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WHOLETRUTH, UNTRUTHS AND LIES: AN ETHNOGRAPHIC STUDY OF COMMUNICATIVE INTERACTION BETWEEN PROFESSIONAL CAREGIVERS AND PEOPLE WITH DEMENTIA

J E MURRAY

PhD

2021

WHOLETRUTH, UNTRUTHS AND LIES: AN ETHNOGRAPHIC STUDY OF COMMUNICATIVE INTERACTION BETWEEN PROFESSIONAL CAREGIVERS AND PEOPLE WITH DEMENTIA

JANE ELIZABETH MURRAY

A thesis submitted in partial fulfilment of the
requirements of the University of
Northumbria at Newcastle for the degree of
Doctor of Philosophy

Research undertaken in the Faculty of
Health and Life Sciences

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Abstract

The current literature highlights that professional healthcare staff admit to regularly telling lies in practice, to people with dementia. This, despite the Nursing and Midwifery Council and the General Medical Council being explicit in their codes of conduct that nurses and doctors must not tell lies to patients. Both codes also highlight the duty of beneficence and non-maleficence, and it is known, that sometimes, telling the truth to people with dementia can cause great distress.

The purpose of this study was to use ethnography to undertake a critical analysis of the concept of lying in clinical practice in the context of people with dementia. The aims of the study were as follows:

- To develop a taxonomy of lies
- To use the taxonomy to develop a model which could be used in practice, to explore the impact of lie telling

Current literature has used either phenomenology or grounded theory to ask staff their perceptions of what they say when they tell lies. Uniquely, the methodology used for this study was ethnography, with the researcher acting as a complete participant observer, observing lies told in practice to people with dementia by staff (nurses, doctors, allied health professionals and healthcare assistants). By using ethnography, this study has recorded previously unidentified phenomenon and brought new knowledge and insight to the topic area. Data was collected from two wards for people with moderate to severe dementia over a period of 45 shifts, equating to approximately 338 hours. The data was analysed using thematic content analysis.

Six categories of lies emerged from the data which formed the taxonomy: familiarity, banter, props, going along with, avoidance and delaying and blatant. The taxonomy was then used to develop the Lie ARM (Affective Reflection Model) to enable healthcare professionals to reflect on the practice of telling lies and consider the effectiveness of them.

Findings from the study can be used to challenge current policies around lie telling; specifically, that whilst truth should always be the starting point, telling lies to patients with dementia can be a kind and effective intervention to support their personhood and reduce distress.

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This thesis is dedicated to Betty: An amazing woman, forever in my heart.

Author’s Declaration

I declare that the work contained in this thesis has not been submitted for any other award and that it is all my own work. I also confirm that this work fully acknowledges opinions, ideas and contributions from the work of others.

Any ethical clearance for the research presented in this thesis has been approved. Approval has been sought and granted by the Faculty Ethics Committee on and externally by IRAS and the HRA.

I declare that the word count of this thesis is 70,131 words.

Name: Jane Murray

Signature:

Jane Murray

Date: 30th April 2021

Chapter One

1. Introduction and background to thesis

This chapter introduces the reader to the background and context underpinning the research study. The study is influenced by a range of both personal, professional and policy drivers which affect how care is delivered to people with dementia. It will briefly explain how I became interested in communication in relation to patients with dementia and, more specifically, the role of truth and lies within those interactions.

1.1 Introduction

Dementia is an umbrella term for a range of progressive conditions that affect the brain (Dementia UK, 2019). Symptoms include memory loss, confusion and problems with speech and understanding, and it is a terminal condition for which there are currently no treatments which can slow or halt the progression of the disease (Alzheimer's Society 2019a). Alzheimer's disease is the most common type of dementia (62% of cases) followed by vascular dementia (17%) and mixed dementia (10%) (Alzheimer's Society, 2019b). One in 14 people over the age of 65 have dementia, rising to one in six in people over the age of 80 years. This increase in incidence continues as people get older which presents a growing challenge given that the UK has an ageing population. In 2018, there were almost 12 million people aged 65 years and above in the UK (ONS, 2018a) with more than 600,000 people over the age of 90 years in 2019 (ONS, 2020). It should also be acknowledged that currently there are more than 42,000 people under the age of 65 in the UK who have dementia. Again, this figure is increasing in line with the increase in obesity, type 2 diabetes, and high blood pressure, all of which are risk factors for developing dementia (Alzheimer’s Society, 2016). As the incidence of dementia increases, so does the demand for health and social care services, both formal and informal (Kelly and Kenny, 2018). In 2017/2018 there were 405,000 people admitted to hospital with dementia in England (Alzheimer’s Research UK, 2020) whilst 70% of people in care homes have dementia or severe memory problems (Alzheimer’s Society, 2019b). There are approximately 400,000 older people living in care homes (Laing-Busson, 2018).

Many people with dementia will at some point, present challenges in terms of the delivery of high-quality care. Some people may present with aggression or be resistive to care, whilst others may become distressed due to disorientation and having a time shifted reality (James 2015). To be able to meet the needs of people with dementia, it is vital that care staff, both qualified and unqualified, can communicate effectively with the person with dementia (Savundranayagam et al, 2007). This can present some major dilemmas in terms of whether the carer should then tell the truth, with the risk that the person may become more distressed, or tell a lie, which may be more effective in meeting their needs (Williamson & Kirtley, 2016). One of the most cited examples is when a person with dementia is looking for a deceased relative and staff have to decide whether to tell the person the truth and say that their relative is dead, potentially causing massive distress to the person with dementia, each time they are told or telling a lie, such as they (the requested relative) are at the shops, in order to reduce the person with dementia’s anxiety (Richard et al, 2010). For qualified staff who are registered with an official body, this dilemma can become even more complex. Nurses and doctors for example, are both governed by codes of conduct (NMC, 2018, GMC, 2019). Both codes are explicit about members prioritising people, practicing effectively, preserving safety, and promoting professionalism and trust.

This is further complicated because the codes also say that registrants must act with beneficence and avoid maleficence. These two constructs contradict each other since, as already pointed out, on some occasions, to tell the wholetruth to someone with dementia may well cause massive distress or do certain harm (maleficence) (Richard et al, 2010). Sometimes, people may act under the guise of beneficence and tell lies to a person with dementia, but this is in direct opposition to being open, honest, and genuine.

It is well established in the literature that care staff do tell lies to patients for a host of different reasons (Turner et al 2017). However, the limitation of existing studies is that they rely on self-report by the participants; that is, they retrospectively ask participants what they think they said (Cunningham, 2005). After reading much of the available literature, I was curious to see if this was what was reflected in practice. With this in mind, I started to consider the possibility of an ethnographic study to observe what was said in practice.

I was also interested in the range of language that was used in the literature. Blatant lies are rarely discussed but a wide range of alternative words which potentially dilute the emotional element of the word lie are apparent; benevolent deception (Jackson, 1991), white lie (Blum, 1984), fiblet (Cress and Boudinout, 2006), therapeutic lie, (Kartalova-O'Doherty et al, 2014), going along with (Savundranayagam et al, 2007). There was no clear definition of these types of lying and some authors even deny that some things such as going along with, are lying at all (Feil, 2002). An early taxonomy of lies was created by Blum (1994) in relation to family carers looking after people with dementia at home. Again, this was a retrospective study asking people what they perceive they had said. Looking at this taxonomy, I also felt that there were likely to be some interactions which had not been captured by this study in people’s homes; that were likely to happen in twenty-four-hour care environments with formal or paid care staff.

The lack of definitive evidence around the practice of lie telling and the language being used stimulated my interest to start developing a research project that could fill these gaps in knowledge.

1.2 My interest in communication and people with dementia

My personal interest in the care of people with dementia started in the late nineties. I qualified as a mental health nurse in 1993 and worked with working age adults initially. After having a break to have my children, I returned to work in a nursing home which was my first experience of caring for people with dementia. It was very daunting and challenging but I really valued the contribution I was able to make to a person’s care. It was a feeling that I had not experienced before, and I felt very privileged to be able to be involved with the care of people with such a complex and debilitating illness. After a few years in private homes, I returned to the National Health Service, working in a rural inpatient unit for people over the age of 65 years. It was here that I had my first experience of being involved in a clinical research trial, which I found both fascinating and inspiring (McKeith et al, 2000). Following this experience, I decided to embark on my academic development as I was starting to realise that in order to change and develop practice, I needed to influence more people. I completed my BA (Hons) in 2004, along with a Specialist Practitioner Qualification. I took the decision to move into higher education in 2008. By doing this, I hoped to inspire the nurses of the future to work with older people, as well as start to develop my own research career.

How people communicate with people with dementia has always been an interest. How carers communicate with patients can be seen to have such a big impact on the person with dementia. Communication can either resolve or inflame a situation, and a skilled communicator is able to deliver a much higher standard of care by meeting the needs of the person with dementia in a kinder, more holistic way. After many years working on the wards and in the community, I have witnessed the difference a skilled communicator can make in terms of the care received by the person with dementia, and I am keen to look at this in more detail. I find the aspect of lie telling versus truth telling particularly interesting. I have witnessed many lies being told in practice but sometimes find the ethical dilemmas quite difficult to resolve. I know that as a nurse, I should not tell lies but, for me, the act of beneficence and non-maleficence override this. I feel that I need to tailor my communication to meet the patient’s needs. Their truth is just as important as mine, even if it is different. In light of this interest, I chose to focus my study on the wholetruth, untruths and lies told by professionals when caring for people with dementia. In terms of this study, professional care givers are anyone who is paid to deliver care, or an element of it, regardless of whether they are a registrant in a specific discipline or not.

1.3 Background to the study

The issue of lie telling is very complicated in professional practice. As already identified, nurses and doctors, as well as other registered healthcare professionals are bound by their Codes of Conduct (NMC, 2018, GMC, 2019) which are explicit about professionals being honest. However, these codes are also specific about the need to act in terms of beneficence or doing good for a patient and, as a minimum, doing no harm or acting in maleficence. These two principles are incongruent when we apply them to the process of telling lies. Sometimes to tell the wholetruth could be considered not to be beneficial to the patient, and in the worst cases it may cause distress or harm to them. Another difficulty is that we know that lies are told regularly in professional care environments, yet people do not consider this poor practice. The disparity between practice and professional guidelines is stark.

Many people would consider person-centred care to be the gold standard of care for people with dementia (Kitwood, 1997). This has been reinforced by a range of policies and legislation over the years (WHO, 2017, Care Act, 2014, DoH, 2010, DoH, 2009). Kitwood was the pioneer of person-centred care and argued vehemently that telling lies to patients formed part of a malignant social psychology that was very damaging. He advocated that truth must always be told. Other, newer proponents of person-centred care argue that it is important to go along with the patient's reality and validate their feelings but deny this constitutes telling lies (Neal and Wright, 2009, Richards, 1994). More recently, The Truth Inquiry contributed that going along with the person with dementia is the most frequently used and effective form of communication (Williamson and Kirtley, 2016). Therefore, based on these authors, if staff are to deliver person-centred care, they must, on occasion, enter the patient's reality. This means going along with the patients' truth rather than their own, as explored below.

Person-centred care is about putting the patient and their needs at the centre of care. If the person is time shifted (James, 2015) then they may be experiencing a very different reality to their carers. When a person 'time shifts' they are relying on their long-term memory, which to them is their present reality. A person in their eighties may time shift back to their twenties. This means that they may mis-identify people in their present lives and use names that they knew in their younger days. For example, calling a son by the name of their husband or brother.

To constantly try to reorientate the person with dementia to the carer’s reality could cause huge distress (maleficence) and would not be considered in the patient’s best interest (beneficence). Therefore, some authors now argue that in order to be person-centred, it is important to accept the truth of the person with dementia (James, 2008) which in some cases would involve telling lies from the carer’s perspective.

1.3.1 Regional position

The mental health trust where this study was carried out openly discusses lie telling with families, when patients are admitted to the service. The use of lie telling as an intervention is discussed with families and their views sought in relation to this. There are rarely any objections from families who are usually accepting that lie telling can be a useful strategy for lowering distress and is often a strategy that they have been using prior to admission. Lies are regularly discussed at multi-disciplinary meetings and in some cases, are used as part of planned care.

1.3.2 Personal position

As a nurse, I understand the requirements of the NMC (2018) and would always consider truth to be an important starting point. However, in order to be a good and effective nurse, I need to firstly do no harm (non-maleficence) and secondly act in beneficence. Therefore, I am comfortable engaging in telling lies to patients when it is with best intention and to prevent or reduce distress. I do not consider my truth to be more important than the patients’ which means that I am happy to enter their reality.

1.4 Summary and aims

Communicating effectively and kindly with people with dementia is an essential part of the role of healthcare professionals. Currently, whilst there are guidelines available from a range of sources, they are not particularly helpful in terms of delivering care. There is little consensus about the language of truth or lies in Practice, or how lies can be potentially used to benefit people with dementia. These represent gaps in the literature around what is happening in practice, what is beneficial to patients, what is harmful to patients and what practices may form the basis of future recommendations. In an attempt to address this gap, the purpose of the study was to undertake a critical analysis of the concept of lying in clinical practice, in the context of people with dementia. To do this, the aims and objectives of the study, which were developed from the literature review, were:

Aims

- To develop a taxonomy of lies
- To use the taxonomy to develop a model which could be used in practice, to explore the impact of lie telling

Objectives

- Identify what lies are told in practice and by who
- Generate an understanding of when, why and how these lies are told (motivation)
- Observe the outcomes of telling lies to people with dementia

The objectives of the study were then answered using the following research questions:

- What lies are told in Practice?
- Who tells lies in Practice and why?
- What effect does lie telling have on people with dementia?
- Can the effectiveness of telling lies be predicted?

These are presented in more detail in Chapter 3, including an explanation of how the questions were developed.

1.5 Structure of thesis

Chapter 1 An introduction and background to the thesis have already been presented in this chapter and the research aims and questions have been identified.

Chapter 2 is the literature review which identifies the search strategy used and then looks at specific areas of the literature. It then identifies the initial research questions.

Chapter 3 is methodology. It explains why ethnography was chosen and looks at how the study was designed and carried out. It highlights the uniqueness and importance of the study.

Chapter 4 presents the findings of the study and the associated discussion. It identifies the six themes that were extrapolated from the data and shows how they were used to create the taxonomy. A visual representation of the taxonomy is introduced and subsequently discussed.

This chapter also considers how reflection and reflexivity contributed to the findings and enhanced the research. It identifies key themes that occurred outside of the taxonomy but make a significant contribution to the study.

Chapter 5 addresses the final research question of whether the effectiveness of lies can be predicted and proposes the Lie ARM (Affective Reflection Model) based on the findings of the study that can be used in practice to help staff to reflect on the effectiveness of lie telling.

Chapter 6 draws the work together by summarising the study and its impact. It also makes recommendations about how the findings can be used to influence practice, policy, and research with the aim of enhancing care for people with dementia.

Chapter 2

2. Literature Review

2.1 Introduction and Aims of the literature review

The overall aim of the literature review was to locate and assimilate what is already known about lie telling, to people with dementia, in practice (Bloomberg and Volpe, 2016). Several approaches to the literature review were consider such as systematic appraisal and critical review. However, the range of literature available in the area of truth and lies in this context would have made it very difficult to follow strict criteria or guidelines. The literature that informed the review came from a wide range of resources including grey literature, narratives, and sociological and cultural theory. The research studies that were reviewed used a range of methodologies as well as having very different participant groups making it difficult to compare them or create strict inclusion and exclusion criteria. Therefore, a more pragmatic, narrative approach was taken as detailed below, using 'questions asked’ or aims of the literature to structure the review . Each aim was addressed individually, in terms of the literature review. Wolcott (2009) suggested that this is an acceptable approach in ethnography that can often capture a broader range of relevant literature.

Findings from the literature were analysed and synthesised to identify any gaps or omissions that exist in relation to telling lies to people with dementia. The format of the search strategy is explained in this chapter and the key themes that were extrapolated are critically discussed.

The chapter seeks to illustrate the complexities of telling both truths and lies and the range of topics that they involve (Figure 3). Whilst this chapter contains the substantive review of the literature, it does not formally end here but continues through subsequent chapters.

More specifically, the aims of the literature review were to ascertain:

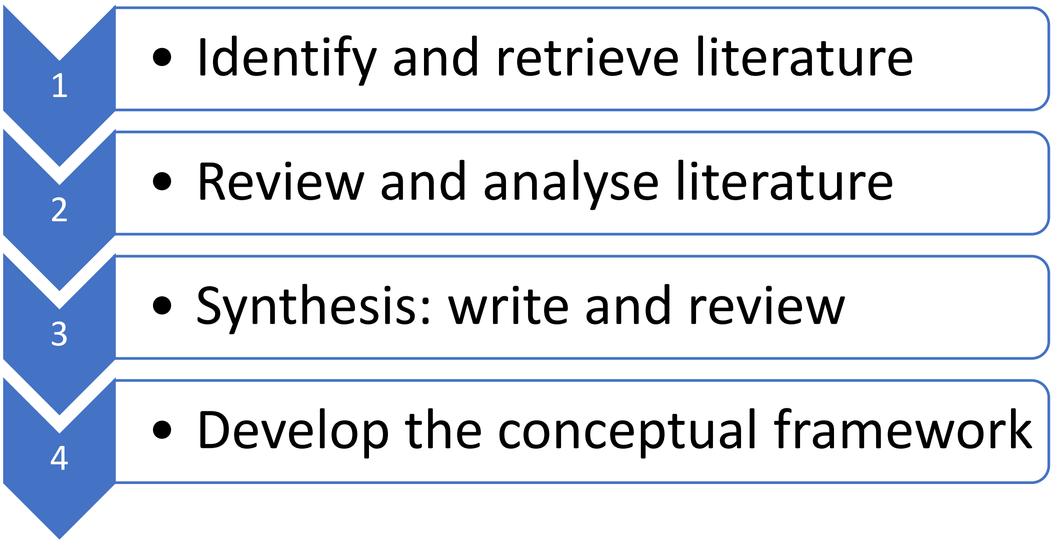
- How are lies defined in the literature?
- What evidence is there to say that lies are being used in practice?
- What methodology have previous studies used?
- Is there any evidence to identify what type of lies are told in practice and by who?
- Is there any evidence to support or refute the benefit of telling lies to people with dementia?

2.2 Search strategy

An initial search of the literature was carried out at the beginning of the study in 2016. This was to help to scope the literature and to consider what information was already available. As Hart (2005) explains, the literature review forms the foundations of the research project. For many ethnographic studies, such as this study, the literature is initially reviewed prior to data collection to serve as a background for the research questions and helping to inform the overall aims of the study, particularly in relation to what will be studied, and how (Bloomberg and Volpe, 2016). The literature search continued throughout the study and concluded on the completion of the thesis. This continuous reviewing of the literature is supported by the work of Silverman who advocates ongoing engagement with the existent literature throughout the study and writing of the thesis and combines argument with critical thought (Silverman, 2014). An essential feature of building a theory is the comparison of emerging concepts, theories or hypotheses using the extant literature from reliable sources (Huberman and Miles 2002).

The review followed the four-stage process developed by Bloomberg and Volpe (2016) below (Figure 1, Literature review strategy):

Figure 1 Literature review strategy



Whilst the model indicates a linear process, this does not illustrate the fluidity of the literature search, with each step being revisited multiple times. It also does not indicate the high levels of reflexivity that were involved when analysing or synthesising the literature to develop the conceptual framework.

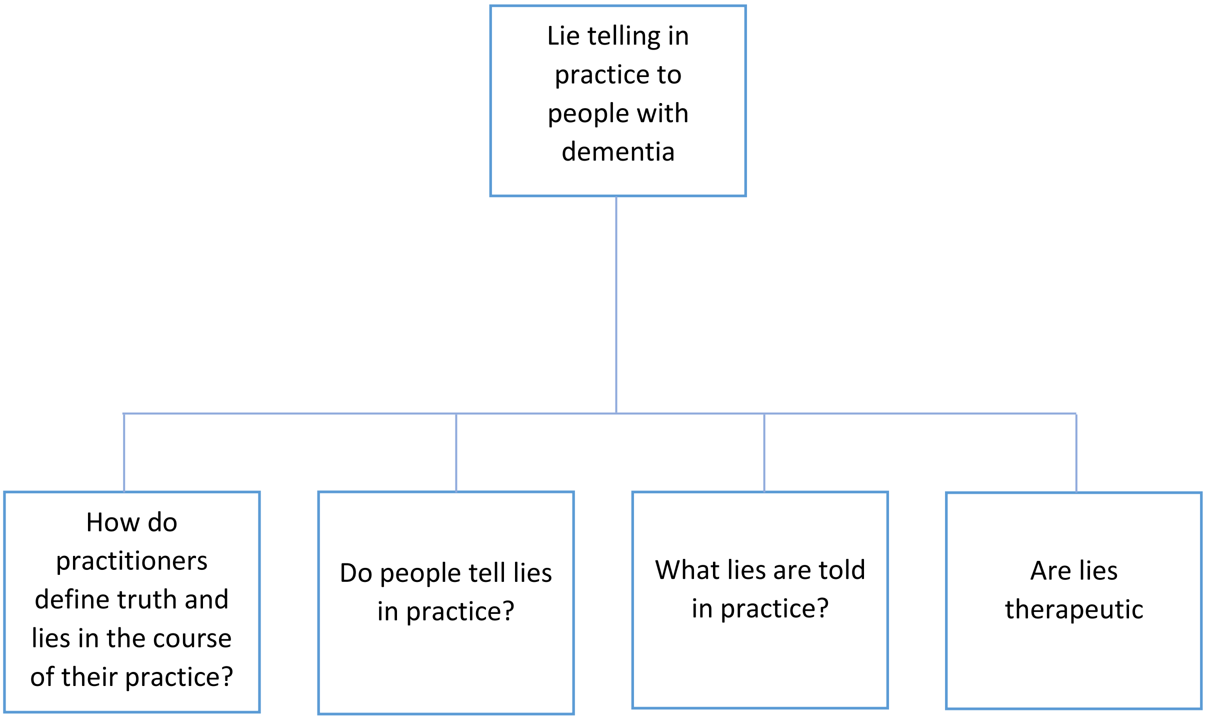
2.2.1 Identify and retrieve literature

Literature was identified and retrieved using a variety of information sources which were accessed via search engines and catalogues. It was important to familiarise myself with data bases relevant to the topic as much of the literature was accessed through (although not exclusively): Web of Science, CINAHL, Medline and Google Scholar. I did not use a specific time frame during which the literature was reviewed as it was an ongoing process throughout the research study (Cresswell, 2003). A range of literature was reviewed, including books, peer reviewed journal article, professional regulatory body publications and published reports.

One of the major challenges of searching the literature was the wide spectrum of language used in relation to telling lies. In terms of British culture, we use a broad range of words such as lie, white lie and fib. The initial searches were guided by the aims of the literature search and illustrated in figure 2. Key words such as truth, lie, deceit, fib, were initially used and the terms nursing and dementia were also added to reduce the number of articles identified and to help to focus the articles that were retrieved. The original scoping of the literature facilitated an initial immersion in the subject (Fanger, 1985).

Figure 2 below illustrates the areas initially covered by the literature search:

Figure 2



When I started searching the international literature, it became clear that there was a range of other words used in relation to the topic which further compounded the issue: fiblet, white lie, and older people (elder in USA). The initial searches using truncation where possible, generated vast amounts of literature, much of which was not relevant to the study. Truncation is a search technique that can be used in databases where the end of the word is replaced with a symbol. For example, dementia could be searched for as dement* and the search results would subsequently include dementia, dements, demented. The difficulty with using this technique is that it can significantly increase the volume of results. Conversely, it can be very useful since it means that results may be captured, particularly from other countries, that may have been missed. For example, in the UK, we would generally talk about people with dementia, whereas literature from the USA often refers to 'the demented'. By using truncation, we would capture both words.

Boolean indicators were also used to try and generate more focused and productive results. Boolean operators are simple words such as AND, OR, NOT or AND NOT which are used to either combine or exclude keywords within the search. It is intended that this will make searching more effective by eliminating inappropriate sources. Some examples of combinations that were used are dementia AND truth, dementia AND lying, lying AND therapeutic, although this is not exhaustive in terms of combinations that were tried.

In the initial scoping of the literature, I considered both primary and secondary sources. Secondary sources can be useful early on in a literature search as they combine knowledge from many primary sources and can provide a quick way of obtaining an overview of the chosen field. However, in the second stage of the literature review, I focused on primary sources since secondary sources are not always considered to be completely reliable and can be open to interpretation (Bloomberg and Volpe, 2016). The initial key words were then broadened as the complexity of the topic became more obvious and further areas were explored (see figure 3 below).

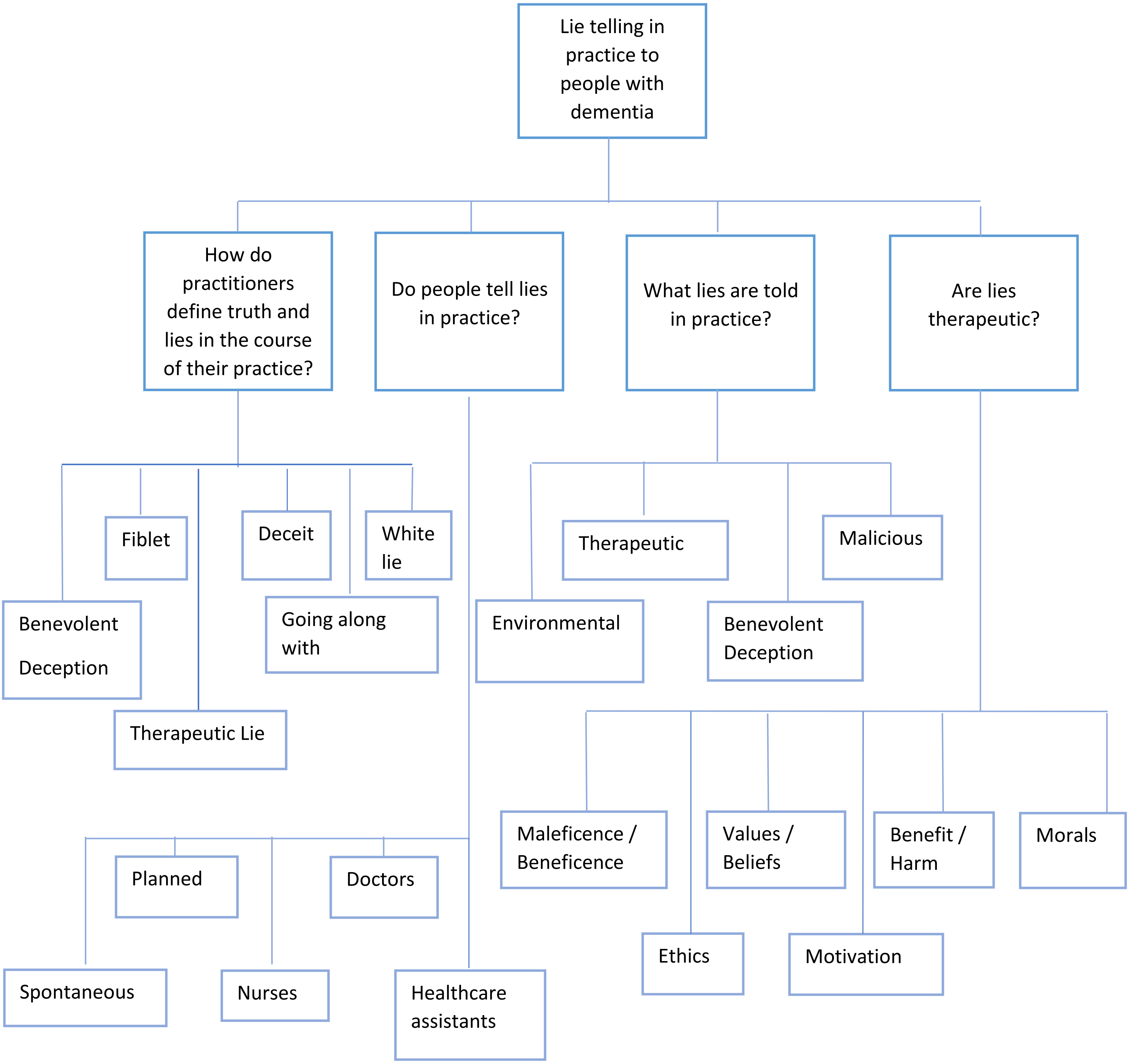
To expand the search, I retained the original key words but then added the third-tier words to the search which resulted in more targeted literature being generated. However, due to the wide spectrum of language used to describe and discuss the field of truth and lies, I found that footnote chasing was particularly useful (Cooper, 1998).

Footnote chasing is also called the ancestry approach (Polit and Beck, 2010). It is classed as a secondary search method which is sometimes also referred to as snowballing (Choong et al 2014). It involves recursively following relevant references cited in already retrieved literature and subsequently adding them to the search results. This can be especially effective for literature reviews such as this, where keyword searching is challenging. One of the difficulties of this search method is that it can sometimes be difficult to obtain the full text of retrieved citations. Several articles had to be requested as inter library loans to obtain copies. It should be regarded as a complementary approach to discover additional information. One study by Horsley et al (2011) found that citation tracking increased the search results by 2.5% and 43%. In relation to this study, I found that by using this method, I generally accessed more relevant literature. Whilst some authors say that this is a time consuming and resource intensive approach, others state that it can significantly reduce the overall time taken to complete a literature search, as well as significantly improving retrieval (Choong, 2014).

It is usually recommended that contemporary research studies focus on literature which has been published in the last 5 – 10 years (Blaikie, 2012). However, it became apparent in the literature retrieval process that there were a range of articles with significant relevance outside of this time frame, particularly from the

1980s and 1990s, and that it would be important to review some of this seminal work (for example Ekman, 1986, Blum, 1994, Kitwood 1997, & Bok, 1999). Therefore, the date restriction was removed to ensure that these original and seminal works were encapsulated. Care was taken to revisit the literature review at regular intervals to ensure any new literature was incorporated.

Figure 3 Expanded Literature Review



2.2.2 Review and summary of the literature

Once potentially useful pieces of literature were identified electronically, the abstract was read to check the relevance. If it was deemed to be potentially relevant it was downloaded and saved. I then skim read the article, focusing on the preface or introduction and the discussion, final chapter or conclusion (Bloomberg and Volpe, 2016). If the article was relevant, I printed it off and read it thoroughly, highlighting and annotating relevant areas. I also dated when it was read and made notes on the frontpage about any key concepts or points. All articles were filed according to being useful, not useful, and maybe. This was particularly helpful as I moved towards saturation of the literature and some articles re-emerged that had already been considered. I also noted if I felt there were any specific areas not covered by the work. I made a summary of each of the useful articles including the full reference so that I had an easy way of finding items that would be needed later.

2.2.3 Analysis and synthesis

Once I had analysed the literature, I assembled it in groups or themes. This gave me the opportunity to integrate the various pieces of literature by making connections between the ideas and concepts that the items covered. It also helped to ensure that the original aims of the literature review were met.

2.2.4 The Conceptual Framework

A conceptual framework follows the literature review and a method of scaffolding the study (Bloomberg and Volpe, 2016). Punch explains that conceptual framework represents “the conceptual status of things being studied and their relationship to each other” (Punch, 2000, p54). Maxwell (2013) identified that a concept map or framework is a visual display of the theory being explored. This is done by defining the territory for the literature search and helping to focus the research project (Blaxter, Hughes and Tight, 1996). Conceptual frameworks are something that people often find difficult to develop due to the general disagreement in the literature about how theory and literature are meant to inform research (Ravitch and Riggan, 2012). Bloomberg and Volpe (2016) highlight that there is no consistent or uniform definition of a conceptual framework identified in the literature which further complicates the issue.

