occasions, staff did not always engage with her or spend time with her. This made me wonder if the staff have become so accustomed to the environment in which they work in that their threshold for distress, anguish, anxiety and anger that they see patients experience increases and they unknowingly lose sensitivity and a sense of compassion towards the people they are caring for.

- **Distress at not being able to meet a person’s essential needs:** Throughout her time of the ward Charlotte had consistently refused to accept diet and fluids from ward staff. These are essential life sustaining needs; needs that were only being met because her family were visiting her twice a day. The question also arises as to
what would happen if Harry and the close family came to a point where they were no longer able to do this? How, then, would Charlotte’s needs be met?

- **Clinical leadership from a nursing office?:** During my observations of Charlotte I became acutely aware that, on most occasions, the day area was staffed by nursing assistants and that qualified staff seemed to spend most of their time in the nursing office. This leads me to think about how teams are clinically led and how specialist nursing knowledge and skill is imparted. What support do nursing assistants have? How do nurses make decisions about people’s future care needs if they have not actually experienced care giving with them? How do qualified nurses know which interventions are effective if they are not delivering these interventions themselves? There were occasions where the day area felt busy, fraught and tense because of the presentation of the people in that space and whilst the nursing assistants were doing all that they could to meet people’s needs on these occasions, strong clinical leadership was needed. In my experience this cannot be delivered from behind a closed office door.

- **Deterioration whilst I observed?:** Looking back at my periods of observing Charlotte I think I watched her deteriorate in front of me. I felt I saw her start to look older and certainly more stressed. Towards the end of my observing Charlotte, she appeared more agitated and distressed. Charlotte was constantly shouting and swearing and looking angry with only short periods of appearing calmer and settled in between. It felt like her presentation had increased in acuity and that partnerships between staff, family, resident and environment were essential to simply keep another person alive in such a complex presentation.

- **Therapeutic Lies:** My observations of Charlotte made me also consider the use of lies in dementia care. The observations reported above include a direct observation of a lie where a member of staff tells Charlotte that her husband sent her the biscuit that she was trying to get her to eat. If therapeutic lies are going to be used as part of a person’s care then this needs to be undertaken as a best interest decision with a rational as to why, care planned and recorded (James, et al., 2006). However, I could find no evidence that this had occurred during the care record review.
4.4.6 Case Study 4: Celia

Main Storyline: ‘The Matriarch.’

Case Study Overview
The case of Celia demonstrated how a person’s pre morbid personality can continue throughout the progression of a dementia. In this case Celia’s husband, George, and the Occupational Therapist Lucy, who was closely involved in Celia’s care, talked about how her complexity stemmed from a mix of a very strong premorbid personality and a lack of insight into her illness. The data collected for Celia comprised of an interview with George, an interview with Lucy, a review of Celia’s care records and periods of observation. A summary of the periods of observing Celia within the ward environment is detailed below in Table 4.7. Seven episodes of observations comprise this data set as a nursing home placement suddenly became available for Celia and she was discharged from the inpatient dementia ward just before Christmas 2015.

Table 4.7 Summary of Periods of Observation for Celia

<table>
<thead>
<tr>
<th>Date Range</th>
<th>Periods of Observation</th>
<th>Location</th>
<th>Longest Observation</th>
<th>Shortest Observation</th>
<th>Total Hours</th>
</tr>
</thead>
<tbody>
<tr>
<td>December 2015</td>
<td>7</td>
<td>Day area</td>
<td>2hrs 45mins</td>
<td>35mins</td>
<td>10hrs 20mins</td>
</tr>
</tbody>
</table>

Background Details
Celia is 82 years old, married and has two sons and a daughter. Celia only received her diagnosis of probable mixed vascular dementia/Alzheimer’s disease with psychosis during her admission. Prior to this, Celia had not had contact with mental health services or memory assessment services. She was admitted to hospital from her own home during an afternoon in October 2015 and Celia’s admission was as an emergency as it was no longer possible for her family to safely look after Celia at home. Celia was assessed as being a risk to herself and others and her admission was compulsory under the Mental Health Act (DH, 1983).
From a physical health perspective, Celia had a history of hypertension, high cholesterol and angina. There was also a possibility that she had arthritis as she appeared to be in pain from her left knee on mobilising; however, Celia would not allow any of the doctors to examine her. Celia was prescribed a number of regular and when required medications. These medications were given covertly, disguised in drinks and food as Celia would not accept them. The administration of covert medication was undertaken following the guidance provided in the mental health NHS trust covert medication policy. Celia’s medications are detailed Table 4.8.

**Table 4.8 List of Prescribed Medications for Celia**

<table>
<thead>
<tr>
<th>Medication</th>
<th>Route</th>
<th>Dose</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lorazepam</td>
<td>Orally</td>
<td>500mcg - 1mg</td>
<td>PRN</td>
</tr>
<tr>
<td>GTN</td>
<td>Sublingually</td>
<td>2 sprays</td>
<td>PRN</td>
</tr>
<tr>
<td>Paracetamol</td>
<td>Orally</td>
<td>1 gram</td>
<td>PRN</td>
</tr>
<tr>
<td>Simvastatin</td>
<td>Orally</td>
<td>40mg</td>
<td>Once in 24 hours</td>
</tr>
<tr>
<td>Atenolol</td>
<td>Orally</td>
<td>50mg</td>
<td>Once in 24 hours</td>
</tr>
<tr>
<td>Risperidone</td>
<td>Orally</td>
<td>750mcg</td>
<td>Twice in 24 hours</td>
</tr>
<tr>
<td>Isosorbide mononitrate</td>
<td>Orally</td>
<td>20mg</td>
<td>Twice in 24 hours</td>
</tr>
<tr>
<td>QV Cream</td>
<td>Topically</td>
<td>Topically</td>
<td>Daily</td>
</tr>
<tr>
<td>Ibuprofen Gel</td>
<td>Topically to back of left knee</td>
<td>Topically</td>
<td>BD</td>
</tr>
</tbody>
</table>

Whilst Celia was on the ward George would visit most days. She would also be visited regularly by her son, daughter and daughter-in-law. Her second son was unable to visit as he lived abroad. Celia had her own room on the ward and her personal possessions consisted of her own clothes, toiletries, her handbag and a bracelet which she used to wear.

Although Celia was only diagnosed with dementia during her admission, she had been experiencing a gradual deterioration in her cognition for two to three years prior to
admission. George talked of not understanding what was going on with his wife during this period and he informed me that:

“I thought it was just either old age or she was being bloody minded or whatever. But gradually it got to the point where she didn’t know who I was. There were three men living here ... me, a bad man and a reasonably good man.”

In the above extract George is talking about Celia not always recognising him and her believing that imposters were in the house. Even though George did not fully understand what was happening with Celia he knew something was wrong “towards the end I knew perfectly well there was something wrong but I refused to accept it; I put up with it. She’s my wife.”

Whilst Celia was living at home her belief that George was not her husband, but an imposter living in the house, caused Celia extreme levels of distress which often resulted in her becoming aggressive and violent towards George. He tells of an occasion where their daughter came to visit and he kissed her and Celia “went absolutely ape” and said to him “take your hands off her you dirty old man” and then proceeded to hit him. He informed me that she used to look at him and “the look on her face was one of hate, not dislike, hate.” This belief that George was not her husband, but an imposter, also impacted upon George in other ways including: Celia hiding the cheque book so he could not pay the bills, hiding all the mail away from him, not letting him in the kitchen to get any food, and locking herself in a bedroom and not letting him in. George’s difficulties in understanding how to best to help is summarised in the following extract from the data:

“...it’s the strangest thing ever because they can be completely out of it one minute and completely rationale the next and it’s hard to keep up with. You don’t know which way they are going to jump.”

Celia’s admission into hospital was initially triggered by her daughter raising concerns with the general practitioner. As Celia would not talk to the general practitioner, or let social services in the house when they visited, an urgent Mental Health Act (DH, 1983) assessment was undertaken in the community, with admission the result. As Celia refused to accept there was anything wrong with her and would not willingly come to hospital, the
police had to be involved to transport her to hospital. By the point of admission, George informed me that the situation at home had “got to be unbearable really” and even though by this time George knew Celia was ‘ill’ he still found her rapidly changing presentation through the course of a day extremely difficult to deal with.

When George talked about Celia’s pre morbid personality, he described her as being “strong, fiery and independent” and he wanted those traits to continue as it meant that his wife is still “there”. George shared that Celia had always been “very independently minded” and, as a family, they would go out of their way not to upset her. George also talked about Celia being a very private person and that in their 63 years of marriage he had never been in the bathroom whilst she has been bathing. George related this need for privacy as being one of the reasons why staff, since Celia had been in hospital, had experienced difficulty in assisting her with personal care.

When talking about Celia and her dementia, George said that the hardest part of it had been “losing her.” When I asked him to clarify if he meant losing her into hospital or losing her in a more symbolic sense, his replied “both ... and that’s the hardest part ... I just can’t elaborate on that because I think that’s it.” When George talked about how dementia had affected Celia, he used the word “erratic” due to the fact that her presentation could change in a second. He also described her as being complex and placed his own interpretation in this terminology:

“You can’t be rational. There is no rational in it at all. Its complex because you can’t apply normal logic to something that isn’t normal. Because the illness isn’t normal and for me and I suppose for everybody it was a learning curve, trying to understand what was going on. And yes its complex.”

George initially found Celia’s inpatient admission to be very stressful as when he left after his first visit, he could hear Celia banging on the door asking to be let out after him and shared that “will live with me for the rest of my life.” Even though George knew Celia needed to be in hospital, he informed me that he still worried about her and would experience guilt. George shared that he did that because he is “a very logical man” and that he keeps trying to apply logic to situation that defies logic, which is his wife’s dementia.
Lucy, an Occupational Therapist on Jasmine ward, had been closely involved in Celia’s assessment, care and treatment throughout her admission. When talking about Celia’s stage of dementia, Lucy described it as being moderate to severe. Lucy then moved on to describe Celia as being complex. Lucy said that this is because she has retained skills in some areas, in terms of her functioning, as she was quite good at house-hold type chores like baking. However, her memory and recall were impaired. It is the combination of this retention of strength in functional ability, coupled with reduction in her memory and cognitive skills, which resulted in Lucy perceiving Celia to be complex. Lucy describes Celia’s level of insight and functional ability as being “quite mismatched.”

Lucy talked about Celia being “an interesting patient to work with” and “it’s been an interesting journey for the staff to understand her and who she is and her personality”. This is because “you have to do things on her terms”. Lucy informed me that the care team have had to try to learn to ask her things, undertake interventions or invite her to participate in an activity in a way where she feels in control of the situation and the direction of things. If this does not happen then Celia “very quickly gets, very upset or irritated or angry” and she will verbally communicate her feelings about the situation.

One of the biggest challenges the care team have faced is how Celia’s dementia has affected her perception of her washing and dressing abilities as Celia does not believe she required any support in these areas. As Celia was such a private person who always needs to feel in control of a situation, she had been very resistant to people coming into her personal space to assist her with her care needs. Such is her level of resistance that, at times, staff had to use restraint in order to meet her needs safely under her best interest. Lucy stated that it was important to understand Celia’s life history in that she came from a large family and helped bring up 12 brothers and sisters, and then brought up her own family; therefore, for someone to now suggest that she wasn’t seeing to her own personal needs properly is a trigger point for upset and distress.

Celia’s need for control also caused challenges with her interactions with other patients on Jasmine ward. Lucy shared that this is because Celia will misidentify male patients as her husband and there is also a female patient on the ward who Celia believes is her child. The difficulties arise when Celia is, for example, trying to make a male patient - whom she believes is her husband - stand up when he doesn’t want to, or she is trying to look after the
patient who she thinks is her child. These actions result in the staff having to attempt to intervene and de-escalate the situation.

When I listened to Lucy talk about Celia’s presentation on the ward, it was very apparent that the strong fiery independent lady that George described and who had spent her life looking after her family, is still very much present and fighting to continue to be seen; however, the changes to her memory, cognition and insight are causing challenges for both Celia, her family and the care team. It seems to be the mix of her personality and her dementia which makes Celia complex. Lucy informed that the care team view was that although Celia was complex she “was as stable as she’s going to be” and her assessment was complete as interventions and approaches had been identified to help meet her needs. Her discharge was therefore in the process of being planned.

When Celia was admitted for assessment George thought that the care team would “give her a pill, cure her and the she could come home.” Now he faces adjusting to the fact that she has an illness that is not curable and she will never come home as it had been decided in her best interests that she would be discharged to a care home registered to look after people with dementia.

**Care Record Review**

When Celia was first admitted to hospital she was admitted to a functional ward for assessment. The rationale for this was that Celia had never been assessed by mental health services and her diagnosis was unclear. Whilst on this ward it became apparent that although Celia would tell staff she was attending to her own care needs and could engage in small talk, she was, in fact, neglecting her personal care needs, she was not washing or changing soiled clothes and when conversation moved above day-to-day pleasantries, her memory impairment was apparent. After a couple of weeks, her consultant psychiatrist concluded that she believed Celia to be living with dementia and she subsequently transferred Celia to Jasmine ward for the rest of her assessment. Due to Celia’s refusal and resistance to care interventions and lack of insight into her presentation, more formal cognitive testing, such as a neuropsychological assessment and brain scan, was not possible. Her care record review focuses only upon her time on Jasmine ward, as per the study protocol.
There was a risk assessment in Celia’s care record. The risks recorded within this document were lengthy and outlined that Celia was: noncompliant with personal care interventions; would not accept medication; was at risk of absconding; could become agitated and aggressive when her beliefs were challenged/prevented from doing something she wanted to do; held a delusional thought that a fellow patient was her daughter and would interfere in her care; not aware she was in hospital; did not believe she had an illness; had poor sleep and was at risk of tiredness and exhaustion; and was at risk of retaliation from other patients when she being abusive to them. The risk assessment also detailed that a safeguarding alert was in place as, prior to admission, Celia had been aggressive towards, and injured, George. The risk management plan made reference to monitoring Celia’s sleep, ensuring her medication was given as prescribed, encouraging her to participate in ward activities and the use of distraction when agitated.

Before focusing upon her needs, Celia’s care plan commenced by highlighting how important it was to her to feel in control, with a sense of independence, and that she values her privacy. It also detailed that she enjoys engaging in groups and tasks on the ward as this gives her a sense of role and purpose. Celia’s care plan then moved on to outline her care needs. Celia had a care plan for mental health needs and these were documented as being: detained on a section of the Mental Health Act (DH, 1983); being argumentative and aggressive at times towards others; and refusing to take medication. There was no reference made as to how Celia’s dementia affected her. Interventions in this section included ensuring that her legal rights are adhered to and the administration of covert medication. From a physical health perspective, Celia’s needs were care planned as having sore red areas on her skin around skin folds, needing an incontinent pad at night and keeping wardrobe locked at night as, if not, Celia would try to wash her clothes. The only interventions in this section talked about ensuring that Celia washed and dried her skin properly every day and prescribed creams were applied.

All of the care needs and interventions identified in Celia’s care plans were brief and not particularly informative nor did they give an in-depth insight into her needs or the interventions. Likewise, the risk assessment and risk management plan was similarly as brief and lacking in detail. A number of assessments had also been undertaken during admission and these included assessments of falls risk, mood, nutrition and skin integrity. I was unable to find any evidence of any cognitive assessments being completed or even
attempted. The most detailed and informative assessment was the specialist health needs assessment. This is an assessment which is undertaken by an individual’s care coordinator to support discharge planning from hospital and is presented to health and social care funding panels to support applications for discharge funding. The aim of the document is to identify an individual’s needs and the level of care they require. This assessment gave a more in-depth insight into Celia care needs and interventions.

**Observation on the Ward**

The following is a selection of reporting’s from my observation of Celia within the ward environment. As can be seen from the extracts below, Celia’s strong personality, need to be in control and need to look after who she sees as her family are reflected in this presented data.

**Friday in December 2015 12:20hrs:** There are eight staff on duty two of whom are qualified. The ward is full with 18 patients, one of which is on continuous observation and two are on one in 10 minute observations. I sit in the doorway of the ward manager’s office. The noise level on the ward seems loud with the radio playing and people talking. There are nine patients sat in the lounge and seven sat in the dining area. The occupational therapist is also in the dining area making smoothies with two of the patients and the physiotherapist is seeing a patient in the lounge area. Celia is sitting at a table and it looks like she is having a late breakfast. She is sitting with a nursing assistant and two other female patients. She looks relaxed and she is talking to the nursing assistant about the toast she is eating. The occupational therapist and physiotherapist approach her at the same time and they greet her by name and ask her how she is. Celia responds smiling and telling them she is all right and is enjoying her toast.

**12:25:** Celia is still sitting at the table with the two female patients and the male nursing assistant. The nursing assistant is chatting to her about Christmas decorations, and what is for lunch. Celia maintains eye contact with him and is smiling and laughing. She appears to be enjoying his company.

**12:30:** The lunch trolley arrives and another nursing assistant brings it into the dining area. The male nursing assistant and the physiotherapist start to bring patients to the table. The
male nursing assistant announces to everyone that its fish and chips or meat balls and another nursing assistant starts to serve lunch. Celia is asked what she would like and replies “fish and chips”. This is brought to her and despite her only finishing breakfast a short time before she begins to eat her meal. In the background I can hear a nursing assistant talking about which patients need ‘feeding’. Celia continues to eat her meal. I note she is wearing a skirt, jumper and slippers. Suddenly the dining area gets louder and two staff assist a male patient to the table who is swearing and shouting loudly. Celia appears unaffected, or concerned, about this and continues to eat her meal. She eats slowly.

12:55: After she has eaten her meal she then drinks the juice that has been placed at the table next to her. It looks like orange juice. This was placed at the same time as her meal and I don’t recall her being asked what she would like to drink. Although this was given to her with her meal she has made no attempt to drink it until the end. The staff are offering people who have not eaten further choices and for those who have eaten seconds. Celia is sat at the table looking around the ward. She watches a member of staff follow a patient who is constantly moving around the ward encouraging him to eat.

13:05: Staff are now offering desserts. Celia remains at the table. Another female patient has just joined her at the table; Celia looks at her smiles and initiates conversation. The conversation is small-talk and focuses upon the plate in front of her and the quality of the food. The other patient laughs. Two other female patients have been brought to the table by staff. This table is now full with Celia and three others.

13:20: Celia has accepted a sponge and custard dessert and is eating it. She looks like she is enjoying it. Celia finishes her dessert and pushes her bowl away. Occasionally she will say a few words to the patient sat next to her, but due to the noise level on the ward, I cannot hear what she is saying. A nursing assistant asks Celia if she has had enough and Celia asks for another drink. The staff are now assisting patients who need help eating their desserts. There have been no qualified staff helping over this meal time.

13:30: Celia is sitting at the table looking around. By now some of the patients have left the meal tables and are walking around the ward. A female patient is shouting and appears distressed.
13:35: Celia stands up, straightens her top, picks up her handbag and walks towards the bedroom area. The day area around her feels busy and loud. There are three staff in a huddle discussing staffing issues, the female patient remains distressed and is vocally loud, a male patient is standing with his trousers down and the psychologist has just arrived on the ward. After a few minutes Celia walks back into the lounge area. She is now carrying her handbag. She looks around and chooses to sit on a chair which is located at the side near the clinic room and under the clock. She looks around the room and then starts playing with a bracelet I notice she is wearing on the left wrist. Facialy she looks anxious.

13:40: Celia continues to sit in the chair. She is staring ahead and still messing with her bracelet. She now looks stern. There is a lot of ward activity going on. Five male patients are walking around appearing very restless. A male patient once again has his trousers down. A female patient carrying an empathy doll is very distressed; the physical health nurse tries to encourage her to sit down. Celia sits on her chair watching all of this, still twiddling her bracelet. Her handbag is next to her. She is perched on the edge of the chair. She does not say anything and no one has engaged with her.

13:50: The ward continues to feel restless, disorganised and busy. There are now five visitors in the lounge and three patients still walking around. There are two nursing assistants trying to help people. The noise level is loud.

14:00: The ward doorbell rings, a member of staff goes to open it. Celia is watching this. George comes through the door. Celia stands up immediately and walks towards him. She is smiling. He holds his arms out and she walks into them and he hugs and kisses her. He says something quietly into her ear. They then go and sit together on the sofa in the day area.

Thursday in December 2015 14.45hrs: There are 17 patients on the ward and six staff; three of whom are qualified. One patient is on continuous observations and three are on one in 10 minute observations. I sit in the dining area. It is visiting time so the ward is busy and feels noisy. There are 14 patients in the day area, four nursing assistants, a student nurse, the occupational therapist and eight visitors. Celia is sat on the sofa in the lounge area with George. They are talking quietly; I cannot hear what they are saying. There is a male patient wandering around the lounge area; he is blowing on the backs of the heads.
and necks of people who are sat in the lounge area including George and Celia. George looks to see what he is doing then says something to Celia and they both smile. They continue to talk quietly on the sofa; periodically George leans over and kisses Celia.

**15:00:** Celia and George are still sitting on the sofa in the lounge area. Celia keeps repeatedly turning and looking behind her to the dining area. She is looking at the patient who she thinks is a child. Celia says something to her husband and they both turn and look at her. There are other patients on the ward in Celia vicinity some of whom are moving furniture; however, Celia does not appear to notice them. Her only interest is the female patient who she believes to be a child. To look at her she has to physically move her whole body in the sofa. She checks her every few seconds.

A male patient walks to the back of the sofa which Celia and George are sitting on; he taps Celia on the back. I do not think he has done this intentionally as he has been moving around the ward constantly active, touching things and picking things up and putting them down as he moves. He tends to walk near the furniture and will run his hands along it. As he touches her Celia immediately turns around. Her facial expression is angry, however George quickly engages her and reassures her and she turns back to him. I can hear her asking George why the male patient did that.

**15:10:** Celia and George remain on the sofa. There are two nursing assistants in the lounge area. George now seems restless and looks anxious. He keeps turning around and looking into the dining area and the ward exit door. Celia asks him what he is looking at and he tells her nothing. He looks again and suddenly he kisses Celia and gets up from the sofa and quickly goes to the ward door and asks a member of staff to let him out. He leaves the ward. I realise now that George was waiting for a member of staff to be near the exit door so he could leave quickly.

Moments later Celia realises George has left and she quickly gets up and goes to the ward exit door which George left through just seconds ago. She tries to open the door by pushing it. There are no handles on this door as it can only be opened by holding a staff identification card to a sensor. Celia tries pushing the door again. She turns and looks around the ward. She sees a nursing assistant and quickly walks to them. She says to the nursing assistant “*let me out as I want to go and see my husband.*” The female nursing
assistant tells her that he has just “nipped to the toilet.” Celia does not look like she believes her. She returns to stand at the door. She looks tense and her facially expression is fixed and stern, she is standing upright, her handbag is over her arm and she is staring through the glass panel in the door.

Celia stays standing at the door. A female nursing assistant tries to distract her by offering her a biscuit. Celia refuses and tells her that she is “waiting for George to return.” Facialy she now looks tired. I notice for the first time that she is wearing two tops.

Celia is still standing at the ward door but she is now looking at the door and then across to the dining area when the patient who she thinks is a child is sitting in a chair at one of the tables. Celia now walks over to her and asks her “when are we going home?” The other patient looks at her but does not answer. Celia, still with her handbag over her arm, now walks across the day area into the bedroom corridor.

15:15: Moments later Celia returns into the day area, she still has her handbag over her arm but is now also carrying a packet of biscuits. Immediately, she walks back to the patient she believes to be a child. She asks her “where is your coat?” This is the first time that I wonder if Celia believes this patient to be her young daughter. The patient does not respond. Celia starts to walk off toward the ward door. She is limping on her right leg. She looks through the ward door and says “where is George? why has he not come back?” Although there are nursing staff in the day area, no one answers her. She stands there for a few moments and then begins to walk around the day area; she is still limping and carrying a packet of biscuits. These are the biscuits I noticed that George gave her earlier when he was sat with her and she put them into her handbag.

Celia walks back to the patient she feels is a child and sits with her at the table. Brian (case study 1) walks toward her and stands closely behind her with his hand on the back of her chair for a few moments, Celia does not look at him or engage with him; she is focused on staring at the patient she feels is a child. I notice that there are no nursing staff in the day area only the occupational therapist who is currently on continuous observation with a patient. The patient Celia believes to be a child is sitting at the table making loud grunting type noises. Celia is sat staring at her, although she does not verbally say anything; facially, her expression seems to be a mix of puzzlement and concern.
15:20: There are 13 patients in the day area, a male patient is continually walking around and vigorously trying every door handle. I realise that there are no staff in the day area. Celia is still sat at the table with the patient she believes is a child. This patient is continuing to make loud grunting noises. Celia has positioned herself so she can look at this patient and also the ward door. I sense she is looking at the ward door waiting for George to return.

15:25: The occupational therapist has returned into the day area with the patient she is observing on continuous observation and, at the same time, the physical health nurse enters the ward. Celia sees the physical health nurse enter and stands up and walks towards her. The physical health nurse greets her by name. Celia says to her “I am looking for my husband” and without waiting for a response “I’m not staying here”. Her tone of voice is sharp and her facial expression is stern. She then walks past the physical health nurse and goes to the exit door and looks through the glass panel into the airlock vestibule.

After a few seconds of looking through the door Celia turns around and notices the occupational therapist who is still with the patient on continuous observations. Celia walks to the occupational therapist who invites her to sit down and talk to her. Celia appears worried and distressed. Her body posture is tense. She tells the occupational therapist that she is worried about her husband as he has not returned. She says “I have been told this tale before and he has not returned” and she continues “how will I look after our child if my husband is not there?” I assume that Celia is referring to the female patient who she thinks is a child. I note her use of language of ‘our child’ indicating that she does believe this patient to be her daughter. The occupational therapist tries to distract her and says “would you like your nails done?” Celia replies “are you trying to distract me?” The occupational therapist perseveres and Celia agrees to have her nails painted. The occupational therapist gets her manicure and nail varnish equipment and begins to do Celia’s nails. The patient on continuous observation is asleep in a chair next to the occupational therapist. Celia chooses a nail varnish and throughout the manicure session talks to the occupational therapist regarding her worries about where George is and who will help her look after her daughter. Facialy she looks worried and anxious.

15:30: Celia is now walking around the day area. She is carrying her handbag over her arm and holding the packet of biscuits that George had given her. The noise level on the ward is
quieter as a lot of visitors have now left. The patient who Celia believes to be her daughter is making loud noises. The deputy ward manager asks her what she is doing and she says she is singing. A male patient tells her to shut up. Celia keeps looking at her and watching what she is doing. She continues to walk around the day area, holding her biscuits and limping. She approaches the patient who she believes to be her daughter; she is sitting at one of the dining tables and says to her “what are you saying”, “not her again”. Celia sits at the table next to her. Every few seconds she glances at the ward door. The other patient says something to Celia but I cannot hear what she says as her voice is really quiet.

15.35: Celia remains sat at the table with the other patient. There are now nine patients in the day area and three staff. Celia is still sat next to the patient she thinks is her daughter. There is no conversation between them but every now and again Celia will look at her. The occupational therapist approaches Celia and asks if her nails are okay. Celia looks at them and says “yes thank you”. The occupational therapist smiles and moves on to talk to another patient. Celia opens the packet of biscuits she has been carrying around with her since George left. I can now see that it is a packet of Jaffa cakes. She puts one on the table in front of the patient she believes to be her daughter. The other patient does not take it but she sits looking at it. Celia asks her if she is not got to eat it but she does not get a reply or response. They continue to sit together, the Jaffa cake remains on the table. Celia does not take one for herself.

15:45hrs: Celia gets up and walks around the day area. She is carrying her handbag and holding the packet of Jaffa cakes. She walks through to the bedroom area. Celia spends time walking between the bedroom area and day area. She is still limping. Facially she appeared stern and also tired. She does not engage with anyone. She then comes and sits back down at the table, next to the patient who she thinks is her daughter. This patient has not moved during this time.

15:55hrs: Celia is still sitting at the table. She asks the patient “are you warm enough?” She is looking at her and her tone of voice appears softer and gentle. The patient does not respond. Celia sits there looking at her. A few moments later this patient says to Celia “What are you looking at?” Celia responds by saying “What are you looking at?” Celia then says “Don’t you shout at me. Silly little witch. I am not here because I like it.” Celia voice is now much sterner and louder. She continues “You are always pulling your face. I
love you. It’s not my fault you are stuck here.” They stay sat in silence for a few minutes looking at each other. Celia is still holding the packet of Jaffa cakes.

16:00hrs: Celia gets up from the table, looks at the other patient then, without saying a word to her, walks off to the bedroom area.

Break in Observations
Observations re-commenced at 16:25hrs: Celia is sitting at a table in the dining area; she is sitting next to the patient she thinks is her young daughter. There are 14 patients and one visitor in the day area but at the moment the noise level is quiet. There are two nursing assistants in the ward kitchen; their voices carry and their conversation can be heard on the ward. Celia says to the patient “what’s the matter with you?”, but she gets no response.

One of the nursing assistants has come out of the kitchen and is moving some dining chairs back into place from where they had been left after visitors had used them. Celia is watching this and says to the nursing assistant “What are you doing with them? .. they were all put up for a wedding.” Her voice appears sharp and clipped and facially she looks stern. The nursing assistant responds by saying “Don’t worry about it” and Celia says “No, you wouldn’t worry as you will not be there.” The nursing assistant does not respond but places the last chair and walks away. Celia sits staring at her, facially she appears angry and her body posture looks tense. She watches the nursing assistant walk through the day area and into the ward office. Celia remains sitting at the table with the patient she thinks is her child. They are now joined by a male patient who pulls out a chair and sits down. Celia looks at him but does not verbally engage with him. Every now and again Celia leans into the patient she thinks her daughter and says something quietly to her. I cannot hear what this is. The female patient never responds and she just continues to sit there. In between times, Celia remains sitting at the table either looking around the ward or looking at the patient she feels is a child.

16.30: Celia continues to sit at the table with the patient she thinks is her child and the male patient. There has been no communication between them and none of them have attempted to move. Celia continues to spend her time looking around the ward and then staring at the female patient. Celia appears unconcerned with what else is happening on the ward. At the time Charlotte (case study 3) is shouting and swearing, a male patient is
angrily trying all the door handles and another female patient is shouting. There are no staff in the day area and 11 patients and one visitor.

16:35: Celia looks at the patient she believes is a child and says to her “What’s your name?” The female patient does not answer but sits looking at Celia. Celia starts suggesting names “Elizabeth?, Carol?, Susan?” The female patient is laughing and saying “No” each time Celia says a name. Celia says “Well, what is your name then?” The female patient laughs but does not answer. They fall silent.

16:40: Celia remains sat at the table. The male patient has got up and is walking around the ward. The female patient Celia thinks is her child is still sat next to her; she has her head down like she is asleep. Celia is looking around the ward and is watching Charlotte (case study 3) who is standing in the lounge shouting. She then watches a male patient who is moving chairs around the dining area. She does not say anything but facially appears stern and, periodically, she will shake her head.

16:45: Celia continues to sit in the same place at the table with the female patient. They have now been joined by two male patients who have sat down. There is no conversation between them. Celia has been sat in this position for some time and no staff have engaged with her since she has been sitting here.

16:55: The tea trolley has arrived on the ward. The nursing assistants start to invite patients to sit at the table for tea and they start serving tea. Celia remains sitting at the table with the patient she believes is her child. A nursing assistant and staff nurse are stood near Celia and are talking. Their voices are quiet but I can hear them talking, the nursing assistant wants Celia to move as she informs the staff nurse that it’s because she disturbs the patient who she believes is a child at meal times. Celia looks at them and says “It’s rude to whisper”. The nursing assistant asks Celia to move tables but she refuses and makes no attempt to move. Celia is not given a reason for the request for her to move. The nursing assistants start to offer patients a choice of meals.

17:05: Celia has not moved and remains sitting in her original position. One of the nursing assistants says to another nursing assistant “can we just sit this lady [Celia] somewhere else as she interrupts this lady [patient Celia believes to be a child]; she keeps telling her
not to eat her food.” This conversation takes place in the dining room in ear shot of Celia and other patients. The nursing assistant initiating this conversation appears stressed and mithered, this is reflected in her body language and voice intonation.

Without further conversation the nursing assistant who has started the conversation approaches the patient Celia believes to be a child, gets her to stand up and starts to walk her to another table. Celia quickly gets up, facially she looks really angry. She follows the nursing assistant and hits her on her arm. Her face is contorted with anger. The nursing assistant says loudly “Let’s move her, she thinks this is her little girl.” Another nursing assistant comes to assist and they stand either side of Celia and supporting an arm each they walk her into the day area and sit her down in a chair. They quickly disengage without a word and walk away back into the dining area. Celia sits on the edge of the chair, she continues to look angry, she is clenching her fists and her whole body posture appears tense. The nursing assistants seem to have now moved on; they are serving tea and complain to each other that they cannot see to all the patients with just two of them doing tea. The patient Celia believes to be a child is sat eating her tea on the table which she was moved to. She appears unconcerned about being moved or Celia’s response to this.

The nursing assistant who instigated Celia moving away for the other patient walks past her. Celia looks at her and starts to shout at her for moving her away from “her child”. The nursing assistant does not connect with Celia. Celia continues to sit in the lounge but she has turned herself in the chair so she can see the other patient who is in the dining area. The two nursing assistants continue to serve tea. The ward atmosphere feels tense and unpredictable.

17:10: Celia is still in the lounge area. She stands up; momentarily her facial expression is one of bafflement. She stands with her hands on her hips and stares ahead. She now looks lost in her own thoughts. Each time she hears a female voice she quickly turns and looks at the patient she thinks is a child. A nursing assistant asks Celia if she would like some tea but she angrily refuses. She does not show any recognition at this time that this is the nursing assistant who instigated moving her. Despite her refusal of food the nursing assistant goes to get a meal and places it on the table in front of Celia. Celia remains standing and does not make any attempt to eat the food. There are currently 12 patients in the day area, one of which is on continuous observations, a relative and the two nursing
assistants who are still doing tea. Celia has made no attempt to move back into the dining area, she remains standing and keeps looking at the patient she thinks is a child.

Celia has still not eaten. The nursing assistant, who moved her out of the dining room, offers her meal to her again and Celia says “you know my feelings I want nothing off you.” The nursing assistant then offers her some toast and Celia replies again “I want nothing off you.” Celia’s manner with the nursing assistant is brusque, clipped and terse. The nursing assistant walks away from her. Celia walks over to the patient she believes is a child and asks her if she has eaten. She does not get a response. Celia then tells her that if she is hungry she will eat. A different nursing assistant approaches Celia and asks if she would like her tea, Celia accepts and allows the nursing assistant to take her to a different table. Celia sits down and starts eating.

17:20: Celia has eaten her meal and has now moved back to a chair in the lounge area. Throughout eating her meal she kept looking at the patient she believes to be her child. She is offered a dessert and accepts. The nursing assistant she accepted her tea from gives her what looks like a trifle and Celia sits in the chair eating this. She is still glancing across all the time at the other patient; this other patient remains sitting in the chair where she was moved to, to eat her tea.

A male patient who has appeared restless all afternoon and has been moving around the ward trying doors and moving furniture throughout the afternoon approaches Celia, who is still sat in the chair in the lounge area. The two nursing assistants are in the dining room and do not see him approach Celia. Celia is sitting in the chair and the male patient is standing in close to proximity to her looking down at her. Celia’s tone of voice is angry as she says to him “go away”. He does not move. I look around the ward for staff as I sense animosity from Celia to this patient. There are the two nursing assistants and now a deputy ward manager in the dining area but none of them seem to have noticed. The male patient has still not moved; Celia starts kicking him in the shins and the male patient immediately responds and hits her in the chest. As this occurs I jump up and shout that assistance is needed. The two nursing assistants intervene and divert the male patient. The incident is over quickly. Celia tells staff to “keep him out of my way.” The moment staff move him Celia walks across to the patient she thinks is a child and tells her she will go hungry if she has not eaten. The patient looks at her and smiles.
The deputy ward manager approaches me and apologises for the incident and informs me she will record it as an unprovoked attack. I resist the urge to comment. Celia is now sitting back in a chair in the lounge but continues watching the patient she thinks is a child.

Clinical Reflection Points

Observing Celia in the ward environment enabled me to see how her premorbid personality traits continued and it was easy to envisage the strong role that she had held within her family. My clinical reflections from the interviews, review of the care records and my observations of Celia are detailed below.

- **Personality transcends dementia:** My observations of Celia really reinforced my belief that personality can transcend dementia. The strong willed, feisty, private person who had such a strong role in caring for her family was very much present in every observation I undertook. Within the ward environment Celia was desperately trying to retain a sense of control and care for those she perceived to be her family. This was observed in her interactions with other patients who she misidentified as family members and her interactions with staff when she felt challenged or not in control.

- **Where is the care in a care plan?:** Care plans should provide direction for individualised care for an individual, based upon an individual’s diagnosis and needs. I am not sure how this would be possible from Celia’s care plans as they were very brief and lacking in detail. They did not mention her dementia or how this affected her or how to manage situations that arose from Celia misidentifying patients as family members. The occupational therapist Lucy talked about Celia’s need to feel in control of situations and the importance of staff communication enabling her to feel in control; yet her care plan provided no guidance as to how this should be achieved or the best approach to use. Celia’s care plan did not give me a sense of what Celia’s needs were, what interventions she required and how these should be best undertaken. For an individual who had been described as ‘complex’ the care plans were worryingly brief.

- **Are incidents really unprovoked?:** During my observation I witnessed an incident where Celia and a male patient became involved in a physical altercation which the ward sister informed would be reported as an unprovoked attack. This made me
reflect upon the use of this term and if, within this environment, the concept on an unprovoked attack actually exists. From my perspective, it was clear that the incident was indeed provoked and was as a result of both patients becoming increasingly stressed as the afternoon has progressed. However, it became apparent that the staff had only related the incident to the immediate ‘here and now’ and had not taken a wider view as to what preceding events of the day may have contributed to the incident. As a clinical nurse I am sure that I, too, have also jumped to this conclusion numerous times without realising that the incident is the accumulation of a number of prior events.

- **The qualified nurse is in the office:** Throughout all of my case study observations I have been surprised at the lack of qualified nurse presence in the day area and Celia’s observations compounded this further. In all of Celia’s observations I did not see a qualified nurse in the day area for more than a few minutes at a time. In the main they seemed to spend most of their time in the office. This left the hands on caregiving to be delivered by nursing assistants with minimal supervision and guidance. On numerous occasions I saw nursing assistants looking stressed trying to deliver care, ensure people’s needs were met and undertake continuous observations without active support or supervision from qualified nurses. This was most striking during my observations of Celia where the nursing assistants tried to move her away from the patient she believed to be her child at a meal time. Whilst I can understand why the nursing assistant at the time thought that this would help, I could not help but wonder if a qualified nurse had been present would the subsequent situation be avoided.

### 4.5 Summary

This chapter has presented the findings from three phases of data collection: an electronic on line survey with national dementia leaders, interviews with dementia clinicians from two mental health NHS dementia inpatient wards and a focus group with staff from the older adult community mental health team and four case studies of people with dementia who were compulsory detained to receive care and treatment in a mental health NHS dementia inpatient ward. Each phase was iterative and shaped the next phase. The findings have highlighted that complexity is constructed of a number of interconnected and interrelated domains and that complexity is not a static state but one which can fluctuate.
The next chapter will use the principles of interpretive description to further develop the findings of phases 1, 2 and 3 and will introduce the 3Fs Model of Complexity.
CHAPTER 5
Integrating the Data: The 3Fs Model of Complexity

“\textit{I think it’s very dynamic, it moves all the time; so it’s waves, I suppose.}”

(Phase 2, Allied Health Professional 1)

5.1 Introduction
This chapter builds upon the findings reported in the preceding chapter in order to assemble an integrated model of complexity; which I have termed the \textit{3Fs Model of Complexity}. The three F’s are Fundamental, Flexible and Fluctuating; terms that best describe the constituent parts and workings of complexity and are seen across the whole data set. The development of the 3Fs Model of Complexity is in keeping with an interpretive description research methodology and the model is presented for future clinical testing and refinement. The steps taken to arrive at the 3Fs Model of Complexity will now be outlined, with particular emphasis on the interaction of factors and domains that stemmed directly from phases 1, 2 and 3 of the study. The chapter will commence with a brief review of the meaning of complexity drawn from the three phases of data collection and supplemented by my own clinical reflections.