The conceptual framework is presented as part of the summary at the end of the chapter.

2.3 Wholetruth, untruth and lies

One of the difficulties in discussing truth and lies, is in their definition. There is no consensus in the current literature. In UK courts, witnesses are asked to swear an oath and state that they will ‘tell the truth, the whole truth, and nothing but the truth’. There is a general acceptance that, in a court of law, ‘the truth’ has the same shared meaning by everyone present, although this could be challenged as it has been identified that there is a whole spectrum of communication that sits between wholetruth and outright lie (Blum, 1994). Ekman (1986) defined lying as deliberately misleading a person using falsification or purposefully altering the facts. This is quite simplistic in its nature; it does not address the level of falsification or the degree to which the facts are altered. Chisholm and Feehan (1977) also included the concept of intent in their definition by identifying lying as an act of communication where the teller intends the receiver to believe or understand something different to that of the teller. Again, this leads back to the intention to deceive. Carson and Bowie (2012) specify that an actual intention to deceive is not an essential condition of lie telling. However, they make no distinction between deception and lying. Day et al (2010, p.255) were more specific in relation to the spectrum of communication stating, “lying is seen as giving factually incorrect statements to mislead, while deception involves misleading without using factually incorrect information (for example, omitting the truth, giving literal truths, withholding key details, etc”).

The cultural stance that telling the truth is good and telling lies is wrong is based on the assertion that a person who is being lied to is somehow being harmed which is not always true (Jackson, 1991). The high levels of emotion attached to the words lie, liar or lying make them difficult to define and perhaps more difficult to use as part of everyday language as it depends how the words are being used, as to how emotive or emotionally loaded they are (Bok, 1999).

2.4 Lying in general

Few words in the English language evoke as much emotion as the word lie and its derivatives. As Lee (2000) states, it is a value laden and morally charged form of communication. To call someone a liar would be derogatory and damning (Bok, 1999). Yet despite the huge weight attached to the word itself, it is actual very difficult to find a clear definition in the literature. In some literature, the term deception is used almost interchangeably with lying; however, there is considerable time devoted to analysing the two concepts and arguing about both the similarities and differences (Alter, 2012). Kristic (2019) is one of the few authors who argue that it is possible to tell lies without deception, but not to deceive without lying. This is discussed later in the paper in relation to Banter (p.132) , which was the only identified category where lying regularly occurs without being underpinned by deception. Whilst in most societies, both lying and deception would be considered negative traits, lying is generally assumed to be the more negative of the two terms (Pepp, 2020). In some cases, people choose to be deceived; a magician or an illusionist seeks to deceive, and people pay for the pleasure of observing the deception. No one expects the magician to saw a person in half, and the audience know they are being deceived or lied to. A magician or illusionist relies on being able to deceive or lie effectively. If they did not lie, they would be unable to deceive. It is perhaps when deception is not expected or requested that it becomes a negative attribute and evokes suspicion (Burgoon & Buller, 1994). Deception, in some fields would be considered a desirable attribute; for example, during wartime or in the fight against crime, the ability to deceive and confound one's enemy would then lead to a person being considered as a great strategist rather than a liar (Bok, 1999).

There is a multitude of literature on both the topic of truth and lies, going back many hundreds of years. The Prince was published posthumously in 1532 (Machiavelli, 2012). The Prince was a series of letters written by Machiavelli to gain favour with the Medici family, who at the time of writing, ruled Florence. Despite the age of this work, it still has substantial cultural and social relevance today. One of the chapters is titled 'Of the need for Princes to keep their word'. This chapter highlights the importance of appearing to be truthful and live a life based on honesty and integrity. However, Machiavelli emphasises that it is the appearance of honesty, rather than the reality of it, that is important. "A wise ruler cannot and should not keep his word when it would be disadvantageous to do so, and when the reasons to do so have disappeared" (Machiavelli, 2012, p. 64). Machiavelli was such a supporter of lies and deceit that, over time, the term 'Machiavellian' was coined, to mean a person who is particularly cunning or deceitful and is still used today.

In complete contrast to this, Immanuel Kant in the 1700s wrote about lying being unacceptable under any circumstances and asks the question "May I when in distress, make a promise with the intention not to keep it?" (Kant and Abbott, 2004, p. 14). He argues that whilst lying may appear to be prudent at the time of distress, it will lead on to more complicated problems and further inconvenience in the future. Kant is absolute in his doctrine that lies are unacceptable under any circumstance.

These two authors reflect the dichotomy and passion with which truth and lies are discussed in the literature. Machiavelli (2012) did not have an issue with telling lies in situations where truth telling itself could be perceived as disadvantageous. This could be said to be using the theory of consequentialism (Parker, 2005), where the consequences of telling the lie are the main consideration. Kant would argue that to lie is immoral and the liar themselves would be discredited by their evil behaviour (Kant and Abbott, 2004). Kant's stance is underpinned by the theory of deontology, which assumes that everyone has a moral duty to tell the truth regardless of potential outcomes (Rawl, 1972).

Someone who is presumed to be truthful is presumed to be 'good', in the same way that someone who tells lies is presumed to be bad (Bok, 1999). There is a very clear dichotomy between the words and the energy that they create. People tend to be quite definitive in their assumptions about what both words mean, yet the reality is that both words mean different things to different people (Kristic, 2019). It is also worth identifying, particularly in relation to truth, that everyone's perception of what constitutes truth is different, even when recounting the same situation. Several people can observe one incident or action and then believe that they have truthfully retold the story of what the saw, but the likelihood is that all the stories will be slightly different (Zacks et al, 2007). This does not make everyone a liar but seeks to demonstrate that truth is an individual perception and that there may well be multiple versions or truths (Plummer, 1997). Whose version of the truth you then choose to subscribe to, becomes a matter of personal choice, although it is likely to rely on personal allegiance and socialisation regarding the teller as oppose to the actual content (Keller, 2004). Plummer (1997) writes about truth being co-constructed (reliant on relationships) or disputed, which emphasises the previous point. In a court of law, there will often be two or more, versions of the same incident retold, with each person adamant that their version is ‘the real truth’ (Lynch, 2010). It then comes down to the judge or jury to decide who is actually telling the ‘real’ truth and who is in fact, the liar. It has been shown time and time again that wrong decisions have been made and, often, further evidence comes to light that discredits the initially perceived truth and that the teller was in fact, simply more skilled in deception (R v Pendleton, 2001).

In modern life, it is perhaps the appearance rather than the reality of honesty and integrity that is most important, as highlighted by Machiavelli (2012). On social media, people constantly post pictures that have been adulterated or ‘photo shopped’ making people look thinner, younger, or more beautiful than they seem in real life. This type of deception appears to be completely accepted on one level with people across the generations engaging with it (Squicciarini and Griffin, 2012). It is more acceptable to deceive than to be perceived as ugly or perhaps less than perfect (Squicciarini and Griffin, 2014). Many people only post pictures of happiness or perceived family perfection, trying to show that everything in their life is good, yet often the reason they are posting is to persuade the reader or perhaps themselves, that this is their life, rather than the more mundane reality that they are living (Squicciarini and Griffin, 2012). Generally, people appear happy to both deceive and be deceived in an almost interdependent narrative (Squicciarini and Griffin, 2104). However, if we changed the context or word from deception to lying, it is unlikely that people would be as comfortable with the label (Timmerman and Viebahn, 2020). There are perhaps similarities to draw between magic, illusions, and social media in the sense that in these instances, the observer is aware that what they are observing is not the reality or whole truth and the magician or media user completely intends to deceive or project a specific image. It is as though that mutual understanding allows the discourse of perception or untruths to proceed (Kawakami and Miura, 2017). There are few people who would consider these strategies as lying even though they are clearly not the truth. As Lindsey et al (2011) highlight, deception is a part of everyday life and it is part of human socialisation as opposed to an exceptional event (Kashey and DePaulo, 1998).

A Kantian perspective in today's world is as inconceivable as it is impossible to achieve. Kant predominantly writes about verbal truth but, in today's world leading on from the discourse about social media, Kant would have a much bigger range of communications to consider. If a person chooses to wear make-up to enhance their looks or false tan to change the colour of their skin, they are clearly wanting the viewer to see something which they cannot naturally project. Again, they are entering into the realms of deception; however, it would be unacceptable to define someone who wears make-up or false tan as a liar (Gillon, 1993). In an age where Botox and feature-enhancing surgery are big business, the market of deception is lucrative. It perhaps just emphasises that deception is acceptable where both parties are aware of it. In the case of make-up and false tan, most people are aware of who is wearing it and who is not. However, this would also present another dilemma; if both parties are aware of the situation, no one has been deceived so has deception occurred? The person wearing the make-up or false tan is still trying to project an image that is not reality, so therefore are still liars. The situation becomes a little more fragile when considering medical or surgical enhancement. Some people are happy to disclose that they have deliberately changed their looks, but it becomes less acceptable if people then move into the realms of lying or deceit by either not disclosing the surgery or attributing it to lifestyle changes and an improved diet (McCord, 2018). A significant difference in these examples is whether one or both parties are aware of the untruth. Deception is discussed in more detail later in the chapter.

We tell many lies or untruths in daily life; we may thank someone for a ‘lovely’ gift that we did not like or possibly the more common ones around Santa Claus and the Easter Bunny. Lies such as Santa Claus and the Easter Bunny are told with the intention of enhancing a child’s life experience (Standley, 2020). The concept of an overweight, oddly dressed man entering everyone’s house via a chimney, goes against everything we tell children – do not talk to strangers, do not go into someone else’s house uninvited (and eat and drink whatever you can find), yet there is an entire social and economic structure established around this very man who does not exist. Teachers and educators become embroiled in the lie by endorsing and perpetuating the myth (Tillson, 2017). When children eventually discover that Santa Claus is not real, parents and family elders are genuinely disappointed, feeling that an era of their child’s childhood is gone and lost (Standley, 2020); now they will have to tell the truth, or at least stop the deceit. Lying and deceiving children is not limited to Santa and the Easter Bunny, there is also the Tooth Fairy to consider and more recently, the Elf on the Shelf.

These societal lies can place enormous pressure on families, particularly in the lower income bracket. When children share the stories of these fictitious beings, they often compare either the gifts or the amount of money left, leading some of them to question the disparity. Some parents go to enormous lengths to demonstrate what destructive activities the Elf on the Shelf has engaged in while children have been in bed or out of the house. These examples are also good illustrations of how a story or event can take on a life of its own. There are many tales of Santa Claus that differ from country to country and recount a range of similar events, but often in a different order (Mishler, 1995). This is highlighted by Plummer (1997) who adds that stories can take on a form of their own to make them more recount-able; this becomes more evident as the stories or lies are passed on and grown through generations. It can be argued that fables and storytelling offer a basis for effective and essential communication, across generations giving people a sense of connection and helping to strengthen social relationships (Downs and Bower, 2014). There is little discussion around the fact that these interactions are often based on untruths or lies.

There is also much disagreement in the literature about what constitutes deception. Some of the literature states that if you deceive someone, you deliberately prompt them to develop or maintain a false belief (Mahon, 2007). Fallis (2010) uses the example of a person wearing a wig to deceive so that people believe that the wearer has hair, rather than being bald. The caveat to deception is that it must be successful. Deception only occurs if the receiver believes it. Based on that assumption, successful lies are deception, but not all lies are successful. Therefore, some authors have identified that to make a deception believable, the interaction needs to be initiated with truth (Burgoon & Qin, 2006). If someone tells a lie to deceive, they are still a liar, even if they do not manage to deceive, because they have still lied. Bell and Whaley, (1991, p 48-49) highlight that deception can occur by “hiding the truth” as well as “showing the false”. This would mean that withholding information from patients is clearly a form of deception. What is unclear is whether it would be considered lying. Fallis (2010, p 19) gives a clear philosophical definition of lying “you lie if you say something that you believe to be false with the intent to deceive about what you say”. But again, this does not work in a practice context since it relies on motivation and excludes conversational and social idiosyncrasies.

Higgs (1985) focusses much more on the significance of intention. Higgs states that if the intention is to deceive then the communication is effectively a lie. He includes evasion, withholding information and other forms of deception which are often considered ‘white lies’ rather than outright lying, if done with the intention to deceive. This is supported by Cox and Fritz (2016) who state that there is no moral difference between withholding information, deliberately misleading or outright lying. However, historically, according to Kant withholding or reticence as he describes it, would not be classified as lying (Mahon, 2006). Bok (1999) also discusses the concept of secrecy and keeping secrets in relation to withholding information. She argues that keeping secrets does not need to be justified; however, equally, secrets may not all be morally acceptable either. Bok separates secrecy (withholding information) and lying, although the division is somewhat tenuous. Jackson (1991) supports this stating that occurrences such as evasion, are not the same as lying, as to define them as such becomes too utilitarian in terms of practice.

Evasion is a communication technique often associated with politicians. Faulkner (2007) recognises this, highlighting that politicians tend to answer the question they want to answer, rather than the question that is asked of them. Brashers (2001) describes avoidance as a strategy for shielding people from information that is overwhelming or distressing. In terms of healthcare, Bok (1999) states that most attempts to avoid both implicit and explicit questions from patients is likely to increase patient anxiety, rather than reducing it.

Jackson (1991) goes on to identify the concept of benevolent deception. This is not significantly addressed in the philosophical literature but becomes a key term in relation to medical and nursing practice. Jackson highlights that benevolent deception by medical professionals may be considered therapeutic in some circumstances. Jackson introduces the concept of deceit being voluntary or involuntary, with intentional deception being a subcategory of voluntary deception. She uses the example of a doctor who has a dour look when talking to his patient and looking out of the window. The patient assumes the non-verbal communication is related to their prognosis when the reality is the doctor is concerned that the looming rain clouds will stop him playing golf later. This is involuntary deception. However, if the doctor realises his demeanour has affected the patient but does nothing to correct it, it becomes voluntary deception. If he allows the patient to continue to believe their prognosis is poor, perhaps with the intention of prompting them to adopt a healthier lifestyle, it then becomes intentional deception.

Higgs (1985) also identifies a continuum between crisis and triviality. At each end of the spectrum, he finds lies acceptable. If a situation has reached a crisis point which represents potential harm to a person, then it becomes acceptable to tell lies to de-escalate the situation and maintain safety. Equally, at times lies are at the trivial end of the scale and are more of a social lubricant. The example he gives is when a patient contacts a doctor outside of surgery hours and says that they hope that the doctor does not mind. The doctor responds saying ‘not at all’ when this is unlikely to be the case. The doctor is simply responding in a way to stop the patient experiencing negative feelings. However, he also identifies that the vast range of communications between crisis and triviality do demand honesty in order that patients can maintain autonomy and choice over their care. Jackson

(1991) supports the assumption that sometimes it would be considered more therapeutic for medical staff to deceive patients and that if deception can be justified, then so can lying. This level of paternalism was much more prevalent at the time of Jackson' s writing (Chin, 2002). Jackson bases the justification for deception and lying on the fact that a medics first duty is to provide care for their patients and the paradigm of maleficence – to do no harm. However, caution must be used when acting under the auspice of duty of care. The measure of this would be 'normal' practice and it is generally accepted that lying should not be representative of 'normal' practice, even though in reality, lying to patients is a regular occurrence.

2.5 Lying to people with dementia

Perhaps the most significant recent attempt to bring some clarity to the situation, in relation to people with dementia is the publication of *What is Truth? An Inquiry about Truth and Lying in Dementia Care from the Mental Health Foundation* (Williamson & Kirtley, 2016). This document will be referred to as The Inquiry in future. As part of The Inquiry, a rapid literature review was carried out (Kartalova-O'Doherty et al, 2014), using limited key words to search a range of databases. Throughout the discussion regarding the literature review, a range of terms are used including truth, lying, deception and therapeutic lies. None of these terms are clearly defined in terms of the review. This presents challenges in terms of discussion as well as more restrictive parameters in terms of searching. However, The Inquiry highlights that most people think of a truth and lies in terms of a continuum (Day et al., 2011) represented by a spectrum of truth and lies (see figure 4):

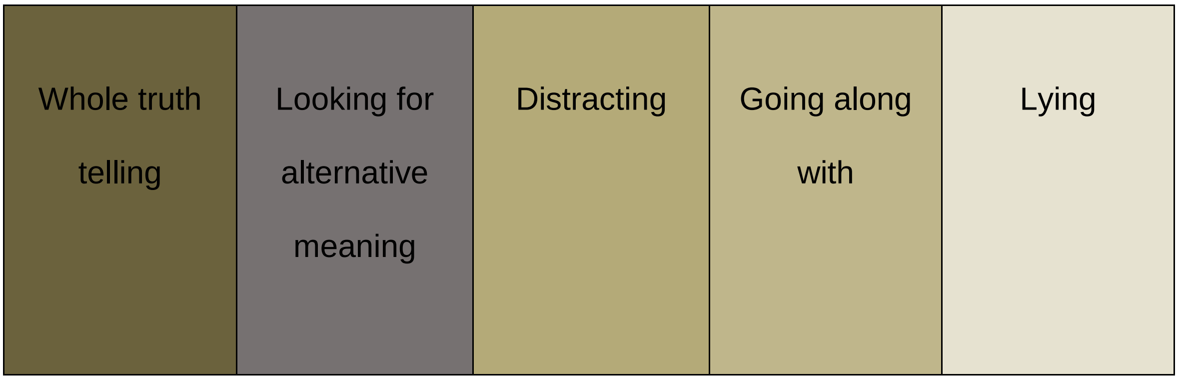
Figure 4

Truth Telling - Reframing – Distracting – Avoiding – Hiding - Going along with – **Lying**

(Day et al, 2011)

Other authors such as Blum (1994), describe untruths with terms such as little white lies and tricks, whilst Cress and Boudinout (2006) talk about geriatric fiblets. These terms are perhaps more acceptable to people generally as they seek to minimise the ‘lie’ element. Somehow people perceive them as softer and therefore kinder to the recipient, however, they are not the whole truth. In The Inquiry a second continuum was identified (Williamson & Kirtley, 2016):

Figure 5



Whole truth telling	Looking for alternative meaning	Distracting	Going along with	Lying

The Inquiry advocates that whole truth telling should always be the starting point, with lying only being used when the patient or recipient is in danger of psychological or physical harm if another approach was used. Williamson & Kirtley, (2016) specify that a lie on this continuum would be a blatant untruth initiated by the teller but do not consider the teller’s motivation; i.e., if there was an intention to mislead or deceive at the point the communication was made. Motivation is perhaps what either increases or decrease the positive or negative feelings related to lie telling. People often talk about therapeutic lies, yet the literature struggles to define lies, let alone start to examine which ones should be considered therapeutic. This can become even more complex when lies are told spontaneously, with no prior agreement or planning. The Inquiry (Williamson & Kirtley, 2016) concludes that kindness, compassion, and respect were the key elements that needed to underpin the interaction, advising validation as the next strategy. They do not actually advise lying but do support reducing distress and meeting the patient’s needs within a legal and ethical framework. Given that they do not provide any guidance on what is legal or ethical, it is questionable how useful the advice is in terms of everyday practice, particularly for professionals. There is a growing use of environmental lies in practice with, for example, the use of robotic animals (Bernabei et al., 2013, Matthias, 2015) and doll therapy. Interestingly, The Inquiry supports the use of therapy dolls and artificial environments, particularly as a means of distraction. This presents a whole range of challenges in relation to what is a lie and what is truth. The use of dolls and artificial environments is discussed in more depth further on in this chapter (P.48).

The closest The Inquiry comes to defining lying is when it concludes that lying is “where a carer initiates purposeful deception” (Williamson & Kirtley, 2016, p.147). The Inquiry reports that this should only happen under two sets of circumstances; first, when there is high risk to the patient or those around them and immediate intervention is required even if it is not planned. Secondly, when a carer wants a patient to engage with a particular behaviour such as getting washed or dressed. The Inquiry based their views on the literature that was available at the time.

The studies described so far asked carers or health care professionals what lies they think they tell. Whilst, valuable, the difficulty is that the data collected is then the individual's perception of what was said. In the case of the Turner et al study (2017), which was undertaken in a general hospital, carers identified three triggers or instances that would prompt them to lie; responding to difficult questions, trying to get a person to engage in a specific behaviour or when sharing medical information. Similar findings were generated by James et al (2006) when they asked professional care givers about their lie telling habits in a study that was conducted in a range of environments including residential homes, hospital wards and Elderly Mentally Ill wards. The literature identifies that lie telling is engaged in by doctors less frequently than nurses or healthcare assistants (Cantone et al, 2019). This would be expected given the relatively limited time doctors spend with patients in comparison to other healthcare professionals and the very specific role that they have.

Tuckett (2006, 2012) has written extensively about lie telling and his work was frequently referred to in The Inquiry (Williamson & Kirtley, 2016). Tuckett (2006) identifies that truth telling is context specific. As early as 1964, authors such as Bonhoeffer suggest that ethical or clinical practice must be grounded in reality. Lantos' (1996) work supports Tuckett and Bonhoeffer, stating that reality is about the lived experience and the context in which it is situated. However, none of these authors specify *whose* reality should be considered as the truth. The reality of someone with dementia is often different to those around them. According to Gold et al (1995) and Tuckett (1998), lying is defined by not only the context, but the nature of the relationship between the people involved in the exchange. In Turner et al.'s study, participants conceptualised honesty as being true to the relationship rather than perceived reality and were happy to adjust information accordingly

(Turner et al., 1975). They did not perceive what was effectively validation as lying, as the main goal was to maintain a genuine relationship. It is interesting that they did not feel that a genuine relationship needed to be based on honesty whilst Kitwood (1997) would argue that a relationship can only be genuine if there is complete honesty. Kitwood's view assumes that the honesty or truthfulness is from the carer or professionals' reality and not the reality of the person with dementia.

Tuckett (2006) writes extensively about the omission of truth where practitioners consider that to tell the truth is harmful. He talks about the importance of maintaining calm, and protecting relatives, so that the withholding of information is not just in relation to the patients, it is about everyone being protected from 'dis-ease' (Smiley, 2000). The difficulty with this approach is that gradually, particularly as the person ages, carers will perceive that the person with dementia is less able to cope with the truth being told, so are likely to continue and increase the pattern of truth omission, leading to decreased disclosure on the basis of non-maleficence (Drickamer and Lachs, 1992). This seems to be a paternalistic view (Lutfey, 2005), where nurses feel they are able to make judgements in the patient's perceived best interest but there is no actual way of clarifying that their decisions are what the patient would have wanted. There is a whole range of literature (Sheldon, 1982, Lavit, 1988, Rosner et al., 2000) that says this is misguided and that telling the truth has many benefits (Tuckett, 2004). It should be highlighted, however, that these studies overall were examining interactions where the patients did not have cognitive impairment and the analysis was often in relation to breaking bad news.

In his 2012 work, Tuckett changed his focus to look at lies and deception when working with people with dementia, finding that carers reported that they frequently told lies when working with people with dementia. This is corroborated by the earlier work of James et al (2006) who identified that 96.4% of carer givers said that they relied on telling lies as a communication strategy. Other research also identifies that whilst staff frequently told lies, they did it in a manner that validated the patient's reality (Wood-Mitchell et al, 2006). The key theme across these pieces of work was the intent of the care givers when telling lies; they did it under the auspice of reducing distress or helping to meet the patients' needs in their own realities (Higgs, 1985). On that basis, the participants in Tucket's study (2012) maintained that their lies were therapeutic (Wood-Mitchell, et al, 2007). If a lie is subsequently labelled therapeutic, it would imply that it has been told with the purpose of doing good, or beneficence, as well as having an observable, positive outcome.

The most recent study looking at telling lies to people with dementia is that of Seaman and Stone (2017). Their research questions are very similar to those used for the present study, although they focus on deception rather than lies:

Research Question 1: What is deception in the context of dementia?

Research Question 2: How is deception used, and by whom, in the context of dementia?

Research Question 3: What are the effects, if any, on those involved?

(Seaman and Stone 2017, p. 61).

Seaman and Stone (2017) used a meta-synthesis to examine existing qualitative literature on deception in the context of dementia; therefore, whilst the questions look similar, my study addresses them in a very different way by using ethnography. What Seaman and Stone's study does do, is to highlight the complexity of deception when directed at people with dementia. It also highlights that the motives for deception are significant, as are the modes it is delivered in and the subsequent outcomes. The difficulty with the study is that all of the papers included had gathered the data by asking ‘the deceivers’ what their perception of an interaction was, with none of the researchers actually observing the deception or lies that were delivered. This study will bring a new lens to a similar problem by using an ethnographic methodology.

2.6 Healthcare professionals and lie telling

The controversy is further compounded if the people who are perceived to be telling lies, are paid carers, particularly if they are professionals and are working under the auspice of a professional body. For example, nurses, where the Code of Conduct dictates that it is essential for nurses to prioritise people, practice effectively, preserve safety and promote professionalism and trust (NMC, 2018) or doctors, governed by the General Medical Council (2019) that also promotes honesty and genuineness as essential trait. Mitchell (2014) questions whether lying is even legal, given the conflict between veracity and beneficence. Marzanski (2000) also takes this stance, arguing that clinicians have a moral duty to always tell the truth.

Most professionals who tell lies to patients with dementia would argue that they are telling lies because to tell the truth would cause harm or distress. In some of the literature, this is referred to as therapeutic privilege (Richard et al, 2010). The term usually refers to medics and their right to choose what to tell a patient and is often based on withholding information as much as actual untruths.

Russell (2018) advocates for lie telling to become part of acceptable care, delivered in the patient’s best interest. Best interest is a complex concept which is covered by both the principle of non-maleficence which directs healthcare professionals to do no harm, as well as that of beneficence or to benefit the patient. Initially, they may look similar but are quite different. Staff may well have to decide to which principle they will give more weight (Cutcliffe & Milton, 1996), since, to do no harm does not necessarily indicate that the intervention is going to be beneficial. Cantone et al (2017) also appear to support the use of lies within the Italian ethical framework which respects the four principles of autonomy, beneficence, non-maleficence, and justice. Cress and Boudinot, (2006) also supported this strategy in relation to a clinical environment, arguing that a clinician should be making decisions dependant on the likely consequences for the recipient, with the least harmful route being chosen.

The current available research about how paid carers and nurses in particular feel about telling lies, reflects a high level of discomfort and unease. Turner et al (2017) found that qualified nurses were the most likely to tell lies to people with dementia. They also identified that staff were reluctant to talk about lies and deception in practice and found it uncomfortable. It is difficult to compare their results with the current study as it was carried out in a general hospital. It used a grounded theory approach to interview staff about their perceptions of what had been said, rather than observation. The triggers or motivations for using lies that were identified in Turner et al’s study (2017) were focussed on activities that the nurses would have engaged in rather than the other people who were interviewed for the study (for example, ward clerk, housekeeper), possibly because nurses were the largest group of staff to participate. The authors identified that they had difficulty recruiting participants from disciplines other than nursing.

James and Caiazza (2018) advocate training clinicians to lie in an ethical and person-centred way. This view has received criticism from some authors, and on occasion, people have walked out of sessions being delivered and debated on the subject (Muller-Hergl, 2007), highlighting the complexity and emotion generated by the topic. In their study, James and Caiazza (2018) administered a pre- and post-teaching questionnaire survey. Most participants were clinical psychologists. The study highlighted that many of the participants, on reflection, lied more than they had thought they did and recognised that they routinely went along with the person with dementia’s incorrect belief. They conclude that clinicians need a better understanding of communication techniques used in practice, to develop more targeted teaching programmes. The present study will help to contribute to this knowledge gap by observing and recording the lies that are told in practice.

MacKenzie (2013) provides a protocol for how lies should be used in practice, adapted from James et al (2006). She advocates that lying should be a last resort and only used after other less contentious strategies have been tried such as meeting the person’s needs (real or perceived), or distraction and only then, therapeutic lying (James and Jackman 2017). The difficulty with referring to therapeutic lying comes back to the lack of definition or observation of outcomes in practice, which the present study will address.

2.7 Lie telling and autonomy

In some of the literature, lying is considered to challenge autonomy which is given a high priority in the literature (Wayne, 2019). However, autonomy is a complex issue in relation to a person with dementia. For someone to be able to act autonomously, it would generally be accepted that they had capacity for rational thinking, choice, and self-determination, giving them the ability to consent or otherwise to their treatment (Campbell, 2017). Ryan (2004) reiterates this by saying that autonomy underpins the right to be told the truth. Whilst it could be argued that choice and self-determination can be supported in people who are quite advanced in their dementia journey, the ability for what would usually be considered rational thinking may be lost (McNess, 2017). Some choices will effectively be habitual, particularly around more mundane, daily issues and self-determination could be based around activities and pursuits that the person has enjoyed for many years and are consequently established in their long-term memory, relatively unaffected in the early stages of the disease (Martyr and Clare, 2012). The rational thinking element becomes more challenging when perhaps a new decision is asked for or engagement in what appears to be a new task. It may in fact be something that the person with dementia has engaged in for years, but for whatever reason, does not recognise it or currently want to participate in, and is unable to think rationally about it (Backhouse et al, 2020).

Refusing to take medication some days would be an example of this. It could be reflected that refusing to take essential medication is a personal choice and exhibits self-determination but could also be deemed as irrational. In that instance, a decision would have to made as to whether lies (such as covert administration) or coercion (if you don't take it your wife will be very annoyed) could be used to persuade the person with dementia to take the medication (Gjerberg et al, 2013). Referring back to the categories of Cantone (2017) (p. 34), staff need to prioritise which category is most significant, given that covert administration could be in the best interest of the patient and completely justified (in the case of essential or life sustaining medication), especially where omission is likely to lead to a deterioration in the patients' health; that is, cause harm. As Pullman (1999) identified, this is a very complex area. They question whether autonomy can be allowed to influence ethical decision making in people who lack the ability to rationalise their thoughts and make independent decisions (Seaman and Stone, 2017).

Some authors such as Racine et al, (2017) define autonomy in much broader terms, with people only needing a minimal level of decision-making capacity. This presents its own challenges since it could be argued that the responsibility for a person's wellbeing is moved back to them, yet, due to their dementia, this may not be in their best interest and present some major safety issues (Fineman, 2012). Dworkin (1986) purports that protecting autonomy is pointless when the person has diminished capacity on the basis that they are no longer able to function autonomously. Healthcare professionals then need to examine the concepts of maleficence and beneficence in more detail, whilst taking care not to revert to a paternalistic stance (Wayne, 2019). Despite the range of views on autonomy and the challenges in sustaining it, most healthcare professionals would see promoting autonomy in people with dementia as a significant part of their advocacy role.

Another consideration when discussing autonomy is the assumption that people are self-determining and therefore make decisions for and about themselves (Zwijsen et al, 2011). People rarely make significant decisions in isolation, particularly if there are family members or carers involved. Whilst person-centred care (Kitwood, 1997) is now well established in the literature, it is perhaps relationship centred care which is of more significance here (Adams, 2008; Nolan et al 2004). It is potentially more useful to consider a family or care group as autonomous rather than the actual individual with dementia.

2.8 Lie telling and personhood

Kitwood and Bredin (1992) identify two phenomena which they say are at the core of the dementia journey. The first is the neurological degeneration, and the second is the individual psychology a person develops, as well as the social psychology that is around them. Kitwood argues that to tell lies to a person with dementia is to engage in a malignant social psychology or treachery (1997). This view may have been appropriate at the time of Kitwood’s original writing but telling the whole truth could now be considered as the damaging discourse. If carers or family members constantly argue with or challenge the reality of the person with dementia, then in time, their personhood will be eroded, if it is accepted that personhood is a state created by the relationships a person has and the interactions associated with them (Kitwood, 1997). Kitwood and Bredin (1992) also identify that the wellbeing of people with dementia can improve when they live in an environment that supports activity and cooperation. It could be argued that on occasions, to tell lies to a person with dementia can help to foster and develop both cooperation and relationships. Kitwood (1990) identified invalidation as part of malignant social psychology. He advocates that the emotions and feelings of the person with dementia need to be accepted and understood by others. For the carer to convey a level of acceptance and empathy, they may need to move into the area of untruths. Kitwood does not prioritise whether treachery or invalidation is more damaging. It may be that carers need to apply a higher level of conscientisation (Freire, 1972) to their communication, particularly when it does not involve the whole truth. Given that conflict in relationships is often associated with poor communication, social isolation and behaviours that challenge (Richter, Roberto & Bottenberg, 1995), the use of the whole truth needs careful consideration when at times, telling the truth might generate far more conflict than going along with or telling a lie.

James (2011) highlights the need to respect the person with dementia, as well as preserving trust and social relationships. To do this, staff may have to go along with the person with dementia’s truth. Tuckett (2012) describes validation as staff aligning their actions to the reality of the person with dementia, which is effectively saying that staff should go along with the truth of the person with dementia, yet Tuckett continues to argue that going along with is not lying.

One method of communication; SPECAL (Specialised Early Care for Alzheimer’s) actively promotes going along with as a humane and person-centred strategy whilst also acknowledging that it is sometimes untruthful and places high importance on the maintenance of ‘face’ (Brooker, 2007). One of the “three golden rules” of SPECAL is not to contradict the person with dementia (Contented Dementia Trust 2012). In other words, go along with them where necessary. In some of the examples given by Riachi (2017), family carers identified where they have moved from simply going along with, into blatant lie telling. They justify this by identifying that their main role is being there to support and protect the person with dementia. The lie was told, in their view, to protect the self-esteem of the person with dementia and not to undermine or embarrass them. This is a core theme running through SPECAL interventions. The Riachi (2007) study also found that the more experienced carers were able to use the SPECAL method more effectively and that these carers identified that they used deceptive practices to ensure interventions were both pragmatic and compassionate. Further, that to use the SPECAL method effectively, carers must validate the emotions of the person with dementia (James, 2008) but not go on to explore them, as would be encouraged by Feil (2002) or Killick & Allan (2001).

Whilst some bodies are very supportive of the SPECAL approach and accept that in implementing it, there may be a level of deception or untruth (Nuffield Council on Bioethics, 2009), it is interesting that the Alzheimer’s Society (2012) publicly does not support the use of SPECAL. The Alzheimer’s Society challenges the approach on the basis that it runs contrary to person centred care and does not believe that systematic deception can be in the best interest of the person with dementia, regardless of the motivation for using it.

2.9 Validation therapy

Williamson (2015) highlights that validation therapy does not challenge the reality of the person with dementia, so therefore appears to condone lying. Something that is vehemently denied by Feil (2002). However, as Williamson (2015) points out, to go along with the person with dementia, is effectively collusion which subsequently will generate untruths or lies. By pretending to understand the person with dementia, and going along with what they are saying, helps to preserve dignity and save face (Smith et al, 2011).

Integrative Validation Therapy (Richards, 1994), which was developed from the work of Feil (1992), also highlights the importance of accepting the subjective reality of the person with dementia. In other words, it is important to go along with them. Richards, however, maintains that the truth must be told to support congruence and unconditional appreciation of and respect for people with dementia. This appears to be somewhat conflicted, as to go along with the person with dementia usually involves a communication that is not based on truth from the perspective of the carer. Richards (2006) also identifies that to validate a person, the carer may have to avoid difficult questions, which again challenges the underlying assertion of truth telling. In this thesis, avoidance (and delaying) is categorised separately as a lie and are addressed later (p 195). The subjective reality of people with dementia in more recent literature, is referred to as dementia orientated reality and defines some patients as being time shifted (MacKenzie et al, 2015).

In earlier literature this was often referred to as reminiscing disorientation (Jones and Burns, 1992). In people who are time shifted, going along with can be an essential strategy to reduce distress. To continue to use reality orientation - to try to convince a person with mid to late-stage dementia, that your reality is the truth - may cause huge distress and mistrust and ultimately, lead to a deterioration in the relationship (James 2015). It also highlights a level of paternalism that is evident in healthcare systems (Schuklenk et al, 2011), where the healthcare professionals are considered to be right, which subsequently brings into question how the power in the nurse / patient relationship is viewed and treated. If the relationship is deemed as equal, it questions why the nurse's truth should be considered more significant or important than that of the person with dementia. We all have our own truth and to have that challenged can be very disconcerting. It is also likely to stimulate a range of emotions from anger, to hurt and upset which are not helpful in maintaining what could already be a very fragile relationship.

James (2015, p10) put forward that the suggestion that it is important for carers to "enter a person's current reality". In other words, go along with the person's reality, rather to try to orientate them to that of the carer. This had been highlighted previously by Mackenzie and James (2010) when they discuss communicating with people in the moment (but their moment, not that of the carer). They are among very few authors who identify that lying has the potential to be a person centred and effective strategy.

The Human Rights Act (Home Office, 1998) provides a good argument for allowing professional carers to tell lies under some circumstances; article 3 states that people have the right not to be tortured or subjected to treatment which is inhuman or degrading. To constantly reiterate the whole truth to a person who is unable to perceive or process it in the same way as others could be seen to contravene this (Kelly & Innes, 2013). Article 5 also identifies that people have the right to liberty and security. In some instances, people may feel very insecure and vulnerable if their truth and reality is constantly challenged and corrected by those around them. In some cases, to tell the truth may cause great distress and constitute degrading treatment since it is likely to arouse feelings of fear and anguish, and possibly humiliation and inferiority (Kelly, 2005), whereas to tell a lie, may promote personhood and enable person centred care to be delivered.

2.10 Attachment Theory

Miesen's work (1993) showed that there is increased parental fixation in people with greater levels of cognitive impairment. If this is accepted, the behaviour of people with dementia who continue to look for their parents can be explained by Bowlby's attachment theory (Bowlby, 1969). Therefore, it would be wrong to use reality orientation at each intervention and continually sabotage the security that parental or familial attachment brings. This presents a strong argument for telling lies and allowing the person with dementia to believe that their parents or spouse are still alive since this will help promote feelings of security and belonging (Miesen & Jones, 1997). It will also help to support personhood by helping to maintain established relationships within the person's present reality. Other studies have also shown an increase in attachment behaviours in more cognitively impaired people (Browne & Shlosberg, 2005) who are also the group least likely to identify that they have been lied to (Ekman, 1986). Some earlier research (Woods & Ashley, 1995) had attempted to address attachment behaviours by using the simulated presence of a family member. This was done by playing an audio tape of family members twice per day and had significant, positive results. This was not done in the context of deceiving the person with dementia, which undoubtedly it was.

2.11 False environments and the use of objects

The effectiveness of doll therapy is also likely to have its roots in attachment theory (Moore, 2001). It is thought, that in instances where doll therapy is effective (Fraser & James, 2008), it rekindles previous bonds and emotions which were important to that person, so arguably helping to support personhood (Bryant & Foster, 2002, Bisiani & Angus, 2012). One important consideration when using doll therapy, is whether the doll is being used as such, or is being given as a form of lie. That is, is it being given as though it were an actual baby to deceive the recipient or simply as a doll for the person with dementia to play with. A study by Stephens et al (2012) examined how people with dementia use physical objects, specifically in relation to Winnicott’s theory of transitional objects (1953). Whilst they confirmed that people with dementia do demonstrate some positive behaviours in relation to the use of objects, it cannot be linked to the transitional or precursor objects that are identified by Winnicott. There are perhaps stronger links to the notion of precursor objects than transition, but it is more likely that people are using them more for tactile sensations. This would be supported by the recent use of twiddle muffs in general hospitals (Hall, 2019). Twiddlemuffs are circular rolls of fabric with a range of attachments on for people to touch and ‘twiddle’. It is also unclear in these studies if whether the people with dementia perceive these ‘props’ as inanimate objects, or whether they are attributing some other guise or reality to them. This is discussed further in the Props section of Chapter 4, (p.154).

An extension of using props or dolls to deceive is when care environments contrive to change the environment in some way that it deceives the patient with dementia into thinking that they are somewhere other than their current environment. There is limited research on the impact of these environments, but the one that is mentioned frequently is the use of fake bus stops (Lorey, 2019). These originated in Germany some years ago and have been the subject of much controversy. Care environments set up a fake bus stop either indoors or outdoors. The level of deceit used varies widely from a simple sign to more complex deception where there are timetables available and perhaps a bench on which to sit (Lorey, 2019). There is virtually no research about whether they are effective in reducing distress but a great deal of expressed opinion about the potential damage they can do in terms of damaging the caring relationship if the deception is uncovered (Schermer, 2007). The likelihood of the deception being discovered is minimal due to the high level of damage to a patient's short-term memory. It may be more useful to consider the use of bus stops in relation to Sumner's (1996) assertion that illusionary experiences should be evaluated by the response of the receiver.

Some care homes have created specific areas to resemble an area that the person with dementia will recognise, albeit a deception. The photograph below is from a care home that I visited, that had recreated a patient's back yard on the corridor (full permission to take and use the photograph). There was no research on which to base this; however, it appeared to meet the patients' needs very well and, without the use of medication which would have potentially impacted her health in other ways.

Photograph 1 Corridor decorated to look like a back yard

When the woman was at home, every day, she would hang her washing in her yard then sit on her stool and watch the children going to school. She found it very difficult to adjust to her new environment and became very distressed. Once this area was created, she re-established her usual routine, talking to people as they walked past. Whilst there is little evidence base to support what was done in terms of the false environment, there is more research that identifies the importance of maintaining established routines (Fetterman, 2010).

There has been more recent media coverage of care homes that are effectively set up as though they are in a different time period (Dementiaville, Channel 4, 2015). Again, there is little research to underpin this approach. Interestingly, whilst most people argue against lies and deception, the home that was the focus of this programme received a lot of positive feedback in the general media (Jones, 2015). One of the main objections to using false environments or telling lies, is that the person with dementia will know they have been lied to and that would jeopardise established relationships. This is refuted by the concept of theory of mind reasoning.

2.12 The detection of lie telling and theory of mind

The fear of being caught telling lies and the subsequent feelings of guilt have been extensively analysed by Ekman (1986) and, within general communication, may present a very real challenge. However, in relation to people with dementia, Ekman (1986) argues that discovery is an unlikely occurrence. In a study by Bond and DePaulo (2006), 206 studies were examined, and it was found that on average people (without dementia) only detect 54% of deceptions and lies and this is not much higher than can be expected by chance. Park et al (2002) also highlight that lies and deception were rarely exposed in the context of the actual interaction. A considerable period of time has often elapsed before the deceit is discovered and often this is by a third party rather than the receiver. This would underpin why Yamaguchi et al (2019) found that people with only mild cognitive impairment find it difficult to detect deception unless it is explicit and people with even mild Alzheimer’s disease are rarely able to recognise it. This is supported by Cantone et al (2017) who state that people with dementia lose the ability to understand and perceive the logic of communication and therefore cannot separate truth and lies. In order to perceive deception, people require theory of mind reasoning (Premack & Woodruff, 1978).

Theory of mind reasoning helps us to make judgements or predictions about other people’s behaviours in a range of social situations (Byom & Mutlu, 2013). Theory of mind is also sometimes referred to as the ability to ‘mind read’ (Schurz et al, 2014). It helps people to perceive the cognitive and emotional state of others which helps to anticipate and interpret their behaviour (Laisney et al, 2013). It is also significantly influenced by the level of education that people with dementia have been exposed to (Laisney et al, 2013). This correlates with the Maylor et al (2002) study which identifies that there were strong links between theory of mind performance and education in general ageing.

Damage to theory of mind reasoning occurs early on in cognitive decline related to dementia and is highlighted as one of the key cognitive domains in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (American Psychiatric Association, 2013). Sandoz et al, (2014) argue that theory of mind reasoning is a secondary deficit; however, the work of Fliss et al (2015) and more recently that of Yamaguchi et al, (2019), indicates that it is a primary deficit in patients with Alzheimer’s disease.

This means that people with moderate to severe dementia would be highly unlikely to detect that they were being lied to; they are much more likely to respond to the emotion rather than the content of the communication. This is further supported by the work of Youmans & Bourgeois (2010) who found that theory of mind is dependent on short term and working memory. As dementia progresses, it becomes less and less likely that a person can identify deceit or lies as their short term and working memory becomes increasingly impaired. However, Sandoz et al (2014) also identify that the deterioration in theory of mind functioning may be secondary to primary or executive function deficits. Regardless of the cause, the outcome is still a deterioration of the person with dementia to detect lies or deception as their primary and executive functions will also be impaired by dementia. It should also be considered that different types of dementia affect different functions of the brain differently, and therefore theory of mind degeneration is likely to be variable between different dementias (Le Bouc et al, 2012).

Fronto temporal dementia is thought to be more susceptible to theory of mind deterioration (Schurz et al, 2014). Fronto temporal dementia shows deterioration in both the cognitive sphere of theory of mind, as well as the affective elements of theory of mind compared with people with Alzheimer's disease who show a greater deterioration in the cognitive theory of mind domain compared to the affective theory of mind domain (Gregory et al, 2002). Again, this is attributable to the greater impact on short term memory in people with Alzheimer's disease whilst retaining much of their emotional functioning throughout the course of the disease (Gregort et al, 2002). In time, the affective domain also deteriorates, due to the general diminishing of cognition (Laisney et al, 2013). Le Bouc et al (2012) conclude that the deterioration in both types of dementia are similar but have a different aetiology in terms of which neural pathways are likely to be affected in each disease.

Regardless of the type of dementia, it is likely that theory of mind reduces the ability of the person with dementia to detect when they are being lied to or deceit is being used. Theory of mind is one representation of cognition and it is situated in the real world (Wilson, 2002). It relies on both participants having some prior knowledge of the person they are interacting with, and the relationship they have with them (Sebanz, 2006). The person with dementia may not be able to demonstrate this level of theory of mind, particularly in the mild to moderate stages since their short-term memory is impaired to a level that they are no longer able to remember this information; indeed, verbal communication places considerable cognitive demands on the person with dementia (Byom and Mutlu, 2013).

Another difficulty in relation to theory of mind for the person with dementia is the inability to recognise or interpret social cues. This may be based around the use of nonverbal communication and, in particular, eye movements (Freire et al, 2004), or it may be that there is no longer a common or shared understanding of the behaviour or interaction (Knoblich et al, 2011). This can become more obvious when the person with dementia has been accused of displaying behaviour that challenges, whereas in their reality it is a reasonable response given that there is no longer a shared understanding or goal (Clark, 1996). The use of eye movement and gaze cues, particularly in relation to deception, has also received much attention in the literature. Eye contact and movement is very culturally specific which also needs to be considered (Williams et al, 2009). Interpretation of these very subtle visual cues requires a high level of processing on the part of the receiver, which a person with dementia, even in the earlier stages, is likely to have difficulty with. The ability of someone with dementia (particularly Alzheimer's type) to maintain the affective element of theory of mind further into the journey (Gregory et al, 2002) could be perceived as being helpful in terms of developing interventions based on deception. If the emotion of the carer can be perceived by the person with dementia, the content and detection of deception become less important. Trust, which is often felt to be fragile in many relationships with people with dementia is much more like to be maintained if the emotional connection is sustained. That is because trust is often unconscious and instinctive, based more on emotion than cognition (Rogers, 2002).

2.13 Habilitation Therapy

Another therapy that embraces the use of lies and deceit is Habilitation Therapy which aims to maximise the functioning of the person with dementia whilst achieving a positive emotional state which is maintained throughout the course of a day (Raia, 2011). Habilitation Therapy identifies five areas or domains in which positive emotions can be created and sustained: physical, social, communication, functional and behavioural.

The physical domain is about the environment in which the person with dementia exists. Often, due to impaired memory the current environment can be a major stressor by presenting too many choices and Habilitation Therapy would advocate reducing the number of choices so that a decision can be made more easily and with less stress (Raia,1999). An example would be where a carer opens a wardrobe and leaves a person with dementia to get dressed – there are too many choices for them to be able to choose the clothes and subsequently get dressed appropriately. Habilitation Therapy would offer the person with dementia a choice of two outfits, perhaps placing them on the bed, and ask them to choose one to wear. Effectively this is withholding information given the wider choice of clothes that are available; but, in withholding that information, the person with dementia can maintain their autonomy and dignity by still being able to dress themselves independently. The physical domain would also ensure that factors like the lighting are appropriate, so odd shadows are not being cast and that the wall decoration is conducive to a calm environment.

The activity domain is very much focussed on what the person with dementia is still able to do. A main paradigm is that it has to be failure-free. It can take a considerable amount of effort to develop a social programme which meets this criterion, especially if the person is time shifted (Turner et al, 2016). It may be that the person with dementia engages with something from their distance past which they have not done for many years, such as ball room dancing. Dancing can be particularly useful since it involves music which is known to have a strong effect on the emotions, even in advanced dementia and can involve a partner or a loved one in a positive and rewarding activity (Raia, 2011).

There are several threads to the communication domain, some of which are based around distraction and validation (Feil, 2002); however, there are two key points: never say ‘no’ to the patient and always work in their reality rather than that of the caregivers. This would support the notion of going along with as an essential strategy for maintaining positive emotions. It must be acknowledged that some family and professional care givers may find this more difficult to do than others, particularly in terms of not saying no, which can be an almost automatic response.

In the functional domain, Habilitation Therapy promotes the independence of the person with dementia by supporting them to engage with tasks in a positive manner for as long as possible. Over time, this often means that the task will have to be broken down into smaller parts or done in a more stepped approach. It also relies on giving visual clues which may involve the carer modelling a task to give the correct cues to the person with dementia. For example, rather than telling someone to get dressed for an occasion, the carer may suggest that they both go and get dressed to go out, and both get dressed in the same room at the same time so the person with dementia has an almost continuous visual aid to remind them of what they are supposed to be doing.

The final domain is focussed on behaviour. Habilitation Therapy regards difficult behaviours or behaviours that challenge as generally defensive in nature and often caused by fear or uncertainty. Behaviour change relies heavily on carers observing the behaviours carefully and recording what they see to establish any patterns or themes which is similar to many other behaviour change models (Jackman, 2020). Caregivers need to consider external triggers which are often more obvious, as well as internal ones, which can be harder to identify, such as pain, hunger, and thirst. Throughout all the domains, the focus is on the internal emotion of the person with dementia and maintaining them in a positive state; accepting that this is likely to involve lie telling at some point since the carer will need to go along with the person with dementia at times, as well as having to move into their reality on occasion, particularly when trying to avoid contradicting them or saying no.

Habilitation Therapy focuses on entering the reality of the person with dementia, arguing that orientation should be avoided as it is likely to cause distress. The focus should be on the truth of the person with dementia, not the truth of the carer. Habilitation Therapy promotes the use of what its supporters call fiblets (see below), in that they sustain the dignity of the person with dementia and increase cooperation in the care giving process which, in turn, helps to maintain relationships.

Proponents of this therapy acknowledge that it can be more difficult to ask family caregivers to tell lies, which is why training in this intervention is delivered by ongoing coaching. This contradicts other studies which have found that family carers of people with dementia are generally more accepting of lie telling as a positive intervention, particularly as the disease advances than professional care givers (Blum, 1994). This was highlighted as an effective strategy to reduce distress which was particularly important for family carers who were supporting people with dementia at home. Whilst this therapy clearly uses lies as a successful and positive intervention, it is still deemed necessary to move away from the term lie and refer to fiblets instead; a word which feels less intimidating or negative than ‘lies’ but perhaps has a childlike sound to it and could be considered by some to be elderspeak.

2.14 Elderspeak

Elderspeak was first defined by Caporael (1981), with one of the multiple categories being “using first names, pet names and inappropriate terms of endearment, for example “darling, mate, and hun’” (McLaughlin, 2020 p.24). Williams et al (2009) acknowledge that this style of communication was intended to convey a caring, knowing familiarity and warmth, but in fact caused frustration and embarrassment in older people, which could result in behavioural challenges within the care environment. Other authors have found evidence of potential benefits of using elderspeak and familiar names (Kemper and Harden, 1999), although this study looked at older people without any cognitive issues. Familiarity is also highlighted in integrative validation therapy. Richard (2010) describes the use of proverbs or wise sayings, in order to engage a person with dementia in meaningful conversations, and biblical sayings as a useful way of generalising feelings and motivation. There are also personal maxims identified, some of which would be consider elderspeak terms; for example, “love, hun, and darling”. In some instances, these words and phrases are undoubtedly used in the context of untruths, even though Richard argues that integrative validation therapy relies on the wholetruth.

None of the studies that looked at elderspeak or familiar terms explored the motivation for using it, in any depth. They retrospectively examined when people thought they used it and, in some cases, considered why, but did not actually observe or clarify what was said. Relying on perceived recall does not provide accurate data in terms of what is happening, which is why the present study used ethnography as a methodology. One study by O'Connor and St. Pierre did consider how older people felt about the use of these terms (2004). They highlighted that familiarity is received differently by different people, and across different social classes, cultures and places; for example, in Sheffield, adults of all ages, both men and women – are often called 'love', in Nottingham, 'Duck' (Comerford, 2015); however, it is generally more positively received by the interactant, than it is viewed by third parties or researchers. The other finding from this study was that older people received familiar terms more positively from family members and people that they knew and trusted. Unfamiliar personnel who used elderspeak were viewed more negatively.

2.15 Summary

The literature review was very wide and broad ranging to ensure that the topic was looked at from a variety of angles and in order to ensure that it met the original aims. The aims of the literature review are broken down below and a summary of the extent to which they were met, is included. It establishes that the topics of truth, and particularly lies, evoke a wide range of emotions depending on the context they are told in, and who the tellers and receivers are. It also highlighted that motivation and understanding in relation to both telling and receiving lies are very important.

- **How are lies defined in the literature?**

  There was little consensus on what defined either truth or lies and, in most cases, it appeared to be very fluid, with most authors opting for a sliding scale of truthfulness. Very few papers discuss blatant lying, with most opting for a softer term such as white lie, fiblet or similar. In a lot of the literature, truth is discussed in relation to the carer's truth rather than the person with dementia's truth. However, some of the newer articles are starting to recognise dementia orientated reality and the importance of the person with dementia's truth rather than that of the carers. There has been no defining taxonomy since Blum's seminal work in 1994. This was carried out with carers in the home environment and relied on carers reporting their interpretation of communications. The present study aimed to develop a taxonomy which addresses this gap in the literature.

- **What evidence is there to say that lies are being used in practice?**

  The literature shows that healthcare professionals report lie telling as a well-established communication style within society which is regularly used in caring environments. Lie telling may be perceived and construed differently, particularly if the teller is a healthcare professional or a registrant with a professional body. The difficulty with the available evidence is that previous studies have relied on participants' self-reporting (as below), and there are no studies that have recorded the lies that are actually told. The present study addresses that gap in the literature by using ethnography to observe and record lies that are told in practice.

- **What methodology have previous studies used?**

  The main gap in the literature was found to be around observation and methodology of existing work.

  Most of the studies adopted a mixed method approach which relied on asking professionals or carers retrospectively what they remember and what their perceptions were of the interaction. None of the studies used an ethnographic methodology whereby researchers had observed or recorded what lies are being told to people with dementia, and by who. This study aimed to fill that gap in knowledge by using an ethnographic methodology to study lie telling in practice.

- **Is there any evidence to identify what type of lies are told in practice and by who?**

  In relation to care environments, families and carers appear to condone lie-telling to people with dementia, especially if it is being used to deescalate a situation or reduce distress. Health care professionals have much more conflict around this and there were differences highlighted even between the different nursing and health disciplines. Those who work with people with dementia on a regular and specialist basis, often expressed less discomfort than those who worked in more general or acute hospital settings. The level of discussion that staff engaged in around the issues of truth and lies, was also variable depending on the environment.

  There are a range of lies identified in the literature, but these are retrospective perceptions rather than observed activities. There undoubtedly is a range of lies being told but there is no observational evidence of what they are. The present study records lies that are told in the clinical setting, and by which professional group.

- **Is there any evidence to support or refute the benefit of telling lies to people with dementia?**

  There is a range of literature from those authors who advocate telling lies as they perceive it is beneficial – therapeutic lying - to those who are vehemently against it and say the truth must always be told. The difficulty with those people who advocate that the truth should always be told, is that they tend not to define truth or lies and could often be challenged that they regularly are not telling the whole truth. Therefore, the current evidence base underpinning the benefits of truth telling or lying is limited. The present study also records and analyses the observable outcomes of telling lies to people with dementia.

The findings from the literature review, led to the development of the following conceptual framework.

2.16 Conceptual Framework

To reiterate, in order to meet the stated aims of the study:

- To develop a taxonomy of lies
- To use the taxonomy to develop a model which could be used in practice, to explore the impact of lie telling

the following objectives needed to be achieved:

- Identify what lies are told in practice and by who

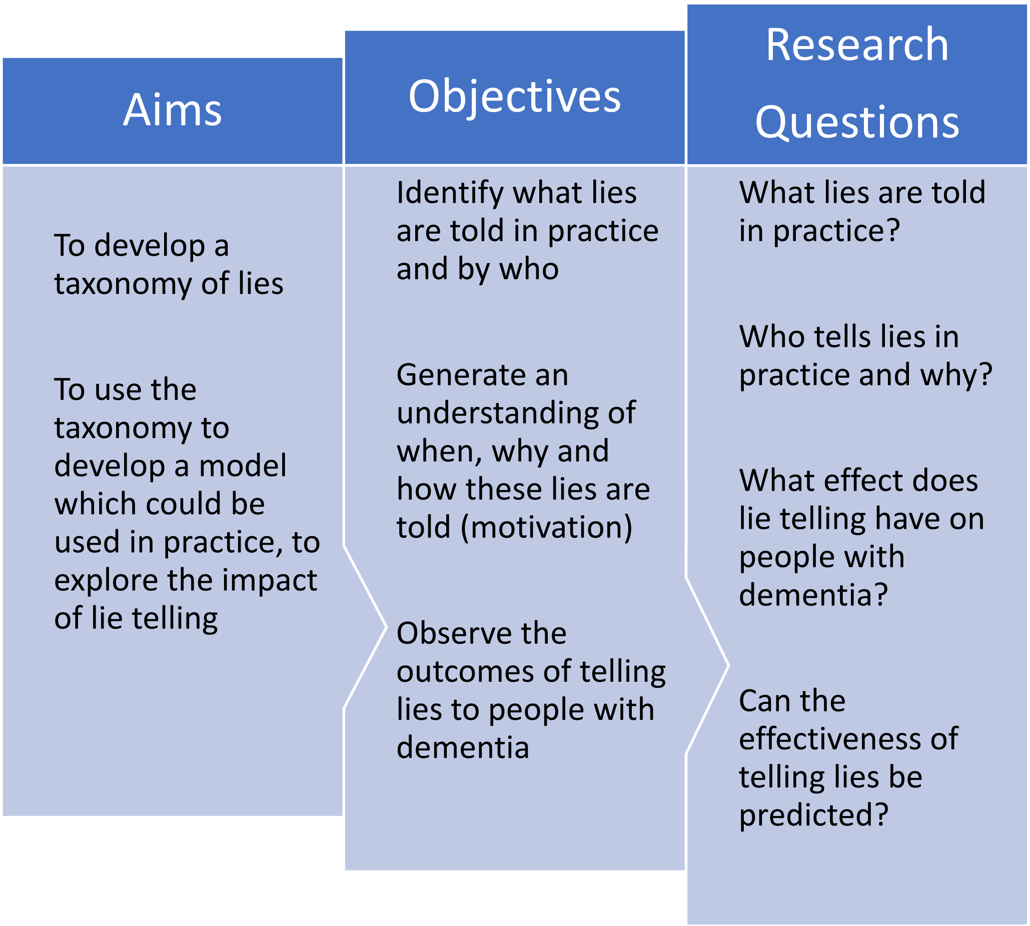
- Generate an understanding of when, why and how these lies are told (motivation)
- Observe the outcomes of telling lies to people with dementia

and this enabled the following research questions to be addressed:

- What lies are told in practice?
- Who tells lies in practice and why?
- What effect does lie telling have on people with dementia?
- Can the effectiveness of telling lies be predicted?

This can be summarised by Figure 6, The Conceptual Framework.

Figure 6 Conceptual Framework



Aims	Objectives	Research Questions
To develop a taxonomy of lies To use the taxonomy to develop a model which could be used in practice, to explore the impact of lie telling	Identify what lies are told in practice and by who Generate an understanding of when, why and how these lies are told (motivation) Observe the outcomes of telling lies to people with dementia	What lies are told in practice? Who tells lies in practice and why? What effect does lie telling have on people with dementia? Can the effectiveness of telling lies be predicted?

This framework represented the initial version of the map of my investigation (Miles, Huberman and Saldana, 2014). Whilst the framework is quite simplistic in nature, it performs the function of providing a structure for organising and supporting ideas (Weaver-Hart, 1988) as well as some methodological order within that process (Bloomberg and Volpe, 2016).

To achieve the aims of the study and answer the research questions, ethnography was used as the research methodology. Ethnography has not been used as a methodology by any of the previous studies in the area and is one of the unique contributions of the study.

The following chapter presents the study’s methodology this in detail.

Chapter 3

Methodology

3.1 Introduction

Lie telling is a phenomenon that we know occurs regularly in health and social care environments (James et al 2006). There is already a substantial body of pre-existing research and literature in relation to telling lies to people with dementia; previous studies across a range of professional groups, have relied on self-report and have generally followed mixed method approaches. The participants in the existing studies either completed surveys or were interviewed and asked about what lies they thought they told. This highlights a gap in the literature as none of the studies observed what was actually said. This study observed what was said and then contextualised it by talking to the participants and reflecting on the interactions in context, as well as considering the response of the receiver. The study was able to capture much more data and examined the complex relationships between attitudes, behaviours and response (Hammersley, 1990). Participants are any paid member of staff, including nurses, healthcare assistants, physiotherapists, pharmacists (who gave consent to participate in the study) who was observed to tell lies to patients. This list is illustrative, rather than exhaustive. All paid members of staff who deliver a level of care, are considered to be healthcare professionals, regardless of whether they are registrants in their particular field.

The purpose of the current study was to observe and directly record what lies and untruths were being told. The study also aimed to identify any common features or links between the observed lies with the view to development of a theory that underpinned them. Considering this, ethnography was chosen as the methodology.

3.2 Ethnography and what else?

This section considers where the study is situated from a philosophical stance then looks at the choice of specific methodology and analysis that were subsequently used.

Ethnography is a qualitative methodology that has the specific purpose of describing and interpreting shared and learned behaviours, languages, beliefs, and values of the community under study (Harris, 2001). It is often used to explore what Malinowski (1967) referred to as a foreshadowed problem. Lie telling can be considered to be a foreshadowed problem, given that it is known to exist but has not been studied as an observed phenomenon in previous research. Generally, ethnography entails extended observation of a group of people through participant observation. Hammersley and Atkinson (2019) advise that where participant observation is involved, the researcher will need to find a role in the area that is being studied. In this case, it was relatively easy to establish my role in the field, since I am a mental health nurse and specialist practitioner in older people's care, as well as an academic. The people who already knew me in the clinical areas refer to me as a nurse, rather than an academic as that is the role most of them have known me in for many years. The disadvantage of this is how it could have potentially affected the data collection and will be discussed further relative to field relations and the Hawthorn effect (Paradis and Sutkin, 2017) (P. 71).