The quotations used in this chapter have been assimilated from phases 1, 2 and 3 of the study. In order to help locate which phase each quotation has come from the study phase will be provided along with the study participant identification. A more detailed sample and participant coding frame for phase 1 can be found in Table 3.3, page 90, phase 2 can be found in Table 3.4, page 97-98 and Table 3.5, page 98, and phase 3 can be found in Table 3.6, page 104.

5.2 Complexity: Meanings and Messages
There was consensus amongst study participants that only people who are complex in their dementia should be admitted to a mental health NHS dementia inpatient ward. Conversely, there was also a view that not everybody who has dementia is complex. Although study participants were not able to define complexity, they were able to describe the
factors/components which they felt contributed to complexity. For example, data from phases 1, 2 and 3 indicated that complexity in dementia is something about being ‘above’ or ‘outside’ the norm for what you would expect at that stage/time of the dementia presentation, as illustrated in this slice of data:

“In other words an above average patient, in the sense that you’d have a diagnostic category and a complex person, is someone who is above average in their presentation within that diagnostic category.” (Consultant Psychiatrist 1, phase 2)

Amongst study participants there was also a view that adopting the term “complexity” in practice is a helpful way of bringing together a number of factors and their interaction with one another, as opposed to just stating the main behaviour, problem, intervention or symptom. The following extract from the data best illustrates this situation:

“I think sometimes we look at things … we don’t look at things joined up enough. We look at things for our own perspective, so we might communicate whether they’ve got disruptive or aggressive or labile mood states … but all of these seem to be not joined up enough. I don’t think we bring them together.” (Registered General Nurse, phase 2)

In other words, the participant (a Registered General Nurse working as a physical health nurse on a mental health NHS dementia inpatient ward health) is questioning if clinicians bring the issues together to look at the whole picture of the person, or just view the issues individually and in isolation. This unifying concept of complexity was repeatedly seen in the data, as these additional quotations from a range of staff illustrate:

“Complexity is about all factors happening in conjunction with each other and you have the patient in the middle, you can’t put any of the factors in silos, can’t just look at one of the areas.” (Allied Health Professional 3, phase 2)

“Complex: you’ve got lots of things to run with in terms of the person as a whole person.” (Deputy Ward Manager 2, phase 2)
“When I think of complex I think of the whole person, you know what it is that makes them complex.” (Consultant Psychiatrist 2, phase 2)

My own clinical experience leads me to believe that we often look at a person with dementia on a mental health NHS dementia inpatient ward in terms of ‘needs’ and ‘problems’ and in isolation from the whole person. As such, I would suggest that the dementia field and nursing practice is currently missing the interaction of factors and the ‘bigger picture’.

Accompanying the view that complexity is about the interaction of factors is the belief that complexity is dynamic and it can move and change, as shared in the quotation at the start of this chapter. Complexity can increase and decrease and as revealed by Consultant Psychiatrist 2 in phase 2 of the study “a person can have a mix of complex and non-complex needs.” Although present across the data set, this view of complexity being forever moving and changing in presentation and degrees of intensity was particularly emphasised within phase 2 data collection when clinicians from the mental health NHS dementia inpatient wards were talking about complexity. This analysis is further elaborated upon below with, the first quotation being the one that is shared at the start of this chapter:

“\textit{I think it’s very dynamic, it moves all the time; so it’s waves, I suppose.}” (Allied Health Professional 1, phase 2).

and

“\textit{It [complexity] can get higher and higher.}” (Allied Health Professional 3, phase 2)

Indeed, in response to this dynamic, evolving, changing picture of complexity, an Allied Health Professional stated that “\textit{you can’t take your eye off the ball}” (Allied Health Professional 3, phase 2). This visual and dynamic view of complexity is something which, from my clinical experience, I can certainly identify with as I have nursed many people with dementia whose presentation has been consistently changing and evolving during their time on the mental health NHS dementia inpatient wards.

Having ascertained that complexity has meaning for the participants in the study, I once again immersed myself in the data through reading and re-reading the study transcripts and my own reflective notes over the course of the entire PhD journey. This familiarisation was
important if I was to start to theorise about complexity and effectively communicate what the research was both telling and showing me. Moreover, it was important in this theorising process that what was developed and discussed at regular PhD supervision meetings was meaningful for practice and in line with the interpretive description methodology, and my own clinical values brought into this research study.

By following this process, it has been possible to identify the first two domains of complexity, a Fundamental domain and a Flexible domain. I will now begin to outline these two domains grounded in the data and empirical research conducted during this study.

5.3 Fundamental Domain of Complexity

The Fundamental domain of complexity is comprised of five components which also have the ability to interact with each other. Each of these five components are fundamental in that they will always need to be present to varying degrees for an individual to be seen as complex. These five components are identified as: i) the presence of dementia; ii) life story; iii) impaired communication; iv) impaired insight and capacity; and v) perceived risk. The numbering is not hierarchical and is just to help locate each of the components of the Fundamental domain of complexity. Each component will be now discussed and supported through phase 1, 2 and 3 data and, as appropriate, my own clinical interpretations, experience and reflections. In each of the five components the data will be presented in the order of the three phases of the study and a critical clinical reflection will be provided at the end of each component. This is to ensure that that representation is given to each component throughout all three phases of the study.

Component i) Presence of dementia

The presence of dementia was seen in all phases of the study. For example, in phase 1, the online survey participants discussed dementia and its relevance to complexity in two ways. Firstly the presence of a dementia which is progressing or deteriorating, and secondly that specific sub-types of dementia and their symptoms can be seen as complex. The following data extracts emphasise these points:

“Worsening of the condition.” (Reader, phase 1)
“Complexity: with regard to the sub type and symptoms such as Lewy Body.”

(Consultant Geriatrician 1, phase 1)

In phase 2 there was an acknowledgement that complexity can be seen at any stage of a dementia: however, greater emphasis was placed on it being more associated with the moderate to advanced stages. This focus upon the moderate to advanced stages of dementia is probably not surprising as there was acknowledgement that the individuals who are admitted to the mental health NHS dementia inpatient ward are usually admitted at this stage of their condition. This is reflected in the following two statements: “people who are admitted are more advanced now” (Nursing Assistant 3, phase 2) and “the ward hosts the more moderate to severe [stages of dementia]” (Consultant Psychiatrist 2, phase 2).

Similar to phase 1, there was a correlation in phase 2 to complexity being related to certain specific types of dementia. The types of dementia that were more associated with complexity were dementia with Lewy body, fronto-temporal dementia and young onset dementia. Within my own clinical experience, these sub-types of dementia are often the ones that staff have most difficulty in understanding. In addition, complexity was also associated with a dementia that is rapidly progressing. Again, within my own clinical practice, staff have experienced difficulty in understanding why a dementia may quickly progress in some individuals causing a rapid deterioration.

In phase 3 all four case studies Brian, Eric, Charlotte and Celia were considered by the care team to be complex. These participants were described by the care team as being moderate to advanced in their dementia. From a diagnostic perspective, two of the cases, Charlotte and Celia, could be considered to have a diagnosis more associated with complexity; Charlotte with young onset Alzheimer’s disease and Celia was diagnosed as having probable mixed vascular dementia/Alzheimer’s disease with psychosis.

When exploring the concept of complexity in dementia, the presence of dementia as a domain seems obvious. However, it is often overlooked; reflected within the clinical record analysis (phase 3). The analysis demonstrated that the type of dementia and how it affects the person was often not documented in care plans and risk management plans. This leads one to wonder, and question, if this is because all the patients on the mental health NHS
dementia inpatient wards have a diagnosis of dementia and consequently, the staff somehow take the presence of dementia ‘for granted’ and overlook the individuals’ diagnosis and how cognitively it is affecting them. If so, this is concerning as the type of documentation is essential for the team in working therapeutically with a person and delivering care.

**Component ii) Life story**

The second factor in the Fundamental domain of complexity is life story. Life story features as a Fundamental component because throughout all phases of data collection the importance of knowing a personal biographical history and how that intersects with their dementia was emphasised. Knowledge of a person’s biographical history focused upon awareness of previous life traumas, the impact of these being relived and the effect of a person’s premorbid personality traits and how these traits react and respond to the current situation. A powerful illustration of the impact of life story, and why it features as a Fundamental component of complexity, was highlighted in phase 2 where an example was given of a lady who had been raped but, initially, staff on the ward did not know this information. The contribution that this life event made to this person’s complexity is presented and discussed on page 210.

In phase 1 the intersection of life events on an individual’s personality traits, and how these traits react and respond to the current situation, was reflected in a statement from a speech and language therapist when s/he is talking about factors of complexity in a person with dementia:

> “Personality. For example, a person’s long-term personality and their reaction to the current situation and their life history factors. It’s about things in the person’s past that may be relevant, for example adults who have experienced trauma or distressing care as a child may find a residential or hospital setting difficult.”
> (Speech and Language Therapist, phase 1)

Similarly, in phase 2, the view that previous life experiences affect the ‘here and now’ was also evident. This was reflected in both the qualified and unqualified clinical staff as the following extracts highlight:
“Everything that been before affects who we are now and how we cope.” (Staff Nurse 2, phase 2)

“[The] past always comes back to present so knowing about it helps and can help explain current issues.” (Nursing Assistant 4, phase 2)

The resurgence of life traumas demonstrate not only why life story sits as a Fundamental component of complexity, but also demonstrates the interaction of factors. In this instance, it is the relationship between the presence of dementia component and life story. The effect of dementia on a person’s memory is contributing to them reliving a previous life trauma as if it is occurring for the first time. This is powerfully reflected when an experienced ward manager was talking about a patient she/he had looked after who had experienced a devastating life trauma. Here, she/he is taking about helping her to the toilet and the effect that the previous life trauma was having on the individual:

“You couldn’t get her on to the toilet, because all of a sudden, when you wanted to help her get on, she was fighting for her life. And then it ended up two, maybe three having to do that for her. And it was horrendous really for her and not pleasant for staff either. But then you learn after that this lady was raped when she was younger. So she’s genuinely fighting for her life. So how must she feel?” (Ward Manager 2, phase 2)

This forceful extract from the data demonstrates how aspects from a person’s life story can contribute towards their complexity and how important it is for care staff to know this information. Within my own clinical practice, I have nursed a number of people with dementia who are re-living previous, often distressing, and at times traumatic, life experiences.

The impact of how a person’s premorbid personality can still be seen in a dementia and contribute to the picture of complexity was also highlighted in the dementia clinicians focus group. This is demonstrated in the following extract from the data where a social worker is talking about a person’s personality traits:
“It’s also a factor about how they might react [pause] … how they are. If a person’s always, say, been a very strong willed, dominant person that could be a reason why they’re acting in the way they are when they no longer have capacity.” (Social Worker 2, phase 2)

However, it was in phase 3 that life history as a component of the Fundamental domain of complexity was most noticeable. The cases of Brian (case study 1) and Celia (case study 4) highlight how life experiences and premorbid personality can still be seen and influence a person even when a dementia has progressed from a moderate to advanced stage. In the case of Brian, Ann, his wife, described him premorbidly as being “moody”, “stubborn” and “his own person” and on observations you could see elements of those personality traits coming to the surface. There were many occasions where I observed Brian to be standing almost outside of the environment he was in, and looking in, so to speak, as if he was trying to make sense of it all and be his ‘own person’. Yet, to achieve this reflective positioning, he was able to psychologically distance himself from the ward environment. A stranger in a strange land.

No matter how often he was encouraged to do something by staff, if he had made his mind up to do something, or not to do something, nothing would change it. Similarly, Celia (case study 4) was described by her husband George as being “strong, fiery and independent” and someone that, when she was frightened, she would become angry. These are all traits that were clearly evident every time I observed Celia. Celia had also spent most of her life looking after others; she came from a large family, had brought up a number of her siblings and, within her own family, had been the matriarch and head of the family. These were all roles that she attempted to continue within the ward environment and she would become angry if she felt that this was being challenged in any way.

Even though life story is a Fundamental domain of complexity, similar to the presence of dementia, it is not always represented within the clinical records. The clinical record analysis clearly demonstrated that there was little recorded information about a person’s life story and personality traits. Entries and information within the clinical records focused upon problems and needs of the ‘here and now’. It was difficult to get a sense of ‘who’ the person really was in regard to their life experiences, careers and roles. Equally, little attention was given to recording a person’s personality traits and how these may affect
their current presentation. The spouses of Eric, Brian, Charlotte and Celia all talked about the type of person they were and their personality characteristics, yet this information was not recorded within their care records. For these relatives, a person’s life story and personality continued and did not stop with the diagnosis of dementia or upon admittance to the mental health NHS dementia inpatient ward. Celia’s care plan was the only one which mentioned that it was important for her to feel ‘in control’ with a ‘sense of independence’. However, it still fell short of actually providing guidance on how this should be achieved by care staff. On observation, you could clearly see these personality traits of Celia and all too often her sense of control and independence was thwarted by staff preventing this from happening.

Despite dementia clinicians all talking about the effect life story events and personality traits can have on a person and the importance of having knowledge and understanding of a person’s life story, there appeared to be a juxtaposition between this opinion and the recording of this information in a meaningful way in the care records. Arguably, the key points of a person’s life story need to be recorded within the care records and more applied knowledge of this information from staff is required.

**Component iii) Impaired Communication**

The third component of the Fundamental domain of complexity is impaired communication. Communication in this context refers to a person being able to initiate and respond to conversation in a way that others can understand, and to be able to receive and process communication from others. It encompasses a person’s ability to be able to verbalise their thoughts and feelings and make their needs known. The presence of impaired communication as a factor of complexity featured in all phases of the study. However, in phase 1, the online survey participants were not specific in what way communication could contribute to complexity other than in identifying communication problems. This is reflected in the extract below when a Consultant Nurse is talking about factors of complexity: “communication problems” (Consultant Nurse 3, phase 1). Similarly, a Professor in the same phase of the study, shared that it was about a “range of manifestations of dementia communication problems” (Professor 4, phase 1).

In phase 2, respondents drew upon their clinical experience from the mental health NHS dementia inpatient wards to support why, and in what way, impaired communication can
contribute to complexity. There was recognition in this phase as to how crucial a component of health and wellbeing the ability to communicate is. This is evidenced in the following data extract where a Staff Nurse is talking about complexity:

“Then, I suppose, it's all the basics, like communication, so when you're talking to someone, but they can't understand what you're saying, and you can see the frustration in their face.” (Staff Nurse 1, phase 2)

Building on this view that communication is fundamental a Nursing Assistant reflected that:

“I think the biggest thing I've seen in my personal life and on the ward is communication. I think a lot of what people term complexity sort of derives from that.” (Nursing Assistant 3, phase 2)

To further emphasise this last point, the participant later on in the interview suggested that:

“I've seen patients become aggressive or people say, you know, they need PRN, they need ... sometimes I think it is just the fact that they're saying something, it might be completely straight and normal in their head but by the time it reaches their mouth, it's gobbledygook, you know, for a better word.” (Nursing Assistant 3, phase 2)

Phase 2 also provided further insights into the ways in which communication can contribute to complexity. This was provided by dementia clinicians being able to talk about the ways in which communication can become impaired and the affect that this can have. The following data extracts demonstrate this phenomenon:

“... if English isn’t their first language, or they’ve got an expressive or receptive dysphasia, so it’s harder to communicate.” (Psychologist, phase 2)

“So they're not able to sort of comprehend, you know, the sentence that you're using.” (Nursing Assistant 2, phase2)
“It’s around the fact that they can’t tell you when they’re hungry, when they need to go to the toilet, when they want something, you know, they’re in pain or they just want to ask a question they can’t communicate the same needs. They can’t communicate their needs over to you.” (Deputy Ward Manager 2, phase 2)

The above data extracts demonstrate how essential to everyday life the power of communication is, how frustrating it must be if the ability to do this is impeded and from the persons with dementia perspective, how frightening it must be not to be able to articulate personal needs.

In phase 3, the lived experience of impaired communication as a Fundamental component of complexity became starkly evident. In the case of Eric (case study 2), his wife tells of Eric’s frustration in not being able to communicate and during my brief period of time observing Eric, I never heard him speak. However, I was witness to him sitting motionless in a chair watching others in his field of vision, but seemingly unable to move unaided and unable to verbalise his thoughts, needs or concerns.

To a degree Charlotte was the polar opposite to Eric. Charlotte was still able to verbalise occasional words and neologisms, her ability to blaspheme had been retained, she could repeat one of two words that she could hear and she could still make verbal noises. However, what Charlotte was no longer able to do, was symptom report or explain to staff, or her family, her thoughts, feeling or concerns or needs in any way. Nor was she able to engage in a meaningful conversation, initiate a conversation or give any indication she could comprehend or process information that was been given to her. Both Eric and Charlotte underscore how impaired communication presents as a Fundamental component of complexity.

As seen in the preceding Fundamental domains, even though impaired communication is a factor of complexity, this is not represented within the clinical records. There was no information documented about a person’s communication abilities, how it affected them and how it may contribute to their presentation. As a person’s communication ability was not recorded, there was no documented advice, or guidance, as to how to best repair impaired communication and understanding with an individual with dementia. This is a concern as within my clinical experience, I have seen people with dementia at all stages of
the illness experience a degree of communication difficulties. What is consistent is that as the condition progresses, these communication difficulties become more marked until often a person cannot comprehend verbal words, cannot follow instruction or initiate comprehensible words to make their needs known.

**Component iv) Impaired Insight and Capacity**

The fourth Fundamental component of complexity is impaired insight and capacity. As seen in Chapter 1 and throughout this thesis, dementia is a progressive condition and, as a result, a person’s insight and capacity can become affected. The phrase ‘lack of insight’ has been used to describe the impaired judgement of people with dementia concerning their awareness of the illness, cognition and behaviour (Karantzoulis and Galvin, 2011). Mental capacity is the ability to make decisions for yourself and, as a dementia progresses, it will affect a person’s ability to make decisions. When this occurs the person is said to lack capacity in regard to specific decisions (Alzheimer’s Society, 2015d). This can mean that individuals are no longer aware that they have an illness, do not always recognise that they require help and assistance, do not recognise risk and are not able to weigh-up the ‘pros and cons’ of a situation to make an informed choice. It is this effect on decision-making due to impaired insight and capacity, which was reflected in the phase 1 data and as a Fundamental domain of complexity. The following extracts from the data elaborate upon this point:

“*Lack of decision making capacity.*” (Professor/Consultant Psychiatrist, phase 1)

“*Lack of insight, inability to make some decisions.*” (Consultant Nurse 3, phase 1)

There was also a recognition that impaired insight and capacity can cause challenges between what the person with dementia wants and what care providers feel they need. This was represented by a Consultant Nurse as follows:

“*Lack of insight on the part of the person and discrepancy between what the person wants to happen and what the team feel is in their best interests.*” (Consultant Nurse 1, phase 1)
In phase 2, participants once again drew upon their clinical experience of the mental health NHS dementia inpatient wards to highlight issues of impaired capacity and insight. Here, it was evident that these issues are features from the moment of admission. This is demonstrated in the following extract from the data where a Consultant Psychiatrist is talking about who is admitted to the ward:

“The typical patients that are admitted to [name of the ward] as a result of the dementia severity do not understand that they have an illness, they do not understand they need to come to hospital for assessment and treatment at all.”
(Consultant Psychiatrist 1, phase 2)

In phase 2, for dementia clinicians, the issues of impaired insight and capacity were very much linked to the difficulties that this creates when a person requires care interventions. This scenario is reflected in the extract below where a Staff Nurse is talking about trying to deliver personal care interventions when an individual has no insight into their needs:

“I mean, if somebody has got no insight into their needs, they have no insight that they actually need help. Maybe, they haven’t got the insight to realise that they need help with personal care, or they need help to go to the toilet, no I’m fine, I can do it myself. And, oh, no, we need to give you some help. But, quite often, they don’t take that kindly, and that can cause agitation and aggression, and resistiveness.”
(Staff Nurse 3, phase 2)

Similarly, a Nursing Assistant talked about a patient he had cared for on the mental health NHS dementia inpatient ward who also used to experience olfactory hallucinations and would smell smoke:

“It's very hard to get through to someone that, you know someone that’s not got any real kind of capacity into their illness to explain to them that, you know, what you're actually smelling or seeing isn't necessarily real.” (Nursing Assistant 3, phase 2)

These extracts from the data highlight the issues and difficulties that arise in regard to caregiving and helping to meet a person’s needs when the person has no insight into how
their illness is affecting them. This lack of insight and impaired capacity has the potential to reach a level where an individual’s health or safety is in danger, particularly when others in a caregiving role may not fully understand the extent impaired insight is having on the person. These points were succinctly highlighted when a Consultant Psychiatrist was talking about the challenges of new doctors starting work on the mental health NHS dementia inpatient ward. He/she shared:

“We have doctors that come onto the ward that’s never worked in a dementia ward and they wouldn’t examine a patient because the patient is refusing, but the patient doesn’t have capacity and they’re so desperately acutely unwell, you need to be examining that patient in their best interest, if you leave them, the chances are that they will die because of an acute problem.” (Consultant Psychiatrist 2, phase 2)

Here it is possible to see the effect that impaired capacity can have on an individual’s health and wellbeing and the importance of a clinician being able to assess this.

In phase 3, Brian, Eric, Charlotte and Celia were all detained in hospital on sections of the Mental Health Act (DH, 1983) as they required assessment and treatment, but due to impaired insight and capacity were not willing to be in hospital voluntarily. The case records also indicated that these individuals did not have the capacity to make a decision about, for example, being in hospital, accepting medication and treatment and their future care needs. During my observations, none of the four cases ever demonstrated that they were aware that they had an illness and that they required numerous care interventions or that they knew they were in hospital. In the case of Charlotte, I also witnessed how the lack of insight and capacity can affect other components of complexity (to be explored in the Flexible domain); for example, assistance with meeting personal care needs and help with eating and drinking as Charlotte would refuse food and fluids unless offered them by her family. Similarly, the Deputy Ward Manager Joan, when talking about Brian in phase 3, shared that he could become restive in receipt of personal care interventions, such as getting undressed at night, as he did not realise that he required help in this area.

The contribution that impaired insight and capacity can make to complexity is something that I see daily within my own clinical practice on the mental health NHS dementia
inpatient wards. My experience in these environments leads me to concur that it is the ‘norm’ for people with dementia’s insight and decision making capacity to be grossly impaired. This, in turn, can result in people with dementia not realising they have an illness/illnesses, nor what their health care needs are. Arguably, resistance to help is a natural outcome to this lack of understanding.

**Component v) Perceived Risk**

Perceived risk is the fifth and final component of the Fundamental domain of complexity and it featured prominently across all phases of the data. In phase 1 perceived risk was featured in terms of the level and willingness to accept help, the risk of harm to self and others and risk stemming from multiple needs and being able to maintain safety. These facets of perceived risk are reflected in the following statements taken from the phase 1 data:

“High levels of risk which the person does not appreciate or accept the help of others in the management of these risks.” (Consultant Nurse 1, phase 1)

“Risk of harm to self and others.” (Professor 2, phase 1)

“Usually a multitude of needs that impact upon level of risk and ability to maintain safety.” (Dementia Lead, phase 1)

In phase 2, dementia clinicians believed that “complexity and risk go hand in hand” (Allied Health Professional 1, phase 2) and that perceived risk was a key indicator for admission to the ward. This is demonstrated when an Approved Social Worker in the older adult community mental health team is talking about assessing individuals in the community for formal detention in hospital, as he/she explained:

“So there we are looking mainly at risk. You know, you’re looking at risk to self, risk to others, risk to health.” (Social Worker 1, phase 2)

This demonstrates that one of the drivers for admission and a component of complexity is the presence of a high degree of perceived risk. Similarly, this presence of a high level of
perceived risk was represented in the following data extract from an Allied Health Professional talking about admission factors:

“Can imagine complexity as a graph [pause] people admitted are at the top of the graph with multiple needs, no capacity and risks.” (Allied Health Professional 3, phase 3)

The above statement also reflects the multiplicity and interactional aspects of complexity, as complexity has been correlated with multiple needs, impaired insight and capacity and perceived risk.

In addition to impaired insight and capacity, high levels of perceived risk featured as a result of the presence of other components. Examples of these components included the presence of behaviour that challenges, for example resistance during care interventions, risk of falls, risk of harm to others and self and medication risks. A number of these components will shortly be explored in more detail in the Flexible domain section of this chapter. The following extract from phase 2 of the data highlights some of the perceived risks where dementia clinicians are discussing complex patients:

“He has actually needed to be on one to one observation because his risks of falling and also his impulsive behaviour at times where he gets an idea that somebody’s against him whatever and he will go across and he will engage. So he has risks that somebody else could become agitated and retaliate to him as well.” (Allied Health Professional 2, phase 2)

This extract vividly highlights some of the perceived risks which are present on a daily basis in individuals who are on the mental health NHS dementia inpatient wards. It was not just singular components of complexity in isolation that effected level of perceived risk; it was also the effect of components interacting with each other as evidenced in the following statement from a staff nurse: “poor sleep to a severity where it causes risk of falls and the person does not recognise it” (Staff Nurse 1, phase 2).

The presence of high levels of perceived risk was evident in all four case studies of phase 3. This was reflected during my observations and in interviews with care staff and
relatives. The case of Eric (case study 2) demonstrated how the perceived risks can change and evolve as a dementia progresses. When Eric was initially admitted he was aggressive and violent, he required covert medication and his mobility was poor. These three factors alone made him a risk of harm to others, risk of his physical and mental health deteriorating if he would not take prescribed medication, and a risk of falls due to poor mobility. These factors were also compounded by the presence of dementia, changes to his cognition and impaired insight and capacity. Within a short period of time, Eric’s dementia had progressed to the terminal phase and, as such, his perceived risks had changed and evolved as he was approaching end of life. He was now at risk of pressure areas developing due to reduced mobility, risk of developing chest infection due to immobility and at risk of attack from other more intrusive patients.

In the case of Charlotte (case study 3, phase 3), I witnessed her on a number of occasions refusing food and fluids from staff and only eating and drinking when her family visited twice a day. This left her at risk of not having one of her essential life sustaining needs met unless her family were able to visit. In addition, I also witnessed Charlotte on numerous occasions becoming extremely distressed in her environment and shouting and swearing, putting herself at risk of retaliation from others patients who may be less tolerant of her vocalising in this manner.

My own clinical experience supports that high levels of perceived risk are usually the ‘tipping point’ for admission to a mental health NHS dementia inpatient ward and that perceived risk is very firmly a Fundamental component of complexity. The existence of which originates from both the presence and inter-relatedness of other components from both the Fundamental and Flexible domains, as will be shortly described. This interaction of factors, and the effect of levels of risk, has been particularly highlighted in the cases of Eric and Charlotte. In addition, the case of Eric has demonstrated the types of perceived risk can change depending upon what is happening to other components, and the levels of perceived risk can also fluctuate in response to changes in the other components. However, as the data and clinical experience has detailed, perceived risk will always be present in complexity.
5.3.1 Summary
The Fundamental domain of complexity comprises of five components; presence of dementia, life story, impaired communication, impaired insight and capacity, and perceived risk. For a person to be seen as complex, all of the Fundamental domain components must be present at the same time. However, the Fundamental domains of complexity are usually accompanied by one, or more, components from a Flexible domain of complexity as I will shortly explain. Furthermore, the components of complexity in each domain can be Fluctuating in acuity demonstrating that complexity is a dynamic changing state. The next section will introduce and explore the second F in the 3Fs Model of Complexity which stands for Flexible.

5.4 Flexible Domain of Complexity
The Flexible domain of complexity is comprised of 15 components. All have been identified from the data. These 15 components are Flexible in that a person’s presentation of dementia may be complex without all these components being evident. The 15 Flexible components may come and go during the course of a person’s dementia and their intensity may Fluctuate. The components in the Flexible domain of complexity will always interact with components in the Fundamental domain of complexity to varying degrees and they may also interact with other components in the Flexible domain. The 15 components of the Flexible domain of complexity are identified as: i) physical health conditions, ii) pain, iii) mental health problems, iv) behaviour that challenges, v) diet and fluid changes, vi) impaired self-care ability, vii) sensory impairment, viii) mobility changes, ix) sleep changes, x) frailty, xi) swallowing problems, xii) medication, xiii) environmental effects, xiv) family dynamics, xv) attitude and approach of others. Within the Flexible domain there is also a degree of overlap within some of the components, for example there is a connection between component v) diet and fluid changes and component xi) swallowing problems. Similarly a connection can be made between component i) physical health and component ii) pain.

The component numbering is not hierarchical and is just to help locate each of the components of the Flexible domain of complexity. Each component will be now discussed and supported through phase 1, 2 and 3 data and my own clinical interpretations and reflections as appropriate.
Component i) Physical Health Conditions

This first component in the Flexible domain of complexity relates to an individual’s physical health and it concerns itself with comorbid physical health conditions, both chronic and acute. It is now acknowledged that there is a high prevalence of comorbid physical health conditions in people with dementia (Bunn et al., 2014; Schubert et al., 2006). The presence of often multiple comorbid conditions was reflected in phase 1 as the following statement demonstrates: “multiple physical conditions and their interaction with dementia” (Professor 2, phase 1).

This prevalence of comorbid physical health conditions featured strongly in phase 2, with the dementia clinicians indicating that it is usual for all the patients who are admitted to the mental health NHS dementia inpatient ward to have comorbid physical health conditions. This is echoed in the following statement from a Consultant Psychiatrist when talking about the patients on the ward:

“It’s the physical health problems that people have and most of the patients on a dementia ward have physical health problems.” (Consultant Psychiatrist 2, phase 2)

Similarly, a physical health care nurse informed that “It would be abnormal if people came in with no physical [illnesses]” (Registered General Nurse, phase 2). Physical health conditions which were frequently seen in the data included: diabetes, urinary tract infections, chest infections, atrial fibrillation, renal impairment, arthritis, chronic obstructive pulmonary disease and coronary heart disease. The effect of a person’s dementia on memory and cognition and impairment in insight and capacity also featured closely when dementia clinicians were talking about physical health. This can be seen in the following extract from the data where the physical health care nurse is talking about physical health needs:

“But when you have no insight whatsoever you’ve lost that ability. You’ve absolutely lost that ability to … even the knowledge that you have this disease process that is making you weaker, more breathless, lack of circulation to any part of the body, including the brain, so that might be making your condition worse.” (Registered General Nurse, phase 2)
This statement demonstrates how complexity is not just the presence of certain components, but it is also about the interaction of components - in this case, it is the relationship between the Fundamental domain component of impaired insight and capacity with the Flexible domain component of physical health.

The presence of a physical health problem may also exacerbate an individual’s dementia, or the dementia may also mask or exacerbate a serious physical illness. This situation is highlighted in the following data extract where a Consultant Psychiatrist is talking about the physical health care issues that can be seen on the mental health NHS dementia inpatient wards:

“Sometimes we see people with cancers and sometimes we have to diagnose the cancers, because they come to us and they deteriorated suddenly and then we examine then and we find things and we send them off to the general hospital and hey how, you know, they have a cancer basically. So that, kind of, may mask some symptoms or may have exacerbated some symptoms.” (Consultant Psychiatrist 2, phase 2)

Once again this statement demonstrates how complexity can arise as a result of factors interacting with each other. Indeed, in my own clinical practice I have nursed people who very quickly physically deteriorate to find that they have an advanced cancer and whose earlier symptoms have been masked by the effect of the dementia on the person. I have also nursed people who have both a dementia diagnosis and a cancer diagnosis and have witnessed these illnesses interacting with each other, the result of which has, all too often, been a rapid progression of both illnesses to where the person quickly reaches end-of-life.

In phase 3, three of the case studies had comorbid physical health issues. Eric (case study 2, phase 3) demonstrates how his complexity had changed from a focus upon his behaviour to meeting his physical health care needs as he was approaching end of life. This can be seen when his Consultant Psychiatrist is talking about how his complexity has changed as his conditions has progressed:
“No, physically complex. Mentally, he’d stabilised. So he’s physically complex, and also I mentioned before, he had these myoclonic jerks which is often what you see in end stages of dementia.” (Case Study 3 Eric, Consultant Psychiatrist, phase 3)

Conversely, Charlotte (case study 3, phase 3) was in good physical health with no physical comorbidities but was still perceived by the care team to be complex. This demonstrates that physical health is a Flexible component of complexity as it does not always have to be present for an individual to be perceived as complex.

My own clinical practice supports that fact people are commonly admitted to mental health NHS dementia inpatient wards with existing physical health conditions. As already highlighted, the management of these conditions is usually compounded by the effect of a person’s dementia, their memory and the level of insight a person may have. It is not uncommon for people with dementia to no longer remember, for example, that they have diabetes and need their blood sugars monitoring and insulin administering. This can result in a person becoming resistive and aggressive when these interventions are being delivered as they no longer have the insight into why this needs to occur. Likewise, with changes that can happen in a person’s ability to recognise symptoms and verbally communicate, it is not uncommon for people with dementia to be unable to say they do not feel well or report their symptoms.

**Component ii) Pain**

The presence of pain as a component of complexity featured openly in phases 1 and 2 and somewhat more covertly in phase 3. It is believed that approximately 50 percent of people with dementia will experience pain (van Kooten et al., 2015) and it is recognised that treatment of pain is sub-optimal. This is reflected in phase 1 of the data as the following extract demonstrates: “under-recognised and under-treated pain is a huge issue in my work” (Speech and Language Therapist, phase 1). Similarly, a Lecturer in phase 1 informed that there are many varied factors that contribute to complexity and “undiagnosed/treated pain is part of this.”

In phase 2 the presence of pain as a Flexible component of complexity featured across the data set. It was also frequently associated with the Fundamental component of impaired
communication as can be seen for the following extract from a Ward Manager, “most people on this ward can’t tell you when they’re in pain” (Ward Manager 2, phase 2).

Following on from this acknowledgement that impaired communication can affect an individual’s ability to report pain, was the overlap between pain and behaviour. Specifically, in deciding if a person’s presentation of agitation and/or resistance to care interventions is as a result of pain. This is demonstrated in the data when a Staff Nurse is talking about a patient he/she had cared for:

“And, there is a definite difference in his presentation when he is in pain, he does become more agitated, he does become more hostile, threatening as well, I suppose, really. He can be difficult to manage, he can be, it can take three to four staff during personal care, but a lot of the time it can be down to pain.” (Staff Nurse 3, phase 2)

This view that pain could have an impact on behaviour was also reflected by a Consultant Psychiatrist as follows:

“The patients that we tend to get on the dementia ward, I think most of them would probably have the first two, the agitation and aggression, present with those two, now then there’s the other thing that I failed to mention was pain, that’s the other thing that can exacerbate those two symptoms and it could be cause, as a result of their chronic illness, another chronic thing we see is arthritis, you know. So it could be complicated by that, that pain could complicate or increase the agitation and the aggression basically.” (Consultant Psychiatrist 2, phase 2)

These extracts from the data highlight how the presence of pain can interact with other factors of complexity and cause fluctuations within these components: this will be returned to later in the chapter.

In phase 3, the presence and effect of pain on the cases studies was perhaps a little more subtle and not immediately obvious. In case study 4, Celia was observed to be limping on numerous occasions and the care team thought she may have had arthritis. However, Celia would not tell staff she was in pain and would not allow a doctor to examine her. So,
potentially, she was being left with untreated pain which could have been impacting upon her behaviour.

Whilst I was observing Charlotte (case study 3, phase 3), I observed an increase in her agitation, verbalisation and distress which made me wonder if there was a chance that this was related to pain; however, Charlotte was unable to articulate this in any other way than via her behaviour. The analysis of her care records gave no indication that this was being considered. On the one hand, pain may not always be present in a person with dementia’s presentation and for this reason it is assigned as a Flexible component of complexity. On the other hand, from my clinical experience, there is a lot that needs to be learnt about the assessment and recognition of pain in a person with more advanced dementia.

**Component iii) Mental Health Problems**

Mental health is the third Flexible component of complexity and this term covers the presence of other mental health conditions, or symptoms, such as depression, anxiety and psychosis for example. The presence of mental health issues was reflected in phase 1 as a factor of complexity as seen in the following extract “*mental health – depression, anxiety and psychosis*” (Speech and Language Therapist, phase 1). Similarly, in phase 2, dementia clinicians talked about mental health problems in the context of a person experiencing hallucinations, depression and delusional thoughts as contributing factors to complexity. The following two slices of data highlight this:

> “*They might have psychotic symptoms.*” (Psychologist, phase 2)

> “*So, for example, they may actually have visual hallucinations or they’re misidentifying people or illusions, or whatever.*” (Consultant Psychiatrist 1, phase 2)

It is in the phase 3 case studies that the effect of mental health problems becomes starkly evident. In case study 1, Brian had a history of depression - which predated his diagnosis of dementia - and for which he was prescribed antidepressants. The effect of his depression continued to be seen in his dementia and was evident on observation of him on a day-to-day basis within the ward environment. Brian was often tearful and I observed him to use
terms such as “dreadlington” and state that he “wants to die”. When the Deputy Ward Manager Joan (phase 3) was talking about Brian she stated that:

“His mood fluctuates on a daily basis and it’s very, very difficult to console him when he’s very tearful. You can sit with him, but he just cries and cries and cries and I think you just have to let him get that out of his system.”

Despite this awareness of Brian’s mood, his care records did not reflect this, or give any evidence of how his mood affects him, or how it should be monitored, or what interventions may help.

In case study 2, when Eric was admitted to the mental health NHS dementia inpatient ward, his Consultant Psychiatrist (phase 3) informed that:

“There was also symptoms of psychosis. He was hallucinating visually. I don’t recall any delusional ideas but there was definitely hallucinations.”

In Eric’s case, his visual hallucinations reached such a degree that his Consultant Psychiatrist tried to treat them with antipsychotics. However, Eric proved to be sensitive to antipsychotic medication and quickly developed side-effects resulting in the medication being stopped. This further provides awareness about how components of domains of complexity can interact with one another and how, on occasions, an action in one component can actually make another component deteriorate.

In my own clinical experience, I have found that not every patient admitted to the ward will experience mental health problems. However, when they do occur, symptoms such as the presence of hallucinations, delusions, mood disorders, intense anxiety or paranoid ideas, can cause significant distress for the individual, increased risk and add a further layer of complexity to a person.

Component iv) Behaviour that Challenges
The fourth component of the Flexible domain of complexity is the presence of behaviour that challenges and this concept was referred to across all phases of the study. In phase 1, the survey respondents acknowledged the presence of behaviour that challenges as a
component of complexity. Examples of such behaviours were provided by a Consultant Nurse and included “shouting, screaming, throwing self on floor and refusal of care” (Consultant Nurse 1, phase 1).

In phase 2, a wide range of behaviour that challenges was identified; however, the most common behaviours were agitation, aggression, violence, physically resisting personal care interventions and intrusiveness. The behaviours identified did not differ from those that are well-documented (see: James and Jackman, 2017; Moniz-Cook et al., 2017). However, it was not just the presence of the behaviours that was a feature, but also the severity of the behaviour or the degree of unpredictability or whether the behaviour was receptive to a solution or intervention for it to be considered as a component of complexity. These issues are reflected in the following data extract when a Consultant Psychiatrist is talking about a complex patient:

“Now the level of aggression we’re talking is out of the ordinary, not what the people…the average patients with that type of dementia will experience, okay? So that would be another characteristic of complexity in this gentleman, okay? So the aggression was very intense, being so many times a day. Unpredictability is another layer or definition or characteristic of that complexity, that unpredictability of the aggression. So right from when the gentleman wakes up you just don’t know what to expect, okay, and he goes off from right when he wakes up until he eventually falls asleep, okay?” (Consultant Psychiatrist 1, phase 2)

The latter point about the behaviour not responding to an intervention or solution is further enhanced in this data extract when a Deputy Ward Manager is taking about behaviour that challenges:

“Well … I suppose, sometimes, we’ve tried lots and lots of different things and then we get to the point where, you say what else can we do, where can we go with this?” (Deputy Ward Manager 2, phase 2)

In phase 3, Charlotte (case study 3) displayed behaviours which were severe, unpredictable and did not have easy solutions. During my observations of Charlotte she had increasing periods of vocalisation and she would shout and swear loudly. The reasons for this were
not obvious. This behaviour was not consistent; it was unpredictable and fluctuated. In addition, I did not read in Charlotte’s clinical record any identified possible causes for these behaviours nor any guidance about nursing care interventions. It was also apparent on observation that clinical staff were unsure at times about how to deal with her presentation. Indeed, I observed a number of different approaches being used, ranging from ignoring her, trying to ascertain if she had an unmet need to removing her from the day area.