Ethnography can adopt a range of philosophical strands and several of these were considered. Critical realism was only briefly considered but it does not acknowledge the role of beliefs and values within the confines of a study (Wainright, 1997). I felt that these were likely to have a very strong influence in this study and it would be important to not only acknowledge them, but to document and subsequently reflect on them.

Positivist ethnography is based on science, particularly physics, and is focused on testing specific hypotheses or theories (Toulmin, 1972). It focuses on objective data, which can be tested and proven or disproven. It often involves generating quantitative data or statistics within a very controlled and often manipulated environment. It is a way of comparing ideas of what may happen under a certain set of conditions compared to what happens in other environments. The research was to take place in a natural setting (i.e., two well established wards for people with moderate to severe dementia), with the research having minimal impact on the participants (Hammersley and Atkinson, 2019); therefore, a more naturalist rather than positivist ethnography was used.

This type of naturalistic enquiry has been the subject of much debate and criticism over the years with many researchers arguing that it is not a science since the results are too subjective and cannot withstand rigorous scientific or empirical analysis. Those that take a more scientific or positivist ethnographical stance, argue that phenomena must be easily or publicly seen, in a manner which can be agreed by observers. The present study takes a much more naturalist stance. The data was collected whilst I was working as a staff nurse as part of a ward team, delivering care to patients as planned. The only evidence that there was research going on was the displaying of posters for staff and relatives / friends to read. The phenomena that I was observing – the telling of lies - was publicly observable by all; however, it is likely that the classification of what is considered a lie would vary considerably between different observers. In this instance, I was operating as a participant observer in what was, to me, a familiar environment. Hammersley and Atkinson (2019, P.9) recommend that in this situation it is important that the participant observer treat the situation as ‘anthropologically strange’. In my case, the phenomena being studied could be considered anthropologically strange given that lie telling and untruths go against usually accepted social norms yet are embedded within the culture of nursing and caring (NMC, 2018). The main goal of the observation was to be able to describe the interactions in detail and identify if there were any social or cultural patterns under pinning them, making ethnography the appropriate methodology.

This led to the exploration of both constructivism and constructionism, which in some literature, are undifferentiated (Young and Collin, 2004). Constructionism takes a broader, more social lens, with the view that knowledge can be the product of social practices or institutions (Gasper, 1999) and is less interested in the cognitive processes that accompany knowledge (Young and Collin, 2004). After careful consideration, it was felt that the most fitting philosophical stance to underpin the study was that of constructivism. Constructivist ethnography purports that social reality is constructed between individuals who generate knowledge, and meaning from their interactions and experiences (Lincoln, Lynham and Guba, 2011), and lying is very much part of an interaction or experience shared by individuals. Constructivism also suggests that individuals construct the world of experience through cognitive processes, which aligns with the theory of mind, discussed in Chapter 2. Constructivism seeks to undertake research in natural settings (Guba and Lincoln, 1981, Guba, 1990). In the literature, constructivist ethnography is sometimes referred to as post-modern ethnography (Ryan, 2017). It shares some characteristics with critical ethnography since the focus is on the participants and can be subjective. However, constructivist ethnography does not seek generalisability but rather aims to improve knowledge and further understanding (Ryan, 2017). It looks at the detailed web of human experience as participants live and function in their own environments. It also aims to understand how people construct their realities and tries to gain some shared meaning (Appleton, 2002). However, the researcher must always be open to new explanations with the benefit of experience and increased information (Guba and Lincoln, 1994).

Robinson (2013) identified that this approach can be particularly useful for nursing research as it values the perceptions, feelings, and experiences of the participants. This aligns to the principles of nursing and can therefore allow nurse researchers to better understand the behaviours of the participants (Robinson, 2013). It also allows for contextual factors to be taken into consideration to gain a fuller understanding of the phenomenon (Appleton, 2002).

The methodology used for the study was that of focussed or rapid ethnography (Wall, 2015). It is also sometimes referred to as micro ethnography (Polit and Tatano Beck, 2008), or selective intermittent ethnography. Focussed ethnography can be used to examine specific questions or phenomenon (Stephens, Cheston, and Gleeson, 2012) or specific, small elements of one society. It generally focusses on selective situations, activities, or interactions, as in the case of this study. It has the advantage of providing an in-depth depiction of a single interaction, rather than trying to portray an entire scene or context which could potentially reduce the depth or detail of the study (Lofland, 1995). As Erickson (1988) identified, it is focussing on the elements of the interaction as it naturally occurs in everyday discourse. Such an approach was appropriate for this research since the data was to be collected by participant observation during short-term field visits, i.e., the duration of a nursing shift, rather than me living within the community. It was also dependant on me having an intimate knowledge of the field to be studied (Knoblauch, 2005). Knoblauch highlights this as being particularly effective for studying communicative activities or experiences by communication.

Muecke (1994) highlighted that focussed ethnography is particularly useful in nursing research where a researcher often already has insider knowledge and may want to focus on a very specific element, particularly in research related to communication in nursing or issues relating to an individual task. In this case, it allowed me to explore the interactions that occurred between the person with dementia and healthcare professionals and, subsequently, attempt to interpret what I saw; making this methodology appropriate for the study's aims (Hubbard et al, 2003). It also helped to generate both an emic and etic perspective (Roper and Shapira, 2000). I was better able to understand the use of lies from the participants' points of view; providing the emic view whilst then being able to reflect on the situations and provide an etic or outsider's view.

3.3 Reflexivity

Reflexivity is an essential part of ethnographic research (Hammersley and Atkinson, 2007). It focuses on making explicit and transparent the impact and the effect of the researcher on the methodology and tools of data collection, as well as on the process of the research and its findings. This is in direct contrast with the aim of quantitative research where the impact of the researcher is sought to be minimised (Murphy et al, 1998). It is a process where researchers clearly identify the interactions that have occurred between their methodologies, the settings they have operated in and the participants they have studied (Denzin and Lincoln, 1998). The effects of my personal characteristics, experiences and the relationships I had with staff, are reflected on as appropriate, as well as the role my prior experiences could have potentially had on the research (Mays and Pope, 2000).

This process of self-conscious reflection has been threaded throughout this work and is identified in boxes throughout the Findings and Discussion Chapter (p.112). This has helped to establish the rigour and trustworthiness of the phenomena being studied, demonstrating that it is not just an expression of my own ideology (Schwandt, 2007). Cruz and Higginbottom (2013) highlight that this is particularly important in focussed ethnography, especially where the researcher is familiar with or has personal experience of the environment being studied. Mays and Pope (2000) argue that reflexivity is one of the main criteria for assessing quality in qualitative research.

3.4 Rigour and trustworthiness

Determining the methodological and analytical rigour of ethnographies is often considered challenging (Higginbottom et al, 2013). This is often primarily established by the researcher adopting a self-conscious and reflective approach (as identified above), whilst using an explicit methodological framework (Higginbottom, 2004). In ethnography, researchers are relied on to represent the data with integrity, so that researcher characteristics can be considered when their conclusions are evaluated. This study uses a high degree of reflexivity and transparency throughout the thesis to support this (Higginbottom et al, 2013). Triangulation is also used by using conversational interviews, respondent validation, and contextualisation of the data (or lies) collected. There was also further triangulation within supervision meetings.

3.5 Hawthorn Effect and participant reactivity

Once the decision had been made to use ethnography as the methodology for the study, there was then much discussion around how I would observe the phenomenon. It was felt that this should be done with me operating as a participant observer, but there was some debate as to whether this would be done overtly or covertly. I felt that this had to be done overtly as a huge amount of suspicion would be generated if I appeared on a ward as a band five staff nurse, given my current senior lecturer status at the University and previous senior roles in practice. Overt participant observation has also been described as a complete participant role (Zempi, 2017), where the researcher becomes an ‘ordinary’ participant in the environment. Interestingly, complete participation often involves being a covert participant, which is the opposite of the stance taken in this study. Some authors have suggested that complete participation is the ideal stance for the researcher to take (Ferrell and Hamm, 1998, Hancock, 2018). If this stance is taken, then Jules-Rosette (1978) calls for the researcher to engage in reflexive ethnography, where the researcher is totally immersed in the environment and culture. This was relatively easy for me to do given that I was effectively already a member of the larger group, that is, an established nurse, and had some gauge of the culture with which I was engaging. I also had to be aware of the dangers of being a complete participant or insider.

Whilst the insider roles potentially offer unique insights, it has been highlighted that the researcher may over identify with the participants and fail to treat them as open to investigation due to over rapport (Miller, 1952). There is also a risk that analysis may be compromised in favour of participation and that this may impact on the research (Hammersley, 2004). In this study the impact was minimised using high levels of reflexivity and triangulation.

As the research was being conducted from an emic perspective, the potential impact of the researcher needed be considered (Boet et al, 2012). This is sometimes referred to as the Hawthorn Effect. This term acknowledges the fact that, as researchers, we may have an impact on those we study with the result that we record what the research participants want us to see rather than what happens when they are not being observed. It is important to recognise and monitor any effect, and in some cases, the researcher may be able to exploit it.

This emic perspective is often then combined with the researcher's etic perspective, which would reflect their own social origins, values, beliefs, and training. However, for me, both my emic and etic perspectives are quite similar, given that I am a qualified nurse who has not only undergone the same training as many of the participants, but has also taught many of them at both pre- and post-registration level. This meant that we already had a range of shared beliefs and values related to both people and nursing.

The Hawthorn Effect was of major concern to the Research Ethics Committee (REC) when ethical approval was applied for to conduct this study. There were repeated questions at both panels about how my presence would influence behaviour as the panel generally felt that by acting overtly as a participant observer, people were less likely to tell lies and would be very careful during any interactions that were observed, effectively invalidating the research. Hammersley and Atkinson (2019) identified that there can be a tendency to dramatise the potential impact of ethnographic research, implying a level of potential harm that is far more than what is usually experienced. A concern was also raised as to whether my seniority as a Specialist Practitioner and Senior Lecturer would cause a change in behaviour in staff if there was a perceived imbalance in power. Although I would be working as a band 5 staff nurse, in the appropriate uniform, it needed to be acknowledged that most other staff who knew me, would regard me as more senior, given the number of years I have been qualified and the senior roles I have held. This was of particular concern in relation to those more newly qualified staff who had only known me as a senior lecturer, or those more established staff who had perhaps attended a module, which I run on the post qualifying programmes. The REC also raised concern that ultimately that this could have a negative impact on patient care, as healthcare professionals may not sustain relationships in the usual or expected way whilst being observed. The concerns of the REC were also in contrast to much of the research into the Hawthorne Effect in health professions research which suggests that significant changes in behaviour are unlikely and that sustained contact over a period, with the participants can improve the quality of data collection (Paradis and Sutkin, 2017). This happens as trust and rapport are established so that participants are less likely to conform to social norms as they would with a stranger. People quickly begin to behave in their usual way as they would with anyone they know and feel comfortable with (Ridgeway, 2011).

It is perhaps useful to contextualise the origins of the term Hawthorne Effect. The Hawthorne experiments took place in America between 1924 and 1933, in an industrial environment examining the relationship between supervisory activity and productivity (Gillespie, 1991, Hassard, 2012). These experiments were conducted under artificial conditions, specifically created for the studies (French, 1953). This is in strong contrast to most ethnographic studies, including the present one, where a strong naturalistic stance is taken, and every effort is made to collect data in an unmodified environment. There have been multiple systematic reviews of the Hawthorne Effect (Adair, 1984, Chiesa and Hobbs, 2008, Cambridge et al, 2014) which all pointed to a broad and inconsistent use of the term Hawthorn Effect, which is largely anecdotal in terms of its existence. The only time that there is some empirical evidence to support the notion that a researcher may inadvertently influence a participant’s behaviour is where a participant adapts their behaviour to meet the perceived expectations of the observer (Adair, 1984, McCambridge et al, 2014). This was less likely to be an issue in the clinical environment as the activities being observed were regular occurrences and part of the usual caring behaviours. Considering these findings, and the concerns raised by the REC, it is important that I consider the Hawthorn Effect in relation to the study.

Ng et al (2013) broadly defined the effect as participants acting differently when an observer was present. They also advised that any effects could be minimised by the researcher spending a prolonged period in the field whilst taking the time to establish trust and rapport and acknowledging issues such as dress or uniform to blend in. They also highlighted the need to record and reflect on any incidents that were perceived to occur because of the Hawthorn Effect. Whilst the recording of perceived occurrences of the Hawthorne Effect is a generally recognised mitigating strategy, Paradis and Sutkin (2017) did not find any examples of the Hawthorn Effect during their study. They suggest that this is because healthcare professional participants do not significantly alter their behaviour when watched; perhaps because all healthcare professionals are accustomed to being observed on a regular basis. Both wards that were used in the present study were areas that take students from a range of disciplines including nursing, physiotherapy, occupational therapy, and medicine. It is not unusual to be observed both during specific interventions, but sometimes, for the duration of a shift. There is also an acceptance that as professionals, we constantly observe and monitor each other’s performance for staff development reasons and, in addition, we are observed by patients themselves and their families. Therefore, having another person observing, might not have the impact it potentially could in other environments. Adler and Adler (1994) commented that the naturalness of the observer’s role can make it one of the least obtrusive research techniques. For me, it was natural to function in the role of a nurse and was a role that the teams participating in the research were used to me fulfilling. In relation to my study, it may be more appropriate to use the term ‘participant reactivity’ (Paradis and Sutkin, 2017). Generally, nursing teams will always modify their behaviour to some degree when a new member is added. Effectively it moves the team into a period of change where boundaries are redrawn and relationships are evaluated similar to the process of storming, norming and performing, as described in the seminal work of Lewins (1951). The initial period of ‘storming’ was in fact, very brief as I knew so many staff and they were very welcoming. This enabled moving into the ‘norming’ phase, relatively quickly. I felt the initial responses I received were a result of my presence as a nurse in the team rather than in my role as a researcher. Most people asked questions about where I had nursed previously or brought up anecdotes that they had either heard about me or times we had previously worked together. There were rarely any comments related to my research although sometimes I was asked about my move to the University. Both teams that I joined then moved back to ‘performing’ with me as a member of the team.

Reflection

I had given a lot of thought to how my presence on the ward might be received and what impact that would have, from when I started planning the study. One of my main concerns was that I was going to feel very exposed and vulnerable. I am working as a senior lecturer in mental health, but generally regarded as a specialist practitioner in working with people with dementia. I had not worked on the wards for 4 years and I was concerned that there would be an expectation that I would be able to join a team and function immediately at that specialist level (even though my role was a band five staff nurse). If I was not able to do this, or did not meet people’s expectations, then my credibility not only as a nurse, but as a senior lecturer was in jeopardy. I spend a lot of time talking to people about how things should be done in practice and now there was pressure to see if I could walk the walk, after talking the talk.

After being orientated to the ward after the handover on my first day (ward one) I was talking to two of the staff nurses about these anxieties. They were newly qualified staff who I have taught extensively. They also said they were nervous, not because of the study but because they felt I had very high standards of care. Once we had discussed these, it felt much more relaxed and I felt as though I was quickly absorbed into the team. There were some questions or challenges from healthcare assistants as to whether I could still do the job, but these were often refuted by healthcare assistants who I had worked with previously.

From the start I made a point of helping with some of the more challenging patients and carrying out some of the less popular tasks to ensure that I demonstrated that I wanted to be a part of the team. This worked very well and within a couple of shifts one of the healthcare assistants commented that it felt like I had been there forever. My team membership was further reinforced when the ward manager from the first ward, offered to let me return for a second period of data collection. The response from the wider team was so positive and encouraging, it really boosted my confidence. There were very similar experiences on the second ward.

I think that there was very little Hawthorn Effect observed where behaviour was changed because of the research. I do think for the first couple of shifts there was some reactivity from the staff and their behaviour was perhaps a little guarded, but I would attribute this to having a new team member and the natural resocialisation that occurs whilst the team reforms and builds up trust. As the trust became more established, staff would sometimes let me know if they were going to carry out a planned intervention that involved lie telling and ask if I wanted to be involved. At other times, they would sometimes realise that they had told an untruth but then would check in with me to make sure that I had heard it so I could go and write it down. When this happened, I did reflect that I would need to notice any increase in lie telling, in case some of the interactions were in fact participant reactivity but this was not identified when analysing the data. When I looked at the number of lies collected on each shift it was fairly consistent, apart from one specific day which will be discussed in detail later (p.245) as the changes appeared to be due to the relationships and social dynamics of the staff on duty. I think my experiences reflect the findings in the literature where the actual impact of what is perceived to be a Hawthorn Effect is much lower than perceived and is mitigated by the impact of developing trusting relationships.

3.6 Research field and access

I decided to approach the local mental health trust to request field access. I had previously worked for them and had strong links within my current role. I also knew that there were multiple potential sites that would be suitable for conducting the research. This was an advantage so that I only had to deal with one Trust in relation to things such as honorary contracts, Trust induction etc.

3.6.1 Gatekeepers

When initially considering access to the research field, I was unsure about who would be the first gatekeeper I needed to talk to. After making some enquiries about the overall management structure in the Trust, I was directed to the Clinical Nurse Manager for Older Persons Services who had overall responsibility for the inpatient areas that I was likely to want access to. This was a senior nurse who I had known for many years. I had been a junior staff nurse and worked for them when they were the ward manager. We had maintained intermittent contact but had always enjoyed catching up at conferences and the like. When I made initial contact, she invited me to meet her in the Trust. She was very supportive of the study from the beginning, and we met on a regular basis throughout its duration. She was instrumental in setting up meetings with other relevant people and helping me to overcome some of the challenges of access to the field that presented themselves.

After some discussion with my supervision team and the Clinical Nurse Manager, it was decided that the research would best be carried out over multiple sites that provided care for a similar client group. It is important to identify that for this study, the setting was simply the context where the phenomenon was likely to be observed in the identified client group; that is, people with moderate to severe dementia, who were unlikely to have capacity to make many decisions due to their high level of cognitive impairment affecting their short-term memory. To have capacity to make a specific decision, a person needs to be able to take on board the information, retain it long enough to weigh up the information and then make and communicate the decision (Mental Capacity Act, 2005). Whilst the setting itself did not provide any actual data, the therapeutic milieux of the setting did influence the quantity and type of data collected. This was highlighted by Goffman (1963) who identified that the settings and social space can shape a person’s behaviour. This was captured by daily reflections specifically about the environment and possible outside influences on the data. Reflexivity in relation to context was important to identify any emerging social constructs that influenced communication and to avoid false generalisations.

Often, different sites where similar activities occur can provide a deeper insight and understanding into the observed phenomenon (Hammersley and Atkinson, 2019). It also helps to potentially increase the scope of the research by using multiple sites as it helps to identify which interactions are typical within the specified community rather than those that are specific to a particular ward, team or culture. This, in turn, may help support the transferability of the findings, which is acknowledged as being difficult to do with ethnographic research (Rapley, 2014). Any transferability that emerges from this study will be constrained to a defined and finite population or context (Schofield, 1990). The downside of using multiple sites meant that there was less time available at each site for observation and some researchers would challenge that this could reduce the depth of data collected (Harper, 2018).

Initially, three wards were identified by the Clinical Nurse Manager as having suitable client groups. The Clinical Nurse Manager, who was the first level gatekeeper, made initial contact with the service directors for each area and then the ward managers, to introduce the project. They were very supportive of the study and were instrumental in supporting and reassuring the staff that engagement in the study would be positive and contribute towards new knowledge.

When making the initial contacts with the Trust and other potential gatekeepers, I was very much guided by the Clinical Nurse Manager. The first meetings that I was asked to attend were very informal and were used to start to establish a working and collegiate relationship with the Service Directors and Ward Managers. This could be described as ‘casing the joint’ (Hammersley and Atkinson, 2019). This is a significant level activity required in relation to gaining access to a community as it may highlight potential challenges or barriers that may need to be overcome. It also helps to identify who the key personnel and influencers are in each area. The Clinical Nurse Manager had already told me that the Service Managers were very keen to have research carried out in their area but did have some concerns about the topic. They had also made it clear that the final decision would be up to the ward managers after they had discussed the issues with their teams. This process of ‘casing the joint’ happened over a period of many months but was crucial in ensuring that I had started to develop strong relationships with the gatekeepers who would then be able to talk to their staff in positive terms about being involved in the project.

Lincoln and Guba (1985) described this as ‘mutual shaping’, where the researcher and potential participants start to get to know each other and it is an important part of a constructivist methodology. This is because constructivist researchers believe that “people give meaning to reality, events and phenomena by sustained and complex processes of social interaction” (Schwandt, 1994, p118). This focus on the impact on individuals rather than on society more generally, is something that is often criticised in constructivism. However, this view does not acknowledge that constructivism does recognise the complex interactions that help to form, develop, and alter an individual’s constructions of any phenomena (Lincoln and Guba, 2000).

3.6.2 Site access

When initial access was being negotiated, the very topic of being observed telling lies raised questions and concerns. At the initial meeting with the ward, anxieties were expressed about the recording of lie telling given that this behaviour goes against the NMC (2018) Code of Conduct. Much reassurance was needed in relation to confidentiality and consequences of the study. I also had to bear in mind that whilst I needed the permission of the Service Directors and Ward Managers to access the settings, I also needed the support and consent of the ward staff, both qualified and unqualified. In some ways the healthcare assistants were the most challenging as they expressed the most concern over being observed. They are not constrained by the NMC; however, most had very strong views about telling lies and were concerned at having any lies that they told recorded. Healthcare assistants are the staff group who have the most contact with patients (Chapman and Law, 2009) and therefore were likely to be the greatest source of data. However, I had fewer established relationships in this staff group than for example, amongst the qualified members of staff.

It seemed that that the perception of the qualified staff was that I was an expert and part of my research role was to help provide them with a solution to the problem of lie telling; that is, as a result of the research I would generate some guidance about when and if lies can be used and use this to develop current practice guidelines. This was positive in that it did encourage them to participate but there was still a lot of concerns voiced. As well as the social and cultural implications of lie telling, nurses are very aware of the NMC guidance whose Code of Conduct dictates that it is essential for nurses to prioritise people, practise effectively, preserve safety and promote professionalism and trust (NMC, 2018). This guidance can often be a source of conflict when it also promotes the concept of beneficence and to do this, a nurse may need to tell a lie. There is no current guidance on how a nurse should proceed in these complex scenarios. By participating in the research, most of the nurses were hopeful that the study would be able to provide some clearer guidance on the matter. This contrasts with the perception of the healthcare assistants who initially said that they were worried that my role would be more akin to that of a critic or evaluator and that I was going to openly challenge their practice.

I started the negotiation process with regular meetings with the ward managers to address anxieties and build relationships. Once the managers had agreed in principle to the research going ahead, I started to have meetings with the staff teams. Initially these were very informal chats where I just talked to them about what I wanted to do. Once I had started to establish relationships with the wider staff team, I sent information packs for all members of staff before meeting with them again (Appendix 1 – PHD01, Appendix 2 – PHD02, Appendix 3- PHD03, Appendix 4- PHD04, Appendix 5-PHD05). Once they had received all the information, staff tended to have more questions and probably higher anxiety levels about the research. However, because I had started to build relationships with them, they seemed more comfortable expressing their concerns, so I was able to address them more effectively. Interestingly, staff did not identify the word 'lie' as problematic since they used it routinely with carers on admission when discussing possible interventions for their relative or friend. It also illustrates the importance of the use of self by the researcher in terms of how relationships grow (Goffman, 1955). The minutes of the meetings held are in Appendix 8.

Reflection

Much has been written about the tensions that can arise between the role of the researcher and that of a participant, or nurse in this case. During my data collection I did not experience this frequently. I love being a nurse and I am very comfortable in the role. On the occasions this did arise, I reflected deeply and this is documented as appropriate in the Findings and Discussion chapter (p.112). I felt privileged to be accepted into the teams so quickly and as such was often asked to contribute to discussions or give advice on specific practice issues which I did so readily. On occasion this meant that I was privy to discussions about care interventions that would involve lie telling which was particularly helpful in contextualising some of the data that was collected. I do not think this presented any tensions about my researcher role as I was still able to collect data whenever it was available, but the fact that staff were comfortable with me and trusted me both personally and professionally meant that their behaviour was likely to be more natural in front of me, which enhanced the data collection. I was also shown a huge amount of respect as a clinical nurse. I think that because I was respected as an effective clinician, people seemed to automatically transfer this respect to me as a researcher. This is not entirely comfortable given that whilst I am a very experienced, nurse, I am very much a novice researcher.

To reinforce the perception of me as a nurse, it was important that I wore a staff nurse uniform in practice. I considered whether I should wear a navy uniform akin to that of a clinical nurse lead or ward manager. However, I anticipated that one of the key elements that would facilitate the data collection, was how well and how quickly I was accepted into the nursing team. If I had worn navy, it would have potentially changed the interactions with both staff and patients by visually making a statement about my seniority. I wanted very much to be able to both observe and participate in what could be described as ordinary and regular communications, not influenced by power. This reflects the aim of unfettered enquiry, desirable in analytic ethnography (Lofland, 1995). Equally, I decided that I did need to be represented as a registered nurse, rather than wearing a healthcare assistant uniform. If I had chosen this route, I would have been able to participate in patient care but not in a role that was familiar to me or those around me who knew me as a nurse. I may also have been perceived as an imposter (Moreto,2017). It was important to maintain my identity as a nurse to establish myself within the team and build trust. Socialising into the ward team, to help minimise the risk of any reactivity impacting on the data collected (Paradis & Sutkin, 2017). Dressing and functioning as a staff nurse helped me to exploit the relevant skills and knowledge I already had, to accelerate acceptance as a team member. It also made me feel more comfortable when I was providing care as I feel my uniform helps to validate me as a nurse. As Rowe (2014) commented, it is important to dress in a credible manner which allows the researcher to develop relationships with a range of audiences. In this case, it helped to illustrate an affinity between the hosts and me.

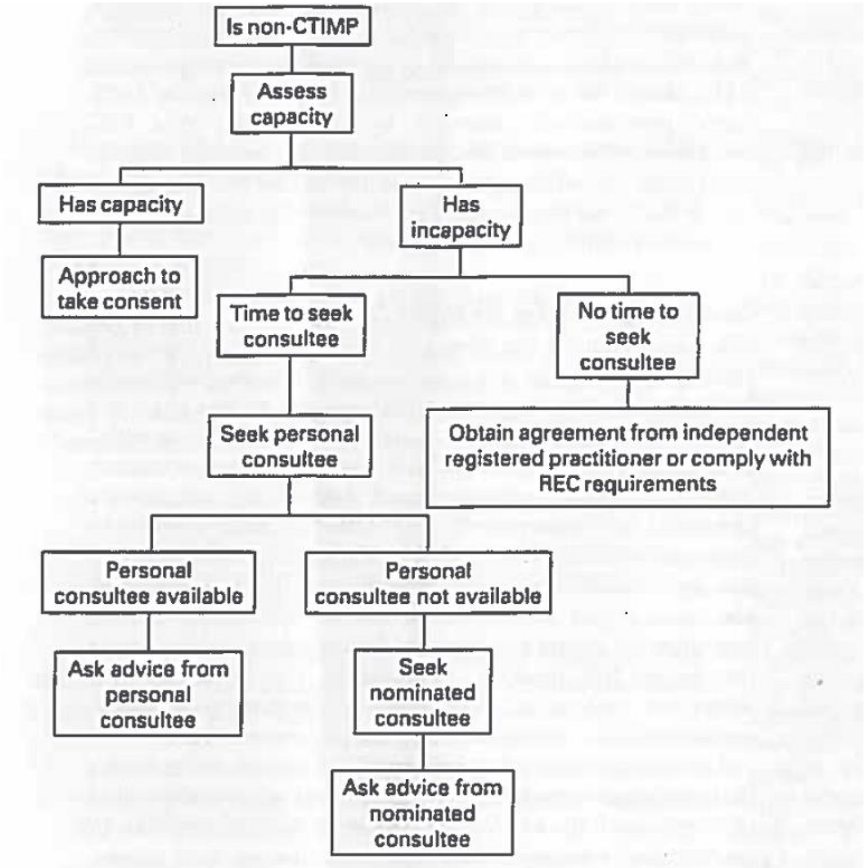
3.6.3 Gaining consent

To gain informed consent from staff, I was explicit in my purpose and how the research would be carried out. This effectively became a ‘research bargain’ (Hammersley and Atkinson, 2019). In return for being allowed to collect data, they would gain an extra member of staff who would be supernumerary and was willing to engage in all tasks on the ward. The wards were extremely busy, and an extra pair of experienced hands was a strong bargaining tool. There was a danger that staff then felt obliged to participate to have more staff. However, once I had started to collect data, and had been able to talk to staff more about the research I felt comfortable that they were participating because they wanted to and felt there was value in the study. During general discussions, staff would often remark about how important it was to challenge the current guidelines from the NMC (2018) and GMC (2019) in terms of lying as it was an important part of their toolkit.

The other group of people from whom I had to seek permission were the relatives and carers of the people with dementia. Whilst the staff were the participants who were being observed, I felt it was important to gain consent in relation to the people with dementia as well, as I would be recording their responses during the interactions. Most patients who were likely to be involved in the communications to be observed and subsequently recorded, were likely to lack capacity under the Mental Capacity Act (MCA, 2005) in relation to most decisions, including the ability to give informed consent to participate in the research. The wards they were on specifically cared for people with moderate to severe dementia and who had very limited short-term memory. This meant that they were unlikely to retain information long enough to weigh it up, and subsequently communicate their decision. I consulted the carers, Lasting Power of Attorney's and significant others, where the people with dementia were unable to give consent due to lack of capacity, and although they could not give consent or otherwise for the person with dementia, they could give their opinion, which was documented on the consultee declaration forms, in line with the MCA (2005). Any advanced decisions were also considered so that a best interest decision could be taken for each individual in relation to participation. This was done by the multi-disciplinary team. Anyone consulted could opt for their friend, relative or appointee to be excluded from the study at any point. Information was given as per Appendix 6 and consent obtained via Appendix 7). The information posters and cards were also widely visible to people when they visited the wards. This is illustrated in the algorithm below (Dixon-Woods & Angell, 2009, Figure 7). This is further discussed in the section in section 3.7, Ethical approval, informed consent and confidentiality (p.95).

Despite the risk of the study causing distress to patients during the study being minimal, the study was automatically rated as red or high risk due to the patients on the ward being covered by sections 30-33 of the Mental Capacity Act (2005). The risk was minimised as the study was ethnographic in nature and required all participants (professional care givers) to carry out their normal daily routines and behaviours as usual and in line with planned care so that I could observe the regular interactions and communications with patients (Fetterman, 2010). This was assessed as illustrated in Appendix 9. The other risk that was identified was potentially injury to me whilst on the ward. This is captured in Appendix 10 - Risk Assessment for risk of researcher being the subject of violence and aggression on the ward. As part of this risk assessment, and to fulfil my honorary contract within the Trust, it was decided that I would have to complete the Trust Prevention and Management of Violence and Aggression (PMVA) five-day training. This was completed before data collection commenced.

Figure 7 Dixon-Woods & Angell, (2009)



(CTIMP – Clinical trials of investigational medicinal products)

Reflection

Initially when I was told I would have to complete the 5-day PMVA course I was really irritated. I have been a nurse in older person's services for many years and have only had to restrain a person once. This showed a lack of insight on my part as to how the older inpatient population has changed over recent years. It was approximately 5 years since I had worked on the nurse bank. I found the course quite challenging since it is very physical and covers everything from simple holds to face down and mechanical restraint. Prior to my data collection, I have never been involved in an incident where this would be considered on an older person's ward.