In case study 2, phase 3, Eric was reported by his Consultant Psychiatrist and his wife to be displaying aggressive and violent behaviour during the first part of his admission. However, as his dementia progressed to the terminal phase, these behaviours had reduced and were no longer classified as challenging. Despite this, Eric was still perceived by the care team as complex due to his physical health presentation and the terminal phase of his dementia. This case demonstrates why behaviour that challenges sits in the Flexible domain of complexity as they do not have to be present for an individual to be seen as being complex.

Although behaviour that challenges features as a Flexible component of complexity, and featured in all three phases of the study, within the care records of the case studies an accurate description of the behaviour and formulation as to the possible causes was missing. There was no evidence of a needs-led approach being adopted and there was little, or any, guidance as to what interventions should be employed.

**Component v) Diet and Fluid Changes**

The fifth component of the Flexible domain of complexity relates to problems with diet and fluids. In phase 1, reference to diet and fluid as a component of complexity was brief and non-specific in that no further details were provided other than listing it as a factor of complexity and identifying that people may require help with eating. However, in phase 2, dementia clinicians were able to provide further insight into why diet and fluids can be a component of complexity for some people. Issues that were discussed included: the effect of not taking enough diet and fluids and the subsequent increased risk of dehydration, malnutrition and/or infection, forgetting how to place food to your mouth, not recognising food and people just wanting to eat sweet foods. The following data extracts from phase 2 demonstrate some of these issues. The first is from a Staff Nurse talking about factors of
complexity and the second is from a Senior Practitioner who is describing a patient that she/he perceived to be complex and what factors contributed to her complexity:

“Things that I feel, to me, are really important like being able to eat, knowing to eat, and when people can’t eat or recognise food.” (Staff Nurse 1, phase 2)

“She has got a very, very sweet tooth, again very much a frontal temporal kind of presentation. So if you can get away with giving her any sort of pudding as long as it’s got massive amounts of sugar in it she’s fine. Chocolate, crisps, anything like that she’s more than happy to eat.” (Senior Practitioner, phase 2)

In phase 3, diet and fluid as a component of complexity was reflected in case study 3 Celia. During my observations of Celia, I witnessed staff, on numerous occasions, trying to get her to accept diet and fluids from them with little or no success. The most I observed her accepting from the ward staff was a couple of chips, yet she would accept food and drinks from her close family. The following extract from the data reflects the concern that her Named Nurse Linda (phase 3), experienced in trying to get Charlotte to accept food and fluids:

“It’s the eating and drinking that really bothers me; not to have anything to eat or drink off us. It’s so fixed that, and no matter which way you go it’s so hard to…well, we’ve just not been able to break it down at all or get past it or find out why…why she’s so determined not to.” (Case study 3, Named Nurse, phase 3)

In this extract you can almost feel the exasperation of Linda. As a mental health nurse I could fully understand the concern and worry of the care team when Charlotte consistently refused diets and fluids from them. If it was not for her family's intervention, this life-sustaining need of Charlotte’s would not have been met.

**Component vi) Impaired Self-Care Ability**

The sixth component in the Flexible domain is impaired self-care ability. This relates to the individual’s ability to maintain their own personal care and hygiene needs and includes washing, grooming, bathing and toilet needs, including problems with continence. As a person’s dementia progresses they will require assistance to meet their self-care needs. It
may be that people with dementia are physically no longer able to perform tasks such as washing, showering and changing clothes, or that they no longer realise that these elements of self-care need to be undertaken.

In addition, people with dementia will also experience continence problems in that they may no longer be able to recognise the need to go to the toilet, that they no longer remember where the toilet is or that they are no longer able to recognise it as a toilet and they will become incontinent. Furthermore, for some people with dementia when they have been incontinent, they may not realise that this has occurred.

These changes result in a person requiring assistance in meeting their self-care needs. The requirement for personal care to meet these needs featured across the data set, but was particularly seen in phases 2 and 3 of the study. The following extract from Staff Nurse in phase 2 demonstrates just how many patients on the ward required assistance:

“The majority of our patients need full assistance. Some just need prompts, but I’d say a good 80 per cent of the patients need full assistance with diet and fluids, washing and dressing, bathing.” (Staff Nurse 3, phase 2)

In addition, the following extract from a Ward Manager succinctly highlights the importance of these self-care needs in being met:

“Probably for me, complexity would be in the amount of interventions we have to do to ... for that person to remain alive. For instance, if we didn’t feed them, get them out of their bed; change them when they’re soaking wet or doubly incontinent. Just leave them where they were. Give them a drink. Give them the medication that they require to remain pain-free and manage whatever breakdown needs assisting with at that time. That is the higher end of complexity to me. And I can name ... you know, I could probably point out on the ward the majority of the people in there, if you did not do that for that person on a day-to-day basis, they probably wouldn’t be around.” (Ward Manager 2, phase 2)

However, it is not just the requirement of assistance with self-care needs that makes this a Flexible component of complexity, it is also the interaction between this and the
Fundamental component of impairment in insight and capacity, whereby a person no longer has insight into their self-care needs and, as a result, they can become resistive or aggressive when care staff try to help. This interaction subsequently results in another component of the Flexible domain contributing to behaviour that challenges. It was the interaction of these components which featured in phases 2 and 3. The following two data extracts from phase 2 reflect this. The first is a Deputy Ward Manager talking about providing physical care on the ward and the second, a Senior Practitioner talking about a patient she/he has cared for who was complex, and how difficult it was to meet her personal care needs due to her level of resistance to care:

“Any intervention…any patient that needs to go to the toilet it’s nearly always three staff needed. The majority of them are men but now we’ve got a few females in at the moment that need three as well, so, and it is just because of the complexity of the patient.” (Deputy Ward Manager 2, phase 2)

“She now perceives…she misidentifies anybody’s interaction with her physically and despite being in her late 70s is actually relatively physically fit and will not, to this day, allow people to actually support her personal hygiene. Consequently numerous members of staff have been injured. It’s taken…it can take three to five staff just to get her up and dressed and showered in the morning.” (Senior Practitioner, phase 2)

All four case studies in phase 3 were described by the clinical staff interviewed as requiring assistance with washing, dressing, toileting and changing continence aids. Interviews with care staff for each of the case studies identified that staff assistance in personal care was frequently refused, or resisted, and at times had to be undertaken using restraint. Within my own clinical practice the majority of patients who are admitted to a mental health NHS dementia assessment ward require assistance with, for example, personal hygiene, dressing and elimination as they are no longer able to undertake this themselves. In addition, they no longer have the insight into why this needs to be undertaken and resistance, refusal and the presentation of behaviour that challenges are common.
Component vii) Sensory Impairment

Sensory impairment is the seventh component of the Flexible domain of complexity. Not all people will experience a sensory impairment, but for those who do, it can contribute to a state of complexity. In phase 1, sensory impairment was listed as a factor in complexity but no further detail was provided. This can be seen in the following extract from the data: “visual impairment, sensory issues” (Consultant Nurse 3, phase 1).

In contrast, when dementia clinicians in phase 2 talked about sensory impairment being a factor in complexity, this was situated in them describing patients they have cared for on the mental health NHS dementia inpatient ward. This is reflected below in an extract from the data where a Consultant Psychiatrist is talking about a patient they considered to be complex:

“Now when he comes on to the inpatient ward you find another layer of complexity in the sense that this gentleman has profound sensory impairment, and I must confess that was the first time I had looked after someone in an inpatient like that. So the added complexity in this case was that profound sensory impairment and I, nor the team…neither I nor the team were equipped to look after someone like this because that was the first time we’d come across it. So that adds another layer of complexity.” (Consultant Psychiatrist 1, phase 2)

The above statement also reflects that sensory impairment does not have to be present for a person to be perceived as complex. The presence of sensory impairment can impact upon how staff engage with the person with dementia, and communicate with them, as the individual may not be able to hear the staffs’ words or see them. This is demonstrated in the extract below from a Staff Nurse giving an example of a patient who she/he would class as complex:

“A good example of somebody who’s get some deficit like sensory deficit, it might be that they’ve got visual impairment, or auditory impairment, so they’re not able to see who is approaching to initiate the therapeutic relationship with them, they’re more likely to present with a lot of other signs and-symptoms of the illness that is not what you usually see from other clients who come straight through the door and...
you can introduce yourself to them, not only can they hear that your voice, they can listen and they can see who's talking to them.” (Staff Nurse 2, phase 2)

How sensory impairment can interact with other factors of complexity was also highlighted. This is demonstrated in the data when a Nursing Assistant was talking about a patient with dementia that was experiencing visual and auditory hallucinations. However, the person with dementia was also Deaf and could only communicate using British Sign Language (which none of the care team were able to do):

“Even though he’s Deaf he can still have visual and auditory hallucinations. So that I find quite challenging and complex, his needs, you know his sort of care, sort of trying to reassure somebody that’s clearly frightened and this is why you’re getting all of this aggression and things. So that’s what I consider quite complex, his needs.” (Nursing Assistant 2, phase 2)

This extract from the data powerfully demonstrated how components can impact and affect each other, in this case the Fundamental component of presence of dementia and Flexible components of mental health problems, sensory impairment and impaired communication.

**Component viii) Mobility Changes**

Mobility changes is component eight in the Flexible domain of complexity and includes, for example; unsteadiness, requirement of walking aids, the ability to negotiate changes to floor levels, mobilising around obstacles such as chairs, tables and doors, and the increased risk of falls which occurs when a person’s mobility deteriorates. During phase 2, mobility featured most strongly as a factor of complexity and dementia clinicians closely linked changes to mobility with an increased risk of falls, as this data extract reveals:

“Mobility problems, mobility is a huge physical one, you risk falls, fractured femurs, that’s another one that’s really...quite often they seem to be almost ready for discharge and then have a fall.” (Staff Nurse 3, phase 2)

This close relationship between mobility problems and risk of falling is also mirrored in the following data extract where a Ward Manager is discussing how mobility changes can affect a person:
“The main risk at the moment is the risk of falls which again, I don’t remember the level of people being unstable, to the point where they fall and are unsteady on the feet, you know. So we have to manage that we have to either be with them on a one-to-one basis and give them special observations or, you know, put them on observations every 10 or 15 minutes or...at extremes, we’ve even got somebody wearing a safety helmet, in case they fall and bang their head.” (Ward Manager 2, phase 2)

From my own clinical practice I can relate to how changes in mobility for some people can be a component of complexity. These changes in mobility are usually as a result of changes in other areas, for example cognition, memory and or physical health. The result is that people can become unsteady, weak, forget they require a walking frame or assistance and are not always cognitively able to process the need to move around obstacles or negotiate different levels - or changes - in flooring. Promoting a person’s safety, and reducing risk of falls due to changes in mobility, can prove to be very challenging and all too often it results in people with dementia being placed on various levels of observations for example continuous observations. Indeed, during all of the observation conducted in phase 3, there was always a minimum of two people receiving enhanced observation levels (including continuous one to one observation) due to increased risk of falls as a result of mobility changes.

**Component ix) Sleep Pattern Changes**

Sleep pattern changes is the ninth component of the Flexible domain of complexity. Dementia can affect a person’s sleep pattern and cause changes to the sleep-wake cycle and internal body clock (Alzheimer’s Society, 2014c). Sleep disturbances have been found to occur more frequently and be more severe in Alzheimer’s disease (Alzheimer’s Association, 2018). The presence of sleep problems, as a component of complexity featured with some of the participants across the data set. In phase 1 reference was made to sleep disturbances but no further detail was provided.

In phase 2 dementia clinicians referenced sleep pattern changes as being a component of complexity in the context of a person having poor sleep, or not being able to sleep at all during the night. There was also awareness that this change in sleep can also be interrelated
with a Fundamental component of complexity, that of a person’s life story. This is reflected in the following extract from the data:

“We have people that don't sleep at night and then down the line you find out that they've worked nights, they've worked nights for years, so it is important to have background, because are...they're still people at the end of the day.” (Deputy Ward Manger 1, phase 2)

There was also an awareness of the risks that can occur when an individual does not get enough sleep and how these can affect other components of complexity. This is demonstrated in the following data extract where a Staff Nurse is talking about a patient she/he had cared for on the mental health NHS dementia inpatient ward who she/he perceived as being complex:

“Yes, there was one lady, and she just couldn’t go to sleep, and you would see her falling asleep and then she’d wake herself up again, and all you wanted was for her to be able to rest. Because, she was high risk of falls, because she would fall asleep standing up, and you’d be following her around, sort of, because you didn’t want her to fall. That was really difficult, because we were trying all sorts of things to encourage her to be able to rest, but then she didn’t want to.” (Staff Nurse 1, phase 2)

Although sleep problems do not feature in everybody, for those where it does, it can cause significant issues due to the effect that sleep deprivation or sleep reversal can have on an individual. It is, therefore, appropriate that sleep is a component in the Flexible domain of complexity.

Component x) Frailty
Component 10 of the Flexible domain of complexity is frailty. Frailty is described by the British Geriatric Society (2014) as “a distinctive health state related to the ageing process in which multiple body systems gradually lose their in-built reserves” (p.6). In essence, people living with frailty will not recover as quickly after an illness, accident or stressful event. Frailty features as a Flexible component of complexity as a number of people with dementia are at high risk of losing their inbuilt reserves as a result of the progressive nature
of dementia and other physical comorbidities. This awareness was demonstrated in phase 2 of the data in the following two extracts where a Staff Nurse and a Consultant Psychiatrist are, separately, talking about why frailty is a component of complexity:

“Because of the risk of falls, and when older people fall and break their hip or their leg or something that’s a really serious … younger people would recover much more quickly, but for a lot of older people it can be really serious.” (Staff Nurse 1, phase 2)

“Then if we put the mental health problem, which is dementia, to one side, okay, we’ve got a number of patients who are presenting with physical comorbidities as well, or physical frailty, okay? So, straightaway, the combination of the physical frailty with the mental disorder, okay, can be defined as complex. So you may have, maybe, that diagnostic category with dementia, but it’s not out of the ordinary in terms of their presentation. But the added frailty to that would make it complex as well.” (Consultant Psychiatrist 1, phase 2)

This added component of frailty to a dementia was reflected in phase 3 case study 2 (Eric). At the time I observed Eric he was believed by the clinical team to be reaching end-of-life. His picture of complexity had evolved and changed during the course of his admission. Although his dementia had progressed, his behaviour that challenged had stabilised. However, physically he had deteriorated and had become much weaker and frailer with increased physical health needs. It was this combination of his dementia, increased physical health needs and frailty that resulted in his complexity.

**Component xi) Swallowing Difficulties**

The next component of the Flexible domain is swallowing difficulties or dysphagia. Although not as frequently represented in the phases of data collection, swallowing problems in dementia become more common as a dementia progresses and can be caused by the progression of the dementia as the area of the brain that controls swallowing can become affected (Alzheimer’s Society, 2016). Swallowing difficulties can also be caused by cerebral vascular events and some respiratory disorders. If swallowing difficulties are overlooked, a person is at risk of weight loss, malnutrition, dehydration, choking and aspirational pneumonia (Alzheimer’s Society, 2016).
In phase 1 swallowing difficulties were referenced as contributing to complexity although no further details were given, for example: “swallowing issues” (Consultant Nurse 1, phase 1). In phase 2, the dementia clinicians talked about swallowing difficulties contributing to complexity where they, for example, prevent a person with dementia from being able to take oral medication. In the data set, a few dementia clinicians used examples of people they have previously cared for where swallowing featured as a component of complexity. The following extract from the data is an example of this where a psychologist is describing a patient who could not take solid food stuff as his swallow was impaired, but he still wanted to taste his favourite foods:

“There was an issue around his eating because he wasn’t allowed to swallow but he really liked chocolate so we tried to find some liquid chocolate as well that would make it easier.” (Psychologist, phase 2)

Within my own clinical practice, although swallowing problems do not occur for everybody, when they do, they can contribute to complexity. I have seen people who will choke if they eat solid food, but due to the effect of their dementia on their memory, are not able to remember this and, if left unsupervised, will try once more to eat things. I have also seen people with dementia who cannot take anything solid due to impaired swallowing, but for whom artificial nutrition is not suitable. In such a situation there is heightened (and understandable) family stress and distress as they feel their relative may be hungry and/or starving.

**Component xii) Medication Issues**

Medication issues concerns itself with polypharmacy, compliance, drug sensitivities, side-effects and covert medication administration. A number of these issues were highlighted in phase 1 of the study, for example “certain drugs for example psychotropic drugs in Lewy body dementia” (Person Living with Dementia, phase 1). This extract highlights the caution that is needed when prescribing antipsychotic medication for people with Lewy body dementia as they are at risk of adverse reactions to this type of medication (Alzheimer’s Society, 2017; Earlstein, 2016).

In phase 2 of the study, the dementia clinicians highlighted the issues of medication non-compliance and demonstrated that non-compliance can occur due to a number of issues.
This is reflected in this data extract where a Ward Manager is talking about the difficulties which are encountered in a mental health NHS dementia inpatient ward in getting patients to take medication:

“I think sometimes people don’t recognise that it is medication any longer. I think that maybe often it’s not inviting. It’s not…they don’t recognise it as a medication and they don’t recognise it that it’s something that is going to do them good. But … or the benefit of it. They can’t remember that they used to take it. And you can’t rationalise why you need to take this now and we need to … you know, you need to take it within this time limit.” (Ward Manager 2, phase 2)

It is in this context that the need for covert medication can arise and this was also reflected in the phase 2 study. Covert medication involves disguising medication, usually in food or drink, for a patient who lacks the capacity to consent to treatment in their best interest (Smith 2015).

In phase 3, Eric (case study 2) provides further insights into why medication features as a flexible component of complexity. The interview with Eric’s Consultant Psychiatrist highlighted a number of medication issues which were contributing to his complexity. These included balancing the need for covert medication due to a lifelong dislike of medication and the risk of prescribing medication to treat some of the distressing symptoms Eric was experiencing against the potential for side-effects or further deterioration. The following data extract from his Consultant Psychiatrist (phase 3), develops this further:

“He was on covert medication. He didn’t like taking medication and we got that from his wife. He never liked taking medication”

However, Eric’s complexity regarding medication did not stop there as there were also issues in prescribing medication for him due to his dementia diagnosis. This is reflected in the following data extract where, once again, his Consultant Psychiatrist is talking about prescribing medication for Eric:
“So the reason for his complexity was, and again, you need to look at the patient holistically. He had vascular dementia or he has vascular dementia. He presented with these challenging behaviours with hallucinations, agitation, aggression. He already had vascular risk factors from a physical point of view, so you needed to be very careful about what medications to choose if you were going to treat him. And of course, we found out he’s very sensitive to medication, so again, we need to be extra careful, not just in the way he would respond to the medication, but also the interactions with other medications.” (Case Study 2 Eric, Consultant Psychiatrist, phase 3)

In my own clinical experience as a non-medical nurse prescriber, I have faced many challenges when prescribing for individuals on mental health NHS dementia inpatient wards. These have included decisions about when to give medication covertly and balancing the potential risks and benefits of prescribing a medication to treat one symptom when the drug may make another symptom worse. An example of this is when an individual with dementia is experiencing severe and distressing psychotic symptoms, for example visual hallucinations, which are placing them and others at risk. In this situation, as a prescriber, you are faced with the decision to treat with an antipsychotic which may improve the distressing psychotic symptoms being experienced, or not to treat these symptoms as the medication is also associated with an increased risk of death or a cerebrovascular adverse event in people with dementia (Banarjee, 2009).

**Component xiii) Environmental Effects**

This component of the Flexible domain of complexity concerns the effect the environment can have on some people with dementia resident on the mental health NHS dementia inpatient wards. For some people, it is the effect of the physical environment such as the layout, lighting, heating, locked doors which they may react and respond to. For others, it is living in such close proximity to other patients in an unfamiliar and shared environment. The effect that the environment can have on complexity is demonstrated below in extract from phase 1 of the data:

“Environment – physical environment, for example noise, light, heat and the effect that this has on the person.” (Speech and Language Therapist, phase 1)
There was also awareness amongst participants in phase 1 that, for some people, an admission into hospital could also cause deterioration in their dementia, thereby demonstrating the interaction between domains and components of complexity. The following data extract from a person living with dementia highlights this concern:

“Dementia becomes worse in hospital because of the unfamiliarity of the environment and people, the noise, the unexpected, the complexity of any task in a strange place quite apart from any other illness.” (Person Living with Dementia, phase 1)

The effect the physical environment in a mental health NHS dementia inpatient ward can have on patients was also prevalent in phase 2 of the study:

“You know, so like environmental changes, and different things like that, you know, being moved or coming into hospital, you know, can sort of make them feel more brittle and more agitated because they feel like … some of them will say it’s a prison and they’re being kept here.” (Nursing Assistant 2, phase 2)

Dementia clinicians in phase 2 also highlighted what the effects of living in a shared environment with others could have. This concerned itself with the number of people living together in a contained space and the effects of their presentations on one another. For example, people with dementia who are intrusive to others, or require lots of space as they like to walk and be ‘on the move’, or like their own space. Running at full bed capacity means that there are larger numbers of patients in the same space. In this scenario, the effects of the environment were inter-related with the Fundamental domain of perceived risk, as there was concern about patients responding and reacting to one another in the same shared space. The following data extracts reinforce this point:

“It [the environment] will definitely play a part in their presentation, their reaction to their environment. Everybody’s different obviously and everybody wants a different type of environment and that can be quite difficult can’t it when you’ve got a ward full of different individuals with different needs. Some people enjoying and responding well to music and stimulus and other people would not like that and it could make them more agitated.” (Allied Health Professional 2, phase 2)
“For instance, I have a patient at the moment who is very protective over his own space basically, so when he goes for his meals or just to have a drink, he’ll sit two chairs at the side of him and he’ll sit in the middle and anybody who comes into that space they will get hit basically and it has happened, they will get hit.”

(Consultant Psychiatrist 2, phase 2)

This latter data extract powerfully illustrates the impact that the environment can have on a person with dementia and how it contributes to their complexity. It is apparent that this patient requires his personal space to be protected at all times; however, in the confines of a busy inpatient ward this is always going to be a problem, particularly when other patients may unintentionally be intrusive.

The case of Brian (phase 3 case study 1) also demonstrated how environment can affect an individual. In my clinical reflections of Brian (see page 154) I have previously discussed how he constantly seemed to be trying to make sense of his environment. His behaviour in this space was reflective of a man ill at ease, who knew he was not in a familiar space and, as a result, constantly appeared anxious. Although the dementia clinicians in phase 2 of the study were able to verbalise an awareness of the impact the environment can have and contribute towards patient complexity, in the case of Brian this awareness did not seem to fully translate into practice. Brian’s clinical record made no mention about the effect the environment was having on him.

As a clinician reflecting upon my own practice, I cannot help but wonder if dementia clinicians working on mental health NHS dementia inpatient wards have a tendency to take the environment ‘for granted’ as we can make sense of it, contextualise it and know why people are there. In adopting this position, we do not always see how it is contributing to, and affecting, a person who has been admitted for assessment, care and treatment of their dementia.

**Component xiv) Family Dynamics**

The penultimate component in the Flexibility domain is family dynamics. This may, at first, seem a contentious component of complexity, but it is one which has been visible throughout the data set. It concerns itself with family dynamics and how these affect the
person and differing views on management and care options. This is reflected in the following data extract from phase 1:

“Complex family dynamics impacting upon the problems, particularly disagreements about management and care options.” (Speech and Language Therapist, phase 1)

The following extract from phase 2 outlines a families’ differing view of care options. Here a Consultant Psychiatrist is talking about a case from the ward:

“So the family, we’ve had several meetings with the family, they are part of the complexity, basically. Yeah, they’re part of the complexity in that the more, us as a team, keep saying to them ‘this is where your mother needs to go’, they have gone to every single place, that’s not where she’s supposed to go. They’re going and looking in all the residential homes where we’re saying ‘it’s EMI nursing or specialist behaviour unit.’” (Consultant Psychiatrist 2, phase 2)

On occasion, the family may also be contributing to the complexity of the person due to a lack of knowledge about dementia and related care needs, or they are in a degree of denial about the illness and its effects and there are occasions when their contact with the person may actually make their presentation worse. It was these aspects which also featured in phase 2. The following extract from the data reflects these points. In the first, a Nursing Assistant is talking about how family can contribute to complexity:

“Sometimes I think their families make the patients complex because it’s like a conflict of interest.”

She/he moves on to say:

“Like a family will say to you, ‘my mother doesn’t have sugar’, but that patient might want sugar, or, ‘oh my mother’s never wet herself’, but that patient might be incontinent, and sometimes if the relative takes the patient to the toilet and they find they’re wearing an incontinence pad that can upset the relatives.”
and concludes with:

“So it’s like a lot of times the families don’t realise that the illness is progressive and, yeah, they might have only been in here a couple of weeks but they might have moved on slightly from when they came in.” (Nursing Assistant 1, phase 2)

In the second illustration, a Staff Nurse is talking about relatives contributing to a person’s complexity:

“Also, you as well, but if you’re upset and stressed, and sometimes relatives are not great maybe with their relative, and they can say things that upset them, like, remind them... ‘Oh no, it wasn’t that, mum, no, no, it’s Tuesday not Saturday’, you know, maybe not understanding dementia. And you can see them all becoming upset, and then when they leave the relative is walking round distraught and upset. That’s difficult because you want them to have visitors, you want people to see their family, but it’s not always maybe the best thing for their mental wellbeing or their mood at that time, I suppose. Yes, so family is a big one.” (Staff Nurse 1, phase 2)

In most cases the family are extremely supportive and want what is best for their relative. However, as the data demonstrates, there are occasions when, due to existing family dynamics, a lack of understanding about dementia and its progressive nature or as a result of their own stress, they may not cause a person with dementia’s complexity but, as had been demonstrated, it can contribute towards it.

**Component xv) Attitude and Approach of Others**

The final component of the Flexible domain of complexity is ‘attitude and approach of others’ and how this can contribute to a person’s complexity. This concerns itself with how a person may connect, engage, communicate and deliver care to the person with dementia. Often, it may stem from a lack of awareness and understanding of dementia and how it affects the person. This was an area which was reflected in all three phases of data collection and something which I have also witnessed on occasions within my clinical role.
The following extracts from phase 1 of the data outlines how participants taking part in the online electronic survey identified attitude and approach of others as being a contributory factor of complexity:

“Responses to the dementia by relatives/carers.” (Professor 4, phase 1)

“Lack of awareness and understanding on the part of the carer about how the person is being impacted cognitively.” (Development Lead, phase 1)

“Poor understanding of dementia and its presentation.” (Reader, phase 1)

In phase 2, the dementia clinicians again used their experience of working on the mental health NHS dementia inpatient ward to demonstrate how attitude and approach can affect a person. The importance of approach and the effect that a negative approach can have on contributing to a person’s complexity held particular resonance with the Nursing Assistants. The following data extracts from a Nursing Assistant highlights the effect that the staff approach can have on a patient:

“I've seen first-hand where I've seen people go in and, you know, they've given all this, and they'd be surprised when that person was hostile. And even when you try to explain it to them, you wouldn't be happy if I did it to you, I think sometimes they don't...it almost becomes like muscle memory, you know, they're not even thinking about what they're doing or the person in front of them, they're just thinking of the actions that need doing” (Nursing Assistant 3, phase 2).

“I think sometimes, a member of staff, you know, sort of how they're approached. You know sort of ... you know, if you walk up to somebody quickly and you start shouting at them it can be quite frightening, I think, you know, for an elderly dementia patient it can have ... because somebody can be quite calm and then you can have a patient kicking off royal all down to a member of staff. Just down to a member of staff's interaction with that person can create chaos, yeah.” (Nursing Assistant 3, phase 2)
In phase 3, the case study of Charlotte enabled me to observe at first-hand how the attitude and approach of staff at times contributed to her presentation of complexity. During my observations (see page 176) I witnessed a staff nurse walk out of an office and without engaging with Charlotte, get her out of a chair and walk her to the bedroom area. In this interaction there was no verbal communication and no eye contact from the staff nurse. At the time I made an assumption that the staff nurse had taken Charlotte to the toilet a short while later, Charlotte returned to the day area accompanied by the same staff nurse and a nursing assistant. Again, there was no verbal interaction to her from either of the staff members, but Charlotte appeared very angry and distressed. This emotional state did not resolve and Charlotte continued to be distressed and angry for most of the day. How much of Charlotte’s emotionally charged state was as a result of the attitude and approach of staff during their engagement with her, and subsequent intervention, was unknown. Accordingly, this component is positioned within the Flexible domain of complexity, but the actions of staff to either cause or exacerbate complexity needs to be acknowledged.

5.4.1 Summary
The second F in the 3Fs Model of Complexity stands for Flexible. The Flexible domain of complexity consists of 15 components. A person may experience any number of components of the Flexible domain at any time. These components will interact with each of the five Fundamental components of complexity and also will interact with other components in the Flexible domain. Examples of this occurrence have been provided throughout this section. Components in the Flexible domain have the capacity to change and evolve. In addition, all components across both the Fundamental and Flexible domains have the ability to fluctuate in their acuity and effect on the person with dementia. It is this Fluctuating that is the third F in the 3Fs Model of Complexity and which will now be discussed in more detail.

5.5 Fluctuating
The third F on the 3Fs Model of Complexity stands for Fluctuating. This means that the components of both the Fundamental and Flexible domains of complexity are not static and their presentation can change with acuity. This will now be discussed in more detail
and supported through phases 2 and 3 of the data and where appropriate, my own clinical reflections and experience.

The view that the components of complexity are not static and can be fluctuating in their presentation and intensity was supported by dementia clinicians in phase 2. The following extracts from the data demonstrate this statement:

“Absolutely it can go up or down [complexity], absolutely.” (Consultant Psychiatrist 1, phase 2)

“I mean, from my thoughts of complexities, as I’ve mentioned, is different factors, so if you can remedy one of the things that’s wrong then that leaves you with less things to address; so in that sense it’s if you’re addressing something and remedying it, then it starts to become less complex. But it changes, there might be another thing added in, someone might get an infection, or something else happens.” (Allied Health Professional 3, phase 2)

The data indicates that Fluctuating can occur in the components of complexity for three main reasons: i) when something changes in an existing component; ii) when an additional ‘new’ component comes into play; and iii) in response to an intervention. This can result in an increase in acuity or a person with dementia becoming more stable or less complex.

In the following data extract a Deputy Ward Manager is reflecting upon the fluctuating nature of complexity:

“Obviously, as people get further on, needs can become more complex, but then people get to a stage where they become less complex, because of the nature of the illness and it progressively gets worse.” (Deputy Ward Manager 1, phase 2)

The participant moves on to clarify that this reduction in complexity is in relation to the behaviour that challenges (component iv in the Flexible domain) diminishing:

“I would say when the behaviours have diminished, the challenging behaviours have diminished.”
In the following extract from the data, also from phase 2, a Consultant Psychiatrist is talking about how components of complexity can be fluctuating in their acuity:

“Yeah, yeah, but then there are certain factors that we’ve mentioned that can complicate the complexity, you know, when they go off physically, when the pain seems worse.” (Consultant Psychiatrist 2, phase 2)

In phase 3, Fluctuating in the Fundamental and Flexible domains of complexity was highlighted in the cases of Eric (case study 2) and Charlotte (case study 3). Eric experienced a further deterioration in his dementia and was believed to be at end-of-life. This, in turn, had reduced his behavioural complexity as it was no longer acute or intense, but his complexity in the component areas of physical health, diet and fluids and frailty all increased.

In the case of Charlotte, when I interviewed her named nurse, Linda, she informed me that with regard to complexity, her behaviour that challenges (Flexible component iv) had appeared to reduce in acuity since she had been admitted. This is reflected in the following data extract:

“She’s certainly a lot more settled. The periods of shouting and agitation are few and far between now really.” (Case Study 3 Charlotte, named nurse, phase 3)

However, shortly after this interview, I commenced my observations of Charlotte and witnessed Charlotte becoming very angry with increased frequency in her shouting; in other words, Fluctuating was an ever-present part of the picture of complexity. Moreover, my own clinical experience suggests that the Fundamental and Flexible components of complexity will be always be Fluctuating and evolving and interacting with one another.

5.6 Summary
The third F in the 3Fs Model of Complexity is Fluctuating. Fluctuating represents the dynamic nature of the components in both the Fundamental and Flexible domains and how components can change in their acuity and effect on the person. This fluctuating nature of complexity has been supported with extract from phases 2 and 3 of the data.
5.7 Summary of the 3Fs Model of Complexity

I will now briefly summarise the contents of 3Fs Model of Complexity, which this chapter has explored in detail. The 3Fs in this model of complexity are Fundamental, Flexible and Fluctuating. The Fundamental domain consists of five components: presence of dementia, life story, impaired communication, impaired insight and capacity and perceived risk. For a person with dementia to be classed as complex these five Fundamental domains always have to be present. The Flexible domain consists of 15 components: physical health conditions, pain, mental health problems, behaviour that challenges, diet and fluid changes, impaired self-care ability, sensory impairment, mobility changes, sleep pattern changes, frailty, swallowing difficulties, medication issues, environment effects, family dynamics, attitude and approach of others. A person with dementia may experience any number of Flexible domain components at any time. Moreover, the components of complexity may interact with one another both within and across domains. The third F in the 3Fs Model of Complexity is Fluctuating and represents the fact that components in both the Fundamental and Flexible domains have the ability to fluctuate in their acuity and effect on the person. It is this fluctuation that reflects the dynamic, evolving and changing nature of complexity. The 3Fs Model of Complexity and its associated components has been diagrammatically represented; see Figure 5.1 page 250.

5.8 Chapter Summary

This chapter has presented and discussed the 3Fs Model of Complexity which is an integrated model of complexity. The three F’s stand for Fundamental, Flexible and Fluctuating. The five Fundamental components of complexity have been presented along with the 15 Flexible components of complexity. Data from phases 1, 2 and 3 of the study along with my own clinical experience have been used to highlight and support this analysis. The Fluctuating nature of complexity has also been presented and discussed and supported by data from phases 2 and 3 of the study and my own clinical experience. I will now elaborate upon the 3Fs Model of Complexity in the Discussion and Conclusion chapter of the thesis that now follows. In this chapter I will discuss the original contribution that the 3Fs Model of Complexity has made to theory and the potential contribution to dementia care practice.
Figure 5.1 The 3Fs Model of Complexity

- **FUNDAMENTAL DOMAIN**
  - Presence of dementia
  - Life story
  - Impaired communication
  - Impaired insight & capacity
  - Perceived risk

- **FLEXIBLE DOMAIN**
  - 15 components
    - Physical health conditions
      - Pain
    - Mental health problems
    - Behaviour that challenges
    - Diet & fluid changes
    - Impaired self-care ability
    - Sensory impairment
    - Mobility changes
    - Sleep pattern changes
    - Frailty
    - Swallowing difficulties
    - Medication issues
    - Environment effects
    - Family dynamic
    - Attitude & approach of others

- Complexity
CHAPTER 6
Practice Application of the 3Fs Model of Complexity

6.1 Introduction
In keeping with an interpretive description approach, this chapter explores the practice application of the 3Fs Model of Complexity. As the origins of this study stemmed directly from clinical practice, and as I also continue to work clinically, it was essential that the study generated findings that could be translated back into practice. Thorne (2014, 2008) refers to this as the ‘so what?’ element of interpretive description, which is the point where the researcher makes explicit which elements of the findings can, and cannot, be taken back to inform practice. Therefore, in order to explore the authenticity and applicability to practice of the 3Fs Model of Complexity, I took the 3Fs Model of Complexity and retrospectively applied it to case study 4 Celia. I first undertook the process myself - the outcome of which is placed in Appendix 9. Once I had done this and ‘proved’ to myself that the model had both face and practice validity, and in line with my research protocol and ethical approval processes, I then contacted two mental health nurse participants who had previously taken part in phases 2 and 3 of the study. The purpose of this contact was to ask the two mental health nurses to apply the 3Fs Model of Complexity model to two case studies that were contained in phase 3 of the PhD study. This is in keeping with an interpretive description design as it allows an opportunity for reflection as to what extent the development rings true for practice and is referred to as the “thoughtful clinician test” (Thorne, 2004, p.8). This is when those with knowledge of the phenomenon support that the outcomes of the research confirm their clinical instincts, but they also bring new understanding and connections regarding the phenomenon under study.

6.2 The 3Fs Model of Complexity: Application to Practice
Two mental health nurses, a Staff Nurse from phase 2 (Staff Nurse 3) and the Deputy Ward Manager, Joan, from phase 3 who had previously been interviewed for case study 1 Brian, were approached. Following their agreement to undertake this task in hand, I met with both participants individually on 26th March 2018. I initially explained how the findings from the study had been used to develop the 3Fs Model of Complexity and then
introduced them to the model. I paid attention at this meeting to explain the Fundamental, Flexible and Fluctuating underpinnings of the model. All components of the 3Fs Model of Complexity were also explained. The two participants were able to ask questions and clarify any points with me about the model and they both agreed to try to retrospectively apply the 3Fs Model of Complexity to one of the four case studies. As both participants had worked on Jasmine ward during phase 3 data collection, they could recall the four case studies; however, each participant remembered a different case study in more detail. For the Deputy Ward Manager this was case study 1 Brian, and for the Staff Nurse it was case study 3 Charlotte. It was these individual cases to which they agreed to retrospectively apply the 3Fs Model of Complexity. The two participants were given a paper copy of the domains and components of the 3Fs Model of Complexity. I then asked them to first highlight which components were applicable to the case they had chosen, and then to identify any ‘within’ domain interactions and then any ‘between’ domain interactions. As a final task, they were asked if any of the domains had changed in acuity or intensity during the time of the person’s admission.

The process of completing this activity took each participant approximately 30 minutes. The result was two similar looking diagrams and I will now explain this application in more detail. However, due to the time constraints of both nurses, it was not possible to provide as comprehensive a description of all the factors and interactions between components as I provided for the case study of Celia in Appendix 9.

6.2.1 Practical Application of the 3Fs Model of Complexity: Brian
The Deputy Ward Manager was familiar with the case of Brian and, despite the passage of time; she was able to recall Brian and his presentation and needs. As a reminder, Brian was admitted to Jasmine ward from a nursing home registered to look after people with dementia as an emergency admission due to reported aggression. Brian’s admission was a compulsory one and he was detained under the Mental Health Act (DH, 1983). Brian had a diagnosis of Alzheimer’s disease. He also had a number of comorbid physical conditions which included long-standing depression, osteoarthritis, retinitis and an inguinal hernia. As a result of falls, Brian also had three previous head injuries. He wore hearing aids in both ears. At the time of the case study, Brian had been described by the Deputy Ward Manger
as complex as “he’s not just got dementia he’s also got his depression and he’s got his behaviour stuff, he’s got his hearing problems.”

All the components of the Fundamental domain were identified as present. From the Flexible domain the components of: physical health conditions, pain, mental health problems, diet and fluid changes, impaired self-care ability, sensory impairment, mobility changes, frailty, medication issues, environmental effects, family dynamics and attitude and approach of others were also identified as being present.

As seen in Figure 6.1, page 255, the Deputy Ward Manager drew lines and arrows to identify interactions within and between domains. The participant was able to confirm that all of the components in the Fundamental domain interacted with each other and that a number of components in the Flexible domain interacted with each other. In addition, there was also significant ‘across domain’ interaction. Sometimes this across domain interaction was in one direction, that is, from Fundamental to Flexible component(s) or from Flexible components to Fundamental components. Interestingly, and on many occasions, the interaction was a two-way process; for example, the ‘presence of dementia’ interacting with ‘physical health’ and ‘physical health’ also interacting with the ‘presence of dementia’.