Once I started my data collection, I was very relieved that I had done the training. I had not anticipated the physicality of some of the patients or the levels of aggression exhibited. Some level of restraint was seen or carried out on most shifts. On three occasions, I witnessed staff being seriously injured and subsequently hospitalised. During these incidents, my primary role became that of a nurse, rather than a researcher, although sometimes I was able to collect data in the process. As I am governed by the NMC and the Trust legislation, it was important at times of emergency that I was able to fulfil my role as a nurse and a registrant to preserve the safety of both staff and patients. If any lies were witnessed during an incident, they were documented as soon as possible after the environment and people were safe.

3.6.4 Consulting with relatives and carers

Consulting with relatives and carers prior to starting the study proved to be challenging as there was a high level of indifference expressed by families. This can often be experienced by researchers (Shaffir & Stebbins, 1991) and was quite disconcerting. I arranged multiple meetings with families prior to staring the research but only got to meet with a few. This can be seen in Appendix 8 where it is documented that no relatives came to the final consultation meeting. The general feelings expressed were that as family members, lie telling was an important part of their tool kit and they did not have any issue with it. They were quite happy to complete the consultee declaration forms on behalf of their relative but did not want any other participation in the research. This is understandable given the point at which their relatives or friends were in their dementia journeys. The home situation had reached crisis point resulting in an admission to hospital. Relatives and carers wanted the time on the ward to be spent with the patient, or staff in understanding the illness and looking to how to improve the situation. They did not have capacity to include a research dimension into their visits. Rather than organising repeated meetings, once it had been agreed that the research could go ahead, staff gave out information packs to relatives and carers for them to take home and read. No relatives or carers refused to give consent for the patients to be included in the research. They were very supportive of the purpose of the project but did not want it to impact on the time they were visiting the ward. Hammersley and Atkinson (2019) identified that this is often an issue in ethnography, as often people have alternative agendas which give them little motivation to engage with the research. The minutes from meetings with carers that did take place are in Appendix 8.

Once the data collection started, the third identified ward declined access and would not give a reason. The first ward where I was collecting data at the time said that they were more than happy to have me go back to them to collect more data. This worked very well as when I returned; I knew the ward routine and the staff well, but the client group had changed therefore there was a range of different interactions occurring, compared to the first visit. There had also been some staff changes amongst both the qualified and unqualified staff. However, it is also necessary to acknowledge that this could have potentially represented a limitation of the study as overall it reduced the number of participants, though not the number of pieces of data.

Reflection

When the third ward area declined access, I had mixed feelings and some relief.

Initially, I was concerned that losing the third site might limit the data I would be able to collect. However, when the manager from ward 1 offered me the opportunity to return, I was both relieved and pleased. The feedback that they gave was that the staff team had thoroughly enjoyed having me on the ward as a staff nurse and were now much more interested and engaged in the wider remit of research. This made me feel more comfortable, and ultimately was positive for the research as when I returned, I did not have to go through a repeated process of re socialisation, I was simply welcomed back as a member of the team. However, I was concerned that it may limit the data collected due to the reduced number of participants overall. Whilst the number of participants was reduced it did not seem to affect the episodes of data collected.

The importance of my personal characteristics became more evident once the data collection had begun. Brewer and Magee (1991) highlighted the importance of developing trust with the research participants to enhance the quality of data collected. The more shifts I did, the more I felt I was trusted by each team. Jefferson (2015) would attribute this to the fact that as time went on, I was able to demonstrate my reliability and dependability in a range of circumstances, which contributed to the development of trusting relationships.

Whilst the literature spends considerable time looking at how to access the field to be studied, relatively less time is given to leaving the field (Hammersley and Atkins, 2019). In my case, I was entering the field for a defined period of time, with the option to extend if I felt I had insufficient data. There were no logistical issues in leaving either field, I was simply not added to the rota; however, I had not anticipated the emotional impact of leaving each field, either on me or the participants.

Reflection

I was perhaps rather naive in terms of my anticipation of leaving the fields. I had presumed I would complete my last shift on each site and go. However, it involved a lot more emotion than that. The first time I left site 1, it was not a big issue as both the staff and I knew that I would be returning. There were several goodbyes and comments about looking forward to my return. As I left after the first period, I felt very relieved. I had collected some data, established what felt to be strong relationships and was looking forward to returning. I had gained confidence in the sense that I was still able to demonstrate a high level of nursing skill which had been openly valued by other staff. I had felt comfortable in the role of the nurse and the researcher and had experienced minimal conflict between the two roles. It made going to the second site much less anxiety provoking.

When I left the first site for the second time, it was much harder. The relationships that I had built up were surprisingly strong and the ward manager asked if I would return on the nurse bank. The other staff reiterated that. I felt valued by the team and felt I was making a useful contribution to it. These feelings were not really related to being a researcher as the data collection was a process that was running concurrently with being a nurse. It is difficult to know what impact my leaving the site had on staff or patients. I think the impact on individual patients would be minimal as most of them could not remember individual staff. It may have made a difference in terms of activities or extra interventions that could be carried out on the ward as I was supernumerary, and this facilitated the team being able to spend a little more time with the individuals. In terms of impact on the staff, I think the main thing would be that it had been nice to have an extra pair of extra hands when the ward was busy. However, ward teams are in a constant state of flux with team members coming and going so the team would quickly storm and reform once I had gone (Lewin, 1958). On occasions when I have returned to the ward as an academic, I have been warmly welcomed, and I am always invited to rejoin to the staff team.

When I left the second site, I had spent less time (half) with this team. However, many of the same sentiments were echoed. I have not revisited this site as it subsequently had its remit changed and was then closed.
When data collection was finished and I completed my last shift, I felt almost hollow as I walked away. I felt that I was leaving the ‘nursing me’ behind and stepping back into my academic role, and I think I will always primarily identify as a nurse. I also felt a weight of responsibility. I now had the data, and it was up to me to now use the information to develop practice and write my thesis. This was very daunting as I find it hard to identify as a researcher given how early in that journey I am.

As Hammersley and Atkinson (2019) point out, as an overt participant observer, you are often positioned between stranger and friend. This can cause mixed feelings when leaving the field, with Desmond (2016) describing the feelings of divided loyalties, which I experienced. Morris (2016) further explores in terms of the researcher leaving their comfortable and familiar (clinical) environment to return to the role of researcher.

3.7 Ethical approval, informed consent, and confidentiality

From the beginning of this study, it was always anticipated that there would be some ethical challenges, even though it met the criteria for approval of research involving adults who lack mental capacity (MCA, 2005). Generally, the challenges were not related to the activity of the study, but predominantly caused by the wording of it; to undertake a critical analysis of the concept of lying in clinical practice, in the context of people with dementia. As discussed in previous chapters, the word lie tends to evoke strong and usually negative emotions in people (Elvish et al, 2010). There are other terms that perhaps soften the emotional impact such as white lie or fiblet but, after much discussion with my supervision team, it was felt that these words did not effectively identify what the study intended to do and could potentially be construed as deceptive in themselves.

The study itself focussed on the communication of the healthcare professionals (any member of staff who delivered care as part of their job), who would only be identified by role and no other data recorded. All data was completely anonymised. On the basis that participants would be being observed interacting with people with dementia, who were likely to lack capacity (MCA, 2005) and both parts of the interaction would be recorded, I felt that a declaration should also be sought from identified consultees of the patients in line with section 33 35 of the MCA. When carrying out research with people who lack capacity, the Mental Capacity Act states that you should ask the advice of a consultee rather than seeking to gain specific consent from the person who lacks capacity (Dixon-Woods & Angell, 2008). This inclusion was one of the main reasons that ethical approval was initially withheld by Northumbria University internal ethics reviewers. After meeting with one of the internal reviewers, I was advised to remove this section as the patients were not the focus of the study. Once removed, the study was given ethical approval by the institution.

The proposal was then submitted to the Regional Ethics Committee (REC) and subsequently examined. There has been considerable criticism of RECs, highlighting that they usually have limited knowledge of ethnographic methods of study and often do not understand the contexts that the researcher will be working in (Hammersley and Atkins, 2019). Following a meeting of the Committee regarding the study, an unfavourable opinion was given, although they did say that *in principle*, they supported this field of research. On the day, the panel had many questions and subsequently asked for ten specific points to be addressed in their formal response. They were particularly concerned about why I had not included patients as participants. This led to further questions about my own ability to carry out accurate assessments of mental capacity and the suitability and experience of my supervisors.

There was a strong recommendation that I engage with patients and carers in the redesign of the research, including the acceptability of the information sheets, and consultee declaration forms. Ultimately, the amendments were made in relation to the consultees, but patients were not included in this as it was agreed by the ward areas that this would be inappropriate due to the very limited short-term memory of the patients. Consultee declaration forms were developed in line with the MCA. The REC had challenged the use of the word ‘lies’ on public facing documentation. This perhaps stems from a frequently expressed concern about ethnographic research; that a study will make previously private phenomena public, with negative consequences (Mckenzie, 2015). The concerns raised by the REC were very similar to those identified by Chege (2015) where there was concern that some private issues may become public, and the committee specifically explored what would happen to public confidence and perception if the media were to headline stories about nurses and healthcare staff telling lies. The REC was subsequently reassured that this did not present an issue for consultees or potential participants after I had engaged with them more extensively and they agreed to the terminology that had been proposed. The IRAS form was submitted for a second time and I attended a second REC. The project received full approval from both the REC (Appendix 13) and the Health Research Authority (HRA) (Appendix 14) in May 2018.

During the REC meetings, other concerns were also raised. The REC was keen to ensure that I put measures in place to mitigate any discomfort or distress caused to the participants (in this case, staff). It was explained and documented that due to the nature of the study (observing usual and regular practice) these were not anticipated outcomes. However, it was highlighted that the fact that the study was being conducted was likely to make people more aware of their own practice and the concept of truth and lies could elicit strong emotions in people. All staff had access to clinical supervision as per the Trust policy, where any issues could be discussed. They also had the opportunity to discuss and reflect with me whenever they felt they needed to. There was regular discussion and reflections about the study on the ward, but no one ever became distressed or expressed discomfort whilst participating. If staff had felt they needed further, ongoing support, they had access to the Trust Occupational Health service. This was also been risk assessed (Appendix 9) and the potential risk of this occurrence minimised.

Another concern raised was what action would I take if there were any disclosures or concerns around unsafe patient practices. As an NMC registrant, I would follow NMC guidelines (NMC 2015). I would also be employed by the Trust during the data collection period on an honorary staff nurse contract. This meant that I was bound by the same regulations as any other member of staff and had both a moral and legal obligation to report any concerns through the identified channels.

In terms of obtaining informed consent from staff, the ward managers agreed that they would distribute all the relevant information to people and then collect the signed consent forms. If anyone did not want to sign, there was no further pressure to do so, and if there were any further questions that people had they could contact me directly and I would arrange to either speak to them on the telephone or arrange a face-to-face meeting. Neither of these actions were needed as everyone agreed to participate. The named nurses for each patient spoke to family members and consultees during their regular meetings and collected their consultee declaration forms. Again, they were encouraged to contact me directly if they had any concerns or wanted further information. No one did contact me, and all consultees signed the consultee declaration forms. This meant that all interactions were able to be recorded as the patients all had consultee declaration forms completed (MCA, 2005) and all staff had completed a consent form. It was reinforced that any point, people who had previously agreed to be part of the study, could withdraw at any point with no consequence. In line with IRAS guidance, any data which had been collected up to the point of withdrawal could be retained as data could not be directly linked to each participant. Apart from on the IRAS form, neither of the ward areas are identified.

Reflection

Throughout the development and design of the study, I have maintained that participants and patients would be anonymous, but this is quite uncomfortable as it is only true in an academic sense. Generally, anyone reading the thesis or publications generated from the research would not be able to identify any of the staff or patients. However, I do feel some discomfort in the fact that anyone from either of the wards that I had collected data on would be very likely to either be able to identify themselves, specific participants or patients. This was something experienced by Morriss (2016) to such a level that they were unable to continue with their data analysis. The discomfort I felt was not to this level but nevertheless, exists still. I had guaranteed anonymity, yet some of the stories and interactions were so personal in nature and related to very specific behaviours, it would be difficult not to attribute them to individuals. I am uncomfortable with this as it feels I have engaged in some form of deceit as part of the study by guaranteeing anonymity knowing that there will be a small group of people who will be able to identify both participants and patients. However, I also know it is not really an issue as everyone has given consent and there were no negative or detrimental interactions witnessed. The most negative thing was probably indifference, which whilst not ideal was understandable at the points it was observed. Where patients are identifiable, staff are bound either by their professional registrations or their contracts not to identify them or disclose any information in relation to them.

Technically the two ward areas that were eventually used were not identified, anyone working regionally could potentially work out which wards they were as there are a limited number of clinical areas that meet the needs of the specified patient group. This is more difficult to calculate now as one of the wards has been closed.

All potential participants were given copies of:

Appendix 1 PHD 01 - Participant Invitation Letter V2

Appendix 2 PHD 02 - Participant Information Sheet

Appendix 3 PH03 - Participant Information Card for Observation

Appendix 5 PH05 – Participant Consent form V2

All consultees were given copy of;

Appendix 6 PHD 08 - Consultee Information Sheet

Appendix 7 PHD – 09 Consultee Declaration Form

Whilst the participants were recruited as above, posters were also put up around the wards where data was to be collected so that anyone who had not been directly approached was aware that the study was being conducted and had contact details if they required any further information (Appendix 4). This applied to both active participants (staff) and the consultees of the passive participants (people with dementia). This was only likely to happen if there were professional carers visiting the ward or bank / agency staff were used, or there was an emergency admission. Information packs were available to be given to people as soon as was practicably possible and people were given the opportunity to either give or decline consent to have their interactions documented. Whilst this was an eventuality that was prepared for, it did not happen during the study.

Reflection

The journey to gain ethical approval for this study was challenging as had been anticipated. At the REC the main issues raised were that there was nothing about the patients as passive participants or the MCA and the committee were concerned that this raised questions about my understanding of this client group and my ability to carry out the study. This was very hard to hear as I completely agreed with them but had been advised against inclusion at an internal ethics review. The REC itself is a difficult meeting to attend but was very useful. It was the first-time people I did not know in any capacity had examined the study and questioned me on it. Whilst the process is difficult it also gives you a different perspective that helps you to prepare for challenges that may well come. This was particularly the case in relation to the Hawthorn Effect. The questions from the REC prompted me to research the evidence base in more depth and as a result I was much better prepared when those queries came up in the future.

The amendments to the Integrated Research Application (IRAS) form were relatively easy to complete as I had all the information with regards to capacity prepared on an earlier internal submission. The second visit to the REC was much easier as I had been able to include a lot of information I had always felt needed to be there. By the second committee I had also started to carry out more formal meetings with staff and carers in line with the initial recommendation that they should be involved with the development of the study. I had felt uncomfortable starting this process prior to my submission to the REC as I would be carrying them out with no real surety that the study would be able to go ahead. Meeting with carers and staff meant that I could confidently refute the REC's concerns in relation to the use of the word 'lie' as the feedback was that it was not an issue.

Whilst the process of attending the RECs is stressful, they are also excellent learning opportunities that helped me to build confidence in my own ability and decision making. The second committee was much easier, and I felt quite comfortable fielding the questions as I had prepared for it quite differently, based on the feedback from the first one.

3.8 Data collection, Sampling, and the sampling process

The sample was a purposive, criterion sample, which has been identified as useful for quality assurance in ethnography (Miles and Huberman, 1994). It could also be described as multistage (Hammersley and Atkinson, 2019). The initial unit of sampling was the wards. They were selected on the basis that all the patients had a diagnosis of moderate to severe dementia, as this was an admission criterion for both of the clinical areas that were used. Therefore, all staff interactions involving untruths or lies were included in the study. The staff participants then formed the second level of sampling. Fetterman (1998, P.32) describes this as the 'big net approach' which ensures that the widest range of available data is collected initially. In total there were 35 staff from site 1 and 28 participants from site 2 (Site 3 withdrew from the study). There were more from site one as new staff had joined the team who were willing to participate when I went for my second period of data collection, and some of the previous participants had left. It was anticipated that the data collected would be rich (of high quality) and thick (a large quantity) considering the research already done in this field which indicated that I would witness lies being told on a regular basis (Dibley, 2011). It was planned that I would go to each ward for 15 shifts. This equated to approximately 338 hours in total. This could have been extended if there was any concern about the quality or richness of data collected.

Approximately 250 lies or untruths were observed and recorded. The process of thematic analysis was started during the data collection period. At the end of the planned data collection period, it was apparent that no new themes were emerging and therefore continued data collection was unlikely to make further contribution to the taxonomy (O'Reilly and Parker, 2012).

3.9 Method

As the definition of what constitutes a lie is flexible and varied depending on the author, I took the decision to include any interaction which was not the total truth. This ultimately gave a broader range of untruths than perhaps has been previously recorded. No judgement was made as to the level of lying, the interaction was simply documented in as much detail as possible. This also helped to focus my note taking and provide a clear definition – if it was not the wholetruth, for the purposes of this study, it would be regarded as a lie.

In the original submission to the REC, I had said that I would record the content of interactions after they had been witnessed either by using a Dictaphone or a notepad. I decided not to use the Dictaphone as I found it uncomfortable in my uniform pocket and the resulting recording would have to be then transcribed. I would also have felt more conspicuous going into a room and recording what I had seen, whereas carrying a small notebook and then sitting out of the way to write a couple of notes felt comfortable as written notes were made by all staff at intervals throughout the day. Sanjek and Tratner (2015) identify that jotted notes are a useful method of recording; particularly where participant observation is being used. I was aware that I needed to be as factual as possible in the writing down of the interactions and fortunately most of the interactions were short so were relatively easy to recall and write down.

Initially, I was very focussed on recording the interaction itself, with the words that were actually spoken as I wanted to try to dispel any accusations that the notes were in fact a subjective impression and therefore somehow less valuable or important (Hammersley, 2011). It quickly became apparent that there was much more that I wanted to record in terms of the context and environment. Hence my note taking, and reflection developed as the project progressed. I was fortunate that the focus of the research was quite narrow in terms of only recording untruths so that I did not feel that the scope of the research was compromised to gain the depth or detail involved with each piece of data (Hammersley and Atkin, 2019).

Notes were made as soon as possible after the interaction was observed. This was generally done out of sight of participants and patients and as soon after the interaction as possible. After I had observed and recorded an interaction that appeared to be an untruth or lie, I often had informal conversations with the participants. This helped to clarify that it was a lie that I had seen and check the accuracy of my recording. This type of informal conversational interview is useful for increasing the understanding of the phenomenon being observed (Burgess-Limerick and Burges-Limerick, 1998). This is also a method of respondent validation or member checking and is a recognised method of improving the accuracy of the research (Mays and Pope, 2000). However, Bloor (1978) advised that it should only be considered as a method of error reduction, which may potentially generate further data which in turn will require interpretation. This is because the version produced by the researcher is designed for a wide audience and may well differ from that of an individual participant simply because they have had different roles in the research process, which has given them a different perspective.

On a couple of occasions where staff knew they were going to tell a lie as part of planned care, they let me know so that I could be within hearing distance of the interaction so that I was able to document it contemporaneously without raising concern in the patient. I also made further notes about the context in which the interaction happened and added any further information as appeared necessary. Scatzman and Strauss (1973) identified this as an important part of writing up field notes to help with the reconstruction of a specific episode. I did this after every shift bearing in mind that the content and detail can be easily lost or confused over time (Hammersley and Atkins, 2019). I also completed a written reflection about the therapeutic milieu of the ward each day. This contextualising of the data is identified in a range of literature as being an essential component of analytic ethnography (Strauss and Corbin, 1990, Huberman and Miles, 1994). It also provided some interesting insights as to when, where and possibly why untruths were more prolific. I also added some context and notes later when I was analysing the data. I could remember most of the instances quite vividly and when I looked at them, together with my reflections, I was often able to add further context or information.

This construction of analytic notes and memos is significant in analytic ethnography and demonstrates a way of almost thinking out loud, reflecting some of the internal dialogue and challenges that presented themselves. In some ways the notes became more of a fieldwork journal as I regularly documented my feelings and personal involvement in an interaction (Coffey, 1999). It was important to acknowledge and reflect on my personal emotions and feelings so that I could consider the impact, if any, on future data collection or interaction (Atkinson, 1992).

One thing I had not considered in any great depth was whether to record any lies that I personally told and how that might affect the relationships I had with staff. As I was a team member giving care in the same environment and under the same governance as other team members, I decided that my interactions should be documented in line with everyone else's. In terms of reflection, this was very thought provoking and by reflecting on my personal interactions later, I was able to further analyse my own motivations for telling lies. This perhaps reflects the deep familiarity I had with the environment and role that I was participating in and reflected that as a witness I was fully 'tuned in' to what was happening around me (Goffman, 1989).

Reflection

When I started to work on the wards it was very busy and I quickly became absorbed by the nursing teams as a full member, delivering care as planned. For some patient's specific lies were care planned and I engaged with these fully, recording the instances when I did, in full. What I perhaps had not anticipated was the number of spontaneous or unplanned lies that I would personally tell. A member of staff overheard me during one such interaction and immediately afterwards asked if I was recording it. I said that I was, and it was important that I did. They agreed and said that they liked the fact that I was monitoring and recording my own interactions in the same way as I was doing for everyone else. I think this helped build trust and opened the door for much more generalised discussion on the topic of lies, particularly around motivation as staff would sometimes question why I had said or did something in a particular way. It was also interesting to consider how I felt reflecting on lies that I had told which in some cases was quite uncomfortable, although at the time of the interaction had felt appropriate.

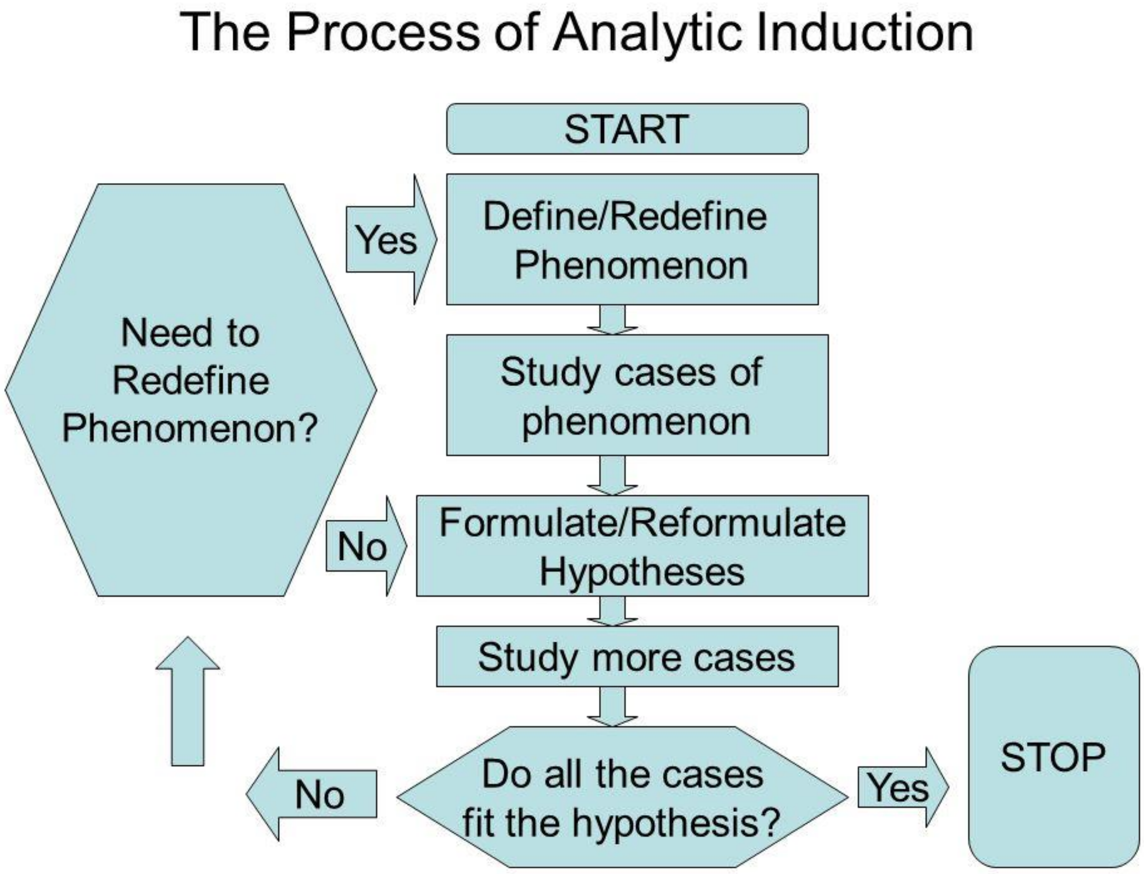
There were some instances where staff would ask if I had heard an interaction as they had just told a lie. In these instances, I only included the interaction if I had heard it. This was to avoid recording another person’s perception of what had happened rather than what was said which would have been outside of the proposed methodology of this study. Of the interactions that were reported in this way, there were none that would have sat outside of the already identified and recorded themes.

In total there were approximately 250 lies or untruths documented, and 100 pages of reflective notes collected.

3.10 Data Analysis

The data analysis was conducted using a combination of methods which could be described as a method of thematic content analysis. The process followed a similar path to that of analytic induction which was originally developed by Znaniecki in 1934 and further refined by Hammersley (1989), in relation to ethnography. The aim was to identify common themes that emerged across the interactions; therefore, the formulate / reformulate hypotheses stage was where the categories or themes were extrapolated, more in line with Burnard's method of analysing transcripts (Burnard, 1991), although only the early stages of this model were mirrored. I had some hypotheses or themes in mind that I thought would emerge given the previous work of authors such as Blum (1994). I did not, however, want to be restricted by previously identified categories as I felt that some of these were self-limiting and did not cover all observed interactions. Dunieier (2011) argues that searching for these exceptions which do not fit with previous work, is central to ethnographic work.

Figure 8



(Hammersley, 1989)

Initially I typed all the notes that I had made into a chronological table, only identifying each piece of data by which site it had been collected at and which item number it was. This was to help with the movement of data and to help finding it in the larger narrative. An example of this is given in Appendix 11. This mirrors stage two of Burnard's analysis method where the researcher begins to immerse themselves in the data (Burnard, 1991). Field and Morse (1985) identified that at this stage there may be 'dross' or unusable data which could have been excluded at this point. However, all the untruths that I had recorded were included. Any exclusion would have come at the point at which I made the original note and the only time that this would have occurred was if I thought that something that was said was a lie, but subsequently was discovered to be a truth. This did not happen, partly because I got to know the patients and their care plans very quickly so was able to separate truth and lies effectively and in real time, but also, I was able to clarify anything I was unsure of with the participants or other staff. I regularly used informal or conversational interviews to check with participants that they agreed with what I had written down and the context in which it had been said (Birt et al, 2016). It was important to do this as soon as possible after I had recorded an item so that the participant's memory of the interaction was still very fresh, and so that I could still identify the right participant to check it with as I kept not data that identified the participant after the event.

The sheets containing the individual pieces of data were printed off and each piece of data was cut out. I then began to put them in piles where I thought there was some similarity. This generated 7 initial piles or themes and was representative of open coding (Berg, 1989). I then went back through the piles, re assigning some of the data each time. I did this multiple times and then realised that I was on occasion, moving a specific piece of data between two groups. This process aligned with the formulate / reformulate part of the Hammersley model (Hammersley, 1989).

The groups were then typed up and I made notes on those which had either been moved or spanned more than one theme. I then reconsidered the themes to see if there were any other defining features of each item in that theme. What became apparent was that where a piece of data spanned more than one category, there was still a dominance that related it to one theme more strongly than the others. In these instances, the data was categorised according to the strongest theme. This was often linked to the motivation or context that the lie was delivered in. To support this process, I also wrote notes on each piece of data which helped me to consider the context or other important pieces of information which I had documented on my daily reflections. For an example of this, please see Appendix 12. As the analysis of data progressed, the significance of motivation, validation, and genuineness on behalf of the teller became more prominent and is discussed in more detail in Chapter 5. This process is like stages three, four and five of Burnard's methodology (Burnard, 1991). This is an essential task in analytic ethnography that forms part of the emergent analysis (Snow et al, 2005).

It was not until much later in my analysis process that I collapsed two themes into one resulting in six total themes. The six themes ultimately have then formed the basis of the taxonomy. It is important to acknowledge that the development of taxonomies does not occur in a vacuum. They emerge, as in this instance from a detailed examination of field notes and are subsequently revised as necessary as the researcher immerses themselves in the data (Snow and Anderson, 2003). The themes were also discussed frequently during supervision and then reflected on before the six key themes of the taxonomy were finalised.

Whilst conducting the analysis, I became very aware that there were also other recurring themes that sat outside of the taxonomy, but also played an important part in interactions where lies were told; that of validation and motivation. What had become apparent was the way something was said was crucial in relation to the way it was received, and this in turn was influenced by the motivation for saying it. After much reflection and consideration of both validation and motivation, the Lie ARM (Affective Reflection Model) was developed (This is discussed in Chapter 5, p.258).

3.11 Summary

The purpose of the study was to undertake a critical analysis of the concept of lying of in clinical practice, in the context of people with dementia. To do this, the aims of the study are:

- To develop a taxonomy of lies
- To use the taxonomy to develop a model which could be used in practice, to explore the impact of lie telling

This will be done by achieving the following objectives

- Identify what lies are told in practice and by who
- Generate an understanding of when, why and how these lies are told (motivation)
- Observe the outcomes of telling lies to people with dementia

which will enable the following research questions to be answered

- What lies are told in practice?
- Who tells lies in practice and why?
- What effect does lie telling have on people with dementia?
- Can the effectiveness of telling lies be predicted?

Creating the taxonomy was a key element of this study. The taxonomy is different to previously published taxonomies as it brings new knowledge to the topic by using ethnography. By observing the interactions, both conscious and unconscious lies were recorded. This is important as it is unlikely that unconscious lies would have been recalled by participants in previous studies.

It is important that the complexities of the interactions are acknowledged by also documenting the context and way the lies were expressed. The findings highlight the role of the affective domain in lie telling to people with dementia.