As shown in Figure 6.1, page 255, the result of this exercise was a very busy looking diagram consisting of multiple connecting lines and arrows highlighting the components of complexity and the interactions with each other. That said, the Deputy Ward Manager was able to share that all the identified components from the Fundamental and Flexible domains were present throughout Brian’s admission, although their degree of acuity differed [Fluctuating]. Some components were consistently acute, others increased in acuity and there were some that were not as acute, but still contributed to Brian’s complexity.

Drawing on the Fundamental domain, components that were identified as consistently acute throughout Brian’s admission included: presence of dementia, impaired insight and capacity and perceived risk, and from the Flexible domain: mental health problems, behaviour that challenges, environmental effects and attitude and approach of others. Those components which fluctuated in acuity were identified as: mobility changes,
impaired communication and frailty. The Deputy Ward Manager was able to describe how Brian’s mobility had deteriorated during his admission and that his communication had further deteriorated with increased expressive and receptive dysphagia that left him becoming increasingly frustrated. By looking at Figure 6.1, page 255, the Deputy Ward Manager also identified that, during his admission, Brian appeared to become increasingly frail - a component that was not present when he was initially admitted to the ward. The components which had a marked consistent presence throughout were: life story, physical health conditions, impaired self-care ability, pain, sensory impairment, medication issues and family dynamics.
Figure 6.1 The 3Fs Model of Complexity Applied to Brian
6.2.2 Practical Application of the 3Fs Model of Complexity: Charlotte

The Staff Nurse, who had previously been interviewed for phase 2, chose the case of Charlotte as a practical example to apply the model as this was the case she/he was most familiar with. As a reminder, Charlotte was 71 years old and was diagnosed with young onset Alzheimer’s disease when she was 64 years of age. Charlotte was admitted to Jasmine ward from the local acute general hospital trust. Whilst in the general hospital, the clinical staff experienced difficulties in meeting her care needs due to Charlotte resisting care interventions and displaying verbal and physical aggression. Prior to being in hospital, Charlotte lived in her marital home and all her care was provided by her husband. Charlotte’s admission to Jasmine ward was a compulsory one. At the time of admission Charlotte was reported to be in good physical health.

On Jasmine ward Charlotte resisted all interventions and staff attempts at help, such as helping her to dress, assisting her to take diet and fluids and taking her to the toilet. She would only accept diet and fluids from her husband and brother. Charlotte was believed to be advanced in her dementia. When her Named Nurse Linda described Charlotte she talked about her being “one of the most challenging people that I have ever had to look after.”

Charlotte: Applying the 3Fs Model of Complexity

As with Brian, the Fundamental components were all identified as being present. However, when it came to the Flexible domain, this study participant believed that all the components in the Flexible domain contributed to Charlotte’s complexity. As seen in Figure 6.2, page 257 lines and arrows were again used to highlight the interaction of components. After the Staff Nurse had completed the model she/he was able to describe that she/he had tried to show that all of the Fundamental domains interacted with each other and, within the Flexible domain, a number of components interacted with each other. Examples of interactions in the Flexible domain were given as: impaired self-care ability with behaviour that challenges; and environmental effects and attitude and approach of others. There was also evidence of multiple ‘between domain’ interactions. These interactions within domains and between domains can be seen in Figure 6.2, page 257.
Figure 6.2 The 3Fs Model of Complexity Applied to Charlotte
On this occasion, the two way interaction that can occur between components across domains is perhaps not as clearly shown as the majority of the arrows face in one direction. However, when discussing the diagram after completion, the Staff Nurse talked about the two-way interaction of a number of components between domains and how if she/he were to repeat this exercise, s/he would highlight this by the use of more two way arrows. She/he also reflected on how, in the case of Charlotte, a number of components were present throughout her admission and, as was identified in Brian’s case, the degree of acuity between some components differed [Fluctuating]. There were components that remained consistently acute, others actually decreased and then increased in acuity and there were components that, although not as acute, were present and contributed to Charlotte’s complexity. There were also six components from the Flexible domain which, after studying the model, the Staff Nurse considered had not been present during the initial stages of admission, but occurred later on in the admission. This demonstrated the importance and existence of Fluctuating and evolving nature of complexity in dementia.

The components which remained consistently acute from the Fundamental domain were identified as: presence of dementia, impaired communication, impaired insight and capacity and perceived risk, and from the Flexible domain: diet and fluid changes, impaired self-care ability, medication and attitude and approach of others. The Staff Nurse also drew attention to two components which, when Charlotte was initially admitted, were acute, and then their acuity reduced slightly; however, this was not maintained and there was another increase in there acuity. These were from the Flexible domain and were identified as mental health problems and behaviour that challenges. The two components which had a consistent presence throughout Charlotte’s admission, but still contributed to the complexity, were identified as life story and environmental effects.

A number of components from the Flexible domain were identified which were thought to have evolved during Charlotte’s admission and further contributed to her complexity. These were physical health conditions, pain, mobility changes, sensory impairment, swallowing difficulties, sleep pattern changes and frailty. Examples that were offered to support this included changes to mobility. For instance, Charlotte’s gait at times started to appear unsteady and she had experienced a number of falls from missing chairs when she was going to sit down. It was also unclear if her unsteady gait related to sensory changes that Charlotte could not articulate to staff or from a physical health condition.
6.3 Similarities and Feedback

The application of the 3Fs Model of Complexity to Brian and Charlotte by the Deputy Ward Manager Nursing and Staff Nurse was undertaken on separate occasions. Yet, despite this occurrence, there are striking similarities between the:

- Diagrams that were produced.
- Rationale regarding components of complexity.
- Interaction of components.

Both diagrams are ‘busy’ and demonstrate the relationship of components which contribute to complexity in dementia. Feedback from both dementia clinicians was positive about the 3Fs Model of Complexity. There was agreement that having the Fundamental and the Flexible domains with their various components helped to identify the areas of need with a person and also facilitated an understanding about how the components interacted with one another. Both participants indicated that, in practice, this would help see a person in their totality as opposed to viewing needs or symptoms in isolation. They also indicated that it would provide a framework for assessment and a language from which to articulate a person’s presentation and needs. In turn, this would provide an inductively generated framework for intervention that was evidence-based. From the perspective of the two participants, they were able to confirm that the 3Fs Model of Complexity confirmed some of their “clinical hunches” regarding complexity but that it also provided new insights and understandings thereby providing “disciplinary relevance” (Thorne, 2014, p.110).

6.4 Conclusion from the Practical Application

Due to time pressures and ethical constraints, it was not possible to take the 3Fs Model of Complexity back to the mental health NHS dementia inpatient ward(s) for additional ‘testing and refinement’ on current patients. Moreover, it is worth noting that when the two study participants were retrospectively applying the model to Brian and Charlotte, the use of the 3Fs Model of Complexity seemed to help facilitate their communication about how both of the individuals presented. The participant’s conversation around each of the selected cases was more structured and focused and there was a realisation of how components affected and interacted with other components. Both participants were also very quickly able to identify which were the components that were more acute in nature.
and which components fluctuated during the individual’s admission. The participants also shared that they thought the domains - and components within the domains - to be comprehensive and nothing had been excluded. There was also agreement that the five components of the Fundamental domain were, indeed, fundamental to that person’s presentation of complexity.

Using the 3Fs Model of Complexity appeared to give the two study participants a framework from which to work from to map the person’s presentation and needs. Verbal feedback from both individuals was that this model would be very useful in practice to facilitate the assessment process and identify where to focus interventions and treatments. The exercise did, however, produce very busy and messy looking diagrams which are difficult to follow and make sense of. This has highlighted the need that when this model is further developed for practice application, the use of an electronic version [possibly on a tablet] requires consideration to facilitate ease of use and visual understanding when completed.

The ‘piloting’ of the model in this way demonstrated that the 3Fs Model of Complexity could be used as a more comprehensive and holistic assessment tool for clinicians working in mental health NHS dementia inpatient wards. The Fundamental and Flexible domains can help structure the assessment process and the emphasis that the model places on interaction of components within and between domains and their ability to fluctuate promotes a more holistic approach to assessment. Having the opportunity to ‘pilot’ the model with two dementia clinicians and gain their insights facilitated a natural end point to the study, as the subject area had been generated from practice and the developed model taken back to practice for initial testing and review. I will now move onto the final chapter in this thesis, the discussion and conclusion.
CHAPTER 7
Discussion and Conclusion

7.1 Introduction
This final chapter will begin with a review of the study aims. I will then go on to discuss the original contribution that the 3Fs Model of Complexity has made to theory and the potential contribution to dementia care practice. The 3Fs Model of Complexity will then be critically discussed in context of other research and publications regarding complexity in dementia. The work of Tom Kitwood (1997) and its relevance to the 3Fs Model of Complexity will also be appraised. In line with the spirit of interpretive description (Thorne 2008) I will also take one component from the Fundamental domain of complexity and one component from the Flexible domain of complexity and consider these against the broader literature. The issue of (my) practitioner-researcher reflexivity will then be discussed, followed by limitations of the study. Implications of the study for practice, education, research and policy will be outlined and finally the thesis will end with concluding remarks.

7.2 Review of the Study Aims
This study has explored the nature and meaning of complexity in dementia within the setting of two mental health NHS dementia inpatient wards in the Northwest of England. The origins of the study are embedded in the authentic roots of clinical practice and stemmed from questions, and discussions, generated by myself and clinicians currently working in mental health NHS dementia inpatient wards. We would routinely describe (verbally and via case records) people with dementia admitted to the wards as ‘complex’ without any shared meaning or understanding about what this actually meant. As shown in Chapter 2, the literature, policy and clinical guidance in dementia care was equally vague and inconclusive on this topic area. The study therefore offered a timely opportunity to provide some clarity to a concept that had largely been omitted from discourses at all levels of dementia care practice, planning and policy-making and to do this in the setting of mental health NHS dementia inpatient wards where, again, limited attention was to be found. In the light of all the focus on dementia in England subsequent to the publication of
the National Dementia Strategy at the end of the last decade (Department of Health 2009), this is a curious paradox indeed.

### 7.3 Original Contribution to Theory and Practice

**Complexity in Dementia**

I have explored the concept of complexity in dementia using a qualitative mixed methods approach over three phases of data collection. The three phases of data collection consisted of: i) an online electronic survey of 19 UK dementia leaders; ii) semi-structured interviews with 20 dementia clinicians who worked on two mental health NHS dementia inpatient wards and a focus group of nine older adult community mental health team practitioners and; iii) four ethnographic case studies of people who were currently receiving care and treatment in a mental health NHS dementia inpatient ward. This third phase consisted of multiple periods of observations of each patient, an interview with the patient, their spouse and a clinician closely involved in their care and a review of their care record.

Data analysis occurred concurrently with data collection thereby enabling the analysis and interpretation of data to inform and influence the next phase of the study. This approach enabled an iterative process to be employed throughout the study whilst mirroring the inductive, analytic process of interpretive description (Thorne, 2014, 2008).

**The 3Fs Model of Complexity**

The 3Fs Model of Complexity draws together the findings from the three phases of data collection and theoretically assembles them into a model of complexity in dementia (shown in Figure 5.1, page 250) As far as I am aware, this is this first time that such an inductively generated model of complexity has been produced that includes the voices and experiences of patients on a mental health NHS dementia inpatient ward who were legally detained in this setting on varying sections of the Mental Health Act (DH, 1983). The research used mixed qualitative methods to enhance rigor and focussed on a real world practice issue that is in keeping with an interpretive description methodological approach (Thorne, 2008).
In the generated model, the 3Fs stand for the domains of: Fundamental, Flexible and Fluctuating. The Fundamental domain consists of five components which are always present in complexity. These Fundamental components are: presence of dementia, life story, impaired communication, impaired insight and capacity, and perceived risk. The Flexible domain consists of 15 components which are: physical health conditions, pain, mental health problems, behaviour that challenges, diet and fluid changes, impaired self-care ability, sensory impairment, mobility changes, sleep changes, frailty, swallowing difficulties, medication issues, environmental effects, family dynamics and attitude and approach of others. All Fundamental domain components will be present all the time, but a person may experience any number of Flexible domain components at any time. Moreover, the components of complexity may interact with one another within each domain and across domains. The third F in the 3Fs Model is Fluctuating and represents the fact that components in both the Fundamental and Flexible domains have the ability to be Fluctuating in their acuity and effect on the person. As shown in Figure 5.1, page 250 it is this fluctuation that reflects the dynamic evolving and changing nature of complexity. The 3Fs Model of Complexity may facilitate a more holistic view of a person with dementia than when ‘symptoms’ are viewed in isolation of each other, as often happens in practice and as observed in my data collection. Hypothetically, the 3Fs Model of Complexity could help guide the selection of tailored, personalised interventions.

Recontextualising the Literature
The literature review in Chapter 2 identified that the concept of patient complexity across health and social care and particularly within dementia is underdeveloped. However, patient complexity is an evolving concept with the recognition that patient complexity is increasing (Shippee, et al., 2012). Although the current body of work on complexity has not provided a consensus definition, the literature review identified that patient complexity is more than the sum of comorbid conditions and has biopsychosocial roots. The research undertaken to-date identifies that patient complexity consists of a number of components/factors and that it is not just the presence of these components/factors but the interaction of them, thereby suggesting that complexity is not a static state (see: Shippee, et al., 2012; Grant, et al., 2011; McGeorge, 2011, 2010; Safford, et al., 2007; Weiss, 2007).

The findings from this study reflect this earlier work and supports that patient complexity has biopsychosocial origins and that it is a dynamic state consisting of a number of
components. However, it builds on and further develops the existing body of literature regarding complexity in a number of ways. For example, The New Ways of Working (DH, 2007) initiative identified that there were a range of options in how complexity could be defined in clinical practice. These options included as a concept, by multiplicity and/or severity of need including risk, intervention and service. The report also suggested that it may be helpful to focus upon the variables that may contribute towards complexity as opposed to seeking to create a definition. This findings from phases 1, 2 and 3 of this study develop these options further and demonstrated that complexity in dementia within the clinically focused environment of mental health NHS dementia inpatient wards is defined in terms of a multiplicity of components, some of which are fundamental and always present, and some of which are flexible. As demonstrated in phases 2 and 3 of this PhD study especially, all components have the ability to interact and affect one another and the severity, acuity and effect on the person with dementia can also fluctuate.

The literature review identified that the Care Program Approach (CPA) (DH, 2008) which is used in secondary mental health services to assess, coordinate and deliver care for people, uses the term ‘clinical complexity’ as one of the characteristics for assessing if an individual requires the support of CPA. However, the term was not described leaving clinicians to make their own judgements about what may, or may not, constitute ‘clinical complexity’. As the 3Fs Model of Complexity was developed from within a mental health NHS dementia inpatient environment, the parameters of ‘clinical complexity’ can now start to be developed to support the CPA process in facilitating a holistic assessment and the subsequent coordination and delivery of care interventions for people with dementia and their care networks. This next stage development of the 3Fs Model of Complexity will start to address the evidence-base gaps in the literature and in the interactions within, and between, co-existing physical and mental health needs as suggested by the All-Party Parliamentary Group on Dementia (2016). It is the focus on documenting the interactions between the Fundamental and the Flexible domains of complexity, as measured by their Fluctuating nature, which helps to provide new directions for clinical practice and the generation of practice-based evidence.

As seen in the literature review chapter in this thesis, Sonola et al. (2013) described the work of the Oxleas Advanced Dementia Service, which worked with people living at home who had moderate to severe dementia complicated by complex physical and mental
comorbidities requiring a palliative approach to care. Examples of complex comorbidity were identified as recurrent weight loss, recurrent infections, poor nutrition, severe persistent distress and frailty. This was the only study located in the literature review which focused on actual care delivery of people with dementia considered to have complex comorbidity. Whilst these individuals were residing in their own home, as opposed to a mental health NHS dementia ward setting, similarities can be seen between the examples of complex comorbidity that were given and several of the components in the Flexible domain of the 3Fs Model of Complexity, such as ‘physical health conditions’ and ‘medication issues’. However, the 3Fs Model of Complexity has developed complexity in dementia further and makes explicit the five (always present) Fundamental components of complexity as well as highlighting the personal, social and environmental components. In this context, the 3Fs Model of Complexity has the potential to be able to further enhance existing models of practice, such as the Oxleas Advanced Dementia Service, and highlights its potential transferability into community settings working with people with dementia and their care networks.

As an illustration, the work of McGeorge (2010) explored the concept of age-related complexity in secondary mental health services. The findings from this study identified that complexity had biological, psychological and social components. These components were divided into internal and external domains. McGeorge’s study recognised that the components of complexity could interact with each other, and complexity was a dynamic state in which there could be recovery. Complexity was also seen to have elements of unpredictability and instability making it impossible to measure. Although some similarities can be seen in McGeorge’s findings to those which I have presented and discussed in the Study Findings in chapter 4, this PhD enhances and develops McGeorge’s work. For example, I focused solely upon ‘dementia’ in the research design and reporting whereas McGeorge’s work included people with functional mental health problems and dementia. In addition, whilst McGeorge’s data derived from nurses working across a range of settings in secondary mental health care, I chose to scope out a national view from dementia leaders whilst also interviewing staff working only on mental health dementia inpatient wards, as reported in phase 1 of the study. Perhaps one of the most significant areas where my study developed the concept of complexity further was factoring in the inclusion of people with dementia into the practice theory. This decision enabled the experience of people with dementia perceived to be complex to be captured along with the
thoughts and experiences of their relatives. Moreover, I was able to interpret and further develop the findings into the 3Fs Model of Complexity with its Fundamental, Flexible and Fluctuating domains. These latter two aspects in particular are developments which, to date, have not been represented in the existing literature on complexity in dementia.

The 3Fs Model of Complexity has built on the existing body of literature about complexity in general and further developed the small body of literature which has concentrated on complexity in dementia. It proposes that for people with dementia within the setting of mental health NHS dementia inpatient wards, patient complexity consists of Fundamental, Flexible and Fluctuating domains. This is the first time, to my knowledge, that Fundamental, Flexible and Fluctuating domains have been identified as the core aspects of complexity and represented in a practice model. Moreover, this study has also established the importance of the interaction of components within and between domains in the presentation of complexity.

The updated literature review revealed that there have been no new studies that have specifically explored complexity in dementia, so it is not possible to critically analyse these against the findings from this study. There have, however, been several recent dementia publications that need to be considered. Prime amongst these are the NICE (2018) dementia guidelines entitled ‘Dementia: assessment, management and support for people living with dementia and their carers’, published in the June of that year. The NICE (2018) guidelines focus on diagnosing and managing dementia whilst aiming to improve care by making staff training recommendations and helping carers to support people living with dementia. Unfortunately, within this set of guidelines, there is no acknowledgement that some people with dementia may become ‘complex’ as their illness progresses due to the presence, interaction and fluctuation of a number of factors. Thereby no guidance is offered to clinicians as to how to begin to assess, or meet the needs of, people with dementia when this occurs. This is a missed opportunity as my PhD study has demonstrated that some people with dementia will become complex as their illness progresses and that this complexity comprises of a mixture of Fundamental and Flexible domains and components which can Fluctuate in their presentation and severity. It is, therefore, essential that national dementia guidance starts to consider such issues so that people with dementia who become complex, or diagnosed as such, start to receive the tailored assessment, care and interventions that they require.
Recently, the Fair Dementia Care Commission (Alzheimer Scotland, 2019) was established to review how the complex health care needs of people living with advanced dementia in Scotland are understood and responded to. The commission reviewed current literature and existing data and held two meetings to seek the views and ideas from expert practitioners and family carers on defining and recognising advanced dementia in practice (Alzheimer Scotland, 2019). One of the findings from this review was that “advanced dementia produces complex health and nursing care needs” (p.10). Moreover, the review also identified that in advanced dementia health care, needs are “complex and requirements for skilled nursing and other expert health care input increases” (p.14). The following definition of advanced dementia is suggested in the review:

“Advanced dementia is associated with the later stages of illness when the complexity and severity of dementia-related changes in the brain lead to recognisable symptoms associated with dependency and an escalation of health care needs and risks. Addressing advanced dementia related health needs requires expert health care, nursing and palliative care assessments together with insights provided by family carers and others, particularly when the person has difficulty communicating their own needs and emotions. Advanced dementia involves living, sometimes for years, with advanced illness and the advanced dementia continuum includes the terminal stages of death and dying. The experience of advanced dementia is unique to the individual and dependent on the aetiology of the underlying illness, comorbidities and other factors relating to health, personality, biography” (pp.14-15).

The commission recommend that this definition of advanced dementia is adopted in practice. The Alzheimer Scotland (2019) review makes numerous references to complex health needs within its pages and describes the cumulative impact of such complex needs as being profound. However, as opposed to the detail in the operational definition of advanced dementia, the same cannot be said for complex or complexity with the reader having to make assumptions about it including communication problems, immobility, weight loss and neuropsychiatric symptoms.
It is clear from the Alzheimer Scotland (2019) review that the authors believe advanced dementia and complexity go hand-in-hand. It is reassuring to see an interest and emphasis on advanced dementia and the need for a definition. Yet, if advanced dementia and complex health care needs do, indeed, go hand-in-hand, then why did the commission not describe, or define, what ‘complex’ means within this patient population? It is in this context that the 3Fs Model of Complexity can add both enhance and strengthen the debate by providing a framework that will enable a more holistic assessment of the person with advanced dementia. It makes clear what the domains of complexity are and would support clinicians to identify which components of complexity are affecting the person with advanced dementia, their interaction with one another and the level of acuity the person is experiencing. This, in turn, can then be used to identify tailored interventions and support the need for skilled nursing and expert healthcare.

This PhD study has enabled a practice based theory about complexity in dementia to be developed and reported. Whilst this has created new insights about complexity in dementia, there are also parallels that can be drawn against Kitwood’s (1993a) seminal work on reframing dementia. As was highlighted in Chapter 1, Kitwood (1993a) believed that the clinical presentation of dementia was not solely as the result of the neurological impairment, but it arose from the interaction of five factors. These factors were identified as personality, biography, health status, neurological impairment and social psychology. These factors are also reflected across the Fundamental and Flexible domains of the 3Fs Model of Complexity, with two of three of them (personality, biography and neurological impairment) being reflected in the Fundamental domain of the 3Fs Model of Complexity. This overlap between the models highlights the authenticity of the 3Fs Model of Complexity and that complexity in dementia is more than the result of the neurological impairment.

In line with the philosophy and requirements of interpretive description (Thorne, 2008), I will now take one component from the Fundamental domain of complexity (life story) and one component from the Flexible domain of complexity (behaviour that challenges) to discuss within the broader context of contemporary literature on dementia care/studies.
Life Story: A Fundamental Component and Contemporary Context

Listening to people with dementia and understanding their stories is now seen as an essential component of good care (Gridley, et al., 2016; Kindell, et al., 2014). In a feasibility study evaluating life story work in dementia care Gridley et al. (2016) concluded that there are two predominant models of life story work; the first being led by the person with dementia and the second found in care settings and occurring at a later stage of the illness. In this latter model the focus is on aspects of a person’s life that will aid communication, increase staff understanding of the person and using life story information as an intervention to calm a person for example who may be distressed, anxious or agitated.

Knowledge about an individual’s life story can help challenge clinical staff views regarding people with dementia that they perceive to be challenging as this helps staff see the ‘person’ beyond the behaviour and that knowing about their life improves clinical staffs understanding of that person (McKeown, et al., 2010). These points were reflected in all phases of data collection and study participants in phase 2 were able to inform that knowledge about a person life story could aid communication, help facilitate interventions and facilitate an understanding of the possible causes for behaviour which challenges. Yet, despite this there was no information about any of the life histories of the four case studies in their care records.

Developing the 3Fs Model of Complexity within mental health NHS dementia inpatient wards therefore, could facilitate an increased awareness amongst clinical staff regarding the importance of gathering life story information to help develop an understanding of the person with dementia and to use it to promote further understanding regarding how the person’s life history and personality characteristics are affecting their current situation. By developing this area of practice it could actually reduce a person’s perceived level of complexity, as clinical staff would have a greater understanding of the person behind the dementia (McKeown, et al., 2010) and allow their identity to be maintained (Kitwood, 1997).

Behaviour that Challenges: A Flexible Component and Contemporary Context

The presentation of behaviour that challenges in dementia is associated with causing significant causes of distress to the person with dementia and for both informal and formal
care givers (Moniz-Cook et al., 2017). Behaviour that challenges featured in all three phases of data collection and was cited as a reason for admission to mental health NHS dementia inpatient wards. The causes of behaviour that challenges are multiple and can include physical, medical and psychosocial factors (James, 2011; Bird, 2010; National Institute for Health and Clinical Excellence/Social Care Institute for Excellence, 2006) which often interact with each other (James, 2011) in ways which are idiosyncratic to the person. Therefore, approaches are required that are able to provide an assessment of these multiple causes of behaviour (Holle et al., 2017).

Formulation approaches are one way of exploring the causes of behaviour that challenges. The use of formulation enables a hypothesis to be developed that identifies why and when behaviour might occur, thereby enabling individual interventions to be identified that target the behaviour (Jackman and Beatty, 2015; James, 2011). Formulation approaches are usually led by psychologists or other staff who have had additional training (Holle et al., 2017; Jackman and Beatty, 2015). There are a number of formulation approaches/models in existence and examples of such include Newcastle Model (James, 2011; James et al., 2007; James et al., 2006), Grip on Challenging Behaviour (Zwijsen, et al., 2015, 2014) and Clear Dementia Care Model (Duffy, 2016).

Formulation consists of four phases: a description of the behaviour, analysis of the causes of behaviour, identification of interventions and following the implementation of interventions a review (Holle et al., 2017). In order to analyse the cause of behaviour a detailed assessment of the individual is required. This assessment includes for example, details of a person’s life history, premorbid personality, cognition, physical health, and social situation (Duffy, 2016; Jackman and Beatty, 2015; James, 2011). The 3Fs Model of Complexity has the potential to support formulation approaches as it outlines all the components of a comprehensive assessment. With its focus on the interaction within and between domains along with the fluctuating nature of complexity it serves as the biopsychosocial framework needed from which staff could identify the often multiple interlinked causes of behaviour that challenges and the context in which they occur. Without the provision of a comprehensive assessment to facilitate this understanding as to the causes of behaviour then identified interventions may not lead to a reduction or removal of the behaviour (Holle et al., 2017). Furthermore, the 3Fs Model of Complexity could support the development of a formulation led models to exploring behaviour that
challenges in mental health NHS dementia inpatient wards as existing formulation led interventions/approaches have been developed for use in nursing home setting (Holle et al., 2017).

With further testing this developed 3Fs Model of Complexity has the potential to become the assessment framework for people with dementia admitted to mental health NHS dementia inpatient wards and could help guide the development of personalised interventions. The 3Fs Model of Complexity also has the scope to underpin current developments and further extend knowledge in a number of areas of dementia practice. However, it is essential that the 3Fs Model of Complexity is used in a person-centred way keeping the person with dementia at the centre of all caring practices and work. This standpoint once again brings us back to the work of Kitwood (1997) and his visualisation of a flower to illustrate what a person with dementia needs from those around them in order to be seen and to exist as a person (i.e. attachment, comfort, inclusion, occupation and identity and love - see Chapter 1 of this thesis for more detail). The interface between this model and the 3Fs Model of Complexity to help frame day-to-day care practice and decision-making, and generate an evidence-base through a person-centred philosophy, requires additional research. However, developing such next-step evidence is crucial and it needs to be undertaken alongside effective practitioner reflexivity, as I will advance further in the next section.

**7.4 Practitioner Reflexivity**

Researcher reflexivity can be described as the ability of the researcher to recognise how their own experiences and circumstances can affect the research and its processes and outcomes (Fox et al., 2007; Etherington, 2004). Etherington (2004) writes that reflexivity has now become an important theme within present day social research studies. Issues of practitioner-researcher reflexivity have already been discussed in Chapter 3. However, it is fitting that I now turn once again to this important area to discuss a number of final points. I have already outlined in Chapter 3 how reflective journals were kept throughout the duration of the study. I found this to be helpful when exploring issues of practitioner-researcher reflexivity. The recording of my experiences in a journal provided me with the time and space to work through and make sense of situations and encounters (Oelofsen, 2012). These experiences were recorded using structured reflection as this enabled me to
explore what I had learned about the situation, what insights had I developed and what factors from either practice or theory had could further develop my understanding.

As an advanced practitioner I had engaged in reflective practice for many years and this had taken three forms, written reflection’s, reflections undertaken in clinical supervision and mental reflection, which would happen immediately after an event or incident. The model of reflection I am comfortable with working with is Johns (2017). This model facilitates reflection by asking a series of questions regarding an event/situation which include: what happened/what was the situation, what was significant, what was important, what was I trying to achieve, why did I respond the way I did, did I act for the best, what knowledge did or could have informed me, what insights can be drawn, how does the experience relate to previous experience and what could be done differently (see Johns, 2017, p.37). When I describe my reflections it is this model which has been applied.

As part of phase 3 data collection I was undertaking non-participant observations on Jasmine ward. This was the first time in my career that I had sat on a mental health NHS dementia inpatient ward with the purpose of undertaking research observation. After I left the ward following my first observation I did not have the sense of excitement that I had envisaged, instead I felt flat and drained. Using Johns model of reflection (2017) I was able develop insight into why this was. As an observer I saw that the day area space of the ward provided little in terms of homely furnishings, or privacy. I realised that in this space there were individuals with dementia who were often anxious and in distress and trying to make sense of where they were. I witnessed patients trying to connect with staff, as they passed through the area, to be responded to by staff briefly connecting to say they would come back in a minute. All too often staff did not return and patients were left watching and waiting. Through the process of reflection I recognised that the feelings I had associated with my first observation were as a result of viewing the ward and the environment through the eyes of someone living in it as opposed to the nurse that passes through it in the course of my day to day job. Only when I was fully emerged in the environment did I become aware of the impact of it and the full extent of the anxiety and distress of some of the patients living in such a communal space.

Another area which proved to be a challenge was supressing the need on occasions to step out of researcher mode and into advanced practitioner mode. This was particularly difficult
when I was observing nursing assistants for hours on end delivering hands on care with no
direct supervision or support from qualified staff. Nursing assistants were frequently left
dealing with various forms of behaviour that challenges without the support from a
qualified nurse. Through the process of reflection I was able to explore that these situations
left me feeling frustrated as a researcher, because I wanted to provide clinical leadership
and guidance to this staff group. The undertaking of written reflections and having regular
supervision proved particularly useful here.

The last point I wanted to explore was the time that was invested during phase 3 with
relatives prior to them agreeing to act as personal consultees. This consisted of me visiting
the four relatives one or two times to talk to them about the study and what participation
would entail for their loved one and themselves. The time spent with each relative varied
between two to five hours. This was not something that I had expected. When planning the
study I had assumed that I would meet with a relative for an hour, explain the study, leave
the information with them and give them time to think about if they wanted to take on the
role of personal consultee. However, each relative wanted to tell me their story first. This
story involved talking about their lives with their loved one and sharing aspects of their life
story from when they met including holiday memories and their plans, hopes and dreams.
This often involved showing me photographs or home items which supported the aspects
of the story they were telling. Using Johns model of reflection I was able to take a step
back and explore why this happened with all four relatives. I came to the conclusion that
these were positioning statements (Thorne, 2008, p.150) on the part of the relatives in that
it was important for them to provide me with a sense of who the person with dementia is,
their lives and their experiences before issues of complexity can be explored. I also
realised that for these relatives it was perhaps the first time they have had this opportunity
to tell their story and by doing this they were also sense-making about their lives and
current situation. Through the process of reflection I came to the conclusion that I was
naïve and short sighted to have not envisaged that people would need more time prior to
consenting to become involved. I also became aware that if I had not facilitated this extra
time with relatives, then I don’t believe that I would have been able to recruit patients to
phase 3 of the study.
7.5 Interpretive Description: Emerging Reflections

As interpretive description is still in its infancy compared to other methodological approaches, reviews about its strengths and limitations have yet to be widely reported. Hunt (2009) in a publication reflecting upon the use of interpretive description for his thesis, discusses his thoughts on the strengths and limitations of this methodology. Strengths included the provision of a methodology which oriented the research towards a clinical context, generation of practice relevant findings, provision of a coherent logic to focus the design and implement a research study and the provision of acknowledging clinical knowledge and experience during theoretical scaffolding. One of the challenges of utilising the approach, raised by Hunt, was in relation to interpretive description being a relatively new methodology and as a result methodological texts available as guidance were limited. As demonstrated throughout this study, for me interpretive description offers the practitioner-researcher a methodological approach that provides an explicit theoretical underpinning and a detailed approach to research design and analysis, whilst keeping its roots firmly in clinical practice. It allows multi-faceted experiential questions from practice to be addressed, values clinical knowledge and expertise and focuses on developing knowledge that in turn will inform clinical practice, as in the development of the 3Fs Model of Complexity for piloting and refinement in the first instance, in mental health NHS dementia inpatient dementia wards.

7.6 Study Limitations

The qualitative mixed methods approach of this study is in keeping with the methodological framework of interpretive description. Thorne (2014) encourages researchers to think about appropriate combinations of data collection so as to “enhance a comprehensive understanding without being overly dependent upon the inherent limits of any singular approach” (p108). However, the mixed methods approach for this study presents as both a strength and a limitation.

The three phases of data collection enabled an abundance of rich and detailed data, yet at times this was overwhelming and presented a constant challenge with regards to undertaking a detailed analysis within the required time frame of each phase of the study. A further challenge was finding ways to represent such rich and detailed data within an acceptable word limit for a PhD thesis.
The online internet survey undertaken in phase 1 only had 19 responders, many of whom were from the Northwest of the country. A larger response rate from across the UK may have provided greater insights into how dementia leaders position and construct complexity in dementia.

Data collection for phases 1 and 2 occurred in one mental health NHS trust within the Northwest of the country. In the initial stages of designing the study attempts were made to engage with other mental health NHS trusts and at one point it was hoped that the study would be undertaken in two mental health NHS trusts. Unfortunately, this did not occur due to service redesign demands and priorities of the second mental health NHS trust. After discussion with my supervisors the decision was made to data collect in just one mental health NHS trust due to the lengthy time delays that would have been occurred if I had continued trying to pursue this. This, however, is acknowledged as a limitation of the study as it is not possible to compare and contrast constructs of complexity in dementia across clinical settings in different geographical areas.

Finally whilst this is the first study of its kind that has explored the concept of complexity from within a mental health NHS dementia inpatient ward context, the 3Fs Model of Complexity requires further research to test its applicability further.

7.7 Summary and Outcomes
This study has demonstrated that the clinical staff working on the mental health NHS dementia inpatient wards believe that the individuals admitted to these environments are complex in their dementia. Although study participants could not offer a definition of complexity, they were able to identify the components of complexity through talking about patients they have looked after. This data was then further developed by exploring complexity in four patients who were receiving compulsory care and treatment on a mental health NHS dementia inpatient ward, through the use of observation, interviews and health care record reviews.

The three phases of data collection and analysis have identified that complexity is a multifaceted dynamic state consisting of a number of interrelated components which can fluctuate in their intensity/severity. From this the 3Fs Model of Complexity of dementia
has been developed. This model was retrospectively applied to three of the cases (Brian, Charlotte and Celia). This retrospective application resulted in three very busy and messy looking diagrams; however, it demonstrated that complexity in dementia consists of individuals experiencing a number of active component’s which interact with each other. The 3Fs Model of Complexity has the potential to serve as a model of assessment for people who are admitted to mental health NHS dementia inpatient wards. It can provide a detailed picture of the person with dementia’s presentation, how areas affect each other and the degrees of fluctuation present.

I will now present the key implications that this study has generated in terms of practice, research, education and policy.

7.7.1 Key Implications for Practice

- The findings of the study to be disseminated locally, to promote a greater understanding of the concept of complexity in dementia and to promote the adoption of the term locally.

- When disseminating the findings of the study at a practice level, clinicians to be invited to review the 15 components of the Flexible domain to explore if any of these components can be amalgamated.

- This study has demonstrated that complexity in dementia is as a result of multiple interacting components which can fluctuate in intensity and acuity. At a local level managers of services need to be aware of this and the subsequent level of care that a person needs as a result.

- Clinicians working in these environments need to develop the knowledge and skill required to be able to undertake assessments of people with dementia who are complex. The 3Fs Model of Complexity has the potential to act as a framework for this assessment.

- The importance and effect of a person’s life story has featured as a Fundamental component of complexity, however within the clinical records there was little evidence of a person’s life story. There is potential for this to be developed further within the setting of mental health NHS dementia inpatient wards and care records extended to include this.
• A person’s life story needs to be better integrated into the day-to-day caregiving.

• Care records and documentation need to be extended so they capture and reflect the nature of a person’s complexity, their subsequent needs and interventions.

• Processes of assessment need to be identified for people who are admitted to the mental health NHS dementia inpatient wards and the 3Fs Model of Complexity has the potential to become this assessment framework.

• The suitability of the 3Fs Model of Complexity for use in other areas caring for people with dementia should be tested. An example of this could be within care homes specialising in the care of people with dementia.

• Local services need to consider the ways in which qualified nurses can be ‘freed out of the office’ to provide much needed clinical leadership in the hands on care of people with dementia who are complex.

7.7.2 Key Implications for Research

• Interpretive description is a research approach which lends itself well to exploring the kinds of challenging experiential research questions that nurses and other applied health disciplines ask. It has the suitability and flexibility to be used in nursing research where the focus is on developing practice.

• Mental health NHS dementia inpatient wards remain very much ‘in the shadows’ compared to other areas of dementia and dementia care. Further research could explore the work undertaken in these environments and the experience of the individuals who are admitted to these wards.

• This study has demonstrated that it is possible to include people with dementia whose dementia has progressed to the moderate to advanced stage. Consideration could be given to how this can be further developed in future studies as to-date the voices of individuals at this stage, who are patients on mental health NHS dementia inpatient wards, are largely silent within the literature.

• The findings from this study to be disseminated through publication and conference presentations.

• Further research to be undertaken to test the 3Fs Model of Complexity in practice and to identify if clinicians apply it consistently and to explore how it can support the identification of interventions.
• Future research to give thought to developing the 3Fs Model of Complexity into an electronic application which can be used on portable tablet devices giving clinician’s the ability to quickly access and update and its use as an electronic application in clinical practice to be evaluated.

• Studies researching the effect of the environment upon individuals who are admitted to mental health NHS dementia inpatient wards would be helpful as this is identified as a component of complexity. My experience from undertaking observations in this area is of environments which are depersonalised and clinical, consisting of numerous locked doors and with little scope for personal identification or privacy.

7.7.3 Key Implications for Education

• There needs to be local mandatory education and training for staff working on mental health NHS dementia inpatient wards to equip them with the skills and knowledge to provide care and treatment for people with dementia who are complex.

• Education courses such a nurse training, MSc dementia and dementia continuing professional development modules need to consider sessions that focus upon complexity in dementia. The 3Fs Model of Complexity has the potential to be the framework for such sessions.

• Mental health nurse training needs to consider encompassing in its curriculum sessions about mental health NHS dementia inpatient wards and the reasons people are admitted and the focus of the work that this is undertaken in these environments.

• Educational initiatives need to consider situating dementia in a bio-psycho-social-physical model of care and move away from the traditional biomedical aspects as clinical staff need to be able to provide effective care and support for people with this diagnosis as they progress.

• Consideration needs to be given to where dementia sits within a health care model and if it should be a specialism in its own right. This may be the only way nurses for example will develop the wide range of both physical and mental health skills which are required to meet the needs of people with dementia as their illness progresses.
Clinical staff working on the mental health NHS dementia inpatient wards require specific training to work with people who are considered to be complex if they are to be able to assess and understand the multifaceted interrelated fluctuating components of this.