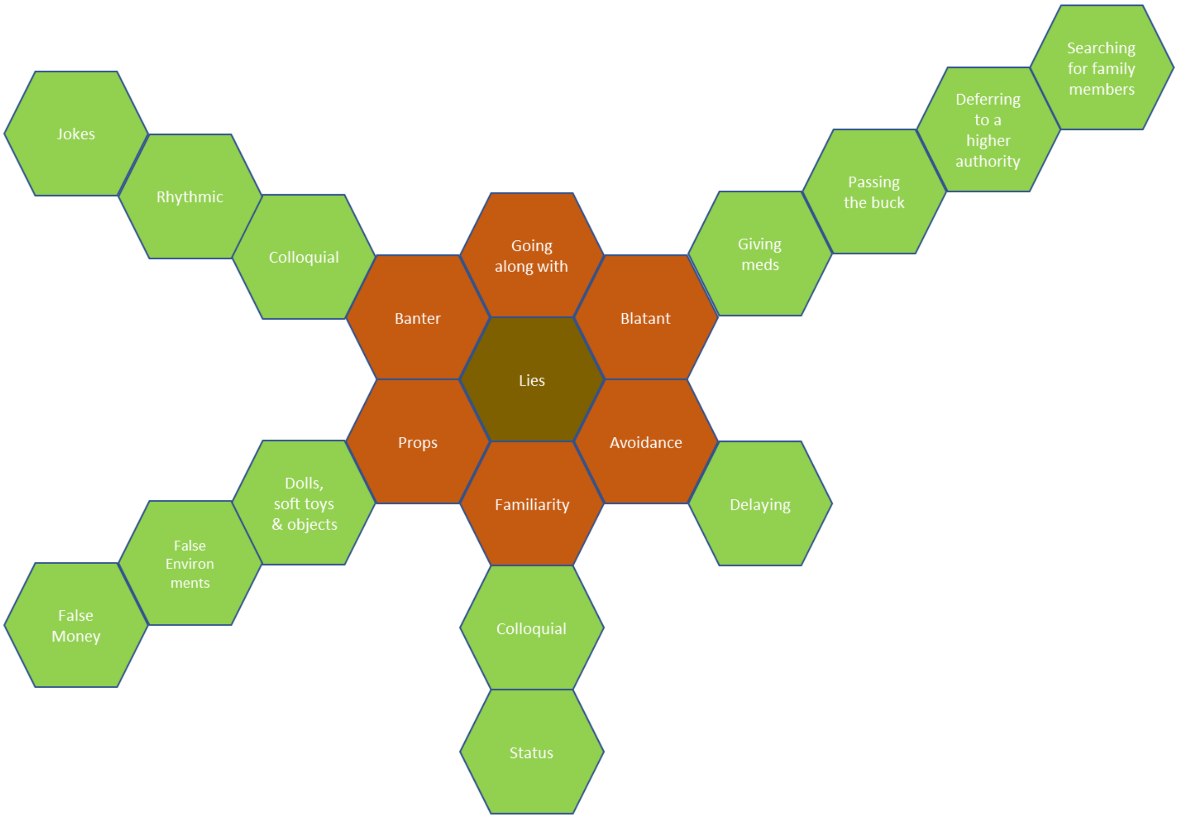
Chapter Four

4. Findings and discussion 1 – The Taxonomy

4.1 Introduction

This chapter introduces the taxonomy that was created from analysing the data. It is broken down into six sections according to an identified lie theme. This forms the taxonomy which was an aim of the study. The taxonomy is discussed in detail further on in the chapter (p. 241).

Figure 9 The Taxonomy



The six key themes are familiarity, banter, props, going along with, avoidance and delaying and blatant lies. Some of the six key themes, then have sub themes that sit within them. Each theme is presented in detail using relevant literature to analyse, contextualise and discuss. Direct transcriptions of recorded data will be used to clearly illustrate what was observed and how and why it was categorised in each theme (example in Appendix 11). Lies were documented in a notebook as soon as possible after the interaction was observed, or contemporaneously. The data was then triangulated using respondent checking via the use of conversational and informal interviews and having access to care plans and multi-disciplinary meetings where interactions were often discussed. My reflective notes are also documented extensively throughout this chapter. This enables the reader to make an informed decision about the genuineness and transparency of my interpretation of the data. There is frequent discussion around context, motivation, and outcomes in relation to each theme.

The chapter starts by describing the two sites where the data was collected.

4.2 Site Descriptions

Ward 1 (Data collection 1 and 3)

Ward 1 was based in a purpose-built mental health hospital that was opened in 2006 on the outskirts of a small and rural market town. It is built in the grounds of an old Victorian psychiatric hospital which was locally known as the asylum. Many of the original buildings are currently being demolished and new houses built in the grounds. It provides inpatient care and is also the base for a range of community staff. Approximately half of the current staff were previously employed in the old hospital although many of them are now quite close to retirement.

Ward 1 is reflective of the mix of staff from the original hospital and people who have joined since the opening of the hospital. It is still usually referred to as the ‘new’ hospital, despite having been open for 16 years and undergone many changes in that time. The cultural distinction between ‘old’ and ‘new’ is important as it can sometimes influence interactions between staff members. It was also quite difficult for staff who transferred to the new hospital, to adapt to newer and different ways of working and there is still evidence of that today. The old hospital is regarded with a level of retrospective falsification where everything in it and about it was good. People quickly forgot some of the challenges of working in an aged environment which at times could make it very hard to deliver the level of person-centred care demanded by today’s standards.

The environment of ward 1 is bright and well lit. It is based on a loop or ‘wander pathway’ that was specifically designed to allow people with dementia to walk around without encountering any locked doors. In total it has 24 bedrooms although the agreed capacity of the ward is now a maximum of 14 patients. Entrance to the ward is from an internal locked door from the main hospital. During both periods of data collection, the maximum number of patients was 12. This was because of the high needs and levels of aggression that were displayed by the current patient population. The ward was established on the premise that the patients would be both male and female, however due to the client group it now accommodates, male and female patients are nursed separately. This has resulted in doors being locked around the wander pathway which can no longer be used. During the time I was on the ward there were always considerably less female than male patients and female patients were allocated a much smaller space in terms of being able to move about freely.

Photograph 2 Looking from the nursing office down the main corridor. There is an accessible toilet on the right and then the doors to lounge 1. The door on the left is into the kitchen and is always locked. Through the double doors to the left is the dining room. Straight ahead is a set of locked doors. Just before the locked doors is a bedroom corridor which is photograph 3.

Photograph 2 Site 1 Looking from the door of the nursing office down the main corridor.

Photograph 3 Site 1 Lounge 1 (main lounge)

Photograph 4 Site 1 Bedroom corridor. There were three identical corridors off the main corridor.

The ward had two accessible gardens. One was in the middle of the ward which could be accessed from corridors and sitting rooms (Photograph 5).

Photograph 5 Site 1 Lounge 2 with central garden access

It was a pleasant area with chairs and tables and a range of plants. All patients were encouraged to go outside and use the garden. Patients were always supervised outside. They were also encouraged to participate in the maintenance of the raised beds and planters. The other larger garden was accessed via the dining room and had a looped walkway which tended to be used if someone was becoming aggressive or distressed. It enabled patients to walk continuously without coming to a barrier or fence by simply following the winding paths round. There were plenty of benches to sit on as people walked round.

There were daily activities and visits from a range of healthcare professionals that were contributing towards patient care. The nursing office was on one corner of a corridor with no vision onto the ward. There was a main sitting room, with a range of separate rooms if patients did not want to be in the main area which could get quite busy. There was also a dining room and activity room. There were several toilets and bathrooms with a range of supportive equipment and all bedrooms were single rooms with an ensuite shower and toilet. All rooms had windows that looked onto an area of garden.

Staffing was dependent on need but usually, 3 qualified staff and three health care assistants plus extra healthcare assistants depending on how many patients were on observations, both eyesight and within arm’s length. This could be as many as 5 and were usually male patients.

Ward 2 (Data Collection 2)

Ward 2 is based in the grounds of general hospital that was opened in 1932. The building that the ward occupies is a standalone building with no connection to the main hospital. The building was refurbished to accommodate the current ward and opened in 2016. Access is directly from outside. It has many similar features to the first ward – individual ensuite bedrooms and it is very light and airy. This is mainly because the communal sitting room / living / dining is all in one main room. During the day, patients have no access to corridors unless escorted by staff or visitors. At one end there is dining tables, in the middle there is a range of chairs and to the other side are some specialist chairs where patients with particularly difficult to meet needs are nursed on a one-to-one basis. There is one quiet area which can be used but is often locked as it is a small area, and it is difficult to observe patients in there from the main ward. There are also two other smaller dining areas; one which is kept locked and one which has free access. The large size of the room and the raised roof, like an atrium in the centre, gives the ward an odd acoustic which tends to make noises feel amplified. The nurses’ office is at the end of this large space, overlooking it. Down one long side of the space is a range of rooms including toilets and the kitchen. At each end of the space there is a door to a corridor which leads to a single row of bedrooms on the outside wall and a range of bathrooms and store cupboards.

As with ward 1, there were a range of visiting health professionals. Whilst the ward had been upgraded in 2016, it did not offer the specialised environment of the purpose-built ward. There were 18 beds, but occupancy was rarely over 12 while I collected data. The staffing was usually 2 qualified staff and 4 healthcare assistants plus extra for any patients on observation. One patient had to be supported by two members of staff at any given time due to high levels of aggression.

4.3 Familiarity

The theme of familiarity is split into two separate subthemes. The first one discussed is colloquial familiarity where a familiar term, or term of endearment is used by the teller, regardless of the receiver. It appears to be said almost unconsciously. The second subtheme - status familiarity - examines when familiar terms are specifically and consciously used, generally as part of planned or accepted care. These are quite separate in terms of the motivation for the teller using them, but both subthemes had either a positive or indifferent outcome. There were no negative responses observed.

4.3.1 Colloquial familiarity

Staff are repeatedly told to use the patient’s preferred name or title and not to use over familiar terms such as “pet, hun, darling, love”. For nurses, this is explicit in the Code of Conduct (NMC, 2018). Some literature refers to these familiar titles as terms of endearment (Comerford, 2015) but other literature uses the phrase elderspeak, of which these terms form a recognised part (Williams et al, 2017) as discussed in Chapter 2 (p.11).

The studies that present this negative image of familiar terms have taken the stance that the teller is making a conscious choice about the term that they use to address the other person (Grimme et al, 2015). The first subtheme of colloquial familiarity stands out from the others because it is the only one where most communications are specific to the teller rather than the receiver and this is not something that has been identified in previous literature. Some people use colloquial and familial terms as part of their daily discourse, regardless of who they are speaking to. This was also identified in my daily reflections.

Reflection – verbatim from notes.

Colloquialisms / familial terms seem to be specific to the tellers not the receivers. People who use them, seem to use them with several people, as it is a speech pattern that belongs to them.

Staff seemed to have a particular term that they would regularly use; one healthcare assistant used “hun and love” during most conversations, whereas another healthcare assistant tended to use the word darling. It was irrelevant who they were speaking to and they tended to use them with both patients and other members of staff:

Healthcare assistant; "Have a seat there love"

Patient; "Here?"

Healthcare assistant; "Yes that's fine."

Another healthcare assistant tended to use the more local word, 'pet':

Healthcare assistant; "Hello pet. Shall we get your horses on later?"

Patient; Did not respond.

The use of the term 'pet' made no difference at all to the patient's response and was more specific to the healthcare assistant than the patient.

Some of the terms used on the wards were very regional and it is likely that older people have grown up with them being used as part of usual conversation, particularly words like 'hinny' and 'pet'. Great care must be taken when using words which are so locally specific since they may well cause offence if used out of the context of the region. One such example where this could occur would be when the term 'bonnie lad' is used, as seen in the interaction observed below:

A male patient whose mood was prone to changing very quickly looked like he might become aggressive towards another patient. A male healthcare approached the patient:

Healthcare; "Alright bonnie lad. Howay down here"

The patient followed him.

‘Bonnie Lad’ is a colloquial term that was familiar both to the patient and healthcare assistant. If this term was used out of context or in another region it could be perceived to have had a different meaning such as being a comment on how someone looks or their sexuality. In the North East, it is simply a familiar term used mainly between men as part of the social construct of conversation. There is little ‘true’ meaning in the phrase; it is more it’s use as a friendly intonation or social lubricant.

This phrase was observed multiple times, but it was always expressed by the same healthcare assistant. They regularly used it to de-escalate situations successfully as in the example below:

Two male patients were facing each other with the potential for aggression.

Healthcare assistant; “Howay bonnie lad. Come down here with me.”

One of the male patients turned and followed him.

The phrase was always said with kindness and empathy and it is more likely that it was the way the message was conveyed that was effective in de-escalation, rather than the actual content. The patient may well have recognised the phrase, which he would have heard many times before, particularly in his younger years, which was where he was time shifted to (James, 2015). The healthcare assistant regularly used this phrase with male patients. It could be argued that by using this phrase, the healthcare assistant was supporting personhood by improving the relational status of the patient (Kitwood, 1997) based on sociocultural norms (Bartlett and O’Connor, 2010). Keady and Burrow (2015) support this use of sociocultural interactions to improve care. However, it also should be acknowledged that this was a phrase specific to that healthcare assistant, who used it regularly with a range of patients, rather than specifically and consciously with this one.

A similar phrase, which again is usually used between men is ‘young un’:

Nurse: “Here you are young un. Here’s your tablets.

Patient; “Ah.”

The patient then took the tablets. Again, it is unlikely to be the content of the familiar phrase but the tone and friendliness that it generated that had the positive effect. Observing both of the above examples, there was seemed to be a shared understanding of the phrases used and both parties appeared to have experienced them as part of positive interactions. The phrases were part of the healthcare assistant’s usual speech, so they were delivered comfortably and genuinely and still more about the teller than the receivers. If the healthcare assistants had been, for example, at home or in a social rather than work environment, they are just as likely to have used them. Such colloquial phrases would be considered to be part of the local idiom and, in some areas of the country, like the North East, are far more acceptable than in others (Comerford, 2015).

It is important that nurses and patients have a level of language or communication consensus. If there is a lack of consensus, particularly if it is caused by different dialects, it can result in nurses and patients not being able to understand each other (Wang et al, 2013). This is a risk where familiar terms that are used are also local or colloquial, potentially using words that are specific to a region when not all patients may be from the direct area. An example for the North East would be the word ‘hinny’ being used as a term of endearment, as previously mentioned. However, the instances of untruths that I put into the colloquial familiarity theme occurred when there was language consensus. Some staff indeed used local and colloquial terms on a regular basis, regardless of the receiver. The two wards I worked on mostly comprised of local staff. Those who were from outside of the area, worked hard to learn some of the local familiar terms, so they were able to engage with patients on that level. Where staff were out of area or for whom English was a second language, local staff would take great pleasure in teaching them the local dialect and would gently tease them when they tried to use the local words such as ‘hinny’ and pet, especially if they were subsequently used out of context. Familiar terms were often used by patients when interacting with staff, although these instances were not separately recorded. It was not unusual for a patient to say:

“Eee, thank you pet” after an intervention or being given a cup of tea.

4.3.2 Status familiarity

Other examples of familiarity were where a particular term or title was conveyed on a patient, that may have been true in the past or in a different context but was not true for their current situation. In these cases, the familiar term was used consciously and was specific to each patient, as illustrated below:

A healthcare assistant approaches a patient to take him for breakfast.

Healthcare assistant; “Morning Boss. Come and get some breakfast”

Patient goes with healthcare.

The patient had been a Captain / chief engineer on a ship for many years. He could be difficult to engage with but sometimes, calling him Boss helped as this is what he had been called throughout his working life. He responded well to being given that extra level of respect and then took on the mantle or behaviour of a ‘boss’. The use of the term ‘Boss’ was also care planned and used consistently by all staff. This is more of an untruth / lie than some of the other terms in this category if it is considered in the context of the healthcare professional’s truth. However, in the context of the patients’ reality, it was the truth, as he was time shifted (MacKenzie et al, 2015) and still believed himself to be ‘the Boss’.

Another similar example of this was with a patient who would regularly be called ‘aunty’:

The nurse was bringing the patient into the main lounge.

Nurse; “C’mon Aunty. Sit here. That’s lovely Aunty [patient]”

The patient responded to the nurse and sat down.

The use of the title ‘Aunty’ was care planned for this patient. She had been married for many years but had no children. She had spent a lot of time looking after her two nieces when they small and still had regular contact with them. She enjoyed being an aunty and usually responded positively to the term being used. She never responded negatively to its use, although sometimes it was unclear if using it had any impact. The patient had very limited interaction of any sort, so it was decided, in negotiation with the family that the term would continue to be used by staff since it was a term and a role which had brought her much pleasure in the past. Staff appeared very comfortable using the term aunty. This would be supported by the work of Bowers et al (2000) who stated that healthcare workers often identify the people they care for as being like family and that staff take comfort from using familial terms (Black & Rubenstein, 2005), particularly when caring for patients who have a terminal illness, which dementia could be classified as. Duncan & Morgan’s research, (1994) highlighted that some families appreciate this sort of communication because it highlights the genuine, caring relationship that staff have with their relative. In this case, the patient’s nieces were more than happy for staff to call the patient Aunty. By increasing the relational familiarity, it is likely that the healthcare assistant unconsciously created a truth bias where, subsequently, the patient was more likely to believe what they were saying hence strengthening the emotional bond and potential effectiveness of future interactions (Burgoon & Buller, 1996).

On one of the wards, a healthcare assistant used the term ‘friend’ with several of the patients, with varying degrees of success:

Nurse (me) sitting with agitated frail patient (F). Healthcare assistant comes across.

Healthcare assistant: “[patient] this is my friend.”

Patient: “What’s her name?”

Healthcare assistant: “Jane. She’s a very special friend. Tell her about……..XYZ”

Patient; “Oh I can’t, I can’t, I can’t.”

The patient responded well to the interaction, smiling while she spoke, although it was unclear if this was influenced by using the term friend which was said with great warmth. The healthcare assistant had worked with the patient for almost 10 years and would undertake all sorts of extra interventions for the patient, such as bringing in her favourite chocolate or ice cream or bringing items for her room. When I discussed the term friend with the healthcare assistant, she felt it was being used in a true sense as she felt that she was a friend to the patient. I have interpreted it as a lie, however, because professional boundaries and roles define that nurses are carers not friends and this sets a precedent which means whilst staff can be friendly, they do not function as true friends. This is supported by the work of Hochschild (1983) who felt that organisations work to oppress the emotional element of the relationships between staff and patients and discourage relationships being defined as friendships. However, research indicates that care workers who, as part of their role, repeatedly engage in deeply intimate and personal exchanges over long periods of time, are likely to foster genuine emotional attachment to the people they care for (Rodriquez, 2011). Emotional attachment can often be strongest with the most challenging patients, and in this case, there were very few people who could successfully make a connection with the patient (Rodriquez, 2011). Lopez (2006) identified the importance of allowing these emotional relationships to develop within an organisation so would argue that they do not challenge the boundaries of professionalism. It was clear in this instance that the healthcare assistant not only cared for the patient, but that the patient recognised and cared about them (Glenn, 2000). This relationship was very important for the patient because she had no family who were able to visit and received no visitors, despite her prolonged hospital stay (10 years). In situations with other patients, the healthcare assistant would use the term and it also could be perceived to be effective:

Healthcare assistant; "Look [patient]. This is my friend [Jane]. She's come to sit with you. Is that alright?"

Patient; "Yes. Yes. Yes."

In this instance, the healthcare assistant was handing over her observations of the patient to another member of staff (a member of staff always had to be within arms' length of this patient). By handing over in such an informal, or familiar manner, the healthcare assistant avoided acknowledging that the patient was in hospital. If this was ever highlighted to the patient, she could become very distressed. This does have elements of avoidance; however, I put it under the theme of familiarity since this was the predominant feature of the interaction.

In this category of familiarity, it could be observed that professional boundaries were being moved or crossed on occasions. In this instance, I was being referred to as the ‘friend’, and whilst I have a positive relationship with the healthcare assistant it was based on a professional relationship, rather than a social one, particularly given the limited time I had known the healthcare assistant. Sometimes, the patient and healthcare assistant became involved in a purely social interaction rather than a professional or care orientated one. On the surface, this feels uncomfortable as nurses are held to professional account; however, perhaps genuinely viewing the patients as friends means that the interactions become more person centred and meaningful as relationships based on friendship are less likely to be influenced by power and the medical model (Rodriquez, 2011). This issue was also acknowledged in my daily reflections.

Reflection – verbatim from notes.

Some excellent healthcare assistants who perhaps almost care too much. They talk about two or three of the patients as being family as they have nursed them for many years.

Whilst it is acknowledged in the previous example that the term ‘friend’ was used in the context of an emotional relationship, other members of staff also used the term friend regardless of the true relationship:

A male patient was walking around the ward spitting at regular intervals.

Nurse; “Stop spitting”

Patient spits again

Nurse: “Stop spitting or we won’t be friends anymore. I’m not being your friend if you spit”.

The use of the term ‘friend’ made no difference to the patient who was an ex-coalman and spitted continually because he thought he was outside on his coal round. He would push a piece of furniture around the ward all day, shouting intermittently as he had done for many years, to let people know he was there. His spitting made it very difficult to discharge him, as no 24-hour care facilities were prepared to deal with this behaviour, and it was unlikely to change. The patient rarely engaged with anyone apart from his wife. In this case, the nurse used the term friend to try to keep the tone of the interaction positive, which was difficult to do, whilst also trying to impact on a behaviour that was presenting longer-term challenges. In this case, the term friend was an untruth, and used for the benefit of the nurse, rather than the patient. The lack of genuineness in how the term was used may have impacted on how it was received, although it was said in a pleasant tone. It can perhaps be argued that if using the untruth was not going to impact on the patient but would make the nurse feel more positive about the interaction, then its use should be supported as the patient then can validate the nurse’s positive emotion (Richard, 2010). Burn out in staff and carers is well recorded (Eggenberger et al, 2013) and if a specific communication helps the staff or carer giver to feel more positive and does not impact on the patient, then it should be considered as a regular strategy. If staff find a positive way of interacting with someone who perhaps might be considered an ‘unpopular’ or ‘difficult’ patient then, overall, the outcomes are likely to improve due to the change in emotion being conveyed.

A further explanation of the effectiveness of familiarity (from both subthemes), as an intervention could be that of semantic elaboration. This is where words are used as a rehearsed stimulus (Craick and Lockhart, 1972). The phrases used here were highly familiar and meaningful and continued to resonate with the receivers, even though they were quite advanced in their dementia journey. Using newer familiar terms that current teenagers would perhaps know and understand for example ‘bae’ (a shortened version of baby or babe, another word for sweetie), would not be effective since it would have to be processed by the receiver. A person with dementia might no longer be able to do this because the phrase has not been rehearsed and therefore, they would not have the same level of recognition.

In summary, this study observed that familiarity (colloquial) is largely used unconsciously by the teller, regardless of the receiver. This is in contrast to the study by Grimme et al (2015) which identified that participants felt that they used elderspeak and familiarity specifically and according to the person they were addressing. During my study, the use of familiarity (both colloquial and status) was either effective in improving or influencing a situation or it was ineffective. It was never observed to have a negative effective on patients. This fits with the findings of the O’Connor and St. Pierre’s (2004) study (discussed in chapter 2, p.11), that highlights familiarity and elderspeak is more likely to be received positively from family members or people that the recipients know well. The patients I observed had been on the ward for some time and had established relationships with the staff. It should also be highlighted that it is often third parties or researchers who express discomfort about the use of familiar terms, rather than those who receive them.

The motivation for using familiar terms (colloquial) is unclear since it appeared to be almost unconscious. Whilst the literature states that these terms are used to convey warmth and caring (Williams, et al, 2009), previous studies have asked participants their opinions about when they used the terms. From my observations, some staff used these terms frequently with little thought. The terms appeared to be part of their regular speech pattern, which was not adjusted regardless of who they were interacting with. Status familiarity was more consciously applied, with some forethought prior to the expression of the term, and in some cases formed part of the plan of care. The motivation behind the use of status familiarity could often be identified as increasing patient engagement. This is clearly to meet the needs of the patient, which staff generally wanted to do. Therefore, motivation and genuineness were key features.

The findings of this study suggest that although familiarity ultimately is based on untruths, it is a positive tool to potentially improve communication with some patients. If staff were constantly corrected when using these terms (colloquial), in line with current guidelines (NMC, 2018), it may be that communication between staff and patients would be reduced or would become much more formal, neither of which is desirable. When status familiarity is used it is used consciously and some effort should be made to monitor the outcome of its use. Healthcare professionals should reflect on their interactions (Nicol and Dosser, 2016) to ensure that their personal communication style is not having a negative impact on the receiver.

4.4 Banter

This theme presented many challenges in terms of labelling and considering whether the interactions were in fact lies. During analysis, I decided that it did have a place in this research since the interactions always involved some sort of untruth. Similar interactions have not been recorded or categorised in previous research in relation to lie telling people with dementia. It is the only category where both the teller and the receiver were aware that what was being said was fictitious, but both still chose to engage in the interaction. In the case of banter, however, whilst I would consider the interactions to be based on untruths, it is lying without deception as both parties were wilfully engaging in a conversation which they did not believe to be true. It is the only form of lying which is not underpinned by deceit. The relationship between lying and deceit is discussed in Chapter 2 (p.11).

In English in the UK, banter is both a noun and a verb. As a noun it means the playful and friendly exchange of teasing remarks or as a verb it means to exchange remarks in a good-humoured, teasing way (Stevenson, 2010). Banter is a mode or vehicle of conversation that is essential in building and maintaining relationships (Buglass et al, 2020). It allows people to belong, or to be part of a group which has a shared understanding of a particular event or interaction (Fine and DeSoucy, 2005). It is not just about humour, although often it is amusing on some level (Dynel, 2008). It is about spontaneity, often with short responses that follow a pattern of conversation that is likely to be well established in a person’s long-term memory. Banter has an established pattern and often uses gently expressed emotion or frivolity – a shared understanding that there is no real malice or negativity associated with the interaction. It is simply an interaction which demonstrates a level of shared communication that both parties are happy to engage with (Haugh and Bausfield, 2012). It may be based on truth but is more likely to be underpinned by a lie (Plester and Sayers, 2002). For many people, it is an essential, appreciated and understood part of usual conversation that may enhance social cohesion and is often regarded as a pleasurable activity between two or more parties (Alexander et al, 2012). However, it must also be acknowledged that in some of the literature, the term banter is associated with negative communication strategies used as part of male culture (Topic, 2020) or in some cases is linked to bullying (Steer et al, 2020). Despite this, the decision was taken that banter in healthcare is generally accepted as a positive communication strategy (Bates, 2017) and therefore the original definition cited (Stevenson, 2010) was appropriate in capturing the essence of this theme.

It is the only theme in which both the teller and receiver were fully aware that the content of the interaction was untruthful, but both were in collusion and happy to continue with the interaction. Banter provides a useful social lubricant for people with dementia which encourages them to participate in a verbal interaction.

Banter allows the person with dementia to engage in positive communication which is an active and fluent process between two or more people who can interact in a timely and effective manner, as it is established in long rather than short term memory (Savundranayagam & Orange, 2011). It appears to be more instinctive and spontaneous than other conversations. The fact that it follows a regular trajectory with an expected emotional outcome makes it easier for the person with dementia to engage in and understand (Mahendra et al, 2005). Hopper and Bayles (2001) support the idea that the structure of an interaction (flow, tone, emotion) when engaging with people with dementia is far more important than the words that are used. Many instances of banter fit a specific speech pattern which can be described as finite, predictable, and not requiring significant conscious attention, which makes this type of communication less susceptible to the cognitive decline apparent in people with dementia. Emery (2000) identified that in people with moderate to severe dementia, people start to separate meaning and thought from sound, with the result that they respond almost automatically to the speech pattern without relying on memory or planning. This gives people with dementia an opportunity to interact in a very non-threatening and social way that is well established for them. Banter also gives staff a real opportunity to engage with patients in a much more positive way, focussing on what people are still able to do in terms of communication. Families can also draw on long-standing patterns of interactions to help maintain communication with their loved ones (Purvis and Phinney, 2012/2013). This may but not exclusively include an element of banter. It could be a long-standing family joke or occurrence which is always spoken about in the same way with the same outcome, quite often involving some sort of mishap and subsequent teasing or ribbing. Sabat and Collins (1999) highlight the importance of recognising intact abilities and focusing on them to enhance interactions.

A patient's ability to engage in banter could be considered a real indicator of their wellbeing, if considered in terms of Kitwood and Bredin's (1992) indicators of wellbeing. These are a set of abilities or behaviours which a person still engages with, despite their dementia, and gives an indication of their current well-being. These include: the assertion of desire or will; the ability to experience and express a range of emotions; initiation of social contact, affectional warmth, social sensitivity, self-respect, humour, creativity, and self-expression; showing evident pleasure; helpfulness; acceptance of other dementia sufferers, and relaxation. When a person engages with banter, they are often displaying a level of emotion and affectional warmth. People need to feel comfortable within a relationship or interaction to have the confidence to engage with banter or what, in some cases could be classed as gentle teasing (Buglass et al, 2020). There is often a level of humour involved as well as self-expression and pleasure from the interaction. The use of humour in people must be monitored carefully (Moore, 2009). Depending on their level of cognitive damage, some people may misunderstand some types of humour (Steer et al, 2020), although I did not witness this when banter was used. Jokes are discussed as a separate concern at the end of this section (4.3.3) Some of the patients who were able to engage in banter, were cognitively quite impaired in terms of assessment using standard testing and staff were often surprised in their ability to engage in what can be a complex interaction.

Within the broad theme of banter, two subthemes emerged from the data: colloquial banter and rhythmic banter, and they will be discussed below. Jokes are discussed separately as they did not come into either theme (p.154).

4.4.1 Colloquial Banter

The first subtheme was where the conversation followed a well-established path, even in terms of content. It used familiar, often colloquial phrases or references. This seemed to create a feeling of safety or confidence in terms of the person with dementia feeling able to respond immediately and appropriately to what was said. The example below was witnessed on both wards which highlights the frequency and generality of some well-established sayings:

Patient turns to other patients in the lounge; "Goodbye everyone" and waves, heading for the door.

Nurse; "See you later alligator"

Patient laughs and continues walking around the ward.

This is a very well used phrase locally and there was immediate recognition from the patient.

Patient trips whilst on within arm's length observations.

Healthcare assistant: "[Patient] are you drunk?"

Patient; "No no no"

Healthcare: "I don't think you had enough water in your whiskey"

Patient laughs and goes off.

Whilst this may seem like a very limited interaction, it was in fact quite significant. The patient was a younger man, in his fifties who had developed early onset dementia which had advanced very quickly. He had virtually no verbal communication and did not interact verbally as part of usual communicative discourse. For him to respond verbally was hugely positive, both for the patient and the staff. It was also noticeable that banter was used on a more frequent basis with this younger patient, compared to some older patients. This was perhaps because of the consistently positive response the patient had to this type of communication. The healthcare assistant involved in the action was visibly delighted that the patient had spoken to them and had laughed. It highlights the benefits of more generalised but light-hearted interactions. Haak (2002) also highlighted that imitation or repetition of previously learned or automatic verbal sequences can provide a secure means of communication with patients who appear to have lost the ability to communicate. Something as simple as counting or an activity which has been developed through rote learning such as times tables, nursery rhymes or church songs could be useful to foster positive engagement (Richard, 2010). An example of this I observed is below:

Nurse (me) and a healthcare getting a female patient dressed. Having difficulty taking nightwear off.

Healthcare assistant: "[Patient's name] put your arms up. Put your arms up"

No response from patient

Healthcare: "Put your hands up for Jesus" {This was said almost rhythmically as though part of the original hymn}

Patient puts arms up.

The patient as a child had been quite religious and a regular church goer with her family. The healthcare assistant was aware of this and was able to revert to a well-established section of hymn that was known to the patient. It was very effective, and one of the few occasions where banter was observed being used without humour; it was, however, said lightly and with kindness.

Several of the observed interactions in this category were focussed on complimenting the patient or boosting their self-esteem.

Patient comes out of sitting room.

Healthcare assistant; "By, that's a nice shirt [patient's name]. You look as smart as a carrot".

Patient smiles.

Whilst the smile might be considered a relatively small reaction, the significance is that the patient appeared to have some understanding of the phrase and what was being said, and clearly derived pleasure from it. This person no longer interacted verbally and appeared to have difficulty understanding many of the verbal communications and instructions that the staff used. To get a reaction, particularly of pleasure, was significant both for the patient and the healthcare assistant. It is very fulfilling to get a positive response from someone who struggles so much to make their feelings and needs known. This also fits in with the work of Sabat (1999) who talks about the social construct of communication in dementia. In the instance described above, the patient was able to identify the emotion and meaning of the interaction by its rhythm and pattern rather than the content and in that way, was able to give an appropriate, though limited response. If patients can demonstrate a symbolic understanding of staff, even when understanding the verbal content is not possible, it can result in a warm and positive interaction (Hansebo and Kihgren, 2002). These often short interactions could be very effective in helping a patient to experience positive feelings and there were multiple examples of these in the study.