7.7.4 Key Implications for Policy

- Within local services work needs to be undertaken to promote a greater understanding of the types of people admitted to the mental health NHS dementia inpatient wards and their level of need.
- Local policy need to demonstrate an understanding of complexity in dementia.
- The representation in general of how moderate to advance dementia is represented in policy is an area requiring consideration.
- Mental health NHS dementia inpatient wards need to be recognised and acknowledged within policy guidance as currently the focus of dementia within hospital remains on the general hospital ward/area/building.
- As opposed to reporting that people with dementia can be complex or have complex needs, policy needs to start to describe what this actually looks like, how this can be assessed and what interventions are available.

7.8 Concluding Remarks

This study is one of the first to explore the concept of complexity in dementia and to have located it within mental health NHS dementia inpatient wards and involve the experience of those that are admitted and legally detained. The methodological approach of interpretive description (Thorne, 2008) was well suited to the study as it supported an area stemming from clinical practice to be explored which little was previously known about. The mixed methods approach which this methodology supported enabled a wide range of data to be collected in order to understand the concept of complexity in dementia. The end result of this work is the 3Fs Model of Complexity in dementia. To my knowledge this is the first framework of its kind which has provided description as to what complexity in dementia may look like. It is hoped that taking forward the 3Fs Model of Complexity in dementia will ignite a renewed interest in mental health NHS dementia inpatient wards and provide the start of an evidence-based practice that is built from theoretical innovation.
References


Appendix 1

‘Scaffolding the Study’: Additional Information

- Initial literature search terms and search term combinations.
- Critical synopsis of a text example.
- CASP qualitative research checklist example.
### Initial Literature Search Terms and Search Term Combinations

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4 & 5 & 7 & 22  
7 & 9  
1 & 7 & 9 |

1. “geriatric ward*” OR “geriatric unit*” OR “geriatric hospital” AND dementia
2. “Alzheimer* unit*” OR “Alzheimer* ward*” OR “Alzheimer* Hospital”
3. “mental health ward*” OR “mental health unit*” OR “mental health hospital” AND dementia
5. “long term condition” OR “chronic illness*” OR “life limiting illness*” OR “continuing care”
6. “clinical decision making” OR “decision making” OR “patient care plan*” OR “nurs* practice” OR “clinical competenc*” OR “profession competenc*”
Critical Synopsis of a Text Example

A descriptive survey of acute bed usage in dementia care in acute care psychiatry

a) Why am I reading this?

b) What are the authors trying to do in writing this?

Examine reasons why acute dementia care is admitted to one health authority.
Conclude that need for acute beds is demonstrated by emergency, morbidity, and cost.

(c) What are the authors saying that is relevant to what I want to find out?

Reasons & comments.

(d) How convincing is what the authors are saying?

Possible reasons likely reflect some of the reasons in 1980's but cannot find anything any more.
Offers insight into the population's excitement.
e) In conclusion, what use can I make of this?

first line I have finished. This information in 1993 culled information. The area is partly shaded + area. This does not appear to have changed.

f) References to pursue

Yes - 4.

g) Anything else?

Dea & came out different depending on the variables from

Code:
1 = Return to this for detailed analysis
2 = An important general text
3 = Of minor importance
4 = Not relevant

(Adapted from Critical Reading and Writing for Postgraduates Mike Wallace & Alison Wray 2nd Edition. Sage study skills. 2011)
CASP Qualitative Research Checklist Example

Screening Questions

1. Was there a clear statement of the aims of the research?
   □ Yes  □ Can’t tell  □ No
   HINT: Consider
   • What was the goal of the research?
   • Why it was thought important?
   • Its relevance

   To explore how mental health nurses conceptualised and operationalised the concept of ‘age related complexity’.

   No clear aim - been unhelpful to dangerous.

2. Is a qualitative methodology appropriate?
   □ Yes  □ Can’t tell  □ No
   HINT: Consider
   • If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
   • Is qualitative research the right methodology for addressing the research goal?

   Lack of existing theory used grounded theory. A moment got grounded. May retreat gran.

   People were also used phenomenology goes flat after the need to develop a substantive theory on age related complexity.

Is it worth continuing?

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Detailed questions

3. Was the research design appropriate to address the aims of the research?
   □ Yes □ Can’t tell □ No

HINT: Consider

- If the researcher has justified the research design (e.g., have they discussed how they decided which method to use)?
- If the researcher has demonstrated their knowledge of the topic and are able to articulate a clear rationale for why they selected the research design.
- If the researcher has presented their approach to use research design to answer their research question.
- If the researcher has used a well-defined theoretical framework and meaningful theoretical perspectives to guide their research.
- If the research design is appropriate to the aims of the research.

4. Was the recruitment strategy appropriate to the aims of the research?
   □ Yes □ Can’t tell □ No

HINT: Consider

- If the researcher has explained how the participants were selected.
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study.
- If there are any discussions around recruitment (e.g., why some people chose not to take part).

Finaly needs a more severe role as maybe maybe not experience in complexity - there’s bias + not sure why excuse - miss directly managed by nurse.

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why rationale for mt + not general nurses.

3
5. Was the data collected in a way that addressed the research issue?

HINT: Consider
- If the setting for data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, or did they use a topic guide)?
- If methods were modified during the study, if so, has the researcher explained how and why?
- If the form of data is clear (e.g. tape recordings, video material, notes etc)
- If the researcher has discussed saturation of data

6. Has the relationship between researcher and participants been adequately considered?

HINT: Consider
- If the researcher critically examined their own role, potential bias and influence during
  (a) Formulation of the research questions
  (b) Data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

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4
7. Have ethical issues been taken into consideration?

Yes □ Yes □ Can’t tell □ No

HINT: Consider
- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

8. Was the data analysis sufficiently rigorous?

□ Yes □ Can’t tell □ No

HINT: Consider
- If there is an in-depth description of the analysis process
- If thematic analysis is used, if so, is it clear how the categories/themes were derived from the data?
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

Not mentioned.
9. Is there a clear statement of findings?

HINT: Consider

- If the findings are explicit  - Yes
- If there is adequate discussion of the evidence both for and against the researchers' arguments  - Yes
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

|ship | frauly + complexity = two states related/ not mutually dependent n de caus |
|complexity = specnem of complexity = sl/fine-nd
|people can become less complex |

10. How valuable is the research?

HINT: Consider

- If the researcher discusses the contribution the study makes to existing knowledge or understanding e.g. do they consider the findings in relation to current practice or policy?, or relevant research-based literature?
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Complexity is a consequence of the nature of needs across a number of cases:

A dynamic state

Findings complex + fully different cases

Study does not say background or societal
Appendix 2

Ethics

- Copies of national research ethics permission and mental health NHS trust ethics permission
- Substantive amendment agreement
- Ethical issues considered for the study as documented in ethics application
- Study procedure for consenting patients into the study
20 February 2015

Mrs Lesley Jones
NIHR Clinical Doctoral Fellow
University of Manchester
School of Nursing Midwifery and Social Work
Room 6.332 Jean McFarlane Building
Oxford Road
Manchester
M13 9PY

Dear Mrs Jones

Exploring the meaning, presentation and assessment of complexity in mental health NHS dementia inpatient wards: An interpretive description study.

REC reference: 15/NW/0116
IRAS project ID: 161744

The Research Ethics Committee reviewed the above application at the meeting held on 10 February 2015. Thank you for attending with Professor John Keady to discuss the application.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager Rachel Kalzenellenbogen, nrescommittee.northwest-haydock@nhs.net. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Favourable opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.
Mental Capacity Act 2005

I confirm that the Committee has approved this research project for the purposes of the Mental Capacity Act 2005. The Committee is satisfied that the requirements of section 31 of the Act will be met in relation to research carried out as part of this project on, or in relation to, a person who lacks capacity to consent to taking part in the project.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study 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.rdfforum.nhs.uk](http://www.rdfforum.nhs.uk).

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact [hra.studyregistration@nhs.net](mailto:hra.studyregistration@nhs.net). The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from NRES. Guidance on where to register is provided on the HRA website.

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).
Ethical review of research sites

NHS 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).

Non NHS sites

The Committee has not yet completed any site-specific assessment(s) (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 an SSA application(s) has been reviewed. In the meantime no study procedures should be initiated at non-NHS sites.

Summary of discussion at the meeting

Social or scientific value: scientific design and conduct of the study

The Committee noted that the NIHR had suggested running a pilot study first as it was a complicated study.

The Committee asked you how they felt about the NIHR feedback suggesting a pilot study first.

Yous explained that they did not think it needed piloting first as it was well thought through and a lot of time had been spent preparing and polishing it. Further, it had been developed in consultation with the trust, with carers and with people with dementia and the collaborative nature would help ensure it reached its goal. The academic supervisor also explained that this was the Chief Investigator’s life work and that there were only a handful of practitioners like her and that this was an important study.

The Committee were unclear on how observations would take place if everyone in them had not consented to take part in the study.

The Committee asked you what would happen at a clinical review meeting or handover if one person did not consent to being observed.

Yous explained that the first thing they would be to talk the person and see if they had problems or concerns that could be addressed. If not, then the handover or review meeting would simply not be observed.

The Committee asked you what this study, if successful, would tell the world.

Yous explained that they hoped it would unravel the terminology that is taken for granted and never questioned. They also hoped it would give staff a more accurate language to use and allow them to articulate what complex was to others resulting in people’s needs being more accurately assessed and met which could lead to less time in hospital.

The Committee informed you that when reviewing the study under the Mental Capacity Act requirements it was clear that there was a scientific justification for including adults lacking capacity.
The Committee agreed the research is connected with an impairing condition affecting persons lacking capacity or with the treatment of the condition.

The Committee agreed the research could not be carried out as effectively if it was confined to participants able to give consent.

**Recruitment arrangements and access to health information, and fair participant selection**

The Committee asked you how they would recruit patients who were admitted during a crisis.

Yous explained that they would wait for five days to see if the change in environment made a difference. They would talk to the named nurses taking care of the participant and take their advice on whether the patient was well enough to be approached about the study.

The Committee considered the arrangements set out in the application for appointing consultees under Section 32 of the Mental Capacity Act to advise on whether participants lacking capacity should take part and on what their wishes and feelings would be likely to be if they had capacity.

After discussion the Committee agreed that reasonable arrangements were in place for identifying personal consultees and for nominated consultees independent of the project where no person can be identified to act as a personal consultee.

**Care and protection of research participants: respect for potential and enrolled participants’ welfare and dignity**

The Committee noted that it was unclear where interviews with relatives would happen.

The Committee asked you where relatives would be interviewed.

Yous explained that they would be interviewed where they felt most comfortable, whether that was at the hospital, in their home or in some other place. Yous also confirmed that the university had a remote worker policy and this would be followed.

The Committee noted that it was unclear whether staff would be interviewed during work hours or in their own time.

The Committee asked you when staff would be interviewed.

Yous explained that they had developed the project in conjunction with team leaders and managers, so there was an awareness that interviews would take place. Yous planned to conduct interviews during lunch times and hand over periods when there was a bit more leeway in terms of staffing.

The Committee was satisfied that reasonable arrangements would be in place to comply with the additional safeguards set out in Section 33 of the Mental Capacity Act.

**Informed consent process and the adequacy and completeness of participant information**
The Committee noted that A35 on the NHS REC form stated that if someone lost capacity they would continue in the study. The Committee agreed that this was acceptable providing a consultee was consulted.

The Committee reviewed the information to be provided to consultees about the proposed research and their role and responsibilities as a consultee.

The Committee was satisfied that the information was adequate to enable consultees to give informed advice about the participation of persons lacking capacity.

Suitability of the applicant and supporting staff

The Committee agreed the Chief Investigator was well qualified and the academic supervision was very good.

The Committee thanked the academic supervisor for attending the meeting as all too often students had to come on their own.

Approved documents

The documents reviewed and approved at the meeting were:

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<tr>
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<tr>
<td>Summary, synopsis or diagram (flowchart) of protocol in non technical language [Study Stages]</td>
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Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

After ethical review

Reporting requirements

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
- Notification of serious breaches of the protocol
- 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.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

15/NW/0116 Please quote this number on all correspondence

With the Committee’s best wishes for the success of this project.

Yours sincerely

[Signature]

On behalf of
Dr Tim S Sprosen
Chair

E-mail: nrescommittee.northwest-haydock@nhs.net

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments

“After ethical review – guidance for researchers”

Copy to: Ms Lynne MacRae, University of Manchester
Copy of Mental Health NHS Trust Ethics Permission

Greater Manchester West NHS
Mental Health NHS Foundation Trust

Standardised Process for Electronic Approval of Research

19 March 2015

Mrs Lesley Jones
School of Nursing, Midwifery and Social Work
University of Manchester
Jean McFarlane Building, Room 6.332.
Oxford Road
Manchester
M13 9PY

Dear Mrs Jones

Re: NHS Permission for Research

Project Reference: 855
REC Reference Number: 15/NW/0116
Sponsor: University of Manchester
Project Title: Exploring the meaning, presentation and assessment of complexity in mental health NHS dementia inpatient wards: An interpretive description study
Date of Permission: 19 March 2015

Further to your request for permission to conduct the above research study at this Trust, we are pleased to inform you that this Trust has given NHS permission for the research. Your NHS permission to conduct research at this site is only valid upon receipt of a signed 'Conditions for NHS Permission Reply Slip' which is enclosed.

Please take the time to read the attached conditions for NHS permission. Please contact the R&D Office should you require any further information. You will need this letter as proof of NHS permission. Please note when contacting the R&D office about your study you must always provide the project reference numbers provided above.

NHS permission for the above research has been granted on the basis described in the IRAS application form, Protocol and supporting documentation.

The documents reviewed were:

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The Trust is committed to safeguarding children, young people and vulnerable adults and requires all staff and volunteers to share this commitment.

Greater Manchester West Mental Health NHS Foundation Trust, Trust Headquarters,
Bury New Road, Prestwich, Manchester M25 3BL Tel: 0161 773 9121.

Chair: Alan Maden
Chief Executive: Bev Humphrey
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<td>REC letter giving favourable ethical opinion</td>
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Permission is granted on the understanding that the study is conducted in accordance with the Research Governance Framework, ICH GCP (if applicable), and NHS Trust policies and procedures. Permission is only granted for the activities for which a favourable opinion has been given by the Ethics Committee.

Permission covers all locations within the Trust, however, you should ensure you have liaised with and obtained the agreement of individual service/ward managers before commencing your research.

We would like to point out that hosting research studies incurs costs for the Trust such as: staff time, usage of rooms, arrangements for governance of research. We can confirm that in this instance we will not charge for these. However, we would like to remind you
that Trust costs should be considered and costed at the earliest stage in the development of any future proposals.

May I wish you every success with your research.

Yours sincerely

Dr Stephen Colgan
Medical Director and R&D Lead

cc: Sponsor: University of Manchester

Enc: Approval Conditions Leaflet
     Induction & ID Badge Information
Study Ref Number: 855
Study Title: Exploring the meaning, presentation and assessment of complexity in mental health NHS dementia inpatient wards: An interpretive description study

Conditions for NHS Permission Reply Slip

In order for your NHS permission to be valid, please return this form to the address below to confirm that you have read and understood the conditions of NHS permission to conduct research.

1. I confirm that I have read and understand my duties and responsibilities as part of the conditions for permission to conduct research at this site.

2. I understand that I must submit the following information to the Trust's R&D department:
   - Recruitment figures on a monthly basis
   - New researcher details prior to them commencing on the research project
   - Any amendments submitted to the Ethics Committee
   - Changes to the status of the research project
   - Any urgent safety measure incorporated
   - Untoward Incidents and Unexpected Events within 24 hours of their occurrence
   - A final summary report
   - A copy of the Ethics letter confirming receipt of the End of Study Declaration

3. I understand I must complete and return in a timely manner any audit forms sent to me by the Trust.

Signed: [Signature]
PRINT NAME: [Name]
Date: [Date]

Estimated Start date to commence research at this Trust: [Date]

Which site will you approach first? [Site]

Expected recruitment target at this Trust: [Target]

Please return to: Greater Manchester West Mental Health NHS Foundation Trust, Research & Development Office Room F030, Harrop House, Bury New Road, Prestwich, Manchester M25 3BL
Copy of Substantive Amendment Agreement

Health Research Authority
National Research Ethics Service

NRES Committee North West - Haydock
3rd Floor - Barlow House
4 Minshull Street
Manchester
M1 3DZ
Tel: 0161 625 7827
Fax: 0161 625 7299

18 May 2015

Mrs Lesley Jones
NIHR Clinical Doctoral Fellow
University of Manchester
School of Nursing Midwifery and Social Work
Room 6.332 Jean McFarlane Building
Oxford Road
Manchester
M13 9PY

Dear Mrs Jones


REC reference: 15/NW/0116
Amendment number: 1
Amendment date: 23 April 2014
IRAS project ID: 161744

The above amendment was reviewed at the meeting of the Sub-Committee held on 12 May 2015.

Favourable opinion

Approval was sought to issue a handout to support the verbal information delivered at study awareness raising sessions for dementia clinicians.

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

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Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R&D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

15/NW/0116: Please quote this number on all correspondence

Yours sincerely

Dr Tim S Sprosen
Chair

E-mail: nrescommittee.northwest-haydock@nhs.net

Enclosures: List of names and professions of members who took part in the review

Copy to: Mrs Kathryn Harney, Greater Manchester West Mental Health NHS Foundation Trust
Lynne Macrae, University of Manchester
Ethical Issues Considered for the Study as Documented in Ethics Application

Participant Distress
There is a small risk that patients, relatives/carers, or clinicians may become upset or distressed when discussing issues of complexity, assessment and inpatient care. All questions will be asked sensitively. As a mental health nurse I am very experienced in discussing potentially sensitive issues/areas with people with dementia and their relatives. During all interviews and observations with patients I will observe for any nonverbal signs of distress and if necessary interviews and observations can be stopped. Participants will always be reminded of the right to withdraw from the study and that this will not affect the participating patients care or treatment in any way.

Procedures are in place as to where to signpost individuals to should they become distressed during an interview and require further support. This includes giving staff the staff confidential counselling number, informing relatives of carer support agencies and networks and informing staff on the ward should a patient become distressed. Prior to interviewing or observing a participating patient I will check with the clinical team to see if the patient is well enough to be approached.

Patients will also be given the option of having someone with them during the interview if preferred. I am experienced as observing for changes in nonverbal communication which may be indicative of anxiety or distress. If a patient shows signs of distress or anxiety during the interview I will reassure them whilst taking steps to address the cause of the distress. The nurse in charge of the ward will be made aware immediately and asked to monitor the patient following my departure. I will also consult the patient/ or their consultee and their named nurse to discuss whether continued participation in the research is appropriate.

If during participating patient observations the patient indicates verbally or nonverbally they wish the observation to stop or other patients on the ward become distressed by my presence the observation will stop. The observation protocol provides guidance as to my course of action should this occur. I will also consult the patient or their consultee and their named nurse to discuss whether continued participation in the research is appropriate.
Information Regarding Care and Treatment
If during interview a relative/carer indicates that they need more information regarding the participating patient care or treatment or they raise concerns regarding the care, or they indicate they require further support they will be given information to signpost them to the most appropriate person to contact. This will include the ward team, Patient Advice and Liaison Service, and relative/carer support service.

Professional Issues, Care Issues & Safeguarding Concerns
In the event I observe or am made aware of any substandard care, misconduct or malpractice this will be reported to the service manager immediately and my supervisory team will also be informed. Should I observe, or be made aware of, any concerns in relation to abuse or safeguarding concerns, this will be reported immediately to the service manager and the mental health NHS trust safeguarding procedure will be activated. As a registered nurse I have received safeguarding training and I am familiar with the safeguarding process.

Inconvenience
There is a risk that interviewing dementia clinicians’ and holding a focus group may cause disruption and inconvenience to the participating clinical teams. To help manage this interviews will be arranged in advance, so staff can facilitate their work load and focus groups will be held at a time which is mutually convenient for the community team to release staff. Dates for the focus group will be forwarded to the team leaders to give them time to ensure that participants can be released. All interviews and focus groups for staff will be held in the hospital vicinity but away from the clinical area. This will reduce the time staff are away from the clinical environment but enable interviews and focus groups to be held in a private area.

Participating patients’ and their relatives/friends will be interviewed at a time which is convenient for them. Relatives/friends will be given the option of being interviewed at home if this is easier for them.

All staff in the participating inpatient wards will have been briefed regarding the purpose of nonparticipant observations. In addition notices will also be placed on the ward
informing patients and visitors to the ward that the observations are being undertaken as part of a research study. If at any time the ward team advise that the observations cannot be undertaken at the time planned this will be respected and an alternative time arranged.

Throughout the period of data collection I will frequently be visiting the participating wards so will be available to answer any questions or queries as they arise. Additionally my name, photograph and contact details will be displayed within the ward environment giving patients/relatives/staff a further option to contact me should they have any questions regarding the study.
Exploring the meaning, presentation and assessment of complexity in mental health NHS in dementia inpatient wards: An interpretive description study

Consent Procedure for Patients
Version 1 November 2014

REC ref no: 15/NW/0116

Dementia Inpatients
All patients who are potentially eligible to take part in this study will have dementia and be an inpatient on a dementia ward. Individuals admitted to these environments are normally in the moderate to advanced stages of their illness. Admission often occurs in response to a crisis and individuals at the time are usually acutely mentally unwell. My knowledge and previous experience in dementia care leads me to expect that a significant number of eligible study participants will not be able to give informed consent and given the stage the individual’s dementia has progressed to, it is highly unlikely that capacity will be regained. However it is important that these individuals have the opportunity to participate in this study. If the study was restricted to patients with the capacity to consent then the very people whose care we seek to improve will not be accurately represented.

The proposed consent procedure has been developed to comply with capacity legislation governing England and Wales (Mental Capacity Act, 2005). It is also based on a similar procedure being used in a research study exploring the detection and management of pain in patients with dementia (Ref:12/YH/0363).

All patients who are admitted to the ward with a diagnosis of dementia will be eligible to be approached regarding potential participation after they have been on the ward for a minimum of 5 days. This 5 day period will give the patient and their relatives some initial time to get accustomed to the new environment and staff. It
will also give the clinical team time to begin their initial assessments and interventions with the patient. This will be a flexible approach and the 5 days can be extended if indicated by the ward team.

**Consent procedure**

1) I will check with the ward qualified staff 3 times a week if there have been any new admissions.

2) If there has been an admission I will confirm who the named nurse is for the individual

3) During the first days of admission I will ask the named nurse to make the patient and their relative/friend aware that the ward is participating in a research study

4) Five days after admission I will speak with the named nurse to confirm that the patient has been in hospital for a minimum of 5 days and that they have a diagnosis of dementia. I will clarify with the named nurse that the patient meets the inclusion criteria for the study. If at this stage the named nurse indicates that it is not appropriate for the patient to be approached this will be respected and I will speak to the named nurse again in a number of days’ time for an update.

5) The named nurse will be asked to review the medical/care records to see if there has been any advanced decision or statement made by the participant which has relevance to the research study

6) I will ask the named nurse to approach the patient to see if they would be willing to talk to me regarding the research study. If the patient indicates they would be happy for this to occur the named nurse will arrange a convenient time.

7) I will meet with the patient to give them information regarding the study. The patient will also be given the option to have someone with them. This may be a relative or friend or a member of the ward staff. During the meeting I will undertake an assessment of capacity. As an Advanced Practitioner in Dementia care I have attended training on the Mental Capacity Act and I am experienced and skilled in assessing capacity in individuals with dementia.
8) A record of the assessment of capacity will be kept. If there is ever an occasion where following the assessment there is doubt over an individual's capacity I will seek further advice from their consultant psychiatrist.

9) For patients who are assessed as having capacity, I will explain the research and what will be required and go through the information sheet. The patient will be given a number of opportunities to ask questions. I will encourage the patient to read the information, think about the study and discuss it with their relative/friend. The patient will be informed that they do not have to decide immediately and will have at least 24 hours to decide if they wish to participate. They will also be informed that if they decide not to take part in the study their care and treatment will not be affected in any way.

I will then arrange a time to revisit the patient. I will encourage the patient to invite their relative/friend to this meeting. During this meeting I will informally reassess the patient’s capacity and if they feel that it has changed the meeting will be stopped. If the patient is willing to take part in the study written informed consent will be obtained or verbal witnessed consent if the patient is not able to sign their name. If patients do not agree they will not be approached further.

10) For participants who have been assessed as having capacity to consent, a process consent approach will be used (Dewing, 2007) whereby frequent reminders about the research are given and assent to continue will be sought.

11) If the patient is assessed as not having capacity, the option of a personal consultee will be explored. I will ask the names nurse to identify the patient next of kin, relative or a friend who may be able to undertake the role of personal nominee. The named nurse will be asked to speak with the relative or friend when they are visiting the patient to inform them that the ward is participating in a research study that their relative/friend may be able to participate in and to ask if it would be acceptable for me to contact them to give them some more information. If the relative/friend says no this will be respected and they will not be approached. If the relative/friend indicates that they would like some more information I will make contact with them to arrange a meeting.
12) I will arrange to meet with the relative/carer at a time and place of their convenience. I will give verbal information and a written information sheet about the study and about the role of a personal consultee. They will be encouraged to consider the person’s prior wishes and thoughts regarding taking part in research and asked to confirm if the person with dementia had made any advanced decisions regarding participating in research. 24 hours will be given for the person to consider whether or not to assent to their relative taking part in the study. If the consultee then agrees written documentation of this will be obtained.

13) If the individual informs that they do not want the role of personal consultee but feel their relative would like to be involved they will be asked if there is anyone who could take on this role or if not would they be willing for a nominated consultee to be approached. If they consent to this they will be asked to sign to say this is their decision. If the relative indicates that they do not want to be a consultee nor do they feel there relative would want to participate they will be thanked for their time and not approached again.

14) If it is not possible to meet with the personal consultee as they live some distance away then the researcher will speak with them via telephone and explain in detail the nature and purpose of the study. Any agreement given via telephone will be documented in the medical/care records. The study information sheet and consultee declaration form will be posted to the personal consultee. The person will be included in the study from this point of verbal assent. If after 10 days the personal consultee has not returned the signed declaration form or changes their decision the person will be withdrawn from the study and any data that has been collected with be destroyed. If the personal consultee does not give verbal assent over the telephone the patient will not be approached further.

15) If no next of kin, relative or friend that can act as personal consultee is documented in the clinical notes or after three attempts at telephone contact over 72 hours a personal consultee cannot be contacted, a nominated consultee will be approached. The mental health NHS trust that has expressed an interest in participating in the study has procedures in place for identifying and contacting professionals who have been trained to act as nominated consultees. I will speak with the nominated consultee and explain in detail the nature and purpose of the
study. An information sheet will also be given. If the nominated consultee gives assent they will be asked to sign a declaration form.

If the patient’s personal or nominated consultee indicates at any time during the study that they do not wish to participate/the patient to participate any further, they will be immediately withdrawn and all data that had been collected will be destroyed.

For patients who have been assessed as having the capacity to consent their relative/friend will also be given written information about the study and the opportunity to ask any questions. As the participants are inpatients, copies of consent or assent forms will be filed in their medical records. In addition a record regarding assessment of capacity and details of consultee (if involved) will be kept by the researcher for all patients involved.

If there is an occasion where it is not possible to speak to the named nurse I will speak with another member of the qualified team who knows the patient.

Additionally as patient participants will all have a diagnosis of dementia and currently be receiving care and treatment on a mental health NHS dementia inpatient environment a copy of the signed consent form/nominees declaration form and the participant information sheet will be scanned into their medical records. An entry will also be made into their medical records stating that the patient has agreed to participate in the research study. The mental health NHS trust which has agreed to participate in the study has electronic patient records. Therefore this process will inform their Consultant Psychiatrist and care team of their participation in the research study. The inclusion of the participant information sheet will provide details of what their participation will entail. Participating patients/nominees will have consented to this.

(Complexity and NHS Dementia Inpatient Care Consent Procedure V1 NOV 2014)
Appendix 3
Examples of Participant Information Sheets, Consent Forms and Observation of Patients Protocol

- Phase 1 Dementia leader’s participant information sheet.
- Phase 2 Inpatient dementia clinicians participant information sheet.
- Phase 2 Older adult community mental health team participant information sheet.
- Phase 3 Simplified patient information sheet (pictorial).
- Phase 3 Personal consultee information sheet.
- Phase 2 Inpatient dementia clinicians consent form.
- Phase 3 Simplified patient consent form (pictorial).
- Phase 3 Relative/friend interview consent form.
- Phase 3 Observation of patients protocol
Participant Information Sheet
Dementia Leaders

Exploring the meaning, presentation and assessment of complexity in mental health NHS dementia inpatient wards: An interpretive description study

Version 1 November 2014
REC ref no.: 15/NW/0116

You are being invited to take part in a research study that forms part of a PhD degree at The University of Manchester. Please take time to read this information sheet carefully. If you have any further questions before deciding if you wish to take part please contact the researcher, Lesley Jones (contact details at the end of this document).

What is the purpose of the study?
This study explores the concept of complexity in dementia, in mental health NHS inpatient dementia wards. This is an aspect of dementia care that has previously received little attention. However the terms ‘complexity’ and ‘complex’ needs are often used alongside dementia and are cited as a reason for admission to mental health NHS dementia inpatient wards. The role of mental health NHS dementia inpatient wards is to provide specialist expertise and intensive levels of assessment, treatment and monitoring that cannot be provided anywhere else.

The purpose of the study is to:
• Explore and describe the nature of complexity in dementia.
• Describe the key components of assessment for individuals with dementia who are currently receiving care and treatment on a mental health NHS dementia inpatient ward.

How is the study being undertaken?
There are a number of stages within the study including this email survey. Other stages include interviews and focus groups with clinical staff who work in NHS dementia inpatient wards and an exploration of complexity within the setting of NHS inpatient dementia wards.
Why have I been invited to take part?
You have been identified as a leader in dementia care from an education/research, policy/guidance or clinical practice background.

Do I have to take part?
No, it is completely up to you whether to take part or not.

What will I have to do if I agree to take part?
If you agree to take part you will complete a short online survey about complexity in dementia. Questions are open ended and the survey allows you to write your own responses. At the beginning of the survey there will be general background questions for example current role and how many years you have been in your current position. Participation will take a maximum of 30 minutes.

What are the possible benefits of taking part?
By taking part in the study you will be able to contribute and inform an exploration of an area of dementia care that has previously received little attention. Within the setting of mental health NHS dementia inpatient wards this study seeks to develop a better understanding of the meaning of complexity in dementia and identify the key components of complexity and its assessment. This information can then be used to help assess needs and inform the care and interventions that are undertaken with individuals who are admitted to mental health dementia inpatient wards.

What are the possible disadvantages and risks of taking part?
There are no envisaged disadvantages or risks to taking part. None of the questions in the survey are intended to be upsetting or stressful. If there are any questions you do not wish to answer that is absolutely fine. Participation in the survey is completely voluntary.

Will my taking part in the study be kept confidential?
All personal identifiable information collected will be kept confidential. A unique number is used when you access the survey database. The web survey platform being used is Select Survey, which is used by The University of Manchester. I will be the only person to be able to access participants’ completed surveys on the database. My PhD supervisory team will only have access to anonymised survey responses if required during data analysis. Extracts of your responses may be used in the research and subsequent publications, presentations and conferences but a false name (pseudonym) will be used so that you cannot be identified. All the information that you give will be securely stored at The University of Manchester and held for at least 5 years after the date of the last publication which is based upon it. Data will then be destroyed in accordance with the guidance and
standards specified by the IT Security Coordinators at The University of Manchester.

What will happen to the results of the study?
The information obtained will be analysed and written up as part of my PhD thesis. The findings from the study will also be disseminated into clinical practice so knowledge and practice within this area can be further developed. Academic articles for peer reviewed journals will also be written. Aspects of the study may also be used in book chapters. The study will also be disseminated at health related conferences. Participant’s identity will be protected in publications and conferences.

Who is funding the study?
The study is being funded by the National Institute of Health Research (NIHR)

Who has reviewed the study?
The study has been reviewed by the National Research Ethics Service Committee North West – Haydock (Ref: 15/NW/0116).

When do I have to decide if I want to participate?
The database will open the day you receive this email and it will remain open for three weeks. After three weeks you will no longer be able to access the survey database to participate. During this three week period reminder emails will be sent.

What do I do if I have a concern regarding this research?
If you have a problem or concern regarding the study you can contact me in the first instance or you can contact my supervisors Professor John Keady or Professor Dame Nicky Cullum (Contact details are provided at the end of this document).

If there are any concerns or problems which occur that you would prefer not to discuss with me or my supervisors, please contact The University of Manchester, Medical and Human Sciences, Faculty Research Office, Research Governance Team on 0161 275 5436 or 0161 275 5318 or email fmhsethics@manchester.ac.uk.
Who can I contact for further information?

If you have any questions or require any further information about this research project please do not hesitate to contact me or my supervisors.

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<th>Researcher</th>
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<tr>
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<td><a href="mailto:john.keady@manchester.ac.uk">john.keady@manchester.ac.uk</a></td>
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| **Professor Dame Nicky Cullum** | School of Nursing, Midwifery and Social Work               |
|                                 | University of Manchester                                   |
|                                 | Jean McFarlane Building                                    |
|                                 | Room 6.326                                                 |
|                                 | Oxford Road                                                |
|                                 | Manchester                                                 |
|                                 | M13 9PY                                                    |
| **Telephone**:                  | 0161 306 7779                                              |
| **Email**:                      | nicky.cullum@manchester.ac.uk                              |

Thank you for taking the time to read this information sheet
Inpatient Dementia Clinicians Participant Information Sheet

Exploring the meaning, presentation and assessment of complexity in mental health NHS dementia inpatient wards: An interpretive description study

Version 1 November 2014

REC ref no.: 15/NW/0116

You are being invited to take part in a research study as part of a PhD degree at The University of Manchester. Please take time to read this information sheet carefully. If you have any further questions before deciding if you wish to take part please contact Lesley Jones on the contact details listed at the end of this document.

What is the purpose of the study?
This study explores the concept of complexity in dementia within the setting of NHS inpatient dementia wards. These are both areas of dementia care that have previously received little attention or focus yet the term complexity or complex needs is often used alongside dementia and is cited as a reason for admission.

The purpose of the study is to:
• Explore and describe the nature of complexity in dementia.
• Describe the key components of assessment for individuals with dementia who are currently receiving care and treatment on a mental health NHS dementia inpatient ward.

Why have I been invited to take part?
All clinical staff working on the dementia inpatient ward are being invited to take part. Clinical staff can include Registered Mental Nurses, Occupational Therapists, Doctors and Nursing Assistants.
Do I have to take part?
No, it is completely up to you whether to take part or not. If you do decide to take part you will need to sign the consent form which is attached to this information sheet and return it in the stamped addressed envelope provided.

Even if you consent to take part you can change your mind at any time and withdraw from the study. You do not have to give a reason for this. A decision to withdraw or not take part in the study will not affect you or your career in any way either now or in the future. However, if you decide to withdraw I would still like to use any data collected from you up to the point of withdrawing your permission.

What will I have to do if I take part?
Taking part will involve being interviewed.

This will be an individual face to face interview. The interview will be held at a time which is convenient for you. I will contact you via the telephone or NHS/Trust email to arrange an interview date. Interviews will be held on the trust site, away from the clinical area in which you work and in a private room. This is to ensure that there will be no disruptions during the interview. Interviews will be digitally recorded with your permission.

During the interview I will be interested in hearing your experiences, views and opinions about what complexity in dementia means to you and how it can be described. I will also be interested in hearing your views and thoughts regarding what areas are important when assessing an individual with dementia who is perceived to be complex or have complex needs.

I would like to be able to interview approximately 20 people. If I get more people wishing to participate than needed you will be informed of this and thanked for your interest.

What are the possible benefits of taking part?
By taking part in the study you will be able to draw on your clinical experience and knowledge to participate in an exploration of an area of dementia care that has previously received little attention.

At the end of the study I aim to have a better understanding of the meaning of complexity in dementia, what elements this may comprise of and what the key components of assessment are for people with dementia who are considered to be complex or have complex needs. This information can then be used in practice to help assess needs and inform the care, assessments and interventions that are undertaken with individuals who are on the inpatient dementia wards.
What are the possible disadvantages and risks of taking part?
It is not my intention to ask any questions which you may find upsetting or stressful. If there are any questions you do not wish to answer that is absolutely fine. You can also withdraw from the study at any time.

Should you become upset during the interview and in need of further support then you will be encouraged to talk to your ward manager/team leader, clinical supervisor, or contact the staff confidential counselling service (Oakdale 0800 027 7844).

How long will the study last?
The PhD study is being undertaken over three years. This part of the data collection will last approximately 3 months.

Will my taking part in the study be confidential?
All information obtained from you during an interview will be kept confidential. Names will be replaced with a unique study number. Only the researcher will have access to this code.

With your permission interviews will be digitally recorded. These recordings will be transcribed by a professional transcription service. After transcription the digital audio files will be erased. All data produced from the research will be stored safely. Any paper information will be kept in a locked filing cabinet in an office within The University of Manchester which is kept locked when unoccupied. All electronic data will be kept on a password protected University of Manchester Computer and stored on the University of Manchester Server. All the information you give will be held for at least 5 years after the date of any publication which is based upon it. Data will then be destroyed in accordance with the guidance and standards specified by the IT Security Coordinators at The University of Manchester.

The research study and any publications and presentations related to the research may use things you have said as quotations but any identifiable information will be removed and a pseudonym (false name) will be used.

All information will remain confidential unless disclosure is essential to protect you or others from the risk of significant harm, or information is disclosed by a participant in regard to misconduct, malpractice or safeguarding concerns or the disclosure is required by law or by order of a court.

What if there is a problem or concern?
If you have a problem of concern regarding the study you can contact me in the first instance or you can contact my supervisors Professor John Keady and Professor Dame Nicky Cullum (Contact details are provided at the end of this document)

If there are any concerns or problems which occur regarding the research that you would prefer not to discuss with me or my supervisors, please contact The University of Manchester, Medical and Human Sciences, Faculty Research Office, Research Governance Team by telephoning 0161 275 5436 or 0161 275 5318 or by emailing fmhsethics@manchester.ac.uk

**Who is funding the research?**
The research is funded by the National Institute of Health Research (NIHR)

**Who has reviewed the study?**
The study has been reviewed by the National Research Ethics Service Committee North West – Haydock (Ref: 15/NW/0116).

**Who can I contact for further information?**
If you have any questions or require any further information about this research project please do not hesitate to contact me or my supervisors.

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Telephone: 0161 306 7854
Email: john.keady@manchester.ac.uk

Telephone: 0161 306 7779
Email: nicky.cullum@manchester.ac.uk

Thank you for taking the time to read this information sheet. If you would like to take part please complete and return the consent form attached to this information sheet. Alternatively you can ring or email me.
Dementia Community Mental Health Team (CMHT) Participant Information Sheet

Exploring the meaning, presentation and assessment of complexity in mental health NHS dementia inpatient wards: An interpretive description study

Version 1 November 2014

REC ref no.: 15/NW/0116

You are being invited to take part in a research study as part of a PhD degree at The University of Manchester. Please take time to read this information sheet carefully. If you have any further questions before deciding if you wish to take part please contact Lesley Jones on the contact details listed at the end of this document.

What is the purpose of the study?
This study explores the concept of complexity in dementia within the setting of NHS inpatient dementia wards. These are both areas of dementia care that have previously received little attention or focus yet the term complexity or complex needs is often used alongside dementia and is cited as a reason for admission.

The purpose of the study is to:
• Explore and describe the nature of complexity in dementia.
• Describe the key components of assessment for individuals with dementia who are currently receiving care and treatment on a mental health NHS dementia inpatient ward.

Why have I been invited to take part?
All clinical staff working in the dementia CMHT are being invited to take part. Clinical staff can include Registered Mental Nurses, Occupational Therapists, Doctors, Social Workers, Clinical Psychologists and support workers.

Do I have to take part?
No, it is completely up to you whether to take part or not. If you do decide to take part you will need to sign the consent form which is attached to this information sheet and return it in the stamped addressed envelope provided.
Even if you consent to take part you can change your mind at any time and withdraw from the study. You do not have to give a reason for this. A decision to withdraw or not take part in the study will not affect you or your career in any way either now or in the future. However, if you decide to withdraw I would still like to use any data collected from you up to the point of withdrawing your permission.

**What will I have to do if I take part?**

Taking part will involve participating in a focus group.

The focus group will have between 6-10 participants and consist of staff who work in the dementia CMHT. The group will last for approximately 1 hour. It will be held at a time which is convenient for clinical services to release staff. The meeting will occur on a trust site but away from the clinical areas to ensure that there are no disruptions. The meeting will be digitally recorded with participant’s permission.

During the focus group I will be interested in hearing people’s experiences, views and thoughts about the meaning of complexity in dementia, the reasons people are referred for admission to the dementia wards from the community and what areas are important when assessing an individual with dementia who is perceived to be complex.

If I get more people wishing to participate than required you will be informed and thanked for your interest.

**What are the possible benefits of taking part?**

By taking part in the study you will be able to draw on your clinical experience and knowledge to participate in an exploration of an area of dementia care that has previously received little attention.

At the end of the study I aim to have a better understanding of the meaning of complexity in dementia, what elements this may comprise of and what the key components of assessment are for people with dementia who are considered to be complex or have complex needs. This information can then be used in practice to help assess needs and inform the care, assessments and interventions that are undertaken with individuals who are on the inpatient dementia wards.

**What are the possible disadvantages and risks of taking part?**

It is not my intention to ask any questions which you may find upsetting or stressful. If there are any questions you do not wish to answer that is absolutely fine. You can also withdraw from the study at any time.
Should you become upset during the focus group and in need of further support then you will be encouraged to talk to your manager/team leader, clinical supervisor, or contact the staff confidential counselling service (Oakdale 0800 027 7844).

**How long will the study last?**
The PhD study is being undertaken over three years. This part of the data collection will last approximately 3 months.

**Will my taking part in the study be confidential?**
All information obtained from you during an interview will be kept confidential. Names will be replaced with a unique study number. Only myself as the researcher will have access to this code.

At the beginning of a focus group participants will be reminded of the importance of promoting confidentiality in regard to the discussion which occurs and the group membership. However as the researcher I cannot be held responsible for any of the participants breaking confidentiality and discussing aspects of the focus group outside of the meeting.

With your permission the focus groups will be digitally recorded. These recordings will be transcribed by a professional transcription service. After transcription the digital audio files will be erased. All data produced from the research will be stored safely. Any paper information will be kept in a locked filing cabinet in an office within The University of Manchester which is kept locked when unoccupied. All electronic data will be kept on a password protected University of Manchester Compute and stored on the University of Manchester Server. All the information you give will be held for at least 5 years after the date of any publication which is based upon it. Data will then be destroyed in accordance with the guidance and standards specified by the IT Security Coordinators at The University of Manchester.

The research study and any publications and presentations related to the research may use things you have said as quotations but any identifiable information will be removed and a pseudonym (false name) will be used.

All information will remain confidential unless disclosure is essential to protect you or others from the risk of significant harm, or information is disclosed by a participant in regard to misconduct, malpractice or safeguarding concerns or the disclosure is required by law or by order of a court.
What if there is a problem or concern?
If you have a problem of concern regarding the study you can contact me in the first instance or you can contact my supervisors Professor John Keady or Professor Dame Nicky Cullum (Contact details are provided at the end of this document).

If there are any concerns or problems which occur regarding the research that you would prefer not to discuss with me or my supervisors, please contact The University of Manchester, Medical and Human Sciences, Faculty Research Office, Research Governance Team by telephoning 0161 275 5436 or 0161 275 5318 or by emailing fmhsethics@manchester.ac.uk

If during the course of the focus group any information is disclosed by a participant in regard to misconduct, malpractice or safeguarding concerns I will need to make the senior manager for the service aware of this information. If this occurs, the participant who has disclosed the information will be made aware of my course of action.

Who is funding the research?
The research is funded by the National Institute of Health Research (NIHR).

Who has reviewed the study?
The study has been reviewed by the National Research Ethics Service Committee North West – Haydock (Ref: 15/NW/0116).

Who can I contact for further information?
If you have any questions or require any further information about this research project please do not hesitate to contact me or my supervisors.

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Thank you for taking the time to read this information sheet

If you would like to take part please complete and return the consent form attached to this information sheet. Alternatively you can ring or email me.
A Research Study
Complexity and NHS
Dementia Inpatient Care

Lesley Jones
The University of Manchester

Hello

My name is Lesley Jones. I am a nurse who has worked with people with dementia for many years.

I am currently studying for a PhD at The University of Manchester. This has been funded by the National Institute of Health Research.

My research is exploring how dementia affects people. It is being undertaken with people who are currently a patient on a dementia ward.

The research is looking at the effect dementia can have on a person, the reasons why people are admitted to the ward and how people should be assessed.
Who can take part in the research?

Anyone who has a diagnosis of dementia and who is a patient on xxx Ward can take part in the research.

Do I have to take part?

No you do not have to take part. If you do not take part your care and treatment will not be affected.

If you decide to take part you can withdraw from the research at any time. You do not have to give a reason for this. If this happens your care and treatment will not be affected.

You can talk to a relative or friend about your taking part. You can ask me any questions you have.
If you agree to take part I would like to:

- Talk to you about how your illness affects you
- Talk to your Consultant, nurse and a relative or friend about factors which may contribute to the way your illness affects you and the areas you may need help and support with.

To help me remember these conversations I would like to record them.

I would also like to undertake some observations

I would like to observe you in the ward environment. This is to see how you interact and engage in your surroundings.

I would also like to observe some of your care review meetings. This is to understand how staff communicate and describe the way your illness affects you, your needs and you assessment.

Finally,

I would like to look at your medical records to see how your presentation, care needs and assessment are recorded by staff.
If you agree to take part a note will be made in your medical record to inform your consultant psychiatrist and care team that you are participating in a research study. A copy of the participant information sheet and the signed consent form will also be kept in your medical record.

Confidentiality

All information that you give will be stored securely at The University of Manchester.

Any information you give will remain confidential. Your name and any identifiable information will be removed from any information that may be shared with my academic supervisors.

After you have participated

The information from all the interviews, observations and medical records will be summarised together and combined with findings that have been generated from other stages of the study. Putting all the information together will help me to develop an overall picture of the inpatient care setting for people with dementia.

These findings will then be used to develop knowledge and practice in providing care and assessment for people with dementia who are on a dementia inpatient ward.
Sharing the findings of the research

The findings of the research will be shared in a number of ways and will include:

• In the PhD thesis
• At conferences
• In academic journal
• In lectures

The PhD thesis and any publications and presentations related to the research may use things you have said as quotations. If this occurs all identifiable information will be removed and a false name will be used.

Please take your time to think about whether you would like to become involved in this research

Talk to your family and friends

If you have any further questions or need any more information I will be happy to come back and talk to you

You do not have to agree to take part in the research. If you do agree to take part you can change your mind at any time. Your decision will not affect your care or treatment in any way.
If you have any questions please ask me

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M13 9PY

You can also ask one of the staff on the ward to contact me on your behalf.

You can also ask my supervisor

Professor John Keady

0161 306 7854
john.keady@manchester.ac.uk
School of Nursing, Midwifery and Social Work
University of Manchester
Jean McFarlane Building
Room 6.312
Oxford Road
Manchester
M13 9PY
Research Study

Complexity and NHS Dementia Inpatient Care

Personal Consultee Information Sheet

Version 1 November 2014

REC Ref no: 15/NW/0116

Researchers Details:

Lesley Jones

School of Nursing, Midwifery and Social Work
University of Manchester
Jean McFarlane Building
Room 6.332
Oxford Road
Manchester
M13 9PY

Telephone: 07768202820

Email: lesley.jones@postgrad.manchester.ac.uk
Introduction

Your relative/friend is being invited to take part in a research study which is being undertaken as part of a PhD degree at The University of Manchester.

The research study is exploring the meaning, presentation and assessment of complexity in NHS dementia inpatient wards. As this research study is being undertaken on a dementia inpatient wards and is focused on people who have dementia it is important that people with dementia are given the opportunity to participate in the study.

People with dementia who are being invited to participate in the research may not always have the capacity to consent to participate. This means that the person is unable to judge for themselves whether they should take part in the study or not. Your relative/friend has been identified by the ward staff as someone who is unable to decide for himself/herself whether to participate in this research.

As your relative/friend is unable to decide for himself/herself about participating in the research you are being invited to act as their ‘consultee’. This means that you are being asked your opinion whether or not they would like to be involved in the research. You are being approached as you know the person personally as a relative or friend.

What does it mean to be a consultee?

As a consultee you are being asked to consider and advise about your relative/friends wishes and feelings as to whether they would have liked to participate in the research. It is also very important that you let me know of any advanced decision they may have made about participating in research.

Please try to remember that you are not being asked for your personal views regarding the research. You are being asked to consider only what your relative/friends wishes would have been if they were being asked to take part in the research.

Take time to decide if you wish to be a consultee. If you are unsure about taking the role of consultee you may seek independent advice. You could speak to Elizabeth Mainwaring Research Governance Officer, Greater Manchester West Mental Health NHS Foundation Trust, Telephone: 0161 772 3492 or Email: elizabeth.mainwaring@gmw.nhs.uk. You can also contact INVOLVE who are a national advisory group which supports greater public involvement in NHS, public health and social care research. Their telephone number is 02380 651088.

If, after considering the information provided in this information sheet you decide that your relative/friend would have no objection to taking part you are asked to read and sign the consultee declaration form which is enclosed. You will be given
a copy of this to keep. I will keep you fully informed during the study. If you have any concerns or you think your relative/friend should be withdrawn from the research study you just need to let me know.

If you decide that you relative/friend would not wish to take part, their care and treatment will not be affected in any way

If you withdraw your relative/friend from the study part way through, their care and treatment will not be affected in any way.

I will fully understand if you do not wish to take on the responsibility of being a consultee.

Please take time to read the following information about the study.

I am happy to go through the information sheet with you and answer any questions that you may have. This would take about 30 minutes. My contact details are located on the first page of this information sheet.

What is the research study about?

This research study is about people with dementia who are currently receiving care and treatment on an NHS dementia inpatient ward.

The research study is exploring the meaning, presentation and assessment of complexity in NHS dementia inpatient wards. This includes looking at the various ways dementia can affect a person, how this is displayed, the different needs that may arise, factors that may contribute to this and the key areas of assessment when an individual is admitted to a dementia ward.

It is believed that exploring these areas will help further develop care and practice within dementia inpatient wards.

How will the research study do this?

The research study will do this by using a number of methods. This will include talking with and observing patients in the ward and talking with care staff and relatives/friends of patients on the ward. I will also spend time on the ward to observe ward day-to-day activity of patients, care review meetings and staff hand over times. With permission the study will also look at patient care records.
**Why has your relative/friend been invited to take part?**
Your relative/friend has been invited to take part because they are currently a patient on XXXX Ward and they have been diagnosed as having dementia.

**Does my relative/friend have to take part?**
No.

It is up to you to advise as to your relative/friend’s likely view about whether or not they would wish to take part. You can go through this information sheet and ask any questions that you may have. If you advise that your relative/friend would like to take part, you will be asked to sign a declaration from. At any time you can decide that your relative/friend would no longer like to participate in the research and you can withdraw them from the study. You do not have to give a reason for this. This will not affect their care or treatment in any way.

**What will happen to my relative/friend if they take part?**
In order to gain a comprehensive understanding of the area being researched there are a number of components involved in taking part:

**Interview with your relative/friend**
I would like to talk to your relative/friend to gain an understanding of how they feel their illness affects them, the areas they feel they need help with and why they feel they are in hospital. This conversation would last about half an hour but we can stop at any time should this be indicated.

I am an experienced nurse with many years’ experience in working with people with dementia. All questions will be asked sensitively. If either the ward staff or yourself advise that these questions would cause undue distress or agitation then the interview will not occur.

With permission I would like to record this conversation. This is to remind me later what we talked about.
Observations
I would like to observe your relative/friend within the ward environment. This is to see how they engage and interact in the ward surroundings. Your relative/friend’s privacy would be respected at all times. Prior to each observation I will first check with the ward staff that this is appropriate. It is anticipated that a minimum of 8 periods of observation will be undertaken.

In addition I would like to observe 1 or 2 care review meetings which will be held during their stay in hospital. This could be for example, a care review, a planning meeting, a ward round or a care program meeting. This is so I can observe what words are used when care staff are describing your relative/friend’s presentation, needs and any areas of help and assistance they require.

Other Interviews
I would also like to talk with your relative/friend’s consultant psychiatrist or their deputy, their named nurse/care coordinator and a relative or close friend who knows them well. This would be to further explore how the illness is affecting them, factors which may contribute to this and the areas that they need help and support with.

Review of Medical Record
Finally I would like to look at your relative/friend’s medical records to see how their presentation, care needs and assessment are recorded by the staff.

Throughout this process I will keep you fully informed of research and my visits to your relative/friend.

Should you agree to your relative/friend participating in this research study a copy of the signed declaration form and participant information sheet will be included in their medical records. An entry will also be made in their medical record to inform the care team that they are participating in a research study.

Information about the researcher
I am a qualified mental health nurse who has worked with people with dementia and their relatives/carers for many years both in hospital and community settings. I am very experienced in observing and communicating with people who have memory problems or communication difficulties as result of their illness.
Expenses and payments

There is no payment for taking part in this study. However if you incur any travel costs due to taking part in the study these will be reimbursed to you if you are able to provide a receipt.

Will taking part in the research be kept confidential?

Yes. All data generated by the research will be anonymised.
All the information that your relative/friend gives will be stored securely at The University of Manchester either in computer files or in locked storage cabinets.

Information obtained from the research will be held for at least 5 years after the last publication of the study. Data will then be destroyed in accordance with the guidance and standards specified by the IT Security Coordinators at The University of Manchester.

All information given will remain confidential. The only time this confidentiality will be broken is if disclosure is essential to protect your relative/friend or others from the risk of significant harm, or the disclosure is required by law or by order of a court.

Reporting the findings

No individual will be identifiable in any of the findings that are published from this study. The research study and any publications and presentations related to the research may use things that have been said as quotations but any identifiable information will be removed and a pseudonym (false name) will be used.

How long will the study last?

The PhD study is being undertaken over three years. This part of the data collection will last approximately 5 months.

What are the possible benefits of taking part?

This research study is focused on people with dementia who are currently receiving care and treatment on an NHS dementia inpatient assessment ward. These individuals are often referred to as being complex or having complex needs. Yet this is an area of dementia care which has received very little previous attention or focus. By taking part in this study your relative/friend is helping to explore what the term complex may mean in regard to an individual with dementia. It is believed that exploring these areas will help further develop care and practice within dementia inpatient wards. This information can then be used in practice to
help assess needs and inform the care, assessments and interventions that are undertaken with individuals who are on the inpatient dementia wards.

**What are the possible disadvantages and risks of taking part?**

It is not anticipated that there will be any disadvantages or risks regarding taking part in this study. Your relative/ friend's care or treatment will not change or be affected in any way.

If you relative/ friend at any point in the study indicates either verbally or by their behaviour they do not wish to take part they will be withdrawn from the study. This will not affect their care or treatment in any way.

**What if there is a problem, concern or complaint?**

If you have a concern about any aspect of this study please speak with me, Lesley Jones and I will do my best to answer your questions. Alternatively you can contact my supervisors Professor John Keady and Professor Dame Nicky Cullum.

Contact details are listed below:

<table>
<thead>
<tr>
<th>Researcher</th>
</tr>
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<tbody>
<tr>
<td><strong>Lesley Jones</strong></td>
</tr>
<tr>
<td>School of Nursing, Midwifery and Social Work</td>
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<tr>
<td>University of Manchester</td>
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<td>M13 9PY</td>
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<tr>
<td>Telephone: 07768202820</td>
</tr>
<tr>
<td>Email: <a href="mailto:lesley.jones@postgrad.manchester.ac.uk">lesley.jones@postgrad.manchester.ac.uk</a></td>
</tr>
</tbody>
</table>
If there are any concerns or problems which occur regarding the research that you would prefer not to discuss with me or my supervisors or you wish to make a complaint please contact The University of Manchester, Medical and Human Sciences, Faculty Research Office, Research Governance Team by telephoning 0161 275 5436 or 0161 275 5318 or by emailing fmhsethics@manchester.ac.uk

**Who is funding the research?**

The research is funded by the National Institute of Health Research (NIHR)

**Who has reviewed the research project?**

The research has been given a favourable ethical opinion for conduct by the National Research Ethics Service Committee North West – Haydock (Ref: 15/NW/0116).

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### Supervisors

<table>
<thead>
<tr>
<th>Professor John Keady</th>
<th>Professor Dame Nicky Cullum</th>
</tr>
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| School of Nursing, Midwifery and Social Work  
University of Manchester  
Jean McFarlane Building  
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M13 9PY | School of Nursing, Midwifery and Social Work  
University of Manchester  
Jean McFarlane Building  
Room 6.326  
Oxford Road  
Manchester  
M13 9PY |
| Telephone: 0161 306 7854 | Telephone: 0161 306 7779 |
| Email: john.keady@manchester.ac.uk | Email: nicky.cullum@manchester.ac.uk |
Thank you for taking the time to read this information sheet

What do I do next?

After you have read and considered the information outlined in the information sheet you need to decide if your relative/friend would have chosen to participate in this research and if you are willing to act as their personal consultee.

Once you have made your decision please complete the relevant sections on the enclosed Form 1. Invitation to act as a Personal Consultee. If you believe your relative/friend would like to take part and you are willing to act as a personal consultee please ensure you complete Section D of this form.

If you have completed Section D you will also need to complete Form 2. Personal Consultee Declaration

Please return these forms to me using the enclosed stamped addressed envelope.

If you require further information, support or guidance regarding the research, the role of a consultee or in completing the forms please contact me on 07768202820.
# Inpatient Dementia Clinician Consent Form

**Study Title:** Exploring the meaning, presentation and assessment of complexity in mental health NHS dementia inpatient wards: An interpretive description study  
**Version 1 November 2014**

**REC ref no:** 15/NW/0116

**Researcher:** Lesley Jones

Please Initial

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<tr>
<td>1.</td>
<td>I confirm that I have read and understand the participant information sheet (Version 1 November 2014) for the above study and have had the opportunity to consider the information.</td>
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<tr>
<td>2.</td>
<td>I confirm that I have had the opportunity to ask any questions about the study and that these have been answered satisfactorily.</td>
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<td>3.</td>
<td>I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason.</td>
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<td>4.</td>
<td>I understand that if I withdraw from the study at any time any data already collected may still be used in the study.</td>
</tr>
<tr>
<td>5.</td>
<td>I understand that the interviews will be audio recorded and transcribed and that all collected data will be stored securely within the University of Manchester.</td>
</tr>
<tr>
<td>6.</td>
<td>I agree to the use, where appropriate, of anonymised quotes from the interview or focus group to be used in the research or any publications, reports, lectures, conferences, books or contribution to books.</td>
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<td>7.</td>
<td>I agree to take part in a semi structured interview.</td>
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**Name of Participant**

**Signature**
Qualification if applicable (e.g. SW, Dr, RMN)       Date

Contact Details (you will need to provide either an email or telephone number so you can be contacted to arrange an interview date)

Email:

Telephone Number:

Once the study has been completed would you like a summary of the research findings?

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<th>Yes</th>
<th>No</th>
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(Please initial the appropriate box)

If you have initialled the yes box please indicate where you would like the summary to be sent to. This can be a postal address or email

Please send summary to:
Please return completed form in the SAE provided to:

Lesley Jones, School of Nursing, Midwifery and Social Work, University of Manchester, Jean McFarlane Building, Room 6.332, Oxford Road, Manchester, M13 9PL

Alternatively you can ring or email me to arrange an interview:

Tel: 07768202820 or email: lesley.jones@postgrad.manchester.ac.uk. In this instance you will be required to bring your completed consent form to the interview.
Phase 3 Simplified Patient Consent Form

Patient Consent Form
Study Title: Complexity and NHS Dementia Inpatient Care
Version 1 November 2015
REC ref no.: 15/NW/0166

Researcher: Lesley Jones

1. I have read and understood the participant information booklet

2. I have had the chance to ask questions and these have been answered
3. My participation in the study is voluntary and I can withdraw at any time

4. If I withdraw from the study any data collected may still be used

5. I agree to talking to the researcher

6. I understand that when I talk to the researcher this will be recorded
7. I agree to the researcher observing me on the ward and to her observing some of my care review meetings

8. I agree to the researcher talking to my Consultant Psychiatrist or deputy and my named nurse or care coordinator about my illness and how it affects me

9. I understand that a letter may be sent to my Consultant Psychiatrist or deputy and my named nurse or care coordinator inviting them to be interviewed and that my name and NHS number will be used in order for them to identify me
10. I agree to the researcher talking to a close relative/friend about how my illness affects me

11. I agree to my medical records being reviewed by the researcher

12. I understand that a copy of the participant information sheet and signed consent form will be kept in my medical record. A note will also be made in my medical record to inform the care team that I have agreed to participate in the research.

13. I understand that all information collected will be stored securely
14. I understand that things I have said may be used as quotes and if this occurs my identity will be protected and a false name can be used.

15. I understand that the findings from the research will be used in the PhD thesis, publications for academic journals, in conference presentations and lectures.

Would you like a summary of the research findings once the study has been completed? (If you tick yes a copy of your address will be taken so a summary can be posted to you)

[ ] No
[ ] Yes
Name of the Participant:

Signature of the Participant:

Signature of the Researcher:

Date:

Please Note:
If a participant is unable to write or sign their name, then a witness can be used to observe them verbally consenting to be involved in the study. The witness will be a member of the care team who will need to sign and date the form.
### Relative/Friend Interview Consent Form

**Study Title:** Complexity and NHS Dementia Inpatient Care  
**Version 1 November 2014**

**REC ref no.:** 15/NW/0116  
**Researcher:** Lesley Jones

**Please Initial**

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<td>I confirm that I have had the opportunity to ask any questions about the study and that these have been answered satisfactorily</td>
</tr>
<tr>
<td>3</td>
<td>I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason.</td>
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<td>4</td>
<td>I understand that if I withdraw from the study at any time any data already collected may still be used in the study.</td>
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<td>I understand that the interview will be audio recorded and transcribed and that all collected data will be stored securely within the University of Manchester</td>
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<td>6</td>
<td>I agree to the use, where appropriate, of anonymised quotes from the interview or focus group to be used in the research or any publications, reports, lectures, conferences, books or contribution to books.</td>
</tr>
<tr>
<td>7</td>
<td>I agree to being interviewed as part of this research study</td>
</tr>
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</table>
Name of Participant
Signature

Signature of Researcher

Date

Would you like a summary of the research findings once the study has been completed?

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<td>Yes</td>
<td>No</td>
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*(Please initial the appropriate box)*

If you have initialled the yes box please indicate where you would like the summary to be sent to. This can be a postal address or email

Please send summary to:
This observation protocol provides a guide to the areas I will focus on in my field notes. The focus of the observation is the individual with dementia. Observation will concentrate on how the patient presents and acts within the ward environment. The aim of the observation is to explore how aspects of complexity may be evidenced/ demonstrated in an individual’s behaviour/ presentation and interactions.

The patient will not be observed during the provision of direct care which requires privacy (for example washing, dressing, bathing, and using the toilet). If direct care occurs during the observation a note of this will be made.

Prior to undertaking the period of observation I will check with the care team about how the patient is and the acceptability of the observation for them at that time. If the care team advise against this, perhaps because the patient is unwell or unsettled or there are other risks on the ward this will be respected. The participating patient/ consultee will also be made aware of when the observation will be occurring. If any concerns are raised the observation will not occur.

I will position myself in the ward where I can observe the patient discreetly without causing distress or intrusion to either the patient being observed or the other patients within the ward area. Should either the patient being observed or any of the other patients become distressed, agitated or upset by my presence I will move to another area of the ward. If this does not allay the concerns being demonstrated the observation will be stopped and tried again on a different day. If the patient who is being observed has demonstrated distress or agitation directly related to the presence of the observation on two concurrent occasions then observations for that patient will permanently stop.

As well as taking field notes during the observation following each episode of observation I will also write a short reflection on the period of observation. This will include summary of how the patient presented and any key points observed during the observation. If the patient has been previously observed any noticeable differences in presentation should be noted.

**During the period of observation I will record:**
- Date and time of the observation
• Appearance of the patient
• Where the patient is in the ward and the layout of the ward (this may be in the form of a drawing)
• What the patient is doing (e.g. sitting, walking, participating in an activity)
• How the patient appears (e.g. anxious, happy, angry and what they are doing to portray this)
• Their behaviour (e.g. shouting, rocking, withdrawn, moving furniture)
• Their verbalisations (e.g. content of, volume)
• What is happening on the ward within the patients environment (e.g. is the TV on, are there visitors, noise level)
• Interactions with others (who with staff, patient, visitor), how many, what is said, response of the patient behaviour and verbal response, response of other person to the patient, position of person/people interacting, length of interaction, details of interaction and how the patient appeared after the interaction)

Please note when recording interactions with others no identifiable information will be recorded. Staff will be referred to by their role e.g. qualified nurse, doctor. Other patients will be referred to as a male patients or female patient.
Appendix 4
Phase 1 National Dementia Leaders Survey Additional Information

- National dementia leaders sample identification.
- Copies of emails sent to national dementia leaders.
- Word copy of the electronic online survey.
National Dementia Leaders Sample Identification

A number of mechanisms were used to identify individuals who could be approached and invited to participate in the dementia leaders’ survey. These are identified below:

- A search of Google and LinkedIn using predetermined search terms was undertaken. The search terms used are listed below:
  - Dementia director
  - Director of dementia
  - Consultant nurse dementia
  - Nurse consultant dementia
  - Dementia consultant nurse
  - Dementia matron
  - Advanced practitioner dementia
  - Advanced nurse practitioner dementia care
  - Dementia specialist
  - Dementia nurse specialist
  - Clinical nurse specialist dementia
  - Professor in dementia
  - Dementia lead
  - Dementia lead nurse

On occasions the search terms would provide a name or cite a name on a published paper and from this a more specific name or organisational search would be undertaken to identify if the individual met the inclusion criteria for this stage of the study.

The nurse consultant search on Google identified a link to the Mental Health and Learning Disability Nurse Directors’ and Leads’ forum. When accessed this forum gave a list of some of the nurse consultants practicing within the UK and their general area of practice for example older people. From this information it was possible to undertake more specific name searches and identify nurse consultants who were working within dementia care or old age psychiatry.

- Google was also used to search for Nurse Forums, under graduate and post graduate dementia degree programmes, dementia continuing professional development modules, dementia related psychology and psychiatry networks and forums, recent or forthcoming dementia conference programmes and to identify people with dementia who do public facing work on dementia and who have experience of working in healthcare.
- The Alzheimer’s Society, Dementia UK, Alzheimer’s Research UK, Department of Health Dementia, Stirling Dementia Centre, Royal College of Psychiatrists, University of Bradford School of Dementia Studies and the RCN older person’s forum websites were reviewed.
• The contributor’s list for current national dementia guidance was reviewed. This included:
  ▪ Department of Health (2013) *Improving Care for People with Dementia*
  ▪ Department of Health (2011) *Case for change – community based services for people living with dementia. Evidence*

• Recent copies of dementia journals and dementia related were reviewed to identify relevant authors and the editorial boards of these journals were also reviewed. These journals are listed below:
  ▪ Journal of Dementia Care
  ▪ Nurse Researcher
  ▪ Mental Health Nursing
  ▪ Nursing Older People
  ▪ Alzheimer and Dementia Journal of Alzheimer’s Association
  ▪ Dementia The International Journal of Social Research and Practice
  ▪ International Journal of Older People Nursing
  ▪ British Journal of Psychiatry
Copies of the Emails sent to National Dementia Leaders

Invitation Email

Email Title: Research Invitation: Complexity and Mental Health NHS Dementia Inpatient Care

Dear (add Name here)

Thank you for taking the time to read this email

I would like to invite you to take part in a research study which is exploring the concept of complexity in mental health NHS dementia inpatient wards. This research study is being undertaken as part of a PhD degree at The University of Manchester. My supervisors are Professor John Keady and Dame Professor Nicky Cullum

The full title of the study is:
Exploring the meaning, presentation and assessment of complexity in mental health NHS dementia inpatient wards. An Interpretive description study

REC ref: 15/NW/0116

This study explores the concept of complexity in dementia, in mental health NHS dementia inpatient wards. This is an aspect of dementia care that has previously received little attention. However the terms ‘complexity’ and ‘complex’ needs are often used alongside dementia and are cited as a reason for admission to mental health NHS dementia inpatient wards.

You have been invited to take part because you have been identified as a leader in dementia care from either an education/research, policy/guidance or clinical practice background.

If you agree to take part you be asked to complete a short on line survey about complexity in dementia. Participation will take approximately 30 minutes of your time.

Please take time to read the attached participant information sheet before you decide if you wish to participate in the study

If after reading the participant information sheet you decide you would like to participate the survey can be accessed by clicking on the link below and then entering your identification number.

Link to survey: (Add link here)

Identification number: (put identification number here)

When completing the survey your answers will be saved automatically.
Please note the survey needs to be completed in one go. After completion you will not be able to access your completed survey.

If you wish to change or amend a submitted survey you will need to log in again with the same ID number and re take the survey. If this occurs only the most recent completed survey will be used as data.

If you do not wish to take part you need do nothing further. You can delete this email.

Many thanks for taking the time to read this email.

If you have any further questions or would like to discuss any aspect of this study in more detail please feel free to contact me. My contact details are provided at the end of this email

Kind Regards

Lesley Jones
NIHR Clinical Doctoral Fellow
School of Nursing, Midwifery and Social work
University of Manchester
Jean McFarlane Building
Room 6.332
Oxford Road
Manchester
M13 9PLY
Telephone: 07768202820
Email: lesley.jones@postgrad.manchester.ac.uk

Information submitted online will be held securely on University of Manchester servers. Your data will be assigned a unique code, so that your responses remain confidential throughout the study. You are free to withdraw from the study at any time without consequences or providing an explanation. This study complies with the University of Manchester guidelines for the ethical conduct of research.

If you have concerns or complaints about the conduct of this study, please do not hesitate to contact me - Lesley Jones, NIHR Clinical Doctoral Fellow, School of Nursing, Midwifery and Social Work, University of Manchester, Jean McFarlane Building, Room 6.332, Oxford Road, Manchester, M13 9PY. Tel 07768202820, Email lesley.jones@postgrad.manchester.ac.uk

OR you can contact my supervisor Professor John Keady, School of Nursing, Midwifery and Social Work, University of Manchester, Jean McFarlane Building, Room 6.312, Oxford Road, Manchester, M13 9PY. Tel 0161 306 7854, Email john.keady@manchester.ac.uk, or, Professor Dame Nicky Cullum, School of Nursing, Midwifery and Social Work, University of Manchester, Jean McFarlane Building, Room 6.326, Oxford Road, Manchester, M13 9PY. Tel 0161306 7779, Email nicky.cullum@manchester.ac.uk

Alternatively you can contact the University of Manchester Research Governance Team. Phone 0161 275 5436 or email fmhsethics@manchester.ac.uk
Reminder Email

Email Title

Research Invitation Reminder: Complexity and Mental Health NHS Dementia Inpatient Care

Dear (put Name here)

Re: Exploring the meaning, presentation and assessment of complexity in mental health NHS dementia inpatient wards. An Interpretive description study

Rec ref: 15/NW/0016

This email is a reminder to inform you that this online survey is now open.

The survey will remain open until: (add date here)

Please take time to read the attached participant information sheet before you decide if you wish to participate in the study

The survey can be accessed by clicking on the link below and then entering your identification number.

Link to survey: (add link)

Your identification number: (add code)

Participation will take approximately 30 minutes

When completing the survey your answers will be saved automatically.

Please note the survey needs to be completed in one go. After completion you will not be able to access your completed survey.

Should you wish to change or amend a submitted survey you will need to log in again and re take the survey. If this occurs only the most recent completed survey will be used as data.
If you do not wish to take part you need do nothing further. You can delete this email.

Thank you very much for participating in this research process. If you have any questions or comments, please contact me via return email or by telephone.

Kind Regards

Lesley Jones  
NIHR Clinical Doctoral Fellow  
School of Nursing, Midwifery and Social work  
University of Manchester  
Jean McFarlane Building  
Room 6.332  
Oxford Road  
Manchester  
M13 9PLY  
Telephone: 07768202820  
Email: lesley.jones@postgrad.manchester.ac.uk

Information submitted online will be held securely on University of Manchester servers. Your data will be assigned a unique code, so that your responses remain confidential throughout the study. You are free to withdraw from the study at any time without consequences or providing an explanation. This study complies with the University of Manchester guidelines for the ethical conduct of research.

If you have concerns or complaints about the conduct of this study, please do not hesitate to contact me - Lesley Jones, NIHR Clinical Doctoral Fellow, School of Nursing, Midwifery and Social Work, University of Manchester, Jean McFarlane Building, Room 6.332, Oxford Road, Manchester, M13 9PY. Tel 07768202820, Email lesley.jones@postgrad.manchester.ac.uk

OR you can contact my supervisor Professor John Keady, School of Nursing, Midwifery and Social Work, University of Manchester, Jean McFarlane Building, Room 6.312, Oxford Road, Manchester, M13 9PY. Tel 0161 306 7854, Email john.keady@manchester.ac.uk, or, Professor Dame Nicky Cullum, School of Nursing, Midwifery and Social Work, University of Manchester, Jean McFarlane Building, Room 6.326, Oxford Road, Manchester, M13 9PY. Tel 0161306 7779, Email nicky.cullum@manchester.ac.uk

Alternatively you can contact the University of Manchester Research Governance Team. Phone 0161 275 5436 or email fmhsethics@manchester.ac.uk
Thank You Email

Email Title

Complexity & Mental Health NHS Inpatient Care: Thank you for your participation

Dear

Re: Exploring the meaning, presentation and assessment of complexity in mental health NHS dementia inpatient wards. An Interpretive description study

REC ref: 15/NW/0116

I wanted to take this opportunity to thank you for taking the time to complete the survey regarding complexity in dementia. I am now in the process of analysing the data obtained from this stage of the study. The findings of which will be used to inform the next stages of the study which will include interviews with dementia clinicians working within NHS dementia inpatient wards and exploring practice within mental health NHS dementia inpatient wards.

If requested, a summary of the research findings will be forwarded to you on completion of the study.

Thank you very much for participating in this research process. If you have any questions or comments, please contact me via return email or by telephone.

Kind Regards

Lesley Jones
NIHR Clinical Doctoral Fellow
School of Nursing, Midwifery and Social work
University of Manchester
Jean McFarlane Building
Room 6.332
Oxford Road
Manchester
M13 9PLY
Telephone: 07768202820
Email: lesley.jones@postgrad.manchester.ac.uk
Information submitted online will be held securely on University of Manchester servers. Your data will be assigned a unique code, so that your responses remain confidential throughout the study. You are free to withdraw from the study at any time without consequences or providing an explanation. This study complies with the University of Manchester guidelines for the ethical conduct of research.

If you have concerns or complaints about the conduct of this study, please do not hesitate to contact me - Lesley Jones, NIHR Clinical Doctoral Fellow, School of Nursing, Midwifery and Social Work, University of Manchester, Jean McFarlane Building, Room 6.332, Oxford Road, Manchester, M13 9PY. Tel 07768202820, Email lesley.jones@psotgrad.manchester.ac.uk

OR you can contact my supervisor Professor John Keady, School of Nursing, Midwifery and Social Work, University of Manchester, Jean McFarlane Building, Room 6.312, Oxford Road, Manchester, M13 9PY. Tel 0161 306 7854, Email john.keady@manchester.ac.uk, or, Professor Dame Nicky Cullum, School of Nursing, Midwifery and Social Work, University of Manchester, Jean McFarlane Building, Room 6.326, Oxford Road, Manchester, M13 9PY. Tel 0161306 7779, Email nicky.cullum@manchester.ac.uk

Alternatively you can contact the University of Manchester Research Governance Team. Phone 0161 275 5436 or email fmhsethics@manchester.ac.uk
Introduction

Thank you for taking the time to complete this survey. Participation should take no more than 30 minutes. Before you begin you need to enter your ID number and confirm that you have read the participation information sheet and agree to participate in the study. Your ID number and a copy of the participation information sheet can be found on the email you received inviting you to participate in the study.

1. Please enter your ID number

2. I have read the participation information sheet and agree to participate in the study
   Yes

Background Information

This next section asks you some brief information about your current role.

3. What is your job title?

4. What is your professional qualification? (Tick all that apply)

   Registered Mental Nurse
   Registered General Nurse
   Social Worker
   Psychologist
   Psychiatrist
   Geriatrician
   Speech and Language Therapist

   Other, please specify
5. Please identify where you feel your current role sits (Tick all that apply)
Clinical
Research
Education
Policy and Guidance
Other, please specify

6. Please outline what experience you have had of mental health NHS dementia inpatient wards.

7. How many years have you worked in dementia care?

(A drop down box and participant chose the most appropriate from the list below)
None
6-10 years
11-15 years
16-20 years
20+years

Exploring Complexity in Dementia

8. Please outline the reasons you believe people with dementia are admitted to mental health NHS dementia inpatient wards

(Free text box)
9. Please describe your understanding of the term “complexity” in the context of dementia.

(Free text box)

10. Please describe what factors or components you feel contribute to complexity in dementia.

(Free text box)

11. How should we assess people with a complex presentation of dementia?

(Free text box)

**Final Questions**

12. Once the research study has been completed would you like to receive a summary of the research?

☐ Yes  ☐ No

13. If you have answered yes to question 12 please provide an email or postal address where you would like this information to be sent to
Appendix 5
Examples of Study Notices

- Phase 2 Inpatient staff awareness raising notice.
- Phase 2 Older adult community mental health team awareness raising notice.
- Phase 2 Staff awareness raising handout.
- Phase 3 Staff notice.
- Phase 3 Patient and relative notice.
- Phase 3 Observation notice.
Research Study
Exploring the meaning, presentation and assessment of complexity in NHS dementia inpatient wards

My name is Lesley Jones, and I am currently undertaking a PhD in Nursing at The University of Manchester. From (add month) you will see me on the ward.

My research study is about exploring and understanding complexity in dementia. I then want to identify what should be included in an assessment of people with dementia when they are admitted to a dementia inpatient ward.

There are several stages to this study. This stage involves speaking with ward staff (qualified and unqualified) who are working on NHS dementia inpatients wards about their experiences and understanding of these issues.

Over the next few weeks I will be on the ward recruiting clinical staff to participate in this stage of the study.

If you have any questions about the study or would like more information please do not hesitate to speak to me when I am on the ward or you can contact me on lesley.jones@postgrad.manchester.ac.uk. Tel: 07768202820.

If you have a problem or concern regarding the study you can contact me in the first instance or you can contact my supervisors Professor John Keady on john.keady@manchester.ac.uk. Tel: 0161 306 7854

Or, Professor Dame Nicky Cullum on nicky.cullum@manchester.ac.uk. Tel: 0161 306 7779

Complexity and NHS Dementia Inpatient Care: inpatient staff notice version 1 November 2014

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Research Study
Exploring the meaning, presentation and assessment of complexity in NHS dementia inpatient wards

Ethics ref no: 15/NW/0116

My name is Lesley Jones, and I am currently undertaking a PhD in nursing at The University of Manchester. From *** you will see me on the ward.

My research study is about exploring and understanding complexity in dementia. I then want to identify what should be included in an assessment of people with dementia when they are admitted to a dementia inpatient ward.

There are several stages to this study. This stage involves holding a focus group with staff (qualified and unqualified) from the dementia Community Mental Health Team (CMHT) about their experiences and understanding of these issues and the reasons why they may refer an individual for admission.

Over the next few weeks I will be visiting the CMHT to give more information and to recruit clinical staff to participate in this stage of the study.

If you have any questions about the study or would like more information please do not hesitate to speak to me when visiting the CMHT or you can contact me on
lesley.jones@postgrad.manchester.ac.uk
Tel: 07768202820.