The positive, reinforcing style of banter was regularly used with this patient and always had a positive effect:

The patient was taking their top off in main lounge. The healthcare assistant was helping him to put it back on. When they had their top back on.

Healthcare assistant: "There you are. Smart as a dart"

Patient laughs

Similarly:

Student nurse: "Have you had your hair cut?"

Patient; "Aye"

Student nurse; "Smart as a dart"

Patient; "Divvent say smart. I'm gannin bald" {Laughs}.

The more positive responses the staff got from patients, the more it encouraged them to engage in this type of banter or interaction which gave a very positive and collegiate feel to the ward.

Other forms of banter were also used as a positive reinforcement:

A healthcare assistant was bringing a patient out of their bedroom after helping them to get dressed. The patient was relatively young being under 60. They had been a mental health nurse in the Trust and some staff could remember her when she was a nurse.

Healthcare; "Star pupil. Best in the class"

Patient smiles and nods

Healthcare assistant: "You were excellent".

This interaction and several of the others could be considered quite patronising and a representation of quite negative elderspeak as discussed in the section on familiarity (McLaughlin, 2020), if taken out of context. At times, the insight of the above patient fluctuated, and they could become very distressed if they recognised the ward as being a mental health care environment. Her husband used to visit daily and regularly stayed for both his lunch and his tea. It was noticeable that he did treat her in a childlike manner but that she responded well to it. He had always 'looked after' her and shielded her throughout their marriage so she had always turned to him to help make decisions or reassure her that she was doing the right thing. Hence, using more infantile positive reinforcement worked very well when used in a person centred and targeted way. It is important to acknowledge that this worked because the staff knew the patient and her history very well and it was delivered in a genuine and kind way. There are many patients that this would not work for and would be likely to negatively impact on the caring relationship and potentially cause embarrassment or frustration (Herman and Williams, 2009). There is a range of literature that highlights using praise in care environments when adults are being supported with relatively mundane activities such as attending to personal hygiene or getting dressed could be considered inappropriate or infantilising (Backhaus, 2009, Sachweh, 2003).

Short, familiar phrases that were quite rhythmic were particularly noted, which again is supported by the work of Sabat (1999) who identified that it is the social construct of conversation rather than the content that is significant to people with dementia. It is interesting that this type of phrase can be almost non-sensical in terms of content and therefore not truthful yet are used very successful as social lubricants. They sit under the theme of banter rather than the theme of blatant since there is an acceptance by both parties involved in these interactions that the content is not true, but in this particular social circumstance, not only is this acceptable, but positive. It did not seem to matter how outrageous the actual content of these statements was, they were still accepted in a positive manner:

Healthcare assistant: “Here you are [patient’s name] {The patient was wandering around the ward being supported to eat porridge}

Patient continues to wander.

Healthcare assistant: “Here you are. It will put hairs on your chest”

Patient laughs and continues walking but clearly in good spirits.

Whilst no one actual believes what the healthcare assistant said was true, it provided a positive and effective platform to interact with patient while the healthcare assistant tried to carry out what was in fact, quite a difficult job:

Two female healthcare assistants were sitting either side of a male patient taking their physical observations.

Healthcare assistant 3 (also female); "Oh look. A rose between two thorns. And don't let them tell you any different.

The patient laughed and was clearly amused by this. By helping to relax the staff were able to measure his blood pressure more easily and get a more accurate reading.

4.4.2 Rhythmic banter

The second subtheme of banter identified was where a conversation followed a specific pattern or rhythm without the actual content being previously established. It was generally a short and sometimes humorous exchange. Patients seem to engage easily and fluidly in this type of discourse, perhaps because there was no pressure to tell the truth or be right. This again is supported by the work of Sabat (1999) as previously mentioned. The sole identified purpose of the communication was to interact on a social level, as seen in the observation below:

A patient was in the sitting room with a couple of members of staff. Everyone was sitting down having a mid-morning drink.

Patient: "What is your job today?"

Healthcare assistant: "My job today is to sit in here with you lovely young ladies."

Patient; "Hahahaha. I wish. Young ladies? As if?"

This statement had clearly amused the patient who immediately identified the untruth. However, it was the 'lie' in the sentence that triggered me to put in the subtheme of rhythmic banter and it was observed to make the interaction more positive. Both parties were fully aware that the female patients in the room were not young.

Sometimes, the banter relied on knowing the patient very well since it involved using key words that were well known to the patient as opposed to generally established phrases:

A healthcare assistant was helping a patient to get into a bath which they particularly enjoyed. However, to get the patient into the bath, an electronic bath hoist needs to be used which made the patient very anxious and at times distressed. In order to distract the patient, the healthcare was constantly talking to her.

Healthcare assistant; "Look it's Tesco" {like the shop lift} "First floor, ladies' clothes"

Patient; "Tesco" Smiles.

The patient refocused from her fear of the hoist onto the conversation with the healthcare assistant. Again, this highlights the significance of knowing the patient and their previous routines (Fetterman, 2010). Up until her hospital admission for her dementia, the patient had visited the local supermarket every day and was well known to both the supermarket staff and some of the ward staff who also shopped there regularly. She would go into the shop, take the lift to the first floor, then walk through the lady's clothes to the cafeteria at the back, where she would have a late breakfast. There was clear recognition at the word Tesco, and it appeared to stimulate what was a happy memory. Again, if this was out of context of the patient's history, it could be considered a form of elderspeak which was patronising or demeaning.

The example below was from a patient who had placed bets on the horse racing every day for many years and continued to believe that he still carried out this activity:

A healthcare assistant was guiding the patient from the dining room to the lounge. They had just gone through the motions of selecting horses that the patient wanted to place bets on. This was a daily ritual.

Healthcare assistant: "Let's hope it's a good horse you've got"

Patient: "Aye well it's got two chances. Winning or losing"

Healthcare assistant: "Well let's hope it's a winner and we'll both share it.

In this instance, it was the patient, rather than the member of staff who introduced the element of 'banter' which is unusual. It was debatable as to whether this did involve lying – the banter element does not. However, as the entire interaction was based on an activity that was simulated rather than actually happened, I have included it here.

Some examples of banter could also be considered flirtatious:

It was a very hot day and staff were encouraging patients to go outside and sit in the shade in the garden.

Healthcare assistant 1; "C'mon [patient]. Let's go outside to our secret bench. We'll not tell anyone"

Healthcare assistant 2; "Hey [patient]. I didn't know you had a secret bench?

Healthcare assistant 1; "C'mon. we'll get some fresh air".

The patient smiled and allowed the first healthcare assistant to take him by the hand and lead him into the garden. The healthcare assistant winked at the patient and smiled. The patient looked very happy and went out to sit on a bench outside. The patient could be very reluctant to engage in things he was asked to do and often resisted intervention. By using this strategy, the healthcare assistant was able to encourage him to go outside willingly which, ultimately, was be good for his health and wellbeing (Martins da Silva et al, 2020).

Staff clearly do not have a secret bench to take patients to; however, the patient allowed himself to be guided outside, smiling at the conversation. There was an element of mild flirtation in the way the communication was delivered, and the patient appeared to be enjoying this. Care must be taken when using this type of banter as it may well be misconstrued by a person with dementia. It was very much done in the realm of interactive communication as opposed to encouraging sexual interactions. However, I considered it to be banter because both parties appeared to know it was a social rather than sexual interaction which was untrue and both parties were happy to engage with it. Observing the response from the patient, they clearly derived some positive emotion from it.

Flirtatious interactions would often come into the category of banter since they are often considered open secrets (Kozin, 2015). Heskell (2002) identifies that flirting is a way of enhancing communication, which is how it was being used in the observed instances and can help to contribute to a comfortable social milieu. Heskell also states that flirting is based on a set of positive emotions whose foundations are grounded in the universal ability of a human to enjoy being with others. This may partially explain why it can be an effective strategy for people with dementia, if used within the confines of banter and taking extreme caution not to cross professional boundaries or unintentionally make people uneasy.

The following example of banter was one of the longer and more complex interactions that were documented:

Patient (M); "Have you got any trainers?"

Healthcare assistant (M); "No. Why?"

Patient: "You could do with running a marathon. You're obese"

Healthcare assistant; "No, I'm just not tall enough"

Patient: "When you turn side on that's a hell of a profile"

Healthcare assistant; "I'm switching my hearing aids off". {Puts hands to head and pretends to switch hearing aids off. Walks out of room and comes in another door}

Patient: "I'm telling ya, you need to do something about that."

The above conversation took place in the main lounge. There were five or six patients sitting in the lounge with two patients walking in the corridor. There were three patients on 'within arm's length observations' so there were also four members of staff in the lounge. The ward was generally relaxed and there had been a reasonable amount of communication between staff and patients during the morning. I was sitting next to a patient who was on within arm's length observations. A male healthcare assistant stood up and said he would go and get the trolley (hot drinks and snacks). The patient I was sitting with then shouted across the room – as in the conversation recorded above. After he had said about the marathon and being obese, people in the room (staff) started to smile and laugh quietly. This clearly had an effect on the patient who appeared pleased to have made people laugh. Prior to developing dementia, he had been quite a comedian and was known for teasing people, particularly in the village pub. When the healthcare assistant returned through another door, the patient acknowledged him, but did not recognise him as the person he had just been speaking to. Other staff continued to laugh and gently rib the healthcare assistant, who was indeed overweight. The brief interaction made for a talking point for the rest of the day and was relayed at handover in minute detail.

The significance of this communication can only be understood if it is considered in the context of the level of cognitive impairment experienced by the patient. The conversation was spontaneous and well-constructed as well as being very funny (and quite rude!). The emotional response of the healthcare assistant who was on the receiving end of the comments was that of ‘put out’ or quite irritated. However, the response of the other staff was that of jollity and amusement. This instant emotional response at the initiation of the conversation helped to encourage the patient to sustain the communication. At the end of the communication, the patient sat smiling, clearly having enjoyed the brief period of attention and humour.

4.4.3 Jokes

The issue of joke telling is particularly complex. Many jokes fell into the category of banter, where the interaction followed a well-known pattern and had content that both parties understood and were happy to participate in. However, on some occasions, jokes were made that were only understood by the teller or the staff around them, and not the person with dementia which clearly raised some concerns for me. If the joke was not understood by both the teller and the receiver, it was not classed as banter as mutual understanding was one of the key elements of this theme.

Reflection – verbatim from notes.

Again, humour was an issue. ‘My eyes have always been bigger than my belly’. Joke or a lie? Is it a joke because the teller or the receiver think it is funny? Is it joke if only one party understands it?

Reflection – verbatim from notes.

The issue of ‘joke’ arose again today and perhaps another category of ‘banter’ needs to be considered. The content is known to be acceptable to both parties.

Reflection – verbatim from notes.

Today has made me question the use of ‘jokes’ or humour. They have been outright lies and the patients they have been told to are not able to perceive them as humour due to the point at which they are in their dementia. Does ‘joking’ make the staff feel better? Are they acceptable given the patients did not understand them? It was hard to listen to blatant lies which were unnecessary even if the person was saying them as a joke. They were not funny to the receiver. They would be considered harmless; however, I just feel they were pointless and potentially damaging.

This is illustrated in the example below:

Healthcare assistant; “Come in here [patient]. Come in the quiet lounge for your lunch”.

Patient takes hand but resists.

Healthcare assistant; "Come on in here. It's quiet just like you."

The patient was a very noisy (ex-coalman) who was rarely quiet. His noise levels often caused distress in other patients. This interaction could possibly have been interpreted as banter because the healthcare assistant was effectively teasing the patient in a very gentle way. However, whilst the comment appeared to be said as a joke, I classed the interaction as a blatant lie rather than banter since only the teller, rather than both parties understood it. It is essential for an interaction to be classed as banter that there is shared understanding. I found these instances quite uncomfortable although I am unsure why. It must be deeply unsettling for people when those around you to start to laugh or even just grin when you do not know why and do not feel part of the joke. The motivation for telling the joke is key here. There may also be some similarities with familiarity in the sense that some people are classed as 'natural jokers' and like to make jokes or people laugh as part of who they are rather than thinking about the potential recipient. If this is the case, the interaction is likely to be spontaneous and does not evolve to meet the needs of the receiver. It is almost flippantly said because the teller wanted to say it, with the consequences rarely being thought through. Whilst I may have experienced some discomfort observing these interactions, I did not record any instances where the person with dementia looked uncomfortable or was observed to become distressed. Humour is a very complex interaction which many people with dementia can find difficult as their illness progresses (Mak and Carpenter, 2007) so from an observation point of view, patients appeared to simply ignore the interaction if they were unable to make sense of it.

In summary, banter is a standalone theme of social interactions based on lies. It relies on both parties engaging with a shared truth, or more often shared lie. It does not involve deception. Both parties are likely to have used or heard the phrases used over many years, making them familiar and comfortable, with expected outcomes. There is less emphasis placed on content than there is on patterns of speech and outcomes. Some spontaneous banter can occur which uses new phonology but still has a known rhythm and pattern in which both parties engage. The findings suggest that banter is a very useful intervention with people with dementia. It allows them to interact with people in a more equal partnership which emphasises the communication skills they still have rather than focussing on deficits which is significant. The motivation of staff to engage positively with patients in a more friendly and less clinical manner is evident, as is the pleasure derived from patients during these interactions. The genuineness of staff when engaging with banter is also evident. It was observed to be a pleasurable experience for both parties in most instances. This theme of shared lies has not previously been identified by other studies. This study has elicited this new information by virtue of the ethnographic methodology used.

4.5 Props

This theme considers any instance where an inanimate object was either used to initiate a lie, or to deceive a patient. It covers both planned and spontaneous episodes of lie telling and reflects on the ethics of some of the interventions.

The use of a range of props is debated within the literature particularly the use of dolls (Heathcote and Clare, 2019), bus stops (Lorey, 2019) and false environments (Jenkins and Smythe, 2013). The issues were explored in Chapter 2 (p.11). The observed use of props was very interesting and, in every instance, had a positive outcome. In most cases, the use of a prop was pre planned and carefully documented in the patient’s care plan; however, a couple of spontaneous uses were observed.

The word props, in this instance, identifies that the healthcare professional had used an aid, or object to support or reinforce their communication to engage the person with dementia in meaningful conversation or activity. It was always an inanimate object to which certain, although not always truthful, properties were assigned. In all cases, the prop was something that the patient would recognise from earlier in their life and would have made sense to them in the context of their previous roles or relationships. The props used ranged from soft toys being treated as live animals through to the use of fake money which happened frequently on both wards. There was also the use of non-alcoholic beers and drinks and a bar set up on one of the wards.

It could be argued that by using an object untruthfully, often to reinforce an untrue communication, the healthcare professional had been able to enhance personhood by supporting well established relationships (Brooker, 2019). The patient was often unaware that the relationship they were engaging with or about, had long ceased to exist in other people’s eyes. By doing this, the healthcare professional was able to sustain and develop their therapeutic relationship with the patient by interacting on a level which had real meaning to the patient. If the relationship still existed for the patient and was still sustainable in their world, it could be argued that staff were acting in the patient’s best interest or on the principle of beneficence, to maintain it. They were working with the patient’s truth, which is as important as everyone else’s. Props often provided an effective vehicle for validation. In an impromptu use of props, the spontaneous intervention prevented a potentially aggressive escalation of the patient’s distress and was very effective.

4.5.1 Spontaneous use of props

The male patient kept walking into a ward visitor, making physical contact.

Healthcare assistant: "C'mon [patient's name], help me do this paperwork {showing patient the observation file} then jobs a good un."

Patient follows

Healthcare assistant: "You sit there and help me fill these forms in"

Patient took some blank forms and sat moving them around, completely engaged in the process.

This was the only patient where props were used that were not care planned prior to their use. The patient could become very aggressive and had become very focussed on a visitor to the ward. The patient had hospitalised a member of staff earlier in the week. The situation had the potential to escalate very rapidly if the patient was not distracted effectively. The healthcare assistant was busy filling in charts for other patients about their physical health status. She gave the patient some blank forms which he then sat and engaged with for some time, losing focus in terms of the visitor. The success of the interaction was due to the spontaneous use of the props.

This highlights the importance of health care professional's knowing the patient's history and understanding the patient's values and beliefs (Cooney and O'Shea, 2019). The healthcare assistant knew that the patient had been a businessman and that he had had a very senior role in a successful business. As such, he was used to doing a lot of paperwork. The patient had valued his work and had found retirement difficult. His short-term memory was very damaged, and he had no concept that he was in hospital or retired, therefore engaging him in what appeared to him to be a usual activity met both his psychological and emotional needs. It helped to give him a feeling of value. If he had been able to identify that the sheets of paper were blank, the intervention potentially could have had the opposite effect. A similar situation arose a short period of time later:

A nurse sitting with the same patient (who was on within arm's length observations). The observation sheets were being handed out, which told each member of staff which patient they were responsible for observing at any point in the shift. The patient grabbed one of the sheets.

Patient; "What's this letter? Let me read it"

The patient looks at the piece of paper but is clearly having difficulty making sense of what is written on it. The nurse gently takes it back from the patient.

Nurse: "It says [patient's name] September 16th appointment at general hospital for a check-up.

Patient; "Oh" {Tries to take sheet from nurse}

Nurse; "[Patient's name} September 16th appointment at general hospital. I'll put it in the office."

Patient relinquishes hold.

As previously stated, this patient was very volatile and could become aggressive very quickly. The observation sheet had personal information on relating to other patients and would therefore be classed as confidential. It is unlikely that the patient could have made sense of the information, but the nurse still felt pressured to retrieve it as soon as possible. The patient appeared to have a vague understanding that important documents were kept in the office and relinquished his hold. It clearly did not occur to him that he was already in hospital or that other people were being given copies of the sheet. This instance was unusual as the use of the prop or object was initiated, spontaneously, by the patient rather than the member of staff. However, the actual story that was subsequently built around the prop which was untrue was initiated by the nurse, based on the patients' truth. The motivation for engaging with this level of lies was focused on reducing the likelihood of the patient's behaviour escalating with the potential for them to become aggressive. It could also have been categorised under the theme of going along with on the basis that the nurse was fully aware that it was not a letter for the patient but was happy to go along and make this suggestion as it seemed more aligned with the patient's reality and would potentially reduce distress in the patient. However, the defining feature of the interaction was the use of a prop.

4.5.2 Dolls and soft toys

Perhaps the most ethically challenging use of props was in the case of a woman who believed that two soft toys, a cat and one vaguely resembling a Labrador, were her living pets. I think I found this instance more challenging as it was not only using a prop, but it was also attributing life to it. I found the concept of pretending that something is a living thing, when it clearly is not, difficult but, equally, I could see the comfort the patient derived from this belief. Lash (2005) and Minshull, (2009) found that soft toys often evoke the same caring response as a doll.

My discomfort is illustrated below by the limited response I give and the speed at which I choose to disengage:

Patient: "I need to check on the dogs. Have you got a key?

Nurse (me) goes down to bedroom and opens door

Patient: “Oh there they are. {Gets into bed and strokes 2 soft toys and talks to them as if they are real}. I’ll just stay here as he’s not well. I need to take him to the vets”

Nurse (me); “Oh” Comes out of room.

The props provided real comfort since the patient was able to touch and stroke them and put them on her knee. This interaction also has an element of going along with the patient, although this was only sustained by the use of props. If I had argued or contradicted her it would have resulted in initial distress followed by anger. The woman was very slight and when she became distressed would often run at the locked fire doors, barging them with her shoulder. This put her at massive risk of causing serious physical harm, both to herself and others. The patient knew that the toys were more immobile than a real dog and cat would have been and often justified this by saying they were not well and needed to go to the vet. There is an ethical argument that says by going along with the patient, I was potentially causing her distress as she believed they were unwell and that this therefore forms part of a more malignant social psychology described by Kitwood (1997). However, the patient then sat on her bed without displaying any distress and stroked the toys. By using the props, she was able to engage in a relationship with her environment which supported her personhood as an animal owner and lover. MacKenzie et al (2006) highlighted some of the potential negatives of using props (in her study it was dolls) when patients over invest in them. Some patients want to feed the dolls or animals first before they eat, potentially impacting on their own nutrition, or can become upset if the prop has eyes that open and close as the patient may become distressed thinking that the doll or toy has died.

In this instance to say the toys were not real would have destroyed the patient’s personhood by dissolving a valued relationship that she believed still existed as well as potentially causing a loss of face which would challenge her sense of dignity as a fully functioning adult by contradicting a strongly held belief. At this point I could also have offered further emotional intervention by asking how she felt once she had started stroking the toys. It was difficult to decide whether to continue the interaction and perpetuate the lies or to withdraw, as I chose to do, as the patient appeared comfortable and was showing no signs of distress. In these situations, it is easy to feel conflicted as a nurse. Personally, I would have been happy to continue the interaction based on the props, using them as if they were real; however, I was very aware of the instructions from the NMC (2018) about promoting professionalism and trust and this made me feel uncomfortable in relation to perpetuating the lie. It becomes very difficult to make a clinical decision in these instances as, for me, the principle of beneficence should override the need to always tell the whole truth.

The woman with the soft toys very much regarded them as real animals and there are lots of similarities to the use of doll therapy in this instance. In most cases where a doll is given to a patient, it is given as a real baby and both the patient and staff treat it as such (Andrew, 2019). Whilst the staff on the ward were happy to engage with the toys, it does raise the question as to whether they would have been as comfortable if it had been a doll that was being used as a prop, as doll therapy seems to elicit quite strong emotional reactions from people (Minshull, 2009). The reality is that the ethics underpinning the situation with the patient are very similar to those that underpin doll therapy. The woman in question also had a rag doll she referred to as Sharon. It was very much a cloth doll and not the baby doll type usually associated with doll therapy, that resemble a real baby. The rag doll did not simulate a baby as some of the more lifelike dolls do:

Healthcare assistant: "I'll go and get Sharon" {Returns with rag doll and hands it to female patient} "She's just woken up, give her a kiss"

The patient gives 'Sharon' a kiss but said "It's a lovely doll".

The patient was in the main female lounge with a couple of other female patients and two members of staff. She was starting to become restless, so the healthcare assistant decided to fetch the rag doll. This was chosen over some of the patient's other soft toys since she had raised concerns about them being unwell. When the patient was handed the doll, she took it and kissed it gently, as you would a child but was quick to say that it was a doll. She then went on to nurse Sharon as though she was a small child – bouncing her on her knee and talking to her. There was no obvious reason why she was happy to invest reality into the soft toys but not the doll, in terms of what she was saying. However, her behaviour with them would indicate that they were all living beings, despite acknowledging verbally that Sharon was a doll. When staff utilised Sharon to deescalate or comfort the patient, they were careful not to assign the role of child or doll to it until the patient had intimated how she was going to interact with it at that specific point in time. This often changed several times through the course of a day. Many of these interactions also involved going along with the patient's reality, but the focus of the interaction was the use of a prop.

One of the challenges to using dolls and soft toys as an intervention is the argument that it is infantilising the person with dementia and this potentially challenges their dignity (Mitchell et al, 2016). Fenton and Mitchell (2002) define dignity in a healthcare setting as physical, emotional, and spiritual comfort, in which case it can be argued that the use of dolls and props generally are more often used to support rather than detract from a person's dignity. If that person were to become agitated or distressed, the behaviours they may subsequently display could be considered far more undignified and potentially humiliating. In the example above the patient was able to maintain her dignity by applying her capabilities effectively (Shotton and Seedhouse, 1998). In other words, when she was interacting with the soft toys and treating them as real, she knew exactly how to act and was comfortable doing this, meeting her basic human need to nurture and care for another being. There would be almost no other activity that could have been delivered on the ward and in the context of her dementia that would have met this need. The intervention would be completely supported by the principles of Habilitation Therapy (discussed in Chapter 2, p.55), which strongly advocates the use of props when necessary, including dolls or soft toys. If by providing a prop, the person with dementia can engage in an activity which gives them pleasure, in the here and now, then it should be tried (Moore, 2009).

For the props to be effective, staff also had to go along with the patient's reality. Staff made no attempt to prompt the patient that the soft toys were not real and went along with her perception that they were real. Andrews (2019) would argue that it is the staff's responsibility to reinforce whatever the patient's perception is although she does qualify this by saying it is not a lie, but the avoidance of an unnecessary truth. In the context of this research, I would argue that 'going along with' in this case is a lie, but a justifiable and helpful one. Marzanski (2000) calls this benevolent deception. Whilst going along with formed part of the interaction the significant feature was that of props.

Families of patients may not accept the use of dolls or soft toys as a suitable intervention for their relative which may have to be taken into consideration (Mitchell et al, 2016). In this instance, the patient's brother was involved with the care plan that promoted the use of soft toys and felt it was a much more natural and dignified way for his sister to interact, as animals had played such a large part in her life. Gallagher (2004) would support the notion that her dignity was maintained as they suggest that people have and maintain dignity on the basis that they are human and the subsequent interactions they engage in, regardless of their levels of autonomy or cognition. On occasions where families do object to the use of dolls or toys based on the concept of infantilising or being undignified, Andrew (2006) suggests that it is in fact the family who are experiencing the indignity or embarrassment, as a parent interacting with a toy or doll does not fit with their established relationship.

It is likely that by engaging with dolls or soft toys, that the person with dementia can regain some form of control. Many of the behaviours exhibited by the patient in this case were instinctive and well established and therefore helped to give meaning to her current situation (Pezzati et al, 2014). It allowed her to experience feelings related to significant relationships which she had and valued in the past and is strongly supported by Bowlby's attachment theory (Bisiani and Angus, 2012). The toys helped to create the emotional conditions to meet her needs and could therefore be considered person centred (Brooker, 2019).

4.5.3 False Environments

One of the wards had invested a huge amount of energy in creating a false, or enhanced environment for the patients to watch the football world cup. The physiotherapists had led a project to build a 'bar' which was to be taken into the lounge when there was a world cup game being played. There was to be a range of drinks served from the bar and bar snacks to be laid out.

Below are three images of the bar being used on the ward for National Dementia Week (Photographs 6 and 7). Below that (Photograph 8), is a picture of how the room usually looked. It is decorated slightly differently to when it was used for the world cup but illustrates how it was used. Staff reinforced the false environment by engaging in the social activities such as having drinks and snacks from the bar and cheering loudly when there was a goal, although they did continue to wear their uniforms.

Photograph 6

Photograph 7

Photograph 8

It is debateable as to whether this is a true lie or not. The patients would see it being brought in and therefore it was not being instigated based on deception, although the deceit was later established by how it was used. However, it was hoped that the patients would then go on to use it as they would a bar in a pub and go and stand at it and potentially order drinks. Several patients assumed that they were ordering or drinking alcohol, such as a beer, when in fact they would be given a non-alcoholic drink but were not told. This is illustrated in some of the examples given further on.

In general, most of the team were quite excited about the pending World Cup celebrations and did not raise any concerns about the potential ethics of the situation. Most did not acknowledge that a false reality was going to be created, and from my perspective, it had the specific intent to deceive, even if it was with the best intention. The motivation for engaging with the deception was unclear. Many of the staff were football fans and wanted to watch the World Cup which would have been impossible when they were at work, unless watching it was also combined with patient activity. When this is considered, it is likely that the high levels of investment from the staff came from their own desire to watch the football, rather than creating the adapted environment for the patients. Eyers et al (2012) identified that in care environments, centralised activities are often organised to meet the needs of the staff or the organisation rather than the needs of the patients or residents.

Only one member of staff, a specialist nurse affiliated to, but not part of the ward, raised concerns about the planned activities. They identified that if patients were going to be introduced to the false or modified environment, staff were effectively doing this based on what they felt was in the best interest of the patient (MCA, 2005). Staff had assumed that the patients would want to, and benefit from, joining the party. However, to make a decision in the best interest of a patient, the patient would have to have their capacity assessed as is it only people who lack capacity who can have a decision made in their best interest (MCA, 2005). It is also worth remembering that capacity is specific to each decision being made. In relation to the proposed activity, there were multiple decisions that capacity would need to be assessed for before a best interest decision could be made. There were 14 patients on the ward who were potentially going to engage with the activity. To adhere to the law as specified by the MCA (2005) the nurse raising concerns was correct in what they were saying to the team. However, although not stated, it was clear that the team had no intention of going through the complete process of assessing capacity with each individual patient. Instead, lack of capacity in most cases was simply assumed. This is in direct opposition to the MCA which is specific in identifying that everyone must be assumed to have capacity, unless proven otherwise. This then prompts further ethical debate. The staff knew the patients very well. The patients all had very impaired short-term memory and in general were unable to retain new information. This meant that, under the MCA (2005), they were unlikely to be able to retain any new information (about the impending party and the associated decisions) long enough to be able to weigh up the information given and subsequently communicate their decision. In the spirit beneficence of the NMC Code (2018) therefore, all patients were initially included in the activity.

This assumption, however, only supported some patients as no account was taken of patients who perhaps did not like social gatherings, parties, or football. This is also difficult to assess on historical information as this would be based on the patient’s preferences prior to having dementia. As a person with dementia progresses on their journey, their preferences about social engagement are likely to change (Mitchell, 2014). This may also fluctuate depending on how they feel that day. As their perception of the world changes, to enter a busier or changed environment may become much more unsettling and anxiety provoking, even if they previously had enjoyed parties and socialising. Much has been written about the social isolation that comes with dementia and many interventions are described to prevent this (Rafnsson, 2017). It may be that as the disease progresses, people are more comfortable in their own environment and with their own company. It is often care givers, both professional and friends and family who are concerned about this change in behaviour and perceived isolation. Preparation was made though, that if any patient appeared unhappy or uncomfortable with the gathering, they would immediately be taken to another area of the ward and be supported to engage in an alternative activity that they enjoyed. This then goes along with the principle of maleficence (NMC, 2018).

The first time the bar was used was for England's inaugural game. All patients were brought into one lounge where the bar had been situated. Cherryade was being given out in plastic wine glasses *"a glass of champagne for you?"* to the women and non-alcoholic beer was given to the men; *"Have a beer"*. When a second drink was offered to one of the men, he responded *"No, I know when I have had enough"*, and then slid down his chair as to infer that he had had plenty of alcohol!

The atmosphere in the lounge or 'pub' as it had now been rebranded was sociable and relaxed, with people communicating with each other, although not always understandably. A couple of male patients stood leaning on the bar interacting with each other, although the content of their conversation was unintelligible. It was fascinating to observe how the introduction of a familiar scenario immediately initiated a specific set of behaviours in people, allowing relationships, however temporary, to be established (Son et al, 2002). Despite the whole scenario being based on deception, the activity was clearly supporting personhood, if people subscribe to the paradigm that it is based on relationships. Although some of the environment had been altered and could be said to be a lie, particularly in relation to the actual drinks that were being given out, the emotion and pleasure displayed by the patients and staff, was genuine and real. It could be said that patients were able to validate each other’s positive emotions, which was a rare occurrence. Patients rarely interacted with each other apart from when they were in conflict. To watch them interacting on this emotional level was very special and was an exceptional way to support their personhood. Given that the patients were highly unlikely to remember any of the event, it was important that they experienced positive feelings which would last considerably longer (van Manen et al, 2020). Also, the increased fluid intake by most of the patients was very positive as the weather was extremely hot and there were concerns regarding dehydration for several of the patients. Some patients who rarely communicated verbally went up to the bar to get their own drinks and were able to sustain short interactions which was very positive.