If you have a problem or concern regarding the study you can contact me in the first instance or you can contact my supervisors
Professor John Keady on
john.keady@manchester.ac.uk
Tel: 0161 306 7854

Or, Professor Dame Nicky Cullum on
nicky.cullum@manchester.ac.uk
Tel: 0161 306 7779

Complexity and NHS Dementia Inpatient Care: CMHT focus group notice version 1 November 20th 2014

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Study Title
Exploring the meaning, presentation and assessment of complexity in mental health NHS dementia inpatient wards: An interpretive description study.

Short Title
Complexity and NHS Dementia Inpatient Care.

Funder
National Institute for Health Research Clinical Academic Trainee Scholarship

Ethics
REC Ref: 15/NW/0016
Trust Research Governance Ref: 855

Purpose of the Study?
This study explores the concept of complexity in dementia within the setting of NHS inpatient dementia wards. These are both areas of dementia care that have previously received little attention or focus yet the term complexity or complex needs is often used alongside dementia and is cited as a reason for admission.

Study Aims and Objectives
Aim
The aim of this study is to describe and understand what constitutes complexity in dementia within mental health NHS dementia inpatient wards.

Objectives
The study objectives are:

• To explore with various stakeholders in dementia care how they construct and recognise, report and document complexity in dementia
• To explore how clinical staff use the various discourses of complexity and the different meanings that may be attributed to these terms
• To explore the perspectives and views of complexity by people with dementia resident on a mental health NHS dementia inpatient wards and gain a similar understanding from their relative/friend.
• To describe the key components of complexity in dementia
• To describe key components of the assessment of individuals with dementia who are perceived as being complex

**Methodological Approach**
This will be an applied qualitative research study. The methodological approach is interpretive description. This is a methodological approach orientated toward clinical practice (Thorne et al., 1997). It allows issues that are identified from clinical practice to be explored and the findings of the research to be applied back to practice.

**Overview of Study Design**
The study will be divided into four stages.

**Stage 1. – Scaffolding the Study**
Scaffolding the study is a term used within interpretive description and allows the stage to be set and prepared for the study (Thorne, 2008). Scaffolding consists of two components; a literature review and the outlining of the theoretical premise of the study.

**Stage 2. – Exploring the Views of Stakeholders in Dementia Care**
There are two components to this stage.

**Component 1** will explore how complexity in dementia is constructed and understood from the perspectives of various dementia leaders. Dementia leaders will be individuals who through education, research, policy or practice have influenced dementia care within the U.K. An internet survey will be used for this component.

**Component 2** will explore how complexity is constructed and understood from the perspectives of clinicians working within NHS specialist dementia services within a mental health trust from dementia inpatient wards and dementia community mental health teams. Semi structured interviews and focus groups will be used in this component.

**Stage 3. – Complexity and Inpatient Dementia Care**
The aim of this stage is to explore how complexity in dementia is represented in people with dementia who are currently resident as inpatients. This stage will allow for explorations of how the themes identified in the previous stages are observed and translated into practice. I will observe ward handovers and examine how complexity presents in current inpatients on the ward. Data sources will include interviews, observation and medical/care record reviews.
Stage 4. – Development of Findings
In keeping with an interpretive description methodology, data will be described and interpreted. This will involve:

- The key components of complexity in dementia to be outlined
- The identification of the key components of assessment of individuals with dementia who are perceived as complex.

These developments and interpretations will then be presented back to a selection of study participants and dementia clinicians for final review.
Complexity and NHS Dementia Inpatient Care

CURRENT STAGE
Stage 2 Component 2
Dementia Clinicians

Location
Two dementia inpatient wards in the trust
Associated dementia CMHT’s

Timescale
Up to 12 weeks

Who can be involved?
Any member of care staff who are working clinically in the dementia inpatient wards or CMHT can be involved in this stage. This can include nurses, doctors, SW, OT, nursing assistants and support workers

Purpose
The purpose of this stage of the study is to explore how complexity in dementia is perceived and understood by clinicians working within NHS specialist dementia services.

What is involved?
Clinical staff working on the dementia ward are invited to participate in one semi structured interview. Up to 20 staff across the two dementia inpatient wards will be interviewed

Clinical staff working in the associated dementia CMHT’s will be invited to attend a focus group. There will be two focus groups with 6-10 participants in each.

Semi Structured Interviews?
Semi structured interviews will last up to one hour. They will be held in the clinical area but in a room away from the ward. This is to ensure privacy and prevent interruption. Interviews will be organised around the ward to best fit with the ward routine. Interviews will be conversational in nature and seek to explore clinician’s thoughts, views and experiences of complexity in dementia and assessing people with dementia who may be complex.

Focus Groups?
Focus groups will be held with the dementia CMHT associated with the participating dementia inpatient wards. The purpose of this is to explore with
clinicians who work in the CMHT their understanding of complexity and reasons why they would refer an individual for admission.

A focus group will last for around one hour. It will be held in a trust site but in a private room to reduce interruptions.

**Consent**
To take part staff will have to read a participant information sheet and sign a study consent form. An individual can withdraw from the study at any time.

**What Happens Next?**
All clinical staff working on the dementia ward or in the dementia CMHT will be sent a participant information sheet informing them in more detail about the study and what would be involved if they would like to participate. The information sheet also outlines what to do if individuals would like to participate in the study.

**What Happens After Stage 2?**
Data will be analysed as it is being collected. This will then be used to further inform stage three of the study which explores how complexity is represented in people who are currently inpatients.

**Contact Details**
If you have any further questions or would like more information please contact me.

**Researcher**
Lesley Jones  
School of Nursing, Midwifery and Social Work  
University of Manchester  
Jean McFarlane Building  
Room 6.332  
Oxford Road  
Manchester  
M13 9PY

Telephone: 07768202820  
Email: lesley.jones@postgrad.manchester.ac.uk
Research Study
Exploring the meaning, presentation and assessment of complexity in NHS dementia inpatient wards

Ethics ref no: 15/NW/0116

My name is Lesley Jones, and I am currently undertaking a PhD in Nursing at The University of Manchester. From October you will see me around on the ward.

My research study is about exploring and understanding what complexity means in dementia. I then want to identify the key areas of assessment when caring for individuals who may be complex.

The study is being undertaken in a number of stages. Some of you will have participated in the previous stage which involved interviews with clinical staff.

The current stage involves exploring how complexity and assessment is represented in clinical practice and in people who are currently inpatients. This stage will include observations of handovers and care reviews, interviews and observations with participating patients, interviews with relatives and staff; and a review of participating patient’s medical records.

Over the next few weeks I will be on the ward undertaking this stage of the study.

If you have any questions or would like more information please speak to me when I am on the ward or you can contact me on lesley.jones@postgrad.manchester.ac.uk or by telephoning 07758202820.

If you have a problem or concern regarding the study you can contact me in the first instance or you can contact my supervisor Professor John Keady john.keady@manchester.ac.uk Tel: 0161 306 7954

Or, Professor Dame Nicky Cullum nicky.cullum@manchester.ac.uk Tel: 0161 306 7779

Complexity and NHS Dementia Inpatient Care: Staff notice stage 3 V1 Nov 20th 2014
Research Study
Complexity and NHS Dementia Inpatient Care

Ethics ref no: 15/NW/0116

My name is Lesley Jones, and I am currently undertaking a PhD in Nursing at The University of Manchester.

My research study is focused on people with dementia who are currently a patient on an NHS dementia inpatient ward. The study is about exploring and understanding what complexity in dementia means. I then want to identify the key areas of assessment when caring for a person with dementia who may have complex needs. A number of methods will be used to gather this information. This will include interviews with patients, staff and relatives, reviewing medical records and undertaking observations of practice on the ward.

If you are a patient on the ward or their relative/friend and would like some more information or are interested in participating, please let the staff know and they will arrange for me to have a chat with you.

You are under no obligation to meet with me or take part in the study. Your care and treatment on the ward will not be affected in anyway.

If you have a question, problem or concern regarding the study you can contact me in the first instance on 07759302820 or lesley.jones@postgrad.manchester.ac.uk or you can contact my supervisors Professor John Keady on john.keady@manchester.ac.uk or by telephoning 0161 306 7854 or Professor Dame Nicky Cullum on nicky.cullum@manchester.ac.uk or by telephoning 0171 306 7779.
Research Study
Complexity and NHS Dementia Inpatient Care

My name is Lesley Jones, and I am currently undertaking a PhD in Nursing at The University of Manchester.

My research study is focused on people with dementia who are currently a patient on an NHS dementia inpatient ward. The study is about exploring and understanding what complexity in dementia means. I then want to identify the key areas of assessment when caring for a person with dementia who may have complex needs.

Observations

As part of the research study I am currently on the ward undertaking observations. While you are visiting you may notice me sat on the ward observing and occasionally writing things down. My observations will be focused upon people who have agreed to participate in the study. No identifiable information regarding anyone on the ward or visiting the ward will be recorded.

If you have a question, problem or concern regarding the study you can contact me in the first instance on 07768202820 or lesley.jones@postgrad.manchester.ac.uk or you can contact my supervisors Professor John Kecdy on john.kecdy@manchester.ac.uk or by telephoning 0161 306 7854 or Professor Dame Nicky Cullum on nicky.cullum@manchester.ac.uk or by telephoning 0171 306 7779.

Complexity and NHS Dementia inpatient Care: In patient flyer v1 November 2014
Appendix 6

Interview Guide Examples and What Phase 2 Participants Enjoy About Working in Dementia Care

- Phase 2 Inpatient dementia clinicians interview guide (original and updated versions).
- Phase 2 Older adult community mental health team focus group guide.
- Phase 3 Immediate care team interview guide.
- Phase 3 Relative/friend interview guide.
- Phase 3 Patient interview guide.
- Information / further support for relative/friends post interview.
- Phase 2 interview note examples.
- Phase 2 interview reflection examples.
- What phase 2 study participants like about working in dementia care.
Explain at the Beginning

- What the study is about
- Inform of NIHR funding and being undertaken as part of PhD study
- Check they have read the participant information sheet.
- Re explain: right to withdraw at any time (but info obtained up to that point may still be used), that identity will be protected but extracts from interview may be used, use of pseudonyms, only I will have access to identifiable date
- Security of data (e.g. files kept locked cupboard, locked room, secure computer servers). Identifiable data will be removed from transcripts and replaced with code. Supervisory team will only see anonymised transcripts. Data will be kept for 5 years after completion of the study
- Interview will be digitally recorded. After transcription recording will be deleted.
- They can stop interview at any time
- Options available should they become upset – e.g. manager, clinical supervisor, staff counselling service
- Course of action should evidence of malpractice or poor conduct, or concerning practice occur during the interview
- Re confirm consent or if not already done so get consent form signed
- Explain format of interview, approx how long it will take
- As well as being digitally recorded they may see me make the occasional note – this will be as an aide memoire to myself if needed

My Role as a Researcher

Explain that I am a mental health nurse and acknowledge that some staff may know me or know of me and some may have previously worked with me. However emphasise that I am now here in the role of a researcher and cannot give advice or guidance regarding the care, management or treatment of any patients. Nor can I advise of guide regarding any specific ward related issues. In these instances inform that the participant will be reminded of this and advised to discuss the issue with the most appropriate member of the clinical team
Ask if participant has any questions before we begin

Dementia and Complexity Question Areas

Introduction questions

• Please tell me how long you have been qualified?

• What is your role?

• How long have you worked on the ward?

• What is it you enjoy about working with people who have dementia?

Complexity Question Areas

• Based on your experience if a person with dementia is described as complex or having complex needs what does that mean to you?

• What factors, do you feel; contribute to an individual with dementia being classed as complex?

• Can you think of a patient you have cared for recently with dementia who you felt was complex? Please describe what made them complex.

• Please describe, based on your experience, what other words are used by staff to describe complexity in dementia? (give examples if needed – challenging, complicated)

• If a patient is on the ward who you feel is complex how would this be communicated to the rest of the team? (for example where is this discussed, how would staff know)

• If a patient is complex or has complex needs how would this be reflected within the clinical records? (where would it be recorded, how is it recorded)

• How is this presentation of complexity or complex needs communicated to family?

• Drawing on your own experiences, of caring for people with dementia who are complex, what challenges has this presented to care giving?
• Please describe the reasons why patients are admitted to the ward

• Are the people with dementia admitted to the ward always complex?
  ▪ If not what proportion of the patients on the ward are normally complex

• For patients on the ward who are considered to be complex what to do you believe the essential / key components of assessment should entail. (For example what areas should be addressed /considered during admission)

• In what ways are family involved in the assessment

• If a patient is complex is their length of stay on the ward normally longer? If so please explain/ describe possible reasons for this

End of Interview

Would they be willing to see a copy of developments that stem from the study to check whether the developments and findings are representative of their experiences of complexity and whether the findings are applicable to practice.

If so how would they like to be contacted?

Finally

Remind re support structures available if they feel needed (manager, matron, clinical supervisor, staff counselling service)

Thank the participant for time, information and participation
Inpatient Dementia Clinicians Interview Guide

Updated Version

Explain at the Beginning

- What the study is about
- Inform of NIHR funding and being undertaken as part of PhD study
- Check they have read the participant information sheet.
- Re explain: right to withdraw at any time (but info obtained up to that point may still be used), that identity will be protected but extracts from interview may be used, use of pseudonyms, only I will have access to identifiable date
- Security of data (e.g. files kept locked cupboard, locked room, secure computer servers). Identifiable data will be removed from transcripts and replaced with code. Supervisory team will only see anonymised transcripts. Data will be kept for 5 years after completion of the study
- Interview will be digitally recorded. After transcription recording will be deleted.
- They can stop interview at any time
- Options available should they become upset – e.g. manager, clinical supervisor, staff counselling service
- Course of action should evidence of malpractice or poor conduct, or concerning practice occur during the interview
- Re confirm consent or if not already done so get consent form signed
- Explain format of interview, approx how long it will take
- As well as being digitally recorded they may see me make the occasional note – this will be as an aide memoire to myself if needed

My Role as a Researcher

Explain that I am a mental health nurse and acknowledge that some staff may know me or know of me and some may have previously worked with me. However emphasise that I am now here in the role of a researcher and cannot give advice or guidance regarding the care, management or treatment of any patients. Nor can I advise of guide regarding any specific ward related issues. In these instances inform that the participant will be reminded of this and advised to discuss the issue with the most appropriate member of the clinical team
Ask if participant has any questions before we begin

Dementia and Complexity Question Areas

Introduction questions
- Please tell me how long you have been qualified? And how many years in dementia care?, qualifications /courses in dementia?
- What is your role?
- How long have you worked on the ward?
- What is it you enjoy about working with people who have dementia? why dementia care?

Complexity Question Areas
- What makes someone with dementia complex?
- What factors, do you feel; contribute to an individual with dementia being classed as complex?
- Can you think of a patient you have cared for recently with dementia who you felt was complex? Please describe what made them complex.
- Please describe, based on your experience, what other words are used by staff to describe complexity in dementia? (give examples if needed – challenging, complicated)
- If a patient is on the ward who you feel is complex how would this be communicated to the rest of the team? (for example where is this discussed, how would staff know)
- If a patient is complex or has complex needs how would this be reflected within the clinical records? (where would it be recorded, how is it recorded)
- How is this presentation of complexity or complex needs communicated to family?
- Drawing on your own experiences, of caring for people with dementia who are complex, what challenges has this presented to care giving?
• Please describe the reasons why patients are admitted to the ward

• Are the people with dementia admitted to the ward always complex?
  ▪ If not what proportion of the patients on the ward are normally complex

• Can you describe the assessment process to me –what does it involve?

• For patients on the ward considered to be complex, what do you believe are the essential areas /components to be assessed? / How should we assess someone who is complex?

• If a patient is complex is their length of stay on the ward normally longer? If so please explain/ describe possible reasons for this

End of Interview

Would they be willing to see a copy of developments that stem from the study to check whether the developments and findings are representative of their experiences of complexity and whether the findings are applicable to practice.

If so how would they like to be contacted?

Finally

Remind re support structures available if they feel needed (manager, matron, clinical supervisor, staff counselling service)

Thank the participant for time, information and participation
Complexity and NHS Dementia Inpatient Care

CMHT Dementia Clinicians Focus Group Guide

(Version 1 November 2014)

At the Beginning

Check on arrival that everyone has signed the consent form:

Start by Explaining:

- What the study is about
- Inform of NIHR funding and being undertaken as part of PhD study
- Right to withdraw at any time (but info obtained up to that point may still be used), that identity will be protected but extracts from interview may be used, use of pseudonyms, only I will have access to identifiable data
- Security of data (e.g. files kept locked cupboard, locked room, secure computer servers). Identifiable data will be removed from transcripts and replaced with code. Supervisory team will only see anonymised transcripts. Data will be kept for 5 years after completion of the study
- Focus group will be digitally recorded. After transcription recording will be deleted.
- They can leave at any time
- Options available should they become upset – e.g. manager, clinical supervisor, staff counselling service.
- Explain format of group, approx how long it will take, role of note taker
- As well as being digitally recorded they may see me make the occasional note – this will be as an aide memoire to myself if needed

Agree Ground Rules

- Confidentiality - e.g. do not use patients names
- If possible turn phones off or onto silent
- Respect each other’s views, hear what others say, try not to interrupt
- Try to say your first name as you speak – so it’s easier to know who is saying what on the recording
- Course of action should evidence of malpractice or poor conduct, or concerning practice occur during the interview
- There may be occasions due to time where I will move people on in regard to subject area
My Role as a Researcher
Explain that I am a mental health nurse and acknowledge that some staff may know me or know of me and some may have previously worked with me. However emphasise that I am now here in the role of a researcher and cannot give advice or guidance regarding the care management or treatment of any patients. Nor can I advise of guide regarding any specific ward related issues. In these instances inform that the participant will be reminded of this and advised to discuss the issue with the most appropriate member of the clinical team.

Ask if participants have any questions before we begin

Dementia and Complexity Question Areas
What does the term complexity in dementia mean to them?

Has anyone had a patient who they believed was complex? If so how did they present/ what made them complex?

Why would they refer someone for admission? Are the individuals referred always complex? If no – why

If one of their patients is admitted to the ward do to complexity/complex needs what areas do they feel they assessment should consist of/take into account

How is complexity in patients communicated between the team? What words are used to describe someone who may be complex?

Are they managing people with dementia in the community who are complex? If yes – what factors have prevented these individuals from being admitted?. How are family involved?

In their experience is complexity related to the stage of dementia

Finally

Remind re support structures available if they feel needed (manager, matron, clinical supervisor, staff counselling service)

Thank the participant for time, information and participation

Remind re confidentiality

Ask if they would they be willing to see a copy of developments that stem from the study to check whether the developments and findings are representative of their experiences of complexity and whether the findings are applicable to practice.

If so how would they like to be contacted?
Immediate Care Team Question Guide
Case from Practice
Version 1 November 2014

Explain at the Beginning

• What the study is about
• Inform of NIHR funding and being undertaken as part of PhD study
• Check they have read the participant information sheet.
• If not signed consent form do so now and explain each section
• If have signed consent form re confirm:
  Right to withdraw at any time (but info obtained up to that point may still be used), that identity will be protected but extracts from interview may be used, use of pseudonyms, only I will have access to identifiable date

  Security of data (e.g. files kept locked cupboard, locked room, secure computer servers). Identifiable data will be removed from transcripts and replaced with code. Supervisory team will only see anonymised transcripts. Data will be kept for 5 years after completion of the study

  Interview will be digitally recorded. After transcription recording will be deleted.

• They can stop interview at any time. If they don’t want to answer a question they do not have to, this will not reflect of the job, role etc
• Options available should they become upset (manager, clinical supervisor, staff counselling)
• Confidentiality will be broken if disclosure is essential to protect you or others from the risk of significant harm, or the disclosure is required by law or by order of a court, safeguarding, malpractice etc
• Explain format of interview, approx how long it will take
• As well as being digitally recorded they may see me make the occasional note – this will be as an aide memoire to myself if needed
My Role as a Researcher

Explain that I am a nurse and acknowledge that some staff may know me or know of me and some may have previously worked with me. However; emphasise that I am now here in the role of a researcher and cannot give advice or guidance regarding the care management or treatment of any patients. Nor can I advise or guide regarding any specific ward related issues. In these instances inform that the participant will be reminded of this and advised to discuss the issue with the most appropriate member of the clinical team.

Ask if participant has any questions before we begin

Introduction Questions

How long have you been qualified?

How long have you worked on the ward?

Role in regard to patient (e.g. doctor, named nurse)

Question Areas:

- Approx. how long has X been a patient on the ward?
- MHA or DoLS
- Stage of dementia

- Please explain the reason why XX was admitted to the ward? (what had been happening at home/care home, how was person acting, what things had been previously tried)

- What do you understand the purpose of the admission to be? (why do they feel they are on the ward, what do they expect from the admission)

- Please describe how XX has been since admission to the ward – how do they present, how would you describe them

- What has the assessment focused on and why

- Has there been challenges to care giving and or meeting this person’s needs?
  - If so can you describe what they are

- Would you consider X to be complex?
  - If yes why, if no why not

- Did the persons complexity change during admission? Please explain in what way
• How do you know when the assessment is complete?
• Discharge venue and rationale?
• Is the person still complex

End of Interview

Would they be willing to see a copy of the final work that is developed as a result of the research to check whether the developments and findings are representative of their experiences of complexity and whether the findings are applicable to practice?

If so how would they like to be contacted?

Finally

Remind re support structures available (manager, clinical supervisor, staff counselling)

Thank the participant for time, information and participation
Relative/Friend Interview Guide
V1 November 2014

Explain at the Beginning

• What the study is about
• Inform of NIHR funding and being undertaken as part of PhD study
• Check they have read the participant information sheet.
• If not signed consent form do so now and explain each section
• If have signed consent form re confirm:
  Right to withdraw at any time (but info obtained up to that point may still be used), that identity will be protected but extracts from interview may be used, use of pseudonyms, only I will have access to identifiable date
  Security of data (e.g. files kept locked cupboard, locked room, secure computer servers). Identifiable data will be removed from transcripts and replaced with code. Supervisory team will only see anonymised transcripts. Data will be kept for 5 years after completion of the study

Interview will be digitally recorded. After transcription recording will be deleted.

• They can stop interview at any time
• Options available should they become upset and inform that support/contact sheet will also be given at the end
• Confidentiality will be broken if disclosure is essential to protect you or others from the risk of significant harm, or the disclosure is required by law or by order of a court
• Explain format of interview, approx how long it will take
• As well as being digitally recorded they may see me make the occasional note – this will be as an aide memoire to myself if needed
• If they don’t want to answer a question they do not have to
• Their relatives care and treatment will not be affected in any way
My Role as a Researcher

Explain that I am a nurse but I am currently working as a researcher. Therefore I will not be in a position to offer any specific guidance regarding their relatives care, interventions or treatment. In these situations relative will be advised to speak to appropriate member of the care team.

Ask if participant has any questions before we begin

Introduction Questions

Can you please tell me you relationship to the patient

How long approx. has XXXX had dementia

Where they lived before admission

In what ways are you involved in helping, assisting, providing care for them

Question Areas:

• Approx how long has X been a patient on the ward?
• Please explain the reason why XXXX was admitted to the ward? (what had been happening at home/care home, how was person acting, what things had been previously tried)
• What do you understand the purpose of the admission to be? (why do they feel they are on the ward, what do they expect from the admission)
• Since being on the ward how has X presentation/needs been described to you by the care team
• How would you describe their presentation since admission?
• When someone is admitted to the ward for an assessment what areas / factors do you feel are important to be considered as part of the assessment process
• What has been for you the hardest aspect of the illness to experience? (What have they found hardest to cope with, why, what problems/challenges has this caused)
• How would you describe X presentation/ what words would you use (e.g. difficult, challenging, complicated)
  For what reasons did you choose this word?
• If a person with dementia was described as complex or having complex needs how would you interpret this?
• Would you consider X to be complex/have complex needs?
  If yes why, if no why not
End of Interview

Would they be willing to see a copy of the final work that is developed as a result of the research?

If so how would they like to be contacted?

Finally

Remind re support structures available if they feel needed (ward manager, named nurse, care coordinator, carer support service)

Also external support services – Alzheimer’s society, Admiral Nurse helpline

Give information sheet to support this

Remind that their participation and information will not affect X care or treatment in any way

Thank the participant for time, information and participation
Patient Interview Guide
Version 1 November 2014

Explain at the Beginning

• What the study is about
• Inform of NIHR funding and being undertaken as part of PhD study
• Check they have read the participant information sheet.
• If not signed consent form do so now and explain each section
• If have signed consent form re confirm:
  Right to withdraw at any time (but info obtained up to that point may still be used), that identity will be protected but extracts from interview may be used, use of pseudonyms, only I will have access to identifiable date

  Security of data (e.g. files kept locked cupboard, locked room, secure computer servers). Identifiable data will be removed from transcripts and replaced with code. Supervisory team will only see anonymised transcripts. Data will be kept for 5 years after completion of the study

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• They can stop interview at any time
• Confidentiality will be broken if disclosure is essential to protect you or others from the risk of significant harm, or the disclosure is required by law or by order of a court
• Explain format of interview, approx how long it will take
• As well as being digitally recorded they may see me make the occasional I note – this will be as an aide memoire to myself if needed
• If they don’t want to answer a question they do not have to
• Their care and treatment will not be affected in any way
• IF CONCERNS RE PATIENT NOT HAVING CAPACITY DO NOT PROCEED
• CHECK IF THEY WOULD LIKE SOMEONE WITH THEM
My Role as a Researcher

Explain that I am a nurse but I am currently working as a researcher. Therefore I will not be in a position to offer any specific guidance regarding their relatives care, interventions or treatment. In these situations they will be advised to speak to appropriate member of the care team.

Ask if participant has any questions before we begin

Introduction

Initial opening questions/ conversation. This will be general conversation to initially help relax the person. For example it may be about the weather or what they had for lunch etc

Question Areas:

- Tell me about your illness
- In what ways does it affect you
- Why are you in hospital
- What areas/things do you feel you need help and support with
- How do the staff on the ward help you
- When you were at home who was helping you?
- What sorts of things did they help you with
- What has been for you the hardest aspect of the illness to experience? (What have they found hardest to cope with, why, what problems/challenges has this caused)
- Do you feel you have complex needs?
  - If so why?
  - If not why not

End of Interview

Check if person got any questions

Finish on with general conversation

Remind that their participation and information will not affected their care or treatment in any way

Thank the participant for time, information and participation
Information / Further Support for Relatives/Friends

Thank you for taking the time to talk with me today as part of my research study.

As mentioned in the interview if you have any questions regarding your relatives/friends care or treatment you can speak with:

- The ward manager
- Their named nurse
- Their care coordinator
- The Consultant Psychiatrist

Ward staff will be able to arrange this for you.

Alternatively you can also contact for further support or any questions about dementia in general the:

- Alzheimer’s Society helpline – 0300 222 1122 The Alzheimer’s Society helpline is usually open from 9am to 5pm Monday to Friday and Saturday and Sunday 10am - 4pm.
- Admiral Nurse Direct – 0845 257 9406. The helpline is open Tuesdays between 10am-4pm and 6pm- 9pm and Thursdays 6pm-9pm. Outside of these hours callers may leave a voice message and an Admiral Nurse will return the call. Alternatively emails may be sent to direct@fordementia.org.uk
25/6/15
Interview A

1977
- 38-4
- Crying

"Looking beyond what is real"
"Look out for people"

What physical issue came across?
Was it common for all patients

Physical insight

Open


"Think outside the box"

"Infringement of self-esteem"

Mood and dep.

Risk

Assessment

Mix of patients

Pain not visible
Non magny not really up. Over  

 Sexual dysfunction 

 Love making - eg: Oscar Impotence 
 Compulsive physical 
 Sensualistic 

 Our reaction is pt - some pt's 
 - sad 

 - phallic - "family dynamics"

 3.5 self u n unconscious 
 1. What happens to me 
 pb 

 Insight 
 Progresses 
 Life story 
 Ask 

 Behavior 
 Failed desires & 
 Pain 

 Complexly depends on level -
First qualified staff interview. This one felt a little harder at times – perhaps because she had only been qualified for 6 months so many not have had a much experience to draw on.

Feel I need to review interview questions to include:

How many years qualification?
How many years in demeane role – in what areas.

Also: is complexity related to stage of demeane.

Can you stop being complex?

Is everyone complex.
2/6/15

This was for nurses using fine modified questions to complex

'What makes someone x dementia complex'

This interview seemed to go well & I think I got some good information.

Again complexity felt related to communication problems but this time I was able to ask a bit deeper & he raised about complexity in regard to one factor & also risk.
Phase 2 Interview Reflection Example

25/6/15

Physical health nurse.

This was first interview @!!!
Also first interview of an RGN working with dementia, a new physical health care role.

Farma this interview had to do from the perspective of me not going into clinical mode... As I had used to share an office with this person & we use to work closely together.

Interesting interview as this was the first one which focused on the physical condition more.
This inference has been hard to draw out of one staff.

Also some interesting analogies used:

‘pave nursing’ - dementia nasty

‘look at the pass’

‘Seeing behind what is now’) case analysis

‘There outside the box’ - dementia

‘ball of wool’ - pass x dementia

Aspects of complexity = pass

Complexity = pub a wool r environment

Assessment = people working u

Stu’s, only daughter but

not bringing it here to see

big picture

Almost made me think -

Only see pass + nut whole
What Phase 2 Study Participants Like About Working in Dementia Care.

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Ward Manager 1</td>
<td>“The challenges, the diversity and the client group, I like the age group.”</td>
</tr>
<tr>
<td>Deputy Ward Manager 1</td>
<td>“I love the patients. I think it's really interesting, that every day is really different”.</td>
</tr>
<tr>
<td>Staff Nurse 2</td>
<td>“Dementia is totally different to other mental health that I've worked in, or studied before, so I find it really interesting, and that's why I like it, but also I like working with older people.”</td>
</tr>
<tr>
<td>Staff Nurse 3</td>
<td>“I just like to make a difference really. I enjoyed it before I qualified; I enjoyed actually making a difference to somebody's life.”</td>
</tr>
<tr>
<td>Staff Nurse 4</td>
<td>“I like the fact that obviously it's an illness that is never going to get better, things do get worse, and just sometimes putting that little smile on somebody’s face makes it for me, so, yes, it’s just the little things, the little things, yes.”</td>
</tr>
<tr>
<td>Nursing Assistant 1</td>
<td>“Every day’s different. It’s different from working in a hospital where patients get better and go home but every day is...like I say, every day is different and a person could hate you one day but love you to bits the next and if you can make a person smile then it’s a job well done.”</td>
</tr>
<tr>
<td>Nursing Assistant 2</td>
<td>“I think it’s the fact that because they’re quite vulnerable you’re sort of, you know, taking on a role sort of protecting them, aren’t you, making sure that they’re okay, looking after them, and I think it’s because I enjoy looking after people.”</td>
</tr>
</tbody>
</table>
| Nursing Assistant 4     | “I find it, rewarding because you are helping patients that struggle to help themselves with things. I find that aspect rewarding, they really need your help and support, I find it a
<table>
<thead>
<tr>
<th>Role</th>
<th>Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>Senior Practitioner</td>
<td>“Satisfaction of assisting people who actually require support.”</td>
</tr>
<tr>
<td>Registered General Nurse</td>
<td>“It’s very rewarding when you can actually get that little glimmer of…your approach is working, even if it only works for five minutes. You’re teasing out what…it’s so not routine. It’s so not, I can walk past you on a ward, are you okay? Are you okay? It’s more in depth. I love that.”</td>
</tr>
<tr>
<td>Consultant Psychiatrist 1</td>
<td>“If we can make a difference in someone’s life I think that’s quite fulfilling, not just the patient but the relatives and those who are looking after them, yes.”</td>
</tr>
<tr>
<td>Consultant Psychiatrist 2</td>
<td>“Well it’s interesting and there’s a load of challenges.”</td>
</tr>
<tr>
<td>Psychologist</td>
<td>“It’s very interesting because nobody’s the same. It’s challenging.”</td>
</tr>
<tr>
<td>Allied Health Professional 1</td>
<td>“I really like being able to build a rapport with the person, and I think sometimes we work on an inpatient unit and when people come in they tend to be really distressed and agitated; and it’s really good to see the change.”</td>
</tr>
<tr>
<td>Allied Health Professional 2</td>
<td>“I like the changeability, the fact no morning or afternoon or day is the same, and even if you’re treating the same patients, which we do because people aren’t in and out very quickly, that people change so quickly and it’s just that difference, it’s not boring at all.”</td>
</tr>
<tr>
<td>Allied Health Professional 3</td>
<td>“Where my heart lies. I think in dementia care you meet people from all walks of life, and it’s really interesting to understand that, and understand what makes that person tick and how we can work with that person, and just how different everybody is.”</td>
</tr>
<tr>
<td>Community</td>
<td>“Find working with people with dementia a bit of a challenge”</td>
</tr>
<tr>
<td>Role</td>
<td>Quote</td>
</tr>
<tr>
<td>-----------------------------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Psychiatric Nurse 1</td>
<td>professionally. Looking at the historical picture and what you can do to make life better.”</td>
</tr>
<tr>
<td>Community Psychiatric Nurse 3</td>
<td>“Getting a really nitty gritty situation and problem solving and helping someone work it out and make sense of it al.”</td>
</tr>
<tr>
<td>Community Psychiatric Nurse 4</td>
<td>“I like when you find out who somebody is and what they are and they come alive.”</td>
</tr>
<tr>
<td>Community Psychiatric Nurse</td>
<td>“Finding out about the person and them sharing experiences about how things were in the past and just about their family and things.”</td>
</tr>
<tr>
<td>Occupational Therapist</td>
<td>“Every day is different but we get time to meet people find their priorities and help them work through that.”</td>
</tr>
<tr>
<td>Social Worker 1</td>
<td>“One thing I like working with people with dementia is their disinhibition; they say exactly what they think.”</td>
</tr>
<tr>
<td>Social Worker 1</td>
<td>“I like trying to find out what the person was before they had dementia and try to get the whole picture of them, of the person and their history.”</td>
</tr>
</tbody>
</table>
Appendix 7
Phase 3 Additional Information

- Record review template.
# Record Review Template

<table>
<thead>
<tr>
<th>Patient:</th>
<th>Date of Admission:</th>
<th>Legal Status:</th>
<th>Diagnosis:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Current Medication:</td>
<td></td>
<td>Physical health</td>
<td></td>
</tr>
</tbody>
</table>

**Reason for Admission:**

**Risk Assessment:**
(inc risk identified and words used to describe)

**Care plans**
(incl topic, interventions, words used to describe)
<table>
<thead>
<tr>
<th><strong>Nursing assessments:</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>(look at any specific assessments e.g nursing assessment, cc assessment and areas of need /words used to describe presentation)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>MDT/CPA review notes:</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>(presentation and words used to describe)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Medical Review Notes:</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>(Reason for review and words used)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Progress notes:</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>(How is presentation described /words used/ interventions)</td>
</tr>
</tbody>
</table>

| **Anything Else:** |
Appendix 8
Additional Information Data Analysis

- Phase 1 Data analysis: post-it note organising.
- Phase 1 Data analysis: mind map example.
- Phase 2 Data analysis: familiarisation example.
- Phase 2 Data analysis: creating broad codes.
- Phase 2 Data analysis: thematically related group example.
- Phase 2 Data analysis: mind map development examples.
- Phase 3 Observation reflection.
- Phase 3 Care record review example.
- Examples of reflective journal entries.
Phase 1 Analysis Post-it Note Organising
Phase 1 Mind Map Example

Figure 9.1 Phase 1 Mind Map Example
Then if we put the mental health problem, which is dementia, to one side, okay, we've got a number of patients who are presenting with physical co-morbidities as well, or physical frailty, okay? So straightaway the combination of the physical frailty with the mental disorder, okay, can be defined as complex. So you may have, maybe, that diagnostic category with dementia but it's not out of the ordinary in terms of their presentation but the added frailty to that would make it complex as well, okay?

So in terms of physical frailty what am I actually talking about? I think this is probably better defined. In terms of physical frailty it has to do with people's, being able to live independently. So while that is compromised by virtue of one's problems, with one's physical state of health, then it can be defined as such. People who are no longer upright, are independently mobile need aids, for example, can be defined as physically frail, then in addition the complex physical health problems they present with as well, okay? So if it's just one, or maybe two, then manageable, but sometimes you have three, four physical co-morbidities and the interaction with one another can further compound the frailty the person presents with.

So, for example, you have someone who has problems with their legs, poor venous return, so there's a lot of fluid accumulation in the legs. As a result, the leg is probably swelling, it blisters and then the skin breaks, it gets infected and ends up with cellulitis and the impact of that on their mental state is quite profound. To help with the overall management of that the heart is not very strong, lots of cardiac medications, you try to restore the heart function to help reduce that sort of status. Then you have people who have ischemic heart disease. They're continuing to have chest pain, despite medication, they have that. Then you have people who have been diabetics for a very long time and they've got significant periods of childhood diabetes that's not been well controlled and there's a lot of end organ damage, okay? Then you have people with the motor static autonomic instability as part of their dementia. Therefore, you have fluctuations in their pulse, fluctuations in blood pressure, et cetera, okay? So that will contribute to instability and then to falls, okay?

Having mentioned falls I guess that once a patient has falls, so their risk of falls is significant, it adds another layer to complexity, yes, as well, okay?

So I guess one would have to try to sort of sub-categorise all these into some sort of headings, okay? So on the one hand you've got the mental health diagnosis with dementia, and the other dimension will be the frailty, the other dimension will be the physical health problems, okay? So these will be three main...
categories that will have influence of complexity in one way or the other. So they, in themselves, could help define complexity but I think more importantly the interaction between these will get it for. So if you try to draw a Venn diagram...

I: Do you want to write my PhD?

R: Well draw a Venn diagram and then you might find an intersection of all these key things would help define what complexity is.

I: Do any external factors contribute to that? I know when I’ve spoken to other people they have mentioned things like environment, family dynamics sometimes.

R: Absolutely. So this is what I’ve spoken about is just a patient, absolutely. Then you’ve got the other factors which are equally important, which impacts significantly on the patient’s presentation. So if we take family, for example, yes, the family dynamic is very important. The family’s understanding of the person’s illness, the high expressed emotions interact with what the patient is presenting with and adds another dimension of complexity. That’s also important.

The environment as well is also important. So, for example, if we take the ward, when we’ve got... The ward occupants is about sixteen patients or below, okay? Things are more manageable in terms of the patients’ behaviours. When we’re near maximum occupancy you can tell when you’ve got another complex patient in the environment, okay? It further adds to the complexity, absolutely. Then the physical environment as well, although they may not necessarily cause complexity they compound the problem. So, for example, lack of wandering space. So it’s not the space that is causing a patient to wander; no, it’s wandering behaviour but if the space in the environment is not conducive to manage that behaviour. So if the environment could be modified something that presents initially as complex after a few days or weeks becomes less complex if you can modify the environment.

I: Yeah, I was going to ask that, can the stay of complexity go up or down?

R: Absolutely it can go up or down. Absolutely. So it can go up or down and all these factors can affect that, so even the patients’ factors themselves. So what the patient is presenting with. So, for example, they’ve got cellulitis, once you treat that effectively the level of complexity for there can go down. So complexity is not static at all, it’s sort of fluid.

I: Can people stop being complex?

1st Class Secretarial Services
Phase 2 Data Analysis Creating Broad Codes

Defining/Describing Complexity

It means different things to different people - subjective.

In Nicker - do not your assessment complex for someone who is above average in their perseverance, u diagnose cancer.

This could be cce, making diagnosis, etc.

It could be that looking after poor receive more working support.

One of these terms that most people have idea of what talking about but when come to define it is very difficult.

Vary ofBecause agenda which cannot be measured.

398 dimensions physical health, belief, mobility, condition etc. + the intersection of all these or do you need an intersection of all these?

461 lack of external resource, support can cause complex situation but not the pieces.

This is complex situation not complex.

EspeciallY if piece not complex to begin with.
Changing Faces Complexity

90 talks about layers of complexity

231 Sometimes if you really examine or can reduce complexity

237 Complexity can go up + down.
Complexity is not static in fiction.
If you treat one thing or can make complexity go down.

246 People can become less complex.
Sometimes due to finite deterioration.
Because one improves + behaves. Not
caused complexity is no longer an issue.

256 Complexity continues.
Not all jobs will demise as complex.
Not once complex can reduce back.
We really go away.
If they relate to what they want.
Expect with new life or security has

913 Not being able to meet needs = Complexity

PTO
### Complexity

**Describing Complexity/what makes someone complex**

27 It’s a loaded term. Means different things to different people.

28 I guess in a nutshell, it’s probably not your average patient. An above average patient in the sense that you have a diagnostic category and a complex person is someone who is above average in their presentation within that diagnostic category.

33 this could mean things like:
- coming to a diagnosis – the person may be more difficult to diagnose/take longer than you average pt in that diagnostic category
- treating the person is more difficult, more involving than other pts in that diagnostic category
- a particular pt on presentation is much more intense than the average pt in that diagnostic category
- looking after the person has become more challenging and requires more intensive resources and support to deal with that patient compared to the average pt in that diagnostic category

So complexity had different meanings for different people.

49 I guess its one of those terms that when you use it most people around have an idea of what you are talking about, however when it comes to actually defining what it actually means so that everyone knows what it means it’s very difficult.

63 the dementia intp ward can be defined as reserved for pts with dementia who have complex needs. So all the pts qualify but if you look at the profiles of these pts they are all slightly different.

### Complexity as Interactions

191 – complexity sub categorised into headings – mental health diagnosis dementia, other dimension frailty, other dimension physical health problems. These would be the three main categories that will influence complexity. These themselves could define complexity – but more importantly the interaction between these These are factors which just relate to the patient but other factors can also significantly impact e.g family, environment

403 – frailty, physical mobility, physical comorbidities and then maybe the intersection of these – you can argue do you need an intersection of all three or just one or two

### Factors of Complexity Person

**Fluctuation/unpredictability**

- Unpredictability of aggression
- Unpredictability of sleep wake patterns
- Unpredictability of what form aggression will take e.g. biting, punching , scratching

**Dementia**

- Rapid progression of dementia
- Intensity of symptoms
Phase 2 Data Analysis: Mind Map Development Examples
Physical Health
- dementia
- acute - UTI
- constipation
- chronic - arthritis
- AIF
- COPD
- heart failure
- hypokinesia
- renal problems

Mental Health
- depression
- anxiety
- schizophrenia

Behaviour
- social dysfunction
- lack of tolerance
- aggression

Life History
- PMP
- trauma
- coping skills
- cause
- social status

Complexity Factors
- The person, factors, change, lifestyle

Dementia
- type LBD
- FTD
- presence of psychosis
- social status
- more rapid deterioration
- memory impairment

Sensory
- hearing/deafness
- inaptitudes
- BSL
- communicative difficulties
- English not first language
- visual/spatial impairment
- periphal difficulties

Medications
- S1E
- communications
cognitive
- non-compliance

Functional
- mobility
- falls - speech
- social memory
- incontinence
- self neglect
- medication
13/10/16  RETROS OBSERVATION NOV/REFLECT

Phase 3 Observation Reflection

This was first homeopathic observation for pt 1

Although I had spoken with all the staff it was a hard job and they all said me I think usually my presence sat observing caused some apprehension!

I can understand this though considering all the investigations and tests they had been through.

1 over 2 x persons of observation at a time
11:40 - 12:40
14:00 - 15:00

I found it hard strange & interesting, had strange from clinical view not to be involved, take over, jump up & grasp.

Interesting to actually take that outside view of teaching u & see what life was like in this scenario.

For most part Pt spent time walking around getting connected with staff, majority of the contact of his contact he was ab解散 he wore could he go home & he did not let it on the ward. On occasion his focus expressed looked sad, curious + disabled.

Most occasions staff engaged directly, asking him to sit down, would he like a chair.
Mr. T. would move on.
On whole they seemed obvious that he remained nervous, anxious, sad.
He would often follow them or see guest to cuddle staff member.
Other times, he would look out the window at the garden or read a place at the table.

It really shocked me how lonely I saw pt. Most have felt it has he to respond from staff and not seem to address his feelings or direct him.

On the second obs. pt 4 had a night fit.
An old cook mate.
In the care area, he seemed to describe an event when he had been hit.
I am not sure if his night before no.
But he stilt had hold me come no.

This had occurred. He had been hit by another pt.
No clear pt. 4 could remember how of this - had this can take to his feelings of away / isolates.

On one occasion pt. 4 when eating a biscuit made a joke with staff about it being had.

It was really nice to see him laugh.
Another thing that struck me was conversational sometimes:
eg. long conversational / sentences / with saying do you not remember / events.

Staff - starting conversational / nice leaving it & re-commencing minutes late.

Other Thoughts:

On my part I was wandering / moving / in peoples space / staff seemed to be oblivious.
This at times.
Is it that they have just got used to it ???
Had I got used to it ??

Staff:
On one occasion there was a person
in lounge - young
She looked quiet not confident
& ill at ease.
For a moment it made me not feel
secure in the day care.

Para to consider:

Recollected stuff on
If anyone a l i.
# Phase 3 Care Record Review Example

<table>
<thead>
<tr>
<th>Patient: 3</th>
<th>Date of Admission: XX/7/15</th>
<th>Legal Status: Section 3 (admitted in section 2 )</th>
<th>Diagnosis: AD with early onset Diagnosed 2008</th>
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</thead>
<tbody>
<tr>
<td>Current Medication:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cinacalcet 30mg OD</td>
<td></td>
<td></td>
<td>Physical health</td>
</tr>
<tr>
<td>Trazodone 100mg OD</td>
<td></td>
<td></td>
<td>Recent UTI</td>
</tr>
<tr>
<td>Rivastigmine patch 9.5mg /24hrs</td>
<td></td>
<td></td>
<td>Stopped smoking in 2013</td>
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<tr>
<td>Clonazepam 250mcg 12.00</td>
<td></td>
<td></td>
<td>Raised calcium not treated</td>
</tr>
<tr>
<td>Fortisip compact BD</td>
<td></td>
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<tr>
<td>Zopicolone 7.5mg Nocte PRN</td>
<td></td>
<td></td>
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<tr>
<td>Lorazepam 500mcg PRN oral</td>
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**Reason for Admission:**
Transferred from general hospital where had been admitted following a fall – also had had haloperidol at home and could not move the day after
Last 12 months was becoming increasingly agitated, disorientated, mood swings, doubly incontinent

Behaviour difficult to manage on general ward and admission on Sec 2 arranged for assessment.
On general ward displaying challenging behaviour – non-compliance with medication and diets

Arrived on ward with 2 ambulance men, husband and member of staff from general ward
On arrival resenting as very agitated, shouting and swearing

**Risk Assessment:**
(inc risk identified and words used to describe)

**Risk to self** – doing impulsive behaviour and noncompliance with treatment

**Risk to others** – impulsive risky behaviour, threats of harm to others, concerns from others about risk

**Risk self-neglect** – disabling health problems that increase risk falls/injury and serous difficulties with personal hygiene, history of falls, difficulty communicating needs, failing to eat and drink adequately, refuses to accept dies and fluids from staff but will eat from family when they visit, difficulty communicating needs

**Risk of exploitation and vulnerability** – non-compliance with care and treatment, disinhibited behaviour, impulsive behaviour, wandering

**Formulation of Risk**
- Has Alzheimer’s disease
- Has become increasingly perplexed, confused and distracted
- Recently increasingly aggressive and has become violent

**Nature of Current Risks**
- Currently an incident everyday
- Abusive to other patient
- Violent to staff
- Does not accept treatments of nursing interventions
- Very poor diet and fluid intake will only accept form family
- Very sensitive to medication
- Poor posture – leans when walks
- Increased risk of falls
**Protective Factors**
Good support from her husband son and brother

**Warning signs**
Pacing/ restlessness
Facially tense

**Risk management Plan**
- Increased risk of falls
- Monitor dies and fluids to ensure adequate hydration and nutrition
- Skilled approach during personal care to ensure patient and staff safety and to reduce any distress
- Observe for poor posture/ leaning – would be at increased risk of falls during this time. Consider constipation and tiredness
- Use compliance aid so husband can assist in giving medication safely. Observe for side effects of medication

**Care plans**
(incl topic, interventions, words used to describe)

**Needs with managing mental health**
You have been spontaneously aggressive towards family and staff
You shout out verbal abuse making you vulnerable form others to response/ attack
You will not take your medication consistently from staff
You are on a section three

**Interventions include**
We will observe your behaviour with others and if we feel you or others are at risk we may move you to a quieter area of the ward with staff support
We will observe your relationship with staff members to see if you respond differently towards different members of staff. This may allow us to see to your needs more appropriately
Distract and engage in meaningful activity. We know you like music particularly Elvis Presley
We may need to give you PRN medication and monitor its effects
Your husband and son will offer medication using a compliance aid
We will ensure that we read you your rights 4 times and then months
Waiting for a SOAD to look at your medication

**Needs with Physical Health**
You will not accept adequate diet and fluids from staff members
You are at high risk of falls and appear unsteady at times
You have poor spatial awareness and can miss the chair when you attempt to sit down

**Interventions Include**
We will offer diets and fluids throughout the day
We will find out your likes and dislikes
We will encourage you family to offer you diet and a daily basis and we will record what to accept
Weigh you weekly
Involve the dietician to offer support and advice
Observe mobility
Try and encourage you to engage in general strengthening / mobility exercises
Offer home assessment if the decision is for you to return home
Practice the stairs with your husband
If you fall we will ensure you are checked
Try to ensure you are nursed in the day area where there are staff who can observe and assist you to sit down as you have poor spatial awareness
We are area that a loud environment increase you agitation and this is when a quieter environment is better for you

**Living Skills**
You need assistance with attending to personal care needs and are often resistive to this
You can be doubly incontinent and wear incontinence pads both day and night

**Interventions**
We will support you with your personal care needs
We may need to use restraint holds to ensure your safety and safety of others
We will change you regularly to ensure you are clean and comfortable

**Social Networks**
You usually respond well to your husband son and brother

**Interventions**
Regular contact with family

**Nursing assessments:**
(look at any specific assessments e.g nursing assessment, cc assessment and areas of need /words used to describe presentation)
Falls assessments complete
Nutrition assessment completed
Depression assessment completed

**Continuing Health Care Screen**
A – Behaviour, cognition, mobility, nutrition, drug therapies
B- Psychological/ emotional, continence
C- skin integrity, breathing, consciousness
Rationale for decision – multiple complex problems

**Specialist Health Needs Assessment**
**Personal Hygiene**
Full assistance with personal care
Unable to make informed choices
Resistive during personal care – spit and scratch, scream and shout

**Moving and Handling**
Poor spatial awareness
Misinterprets chairs
Nurse in a high visible area

**Eating and Drinking**
Refuses diet and fluids from staff
Family support her to eat

**Safe environment**
Assessed for hip protectors but is none compliant
Poor spatial awareness

**Elimination**
Doubly incontinent

**Communication**
Unable to communicate with staff
Shouts and swears at other patients on the ward
Can be intrusive to others especially if the ward is loud and unsettled. Will shout at other patients – putting her at risk of injury from others

**Sleep**
Sleeps well from 11pm

**Social and cultural needs**
Becomes increasingly agitated if ward busy and unsettled
Shouts and swears, benefits from less stimulating area

**Relationships**
Visited regularly by family who ensures she eats
When staff offer food she normally shouts and swears

**DATIX (incident reporting)**
2-4 incidents reported each month – falls, violence and aggression to staff on interventions, violence and aggression to other patients

**MDT/CPA review notes:**
*(presentation and words used to describe)*

**Regular MDT reviews with consultant**
Example of entries:
- Lacks capacity to consent to treatment and admission and medication
- Needs assistance of 2 going up and downstairs
- Nurse in eyesight
- Shouts on interventions
- Requires 3 for care interventions- shouts, spits, lashes out
- Times when warm and settled and responds in a warm way. Then will start to swear for no clear reason which can be prolonged
- Diet and fluid provided by family

**Medical Review Notes:**
*(Reason for review and words used)*
Refused physical obs
Appears to be in pain – wincing

**Progress notes:**
*(How is presentation described /words used/ interventions)*

Supported to wash and dress with 3 staff
Showed imitatibility and was verbally aggressive
Assisted with personal care, she was spitting, verbally abusive and aggressive towards staff
Refused diets until husband visited
Unsettled for periods – pacing up and down the ward in an agitated manner shouting at staff and fellow patients in an intrusive manner
Incontinent of faeces this morning, assisted with personal care by 3 staff shouting at the time
Refused supper
Refused diet and fluids
Assisted to wash and dress on rising, was resistive throughout, attempting to spit at staff and was verbally abusive throughout
Refused all offers of diet and fluids despite prompts from staff
PRN lorazepam offered when became very aggressive shouting at other patients but she spat them out
Assisted to shower on rising was verbally abusive and was repeatedly spitting at staff
Offered diet and fluids on rising but has refused all offers from staff
Assisted to be washed and dressed by 3 members of staff – shouting and spitting towards staff during intervention
Refused all diet and fluids this morning and dinner time
At times during the evening was settled however on several occasions displayed verbal outbursts towards fellow peers when she perceived them to be annoying her for e.g in her personal space or on her seat

During afternoon very restless pacing the ward shouting out verbal abuse/ swearing even when sat in the chair, tense, appears to be ‘mocking others’ she is listening to. Refused all diet and fluid. Spent some time in the ladies lounge with staff supervision with no avail. Continues to appear very agitated. PRN lorazepam given
Nursed in the female lounge with member of staff due to being very loud and resistive with aggression if anyone approached her.

Anything Else:
No
Examples of Reflective Journal Entries

The one thing that remains hard is observing - from the inside/outside.

It really gives me insight into my own practice of how it becomes the norm. How does it become the norm? Then as a result do we cease to truly see it?

Do we not see the anxiety, the stress, do we get used to it, does it become the norm, does our tolerance of behavior increase? Or is it a way of coping from staff perspective?

Having a road really made me think about how well sometimes people can really close their eyes, or are we just becoming desensitized? This is often quietly demonized but do we actually?

But that I agree is more true, walking around local, often to see what it is really like to exercise this quality of being silent about our way of going home. Or are we still really see this as we really look at it?
Today made me realize how is... my little relationship with some
how long and lonely time must
so...
Is this a reflection of nos agency
and a dog
Is he emphasis still a day in day
are giving
Certainly he baking group was nice

Also some behaviors just seem to
be nice
Be your pt a cow please

Wendy a curious mumble sound
is go in niche

Would I have been any different?

Does everyone realize just how much
wasting pt 1 does, he really
senses if men the c few onto

May you don't know pt at base
pretexting again?

How do reable feel while they feel
come a he wrong?

Must it feel to be reliant upon
someone else to meet all if you needs?

It's like a dementia case at ICU

without sensing a grade at equipment?
Appendix 9
Discussion Chapter Additional Information

- Practical application of the 3Fs Model of Complexity: Celia.
Practical Application of the 3Fs Model of Complexity: Celia

Celia: An Overview

I will begin by offering a brief overview of Celia; I will then look at each of the domains and components in the domain and describe which ones contributed to complexity. I will also explore and describe the effects of components interacting with each other. An interpretation of the degree of acuity will also be offered.

Celia was 82 years old and had a diagnosis of probable mixed vascular dementia/Alzheimer’s disease with psychosis. She was admitted for a period of assessment as at home her family could no longer safely meet her needs. She was detained on a section of the Mental Health Act (DH, 1983). Celia was married and had three children and her family visited regularly. Celia was described by both her husband and the care team as being ‘complex’ with the Occupational Therapist Lucy, who had been closely involved in her care, describing Celia’s time on the ward as “it’s been an interesting journey for the staff to understand her and who she is and her personality.”

Based on the interviews with Celia’s husband, her Occupational Therapists, the review of her care records and multiple periods of observation I have applied the 3Fs Model in an attempt to test out how the model captured and documented her complexity.

Celia: Application of the 3Fs Model of Complexity

Fundamental Domain: All five components within the Fundamental domain; presence of dementia, life story, impaired communication, impaired insight and capacity and perceived risk, were present and contributing to Celia’s complexity. The five components were all inextricably linked and interacted with each other. I will begin by describing how each Fundamental component presented in Celia and then I will describe and discuss how they interacted with each other.

Presence of Dementia: Celia had a diagnosis of probable mixed vascular dementia/Alzheimer’s disease with psychosis. The diagnosis was probable as she would not comply with any formal cognitive testing, brain scan or even blood tests. Instead, her diagnosis was made after gaining a comprehensive collateral history from her family and reports from the ward staff on how she presented and interacted within the ward.
environment. This led her psychiatrist to believe that the changes that Celia was experiencing were representative of more than one type of dementia. Celia’s dementia diagnosis in itself is outside of the ‘norm’ in that she was believed to have two different types of dementia and a psychosis. Celia’s dementia was thought to have progressed to the moderate stage and it was affecting her comprehension, understanding and memory. Celia did not present as being content in her dementia. Instead she seemed at odds, frustrated and often angry and unhappy.

**Life Story:** In the case of Celia it was her premorbid personality traits which were the focus in this component. Celia was described by her husband as always being a strong-willed, independent and feisty woman. She was a person who was always in control and the one who made all the decisions in the family; a person who liked things to be done her way. Celia was also the person who did the looking after; she had been instrumental in bringing up her siblings and her own children. These personality traits were very clearly evident during my observations of Celia.

**Impaired Communication:** Although Celia could verbally speak her communication skills were impaired. She could initiate ‘social chit chat’ but had lost the skills to verbally engage in any deeper more meaningful conversation. She would quickly become verbally hostile if she was feeling outpaced in a conversation and her body language could become very closed and defensive.

Celia’s communication style to others could also be very short and sharp. She would frequently appear off-hand and hostile to staff and other patients on the ward. Her non-verbal communication would also appear defensive whereby she would stand staring at people and her facial expression would be fixed and stern looking. This would be particularly evident if Celia did not agree with what was being said or she did not like the person she was dealing with.

**Impaired Insight and Capacity:** Celia’s husband informed that Celia had never accepted that there was anything wrong with her even though she had been experiencing changes for a number of years prior to being admitted to hospital and receiving her diagnosis. Celia had been admitted on a section of the Mental Health Act (DH, 1983) and continued to be detained under this Act. This was because Celia was not willing to stay in hospital.
voluntarily and she had no insight into the fact she was unwell. She appeared to live in her own reality where she was very much the strong independent person she has always been. A person who was well, independent and who did not require any help with anything. Celia was not able to enter into anyone’s view of the reality if it differed from her own.

**Perceived Risk:** The presence of the other components of the Fundamental domain resulted in the presence of increased perceived risk in regards to safety (Celia and others), vulnerability and self-neglect. Despite the fact that Celia believed she was fine and capable of looking after herself and her family this was not the case and she now required assistance and help. In addition, Celia also had a number of components from the Flexible domain contributing to her complexity which, in turn, also caused increased perceived risk. These components from the Flexible domain will be discussed shortly.

**The interaction of the five Fundamental components:** Although the five components of the Fundamental domain of complexity have been discussed in the context of how they applied to Celia, it is important to note that none of them are present in isolation. All of the components interacted with each other and it is essential that the effect of these interactions are understood. I will now discuss how this interaction of the Fundamental components presented in Celia.

As a result of the progression of her dementia and its effect on comprehension, understanding and memory this was now interacting with Celia’s insight and capacity. Celia did not believe that she was unwell and that she needed help and support. The progression of her dementia had also affected Celia’s capacity to make some decisions, for example being admitted to hospital and decisions about her care and treatment. Celia was no longer able to retain information for long enough to weigh-up the pros and cons in order to make a decision about being in hospital or the care and treatment that she needed.

Likewise, Celia’s dementia had also interacted with her communication. On observation she was very skilled at social chit chat but moving beyond this to more in-depth conversations was challenging for Celia. This is because her dementia was affecting changes to her memory, recall and processing of information. On initially meeting with Celia, she presented with a good social front in that she could smile and say ‘hello’ and ask how you are and she was able to respond to general chit chat questions about, for example,
the weather and what she was wearing. However, her answers were short and her conversation was not able to progress past this. If you tried to do this, Celia would quickly become angry and defensive and shut the conversation down.

The progression of her dementia had also interacted with Celia’s ability to ‘thought check’. She no longer had the ability to filter her thoughts and make a conscious decision regarding what was socially acceptable to say out loud. This resulted in her frequently saying exactly what she was thinking and the result would be her spoken word appearing sharp, harsh and, at times personal.

Celia’s pre morbid personality traits of being a strong, feisty, independent woman continued to show themselves. This sense of being independent and in control was very important to Celia. However, as a result of changes in the other Fundamental domains and their interaction with the other components, this was challenged. The progression of Celia’s dementia, impaired communication and impaired insight and capacity all interacted with Celia’s dominant personality traits. During my periods of observing Celia, she never seemed at peace with her dementia; she constantly seemed to be fighting against it and trying to carry on as she always had. However this was not possible and Celia was often left appearing frustrated and angry.

It was not only the components and interactions of the Fundamental domain that contributed to Celia’s complexity. Celia also had a number of components from the Flexible domain which were also susceptible to interactions from other components. This will now be explored below.

**Flexible Domain:** There were eight out of the 15 components of the Flexible domain that I was able to identify as contributing to Celia’s complexity. These were: physical health conditions, pain, mental health problems, behaviour that challenges, impaired self-care ability, medication, environment and attitude and approach of others. I will now explain each one of these and identify interactions from other components.

**Physical Health Conditions:** Celia had a history of hypertension, high cholesterol and angina. These are all conditions which require monitoring and if they deteriorate can have serious consequences on physical health. However; Celia would not allow any of the
medical team to examine her. Thereby she was at risk of these conditions deteriorating as a result of her not receiving the right treatments or interventions. There was also a possibility that Celia had arthritis, but again she would not allow an examination.

The Fundamental component of life story interacted with this physical health component. Celia had never liked being ill and always strove to be strong and independent. These were traits that very much continued in her presentation. Therefore, she was unlikely to ask for help or report symptoms. In addition, her dementia had affected her comprehension and understanding; if she experienced any physical health changes she may not of been able to recognise these. Furthermore, changes to her verbal communication ability meant she may not have been able to translate what she was feeling into words or identify it as a physical health concern. Celia was also prescribed medication for a number of her physical health conditions, but would not overtly accept them as she did not believe that she needed it.

This all increased the risk of Celia’s physical health deteriorating. Even though at the time there was no evidence that Celia was acutely physically unwell she did have a number of chronic conditions which had the potential to deteriorate and it was important that these were monitored. As a result of the effect of the interactions from the presence of dementia, life story, impaired communication, impaired insight and capacity and medication issues there was a significant increased risk that at some point Celia’s physical health would significantly deteriorate. However the monitoring of her physical health was very difficult as a result of the interaction of these components.

Celia’s physical health conditions also interacted with the components of pain and medication issues. This was because Celia had a number of conditions which had the potential to cause pain and physical health conditions for which she required the prescription of medication.

**Pain:** There was a view from the care team that Celia may have been in pain as a result of possible arthritis in her knee as she would on occasion limp when mobilising. However, Celia never complained of pain and even when asked directly she would not acknowledge to being in any pain. Celia also had a history of angina which meant she was at risk of sudden onset acute chest pain for which she was prescribed a GTN spray. If she did not get the prescribed medication when needed this would have serious adverse effects on her
health. On the other hand, as Celia was in a hospital ward she did not have direct access to a GTN spray and she would have to tell or indicate to the nursing team that she was experiencing angina pain for them to be able to give her the GTN spray.

It is possible that this non-verbalisation of pain may have been as a result of the interaction of a number of other components. These being presence of dementia, impact of her life story and premorbid personality traits and impaired communication. The progression of Celia’s dementia may have resulted in Celia not being able to recognise or comprehend the feelings she is experiencing as pain. So, in this case, Celia would still experience pain but due to deterioration in her comprehension and understanding she may not associate the sensation as pain. Additionally, the impact of Celia’s dementia on her communication ability may mean that she is not able to find the words to describe and articulate that she is in pain.

Celia was from a large family and as the eldest she looked after her siblings, within her own family she was very much seen by her husband and children as the head of the family and the one who looked after everyone. Celia had a strong personality and was the person who did the looking after not the person who was looked after. These experiences and personality traits will in turn affect how Celia responds to pain and increase the likelihood that she would not report pain or accept treatment for it as she would view this as a weakness.

In addition, if Celia was in pain, it also has the potential to interact with other components. It could interact with her dementia and have a negative impact on her cognitive functioning, her ability to perform self-care tasks could be further impaired as it is difficult to undertake such things when you are in pain, and if Celia cannot verbalise that she is in pain it can be a reason for the presentation of behaviour that challenges as instead of verbalising pain it can be demonstrated through behaviour.

**Mental Health Problems:** Celia had a diagnosis of probable mixed vascular dementia/Alzheimer’s disease with psychosis; for Celia, the psychoses presented in the form of misidentification. Both her care records, and interview with the Occupational Therapist, indicated that Celia would misidentify and believe that other patients on the ward were her husband or members of her family. Prior to her admission, her husband also
informed that she would regularly believe him to be an ‘imposter’ and ‘not her husband’ and that frequently resulted in her becoming violent and aggressive towards him.

During my observations of Celia, I witnessed numerous times her believing that another patient was her daughter. Throughout the duration of observations I saw this belief to grow in intensity with Celia becoming more transfixed and focused on this individual, to the point where it had become a delusional belief. Celia wanted to look after her and protect her. When staff tried to explain that this person was not her daughter or tried to separate them Celia would become angry. She would be verbally abusive to staff and could also become physically aggressive. This demonstrates how components of the Fundamental and Flexible domains can interact. On this occasion it is the components of mental health, with life story, dementia, impaired insight and capacity, perceived risk, behaviour that challenges and attitude and approach of others.

Celia in her way was very much trying to look after this patient demonstrating the interaction of life story component. It was important for Celia to be the head of the family and look after them. It also displays her pre morbid personality traits of being strong, independent and in control. When prevented from ‘caring’ for the patient Celia thinks is her daughter she becomes very angry. As a result of her dementia she is not able to process or comprehend why she cannot care for this individual and she also does not have any insight into her actions. To Celia her thoughts and behaviour were perfectly normal and, when challenged, this triggered aggression which demonstrates the interaction with behaviour that challenges.

The attitude and approach of others can also interact with this component. This can range from the response of other patients to Celia when she believes them to be, for example her husband or child and the attitude and approach of staff when they are engaging with Celia about her beliefs. On one occasion during my observations I witnessed Celia becoming physically aggressive towards staff when she was challenged about the patient she believed to be her daughter and staff removed this individual from Celia’s vicinity. From Celia’s perspective a stranger had just told her that the person she believed to be her daughter was in fact not her daughter and that she was taking her away from her. At that moment in time Celia must have been completely enraged yet also feeling scared and helpless as she watched a complete stranger take her daughter; and she is powerless to do anything. In this
context it becomes understandable that Celia responded with physical aggression. It is the presence of this component and the effect of the interaction of the other components which can cause increased risk to Celia and others.

**Behaviour that Challenges:** Celia presented with a number of behaviours which were challenging. These included resisting care intervention and verbal and physical aggression. However after observing Celia, reviewing her care records and talking to the Occupational Therapist and her husband it is apparent that this component is not present is isolation; it is in fact a result of the interaction of a number of other factors.

The Fundamental components involved are the presence of dementia, impaired communication, impaired insight and capacity and life story. Due to the progression of Celia’s dementia her comprehension, understanding and memory was affected. In addition this had also affected Celia’s insight. This resulted in Celia requiring help with a number of areas of daily living as she no longer realised that something needed doing or believed she had already done it when she had not. Unfortunately as Celia’s insight into her presentation and needs was impaired she did not understand why help and assistance was required. The effect of Celia’s impaired communication meant that it was not possible to have an in depth two way conversation with her about this as she did not have the required communication and thought processing skills. Add into this Celia’s life story and strong personality traits of a lady who likes to be in control, who is strong willed, and a lady who was described by her husband as very private with regards to hygiene and bathing.

These Fundamental components have also interacted with a number of Flexible components to result in behaviours that challenge. The Flexible components are identified as mental health problems, impaired self-care ability, environment, and attitude and approach of others. It is the interaction of these Fundamental and Flexible components that result in the presentation of behaviour that challenges.

An example of this is self-care. Due to the effect of the progression of her dementia and lack of insight Celia’s self-care ability is impaired and she requires assistance from staff. However, Celia does not understand this and her personality traits of control, strength and privacy come into play. This results in Celia actively physically refusing all aspects of assistance with personal care needs and she will become physically violent and aggressive.
to prevent staff from intervening and delivering the intervention. She does not believe that she requires assistance or help and thinks that she is capable of meeting all her needs.

Another example is the impact of the environment. Although Celia is not able to demonstrate that she is aware she is in hospital, she knows she is not in her own home and will ask to be let out of the door to go home. Again as a result of impaired insight, comprehension and understanding when she is informed that this is not possible she will become angry and aggressive in manner as she is not able to comprehend or understand the reason for this.

In Celia’s case the presentation of behaviour that challenges has occurred as a result of the interaction of a number of other components from both the Fundamental and Flexible domains. It is a response to a need or needs not been met and in Celia’s case it is frequently related to the need to feel independent and in control and for her sense of privacy not to be compromised. However, when these needs are threatened Celia responds by becoming hostile, resistive and verbally and physically aggressive otherwise known as presenting with behaviour that challenges. This in turn causes an increased risk of harm to Celia and others.

**Impaired Self Care Ability:** Celia’s ability to self-care was impaired and she needed assistance. Without this assistance she would not wash, bathe or change her clothes; she would wear soiled items of clothing and would wear her clothes in the wrong order or would wear multiple layers of clothing for example three jumpers and two skirts. However Celia did not willingly accept assistance. The impaired self-care ability and resistance to accepting assistance with self-care needs was compounded by the interaction of a number of other components of complexity. These were presence of dementia, life story, communication, insight and capacity, perceived risk, behaviour that challenges and attitude and approach of others.

Due to the affect Celia’s dementia has had on her comprehension and understanding Celia awareness of the need to wash and change her clothes has become impaired and she does not recognise any more when she needs to do this. In addition due to changes in her memory she is no longer able to realise when she last had for example a wash or changed her clothes but when asked she will quickly become defensive and say that she had just had
a wash or changed her clothes. Interwoven into this is the interaction of impaired insight and perceived risk. In this context Celia will not realise the impact of not washing upon for her example her tissue viability and the increased risk of infection, skin break down and body odour. Indeed when Celia was first admitted to hospital she refused all help from staff saying she did not need it however, the result of this was Celia wearing multiple layers of soiled clothes, body odour and a fungal skin infection which required treatment. It is also very difficult to try and communicate with Celia about this as she is no longer able to follow or comprehend any degree of conversation which progress beyond initial chit chat.

Also interacting with this component is the effect of Celia’s life story and personality traits. Celia’s husband informs that she has always been a very private person and never undressed or bathed in front of him or her children. She never allowed anyone in the bathroom with her. In this respect it becomes easy to see how Celia will react when people offer her assistance or try to tell her that she requires help. Celia refuses all offers of help and quickly becomes angry and defensive. In this situation the attitude and approach of others also interacts in the situation. If staffs approach does not allow Celia to feel that she is in control of the situation she quickly becomes angry and will try to disengage. This then results in the presentation of behaviour that challenges as there are occasions when staff have to see to Celia self-care needs against her will. This results in Celia becoming verbally and physically aggressive to the point where staff have to use restraint to be able to safely provide personal care interventions.

**Medication issues:** Celia was prescribed a number of medications. However as a result of the interaction of a number of other components namely presence of dementia, life story, impaired insight and capacity, physical health conditions and mental health problems Celia was not willing to accept medication. This resulted in medication being administered covertly in line with the mental health NHS trust covert medication policy.

The progression of dementia meant that Celia was unable to retain the fact that she needed to take medication for a number of conditions. This was also closely linked with the effect of impaired insight and capacity. Celia has no insight into the fact that she is unwell (physically and mentally) and needs to take medication, but she does not have the capacity to make the decision to refuse mediation. When offered medication Celia refuses saying
she does not need it, additionally she is not able to understand the risk to her health of her not taking her prescribed medication.

Celia's life story also interacts with this component as Celia has always been independent, strong-willed and in control. Being told she requires medication for illnesses she has no insight into challenges all of these personality traits, which results in Celia becoming defensive and refusing to engage.

Therefore a decision has been made to give the medication covertly in her best interests. If Celia did not receive her medication covertly she would be at a significantly increased risk of deterioration in her physical and mental health.

**Environmental Effects:** The effect of the environment also contributed to Celia’s presentation and this was further complicated by the interaction of other components. At the time Celia was in hospital the ward was mixed sex; it was always full and as a consequence it was a busy noisy environment. Although Celia had her own room this was not easy to access and the door was often locked in the day to prevent other patients from entering. In addition Celia’s name was not always on her door as other patients used to take down the name plaques. Other than her clothes and her handbag there was nothing in this environment which would familiarise it for Celia or give her a sense of belonging.

Within the ward environment it was difficult to find a quiet space or a sense of privacy as there were usually always other patients or staff members around. Even when in bed at night privacy was compromised as night staff would enter bedrooms hourly to check patients as per mental health NHS trust policy and on occasion’s patients who could not sleep would inadvertently enter other people’s bedrooms. On top of this there was always a phone ringing loudly or a door bell ringing or a nurse alarm going off. This was not a homely environment. Within this environment it was not possible to freely come and go, even access to the garden was restricted. There were always other patients milling around. There was nowhere where it was possible to listen to music or watch the television alone. Living was communal and focused on the large day area.

Celia was aware that she was not in her home environment although as a result of her dementia she did not seem to demonstrate any awareness that she was in hospital. Due to
the changes to her memory and impaired insight and capacity she could not retain or understand why she needed to stay in the environment and would ask to be let out so she could go home. Celia was not able to understand why she was being kept in a locked environment against her will.

The environment also impacted upon Celia’s privacy and dignity as there was always people around her and in her space. She could not even bathe alone as staff had to be present. This interacted with Celia’s life story as she has always been in control of her environment and her privacy was something which was really important to her. Celia often became frustrated by the restraints of the environment and the close proximity in which she was living with others; who to Celia as a result of her dementia were strangers.

**Attitude and Approach of Others:** In the case of Celia the attitude and approach of other was really important. Due to staff shortages and high levels of patient needs there were often bank or agency staff on duty as well as regular ward staff, resulting in staff inconsistency. This meant that all too frequently a number of the staff on duty at any one time were unfamiliar with the ward and patients and who may not have had any previous experience in working with people with dementia. During the time I spent undertaking observations on the ward it was not uncommon for the qualified nurse to spend long periods of time in the office away from direct patient contact. In these circumstances it becomes difficult to ensure that patients receive the individualised approaches to engagement, communication and care giving that they need. If Celia did not immediately connect with staff she would quickly disengage and become dismissive, sarcastic or even verbally aggressive to them. If the staff were not aware of the communication approaches to use with Celia then the likelihood was that they would never be able to engage with her to undertake any interventions.

This component was also affected by the interaction of a number of other components from both the Fundamental and Flexible domains. Components from the Fundamental domain are identified as presence of dementia, impaired communication and impaired capacity and insight. As Celia was good at social chit chat it was easy for others to assume that her dementia was not as advanced and this would lead people into thinking that she could process and understand more information than she could. This cumulated in Celia becoming outpaced in a conversation and quickly overloaded with information that
cognitively she was no longer able to process. This in turn would result in her not feeling in control of a situation and she would respond by becoming verbally irritable and she would end the dialogue. It was essential when people approached and engaged with Celia that there attitude and approach did not make her feel under pressure and that she continued to feel in control of the situation.

In addition the attitude and approach of others also interacted with all the other components of the Flexible domain that have previously described. These are physical health conditions, pain, mental health problems, behaviour that challenges, impaired self-care ability, medication issues and environmental effects. These are areas where Celia had needs and required assistance of others to meet those needs. In undertaking this it was essential that the attitude and approach of others attempted to make Celia feel like she was in control of the situation. However, it is acknowledged that as a result of the effect of Celia’s dementia and her impaired insight and capacity it could be challenging to think of ways that this could be facilitated.

There were occasions where the staff had to undertake an intervention in Celia’s best interests and on these occasions their attitude and approach was crucial to try and give Celia a sense of control of the situation. If this did not happen Celia would become resistive, and verbally and physical aggressive. An example of this was demonstrated on one occasion when I was observing Celia. It was meal time and Celia was with the patient who she believed to be her daughter. For a few hours before the meal the nursing assistants on the ward had been very busy and short staffed. By tea time a number of them were looking tired and stressed. The staff wanted to separate Celia and the patient she believed to be her daughter for the meal as they believed that Celia was distracting the other patient from eating her meals. Rather than acknowledging the significance of Celia’s beliefs about this other patient and the importance of Celia feeling in control of a situation, a member of staff instead physically stood between Celia and the other patient whilst another member of staff moved her away from Celia to a dining table. There was no attempt to make Celia feel in control of this situation and no attempt at trying to understand the significance of this individual from Celia’s perspective.

On observation the staff involved appeared tense, rushed and brusque in their manner. Communication to Celia was from the stance of talking at her and telling her that they were
moving the individual as Celia was stopping her from eating her meal and interfering with her care. The response from Celia to the attitude and approach of staff was that she immediately felt out of control and threatened and she responded by becoming verbally and then physically aggressive towards the staff concerned. This demonstrates the interaction of attitude and approach with mental health and behaviour that challenges.

The end result of the interactions of the these components with the attitude and approach component means that that there is an increased risk that Celia will disengage with people if their attitude and approach is not right which will result in either an intervention that she requires not being undertaken or the situation escalating to the point where Celia is distressed and verbally hostile and aggressive and an intervention being delivered against her will.

**Fluctuation**

During my observations of Celia the highlighted components and their interactions remained consistent. However what did fluctuate was the severity or acuity of some of these components. There were components which remained acute throughout the duration of my observations, others that were not as acute but none the less contributed to Celia’s complexity and a number of components which fluctuated in acuity or severity.

The components which remained consistently acute from the Fundamental domain were presence of dementia, impaired insight and capacity, life story, perceived risk and from the Flexible domain it was behaviour that challenges, impaired self-care ability and attitude and approach of others. Components which fluctuated and increased in acuity were mental health conditions and environment effects and those which remained present but stable were impaired communication, physical health conditions, pain and medication issues. All of these components resulted in increased levels of perceived risk. Without interventions Celia’s health would significantly deteriorate and her safety and those of others would be jeopardised.

This highlights the fluctuation which can occur demonstrating that complexity is a forever evolving dynamic state consisting of the presence of a number of Fundamental and Flexible components and their interaction with each other.
Mapping the Complexity to the Model

In order to visually demonstrate the number of components that contributed to Celia’s complexity and their interrelationship with each other this was directly mapped to the 3Fs Model of Complexity. Lines and arrows have been used to demonstrate the interaction of components. As can be seen in the diagram (refer to Figure 10.1, page 458) it looks busy and messy with numerous arrows connecting components. The mapping of complexity in this way highlights how multifaceted it is and demonstrated that none of the components identified as contributing to Celia’s complexity have occurred in isolation. They all have some form of interaction with other components within domains and across domains. Demonstrating the components cannot be viewed in isolation and it only in looking at complexity in this manner can the totality of the contributing components be seen. Figure 10.1, page 458, offers a visual representation of Celia’s complexity and how components interacted with each other.

Key to Figure 10.1 (page 465)

Components

The components that I identified as featuring in Celia’s complexity are highlighted in black; for example presence of dementia, life story, pain, environmental effects. To further facilitate the level of acuity of these components different coloured writing has been used. Red represents those components which remained consistently acute throughout, green for components which increased in intensity and acuity and purple for those components which contributed to the complexity but remained stable in their presentation.

Component Interactions

The interaction within domains and between domains is represented by the use of coloured lines with arrows on. Pink is used to show the interaction of components in the same domain and three different shades of blue have been used to show the interaction of components between the Fundamental and Flexible domain. Dark blue is used to identify the components from the Fundamental domain which have interacted with components from the Flexible domain, mid blue is used to identify the components from the Flexible domain which have interacted with components from the Fundamental domain, and the bright blue is used to show a two way interaction between domains.
Figure 10.1 The Applied 3Fs Model of Complexity to Celia