Only one female patient chose to leave the lounge / bar area. She did not like bars or a drinking culture and went to another lounge and watched her favourite film with a healthcare assistant. The other patients engaged readily with the changed environment. This really highlighted the principles of personhood, even though the environment was completely manufactured and not as it appeared.

The whole bar scenario was repeated for every game for the World Cup, so several times a week over a prolonged period. The impact on the ward generally was palpable. It gave staff and patients an opportunity to interact and develop much more equitable and social relationships. It gave them the opportunity to share in a pleasurable activity that made sense to them both on an equal basis creating a level of social validity that can be hard to achieve at this stage in a person's dementia journey (Ryan et al, 2008). All those who chose to be involved, both staff and patients, were football fans. Most of them had followed the football since they were young and for some it brought back cherished memories of going to the match with dads or uncles, allowing staff and patients to participate in a well-established community. It created opportunities for the person with dementia to experience attachment, inclusion, occupation, and identity (Kitwood, 1997b). Nolan et al, (2004) highlight the importance of reciprocity in caring relationships, both for the carers and the cared for. Some patients were able to follow parts of the game, being fully aware of when someone was taking a shot at goal. Others were simply able to validate the positive emotions emanating from people and enjoy the atmosphere.

It was quite challenging to be involved in this with from my perspective. The level of deception that was going on was extreme and, at times, I was unable to document all that I saw in terms of lies and deception. However, reflecting on each session afterward was very useful.

Reflection – verbatim from notes.

Very uncomfortable about staff giving out the drinks. Cherryade was handed out as champagne which it clearly was not. Beer was handed out as alcoholic when it was not. One gentleman refused a second beer as 'I know when I have had enough'. It had already been highlighted at the MDT that everyone should have a best interest decision, therefore necessitating a capacity assessment in relation to using the 'money'. This was not done.

I really struggled with giving drinks out as alcohol, which I acknowledge was a personal issue. I did think the patients could have just been told they were non-alcoholic. However, I am unsure whether many of them would have comprehended what was being said, or whether to tell them would have been for my benefit rather than theirs. The important part of this activity, each time it was engaged with was the positivity and pleasure gained by both parties. Sometimes staff can become quite frustrated and despondent working on wards for people with dementia where they may get very little genuine and emotional interaction on a two-way basis (Eggenberger et al, 2013). To watch the level of engagement, and pleasure derived from the activity, for me, justified the deception. The staff continue to talk about that period on the ward and they all have their own special memories of what a particular patient said or did that made them smile. Person and Hanssen (2015) identify that these shared pleasurable opportunities are essential both for the person with dementia, and the staff. It enhances well-being and connectedness which are essential for maintaining personhood (Ellis and Estell, 2010). To argue retrospectively that this should not have gone ahead based on it being ethically challenging would be very sad. It clearly met the needs of both patients and staff on several levels, and shared moments like this are few and far between on very busy and challenging wards (Slettebo, 2008). The nurse who challenged the ethics of it initially, continued to find the situation difficult. Unfortunately, as she was not ward based, she did not participate in the activity so only heard reports from staff, rather than observing the benefit derived at the time by the patients. I think it is important with these situations that staff are encouraged to raise their concerns and can openly discuss and reflect on the issues they have with any activity (Esterhuizen, 2019). If someone is not happy because lies or deception or being used, they must have the option not to engage with these processes.

Non-alcoholic beer was also used to encourage hydration in two of the male patients who were often reluctant to drink. This was of particular concern at the time because the weather was extremely hot:

Healthcare assistant: “Do you want a beer? {Non-alcoholic} I’ll get you a beer.”

The patient did not respond to the initial question.

Healthcare assistant; “Here’s your beer. I’ll just pour it for you. There you are. A nice cold beer. Is that nice?”

The healthcare assistant brought a can of beer and a glass to the patient’s side then carefully poured it in front of him. The patient took it from them and immediately started to drink it, without prompting:

Patient; “Aye. Aye. That is nice”.

The patient believed that the beer was his usual, alcoholic beer and took it readily. He drank it almost immediately which was significant as he was at risk of dehydration due to his limited fluid intake. The cans were 330mls, so it made a large contribution to his daily intake.

Whilst the bar was being used, one of the other issues that emerged was money. One of the female patients became concerned that she was unable to pay for her drinks:

Patient (F); “I can’t pay for this” {cherryade which was being given out as champagne}

Healthcare assistant: "Here, I'll give you some money" {Hands over two false £5 notes}

The patient then sat feeling them. They had been done on a printer and then laminated so felt thicker and shinier than a real note would have done.

Healthcare assistant; "Here, put them away".

The patient then started looking for her purse but stopped very soon afterwards. She then took the cherryade and drank it, which she probably wouldn't have done without the aid of the false money. The patient was clearly suspicious about the money; however, she seemed unable to process or express what the issue was so accepted it. It is difficult to know why she did not challenge further but for people with dementia, often the fear of asking what could be perceived as a silly question or the risk of embarrassing themselves overrides any suspicion they may have (Mitchell, 2014). Ethically this is challenging because the patient was not comfortable in the situation, which was visible to the healthcare assistant, yet she continued to perpetrate the lie. The difficulty being, if she had not continued and then told the truth, she may well have damaged the relationship with the patient. It also highlights the need for props to be realistic if they are being used to emulate or simulate reality.

4.5.4 False money

False money was also used in a completely unrelated incident, to diffuse a potentially dangerous situation when a patient had become very emotionally elevated and was threatening to become very aggressive:

Patient (Male) in a very aggressive tone; "Where's my money?" {Throws table}

Healthcare assistant: "I'll go and get your money. It's in the safe"

Patient, shouting; “Where’s my money?”

Healthcare assistant 2; “[Healthcare assistant 1} has gone to get your money”

Healthcare assistant 1 returns with fake money and hands it to patient who snatches it from her.

The patient then put the fake money in his trousers, becoming less angry and begun walking around the ward in a calmer fashion. Without the physical prop, the situation would not have been de-escalated as the patient’s total focus was on his money and his ability to rationalise or process what he was being told in terms of his money being in the safe, was limited due to the advanced stage of his dementia. The patient historically always had cash in his pocket and became very distressed if he put his hand in his pocket and could not find any. In this instance, he had already thrown a dining table and the situation had the potential to escalate into something very dangerous. As soon as the healthcare assistant returned with the false money his emotion reduced and I could see how relieved he was. It would not have been possible to de-escalate this situation without the use of props. He had a robust care plan that had been agreed with his wife that documented when and how the false money was used. This was essential in ensuring consistency across all staff given the patient’s propensity for aggression.

The false money was printed off on the ward printer and then laminated or the copies tended to disintegrate very quickly. The lack of authenticity sometimes raised suspicion in patients:

Nurse (me) and a healthcare assistant were sitting with a male patient who was being nursed 2 to 1 within arm’s length observations due to high levels of aggression. The patient took a fake £10 out of his pocket. It had been laminated.

Patient: “What does that say?” {Pointing at fake £10 note}

Healthcare assistant; “Ten pounds [patient]. It just feels funny because it’s one of those new notes”.

The healthcare assistant was referring to the new plastic notes which had just been introduced into circulation. The patient would have no memory or understanding of this statement.

The patient felt the false note between their thumb and fore finger and then put it in his pocket, clearly suspicious but not wanting to challenge further. The patient’s non-verbal expression indicated that he was not convinced that the £10 note was genuine. He did accept the explanation from the nurse which was important because if he had felt he was being deceived, he was likely to cause serious injury to staff or other patients. This highlights the importance of using realistic props when deceiving or there is a risk of either causing more distress to the patient or destroying the existing relationship by having the deceit recognised (Kamphof and Hendriks, 2020).

4.5.5 Complex and consistent use of props

The most consistent use of props was with a male patient who had betted on the horse racing daily for many years. He had a very set routine at home which involved going to the village shop to pick up the morning paper, then spending time looking at the days runners and picking out a couple of horses to bet on. He or his wife would then either go into to town or more often in later years, telephone the bet in. When he was initially admitted to the ward, he could be very agitated in the mornings. After discussion with the family about his routine at home, staff introduced the activity into his routine on the ward with positive effect (Chung et al, 2017). It was an elaborate lie that all staff were very consistent at maintaining and at times embellishing:

Patient: “Can you do my horses?”

The patient asked the nurse to read the racing pages to him so he could decide which horses he wanted to bet on. The nurse sat down and read the horses and jockeys from a random race in an old newspaper. The morning paper had not arrived on the ward and sometimes it was quite late. If the nurse had explained this to the patient, he would not have processed it and subsequently, could have become quite agitated. Due to his impaired cognition, he would not have realised that it was an old paper:

Patient; “What’s the odds?”

Nurse goes back and reads out each horse with the odds. The patient listened intently but was unable to retain the information he was being given. To save any embarrassment or loss of face by highlighting this, the nurse picked one and read that one again, as a question (James, 2008).

Nurse; “12 to 1 Vincent’s forever?”

Patient; “Aye. That one”

Nurse continued reading next race.

Patient: “Have you marked them?”

The nurse made a point of marking the horses in the paper so that the patient could see.

Nurse; “Yes. You’ve got 4. Is that enough?!

Patient; “Aye. That’s enough”

Nurse: "How much do you want to put on"

Patient; "£5"

Nurse (me); "Do you want them each way or to win?"

Patient; "Each way. £5 each way"

Nurse; "Right. I'll get them put on now for you. Mind, I want an ice cream if you win".

The patient then sat down quite contentedly in the lounge. The first nurse left as though she was going to place the bets, although this was never her intent. This process was quite often mentioned in my daily reflections. Below is a reflection written after the first time I observed this.

Reflection – verbatim from notes.

Went through to male end to make tea / coffee. Observed very complex lie being told with regard to putting bets on. If he has capacity to choose horses and bets, does he ever have the capacity to believe he has won? The level of effort and intricacy involved felt very uncomfortable to observe, however, the healthcare assistant was completely convinced of the benefits.

This scenario was played out on the ward daily, sometimes more than once. It only worked if the member of staff had a newspaper which contained racing. It was also better to have another piece of paper and a pen when doing it or the patient became concerned that the nurse would not remember the right horses. It did not matter if it was that day's paper as he would not remember which horses, he had heard the previous day. Some days, false money was also incorporated into the deceit:

A healthcare assistant was sitting at a table with patient after breakfast. The healthcare assistant was reading out lists of horses and riders at various races that day. The patient was picking out various horses on which he wanted to place a bet.

Patient: “I’ve got no money”

Healthcare assistant: “Here. I’ve got your money” {Hands over £30 in fake notes}. “I’ve got your money, here you are”

Patient;” Ah”

More discussion about the bets – some difficult to follow.

Healthcare assistant: “Right, so you want [horses] on? I’ll go and put the bet on now.”

The use of the fake money helped to reassure the patient and allowed him to continue with his usual activity.

By reinforcing the action, the staff were upholding the patient’s personhood, being very focussed on an activity that had a lot of meaning for him and that he enjoyed. Because lies were involved, Brooker (2019) would argue that this demonstrates malignant social psychology and is morally wrong. I completely disagree. This patient enjoyed the time spent looking at the horses and had much more positive and balanced interactions with staff, where he was able to interact on an equal level. This patient struggled to interact coherently on other topics due to his severely impaired short-term memory. Using the newspaper, helped to sustain a much more effective relationship with staff and supported his personhood. On occasions, the patient would sense that something was perhaps not quite right, although he could be easily reassured and distracted:

Patient; “Are the horses on?”

Healthcare assistant: “Yes I put them on this morning”

Patient: “How did you know what to put on?

Healthcare assistant: “You told me {he didn’t}. {Healthcare assistant produces a piece of paper and says “One each way, one straight and an accumulator at Worcester.

It would have been unlikely that the patient would have believed the healthcare assistant if they had not been able to produce the piece of paper as ‘evidence’.

Patient: “Well how did you get my money?”

Healthcare assistant: “I used your winnings off yesterday.”

The conversation then continued re the horse racing.

These interactions enabled the patient to become a much more social being, by allowing him to interact on a level with staff about a topic which he knew a lot about and really enjoyed. Other than the discussions around betting and horse racing, the patient had very little verbal engagement with staff as he struggled to form sentences outside of this topic. This intervention was carried out consistently across the team, including by the ancillary workers such as the ward domestic. It was very effective, and it did not take long before I was comfortable in engaging with it. The only other topics he would engage with were hunting /

shooting and his working gun dog. Since these are quite specialist and emotive topics, staff often found it difficult to engage with him, based on these subjects.

The following interaction highlights the importance of making the deception complete:

A nurse comes in with the patient and hands a health care assistant a piece of newspaper.

Nurse: "Here [healthcare assistant] this is [patient]'s horse for today. Smoking Bandit at Stratford"

Healthcare assistant; "Ah. OK"

Nurse: "Will you put it on please?"

Patient with some anxiety in his voice; "You will put it on?"

Healthcare assistant; "Oh yes"

Patient was reassured by seeing the piece of paper being handed over.

In this instance, it was the use of props that reinforced the genuineness of the interaction in relation to the emotion conveyed but it also helped the patient to believe the lie. As stated previously, this was a very important part of the patient's day and helped to make him feel contented. This was important in terms of his wellbeing. He would remember how he felt, although he would not know *why* he felt the way he did. It is well documented (Oliver, 2019) that feelings about an activity or interaction will have a much greater impact on the person with dementia than the actual content of the activity or interaction itself.

All the regular ward staff were quite happy to engage in this high level of deception. They generally enjoyed the positive interaction and being able to interact with the patient on a more equal platform. Everyone was aware of the care plan and care was delivered consistently, with effective outcomes. However, this was not always the experience of temporary ward staff such as bank staff or students who were new to the ward:

Allied Health Professional (AHP); "Here's the paper. Do you want to put your horses on?"

Patient; "Aye. Aye"

The AHP tells a student who is new to the ward (first shift) to read out horses as though she was going to put a bet on and hands her the newspaper. The student had been helping with breakfast and was trying to take in as much information as they could. Starting a new placement can be very anxiety provoking and often students feel obliged to 'get stuck in' immediately, rather than going to the office to read care plans (Kim and Shin, 2020). The AHP had not met the student before so had no insight into their knowledge base or the point they were at in their education. The student had not seen this activity carried out with the patient and was clearly uncomfortable with the instruction. When the AHP handed the student the newspaper, the student took it and sat down with the patient looking unsure as to what she should do next. I was observing another patient within arm's length but was close enough to speak to the student. I explained to the student how to use the newspaper and that the intervention was care planned in the patient's notes. The patient heard the explanation that was given to the student but was unable to link the activity being talked about, was in relation to him. The student then successfully, although apprehensively, engaged in the activity with the patient. The patient engaged in the activity, focussing on the paper but could sense the anxiety in the student and, as a result, completed the task and then walked away. It was far less positive than it could have been, although still believable in terms of the action. The student was able to engage in this activity much more positively later in the week after they had read and understood the purpose of the care plan and discussed it with her mentor. They were also able to observe other, more experienced staff carrying out the intervention and the positive results that it had. It is very difficult and perhaps wrong to expect another member of staff to engage in a dishonest activity without a full explanation of both the actual activity and the motivation behind it. Staff also need the opportunity to discuss any concerns that they have and be given the opportunity not to engage with deceitful behaviour if they find it is going to compromise their values and beliefs (Casey et al, 2019). If a member of staff does decide that they are unable to engage in a specific behaviour with a patient, care must be taken that the care that the patient receives continues to be consistent and in line with their care plan. It cannot become inconsistent because of different members of staff.

In summary, when props were used with patients to embellish or perpetuate a lie, they were generally successful in maintaining the deceit and subsequently supporting personhood. Props are used most effectively when they are introduced as a result of knowing a patient’s history in detail. That way, staff can ensure that the prop is being used to maintain a relationship that previously existed and had real value to the patient. The findings suggest that consistency is key in terms of a team agreeing how and when a prop will be used as an intervention. Occasionally, they may be used spontaneously with good effect. If this happens, it may be good practice for the team to discuss the situation, motivation, and outcome with a view to incorporating specific interventions into the regular plan of care. The findings also indicate that consideration also needs to be given to how realistic the prop being used is. A lack of realism can raise suspicion and anxiety in patients. If the patient realises that the prop is fake, then they may lose trust in the staff or their environment. There was genuine investment in the use of props, observed by staff and they were always used with the purpose of validating the patient’s feelings, which is reflected in the consistently positive results observed.

Findings suggest that careful consideration needs to be given to environmental changes that may affect a group of individuals who may have different responses to the changes. There needs to be a strategy to support people who perhaps do not want to engage with a change or social situation. Overall, from my observations, props were used thoughtfully and effectively, and no pervasive detrimental effects were seen as a result of their use. On the occasions that patients became suspicious about the realism of an item, they were quickly reassured, and no continuing effects were observed. The staff who were engaged in the use of props appeared well motivated and engaged with the process, particularly when they were used a spart of planned care. They engaged with the props in a genuine and convincing manner that validated the reality of the patients. There were many positive interactions observed which suggests that there are benefits in the use of props in selective situations.

4.6 Going Along With

Going along with encompasses all of the themes of untruths and lies, but also has some stand-alone examples which did not straddle any other categories. If the interaction had another element which directed the discourse, it was categorised with the most prominent feature. However, there were some elements of going along with that did not incorporate other strands of lie telling and were therefore classed solely as going along with.

Most commentators identifying going along with as either not lying or not as extreme or unpleasant as blatant lying (Williamson & Kirtley, 2016). Perhaps this is because going along with does not carry the emotional charge the word lying does or it could reflect the processes involved. To go along with someone is to join them in their reality that they are already in. If someone tells lies, they are the perpetrator as they have initiated the falsehood. This again highlights motivation as an important factor in how healthcare professionals choose to engage with untruths. By removing the emotional element of the word lying, and choosing to go along with, the teller is allowed to move fluidly away from telling the whole truth, whilst allowing them, quite often to avoid feeling that they are telling lies. By reframing an interaction into going along with, the teller or carer (informal or professional) has a way of not telling the truth but being able to demonstrate they are not lying. This may have increased value to family carers who have an increased emotional investment in the interaction and therefore charge the word lie with greater emphasis or meaning than perhaps those who do not. Williamson & Kirtley (2016) identified professional care givers would naturally have lower emotional investment than that of family care givers. However, as previously identified in the literature review, informal carers generally have less discomfort around lie telling than professional carers do (Blum, 1994). This could be because the actions of informal carers are not guided by policy (NMC, 2018) or constrained by best interests in terms of the law (MCA, 2005). Their sole aim of an interaction is to meet the needs of the person with dementia and reduce their distress. Many proponents of validation therapy (Feil, 2012) argue vehemently that going along with is validation of the recipient and cannot be considered lying. Whilst collecting data, the author observed many instances of going along with and would consider this strategy as lying. For example, on the first ward on one shift, there were multiple examples of health care assistants going along with. It was observed frequently with three patients who had very limited verbal skills and were particularly difficult to understand:

“Oh right. I see”

“OK, yes, it will be definitely be fine”

Nodding, “Yes, I’m sure it will be”

As in the examples above, the person who is doing the ‘going along with’ regularly does not know or understand what the patient is saying. The carer may nod or communicate in fragmented sentences, with the intention of conveying understanding, even when they do not. It is often a reciprocal interaction based largely on nonverbal communication (from the patient) relying on facial expressions, sounds or gestures (Eggenberger et al, 2013). What health care professionals do understand or identify with, is the emotion expressed by the patient. They may have to use lies to validate the emotion, but it would be with the purpose of either giving the interaction added value and meaning to the conversation, or reducing distress, as in the example below:

A patient had started to shout very loudly and angrily whilst eating tea. Staff could not make out verbal content.

Healthcare assistant apologises: “everything is fine now”

Patient returns to eating their tea.

This patient was quite advanced in his journey with dementia. He had very limited verbal communication although he could express his emotions. He was sitting at a table by himself and there were other male patients moving around in the corridor and in the dining room. There were quite a few staff assisting other patients. This patient was very fit and strong and could become physically aggressive. Situations tended to escalate very quickly. When he started to shout, two of the other patients immediately became emotionally aroused giving the potential for the situation to become very dangerous. On the ward there were several very strong and fit men who had to be constantly observed to avoid them injuring each other.

As soon as the healthcare assistant apologised, the patient's emotion began to dissipate. As they went along with his emotions, they used their emotional intelligence to validate the patients' feelings as they had no idea what the content of his speech was. If they did not know what he was saying, then their responses could not be truthful as they were purely guesses. They followed up the apology with generic assurances. The patient responded well to the interaction, most likely because of the way it was communicated rather than the content which they may or may not have understood. This fits with the work of Sabat (1999) who looks at the social construct of communication and how that stays intact for much longer than the ability to simply understand words. The fact that the healthcare assistant managed to identify and go along with the expressed emotion and subsequently deescalate the situation ensured that the patient's needs were met and what was a potentially dangerous situation was averted. If the truth had been used in this instance – for example, trying to explore the patient's anger, the situation may well have deteriorated, especially if they had become more frustrated about their inability to communicate effectively or the inability of the staff to understand them.

Humans are narrative beings and an individual's story is key to their identity and personhood (Johnston & Narayanasamy, 2016). If a person is telling their version of their own story, it becomes essential to go along with that person’s truth to maintain both personhood and dignity. Johnston & Narayanasamy also identified that interventions which allowed a sense of continuity for the person with dementia were important as it allows the person with dementia to generate an increased sense of self, therefore, going along with the patient can be a very supportive intervention which helps to fulfil this role in maintaining personhood. Although Kitwood (1997) argues that lie telling is part of a malignant social psychology but he also identifies that there is a necessity to engage with the psychology of the person with dementia (Kitwood, 1989). If a professional is deemed to be engaging with the reality of the patient, then perhaps they would be considered going along with them. However, the communication could not be wholly truthful for both parties. One party (in this case, the professional) would be thought to be lying. James & Caiazza (2018) identify ‘going along’ with as a deceptive practice. This is significant as most authors such as Feil (2002), argue that going along with is not a lie.

The example below highlights how knowing a patient’s back story can be useful in terms of how to respond in terms of going along with someone, as it is not always easy for staff to judge how to go along with the patient:

Patient; “He’s a shit”

Healthcare assistant; “Is he”

Patient: “Yes he certainly is”

Healthcare assistant: “Did you tell him?”

Patient: “Yes I did”.

There was no indication as to who the patient is talking about. Immediately after the interaction, the patient moved away from staff.

This patient was a very fit, strong, and volatile man. His mental health had deteriorated due to dementia and he was being nursed in seclusion on a male acute ward, despite being in his seventies. He had tried to strangle a patient and had seriously injured a female member of staff. The two rooms plus the corridor in seclusion suite were available for him to walk round. He constantly had two members of staff with him. He was a very well-spoken man who had retired to Africa after being a successful businessman. He and his wife had returned to England soon after his dementia was diagnosed. He has always been able to exert power and influence over those around him. In Africa, they had employed house staff. At the start of the interaction, it was clear that the patient had become very angry, very quickly. The minute before he had been walking around in quite a relaxed fashion, interacting with staff, and looking at the newspaper. The healthcare assistant engaged in a conversation about ‘him’, not knowing who ‘he’ was. The fact that the healthcare assistant engaged in conversation showed that the patient was being listened to and that the healthcare assistant was interested in what he had to say. It was part of developing / sustaining a relationship with the patient. The healthcare assistant could not tell the whole truth as it was not clear even what the patient’s truth was, and no one else had entered the seclusion suite. It was very important to go along with the patient’s feelings to prevent the situation escalating. It helped that the staff who were with the patient understood the patient’s history and previous manner in terms of managing people. It once again highlights the importance of validation when telling lies. If the patient is validated emotionally it is likely that their needs will be met, regardless of whether truth or lies are used. Validation can help to save face for some patients which can be important (Smith et al, 2011).

The following exchange took place between a healthcare assistant and a female patient. The patient was an ex-headmistress who believed that the ward was a school and that she was still the principle there:

Patient waving their arm towards the door. "Are all the houses through there private or are they all the same?

Healthcare assistant: "Oh they are just the same"

This patient was physically a very imposing woman. She was very tall, probably about six foot and physically imposing. Her shoulders were very square and straight. She walked with a stick, although she did not rely on it much and would regularly carry it horizontally. She had been a headmistress for many years and was very opinionated. Her short-term memory was impaired to the point she remembered very little from recent times and was effectively time shifted in her conversation (James, 2015). She very much believed that she was still in charge and that she was looking out from her school. She was standing near the door that went into the garden, which was surrounded on all sides by the ward, which was a continuous, almost circular building. She used her stick to point to the building across the way.

Going along with this patient was an essential strategy for maintaining her mental health and wellbeing. It was important not to contradict her as this could cause almost instant anger. Once she had become angry, she was difficult to deescalate and at that point could become a falls risk. Despite her dementia she always conveyed that she had a strong sense of justice and wanted equality. Her intonation when she asked the question, implied that it would not be good if the houses were private, so the healthcare assistant chose to go along with what she had said and echo the last part of her statement, even though the healthcare assistant was aware that this was true, and she was effectively lying to prevent the patient becoming angry or distressed. However, it could be argued that this was not lying to the patient as the healthcare assistant was entering the patient’s reality where in fact the discussion around housing was true to their world, and she was in fact validating the patient. After the exchange, the patient disengaged with no outward display of emotion. If she had lost face due to the exchange, she could have become embarrassed or distressed. This exchange was also considered as to whether it was also a blatant lie. However, because the healthcare assistant replied with ‘they are all the same’ rather than specifying private or some other category, I felt that they had more gone along with the patient’s belief, rather than a blatant lie. As previously said, where an interaction spans more than one category, it was assigned according to its dominant feature.

Saving face could also be considered as a way of supporting personhood (Kitwood, 1997). Going along with a patient can be an important strategy to implement this as sometimes it is about acknowledging or maintain previous relationships:

This interaction took place between a very agitated female patient and a healthcare assistant. The patient regularly threatens staff with legal action but cannot understand that she is detained under Section 3 MHA (1987).

Patient: “My friend is coming later. He’s from Leeds. He’s a barrister”

Healthcare assistant: “Well when he gets here, we’ll make him a cup of tea. Leeds is a long way”.

This patient was very petite and wiry in stature. She was detained on a Section 3 MHA (2007) which she did not understand but was aware that she was being kept on the ward against her will. As such, she believed she had contacted a friend who wase coming to sort out the situation and take her home. In conversations, the patient would often allocate significant job roles to her friends, as though to reinforce to staff that she indeed had some power. If this woman was challenged or contradicted, she would then try to leave the ward. This often involved kicking and hitting the doors, sometimes running at them to try to open them with her shoulder. This put her at great risk of physical harm.

In this instance, the healthcare assistant entered the patient’s reality and very effectively went along with it. The healthcare assistant knew that there was no barrister coming that day. The patient was a very kind woman who liked to help and support others on the ward, and she responded well when kindness was demonstrated. Hence the healthcare assistant saying that she would make the barrister a cup of tea was well received, and the patient appeared happy with the response. In this instance, to try to orientate the patient to the healthcare assistant’s reality would have been extremely detrimental. The healthcare assistant was working with the patient’s dementia orientated reality (Caiazza and James, 2015). Whilst going along with the patient was clearly not truthful from the healthcare assistant’s perspective, it was truthful from the patient’s perspective. James (2015, p10) put forward that the suggestion that it is important for carers to “enter a person’s current reality”. In other words, go along with the person’s reality, rather to try to orientate them to that of the carer. This had been highlighted previously by Mackenzie and James (2010) when they talked about communicating with people in the moment (but their moment, not that of the carer). The findings from this study would support the notion of going along with patients in their dementia orientated reality and accept that the patient's truth is as important as the carers. I would also emphasise that in order for going along with to be effective, it needs to be done in conjunction with validating the patients expressed emotion in order for it to have a positive impact.

There was considerably more going along with was observed than I was able to record as individual items of data. This is because some of it was very subtle and limited to nonverbal communication. However, this was captured in my daily reflections.

Reflection – verbatim from notes.

Going along with has been the theme of the day. Difficult to record though as the patients it involved cannot communicate coherently. When they have said something I and other staff have responded by agreeing and nodding, saying 'really' or 'I'm not sure' depending on the social construct of what the patient iterated.

Reflection – verbatim from notes

Limited data collected today. Very few patients able to engage in verbal communication. Lots of going along with.

Reflection – verbatim from notes.

There is considerable going along with. This continues to be done with the motivation of meeting the emotional needs of the patients as it is very difficult to understand most of them.

In summary, the findings from this study show that going along with is a form of lying. This contradicts much of the previously published literature which generally concludes that going along with is not lying, with the exception of James et al, (2011) and Russell, (2018) as discussed in Chapter 2 (p.11). When staff go along with a patient, they often have little idea of what they are responding to or agreeing with in terms of verbal communication. However, what was apparent, was that going along with plays an important role in meeting the needs of the patient. When staff went along with a patient, the lie was being used as a means of validating the patient’s emotion and showing the patient that they were being listened to and understood. When staff did not understand content, they were able to identify the emotion and demonstrate empathy and kindness by going along with. Staff were well motivated to go along with the reality of the patients and did so in a genuine manner which was reflected by the positive outcomes. The study findings indicate that going along with a patient as a useful form of lying that can support personhood and help to establish and maintain relationships.

4.7 Avoidance and Delaying

I categorised avoidance as not wanting to cause upset by confronting people with the truth. There are a range of avoidance sub types described in the literature: direct information avoidance, (Mishel, 1988) which was seen several times in my study; selective attention (Rateshwar et al, 1997) and selective ignoring (Mishel 1988), where the listener only acknowledges part of the information that has been given to them and social withdrawal (Brashers et al, 2000) where one party seeks to disengage and withdraw from the interaction completely. Avoidance can also be conscious or unconscious (Cohen, 1993).

Initially, when I investigated the data, I had avoidance and delaying as two clear categories. However, after more time I spent looking at the content in each of the categories, I realised that all the delaying examples would also fit into avoidance. Therefore, in terms of this study, delaying is classed as a subtheme of avoidance, rather than a separate theme. This is illustrated on the Taxonomy (Figure 9, p.107).

4.7.1 Delaying

Below is an example of delaying:

Patient; “Can I be out?”

Healthcare assistant; “Not at the minute”

Patient {shouting}; “Not at the minute! I’ve been here since 1985”

Healthcare assistant; “Ditto”

Patient: “Yes but you are paid to be here, and I am just locked up”.

The healthcare assistant here was not particularly engaged with the patient during the interaction and there was no emotional connection. On reflection, this communication was also a direct avoidance as the healthcare assistant was avoiding telling the patient that they could not go out at all and the healthcare assistant also told a blatant lie when she said “ditto”. The patient was clearly unhappy with this interaction which, from the point of the healthcare assistant was more of an off the cuff remark. It showed little warmth or empathy and did not attempt to validate the patient’s feelings in anyway. It was a very surface level interaction and was perhaps a greater reflection on the fact that the healthcare assistant was possibly quite weary as it was early evening and they had been on a long day – so they had already worked on the shift for about 11.5 hours. The healthcare assistant chose not to engage with the patients’ final comment and the patient walked away irritated. This patient was quite advanced in his dementia journey but could still give quite a quick retort during conversations, although he would forget what had been said almost immediately. After his initial irritation, he walked away and then began an interaction with another member of staff, who used a similar delaying strategy:

Patient: “I’ve lost me cases. I’ve got two cases and they’ve gone”

Nurse: “We’ll find them later”

Patient: “I want them now”

Nurse: “I’ll go round and ask all the staff if they’ve seen them”

Patient: “Well make sure you do”.

The second part of the interaction was a blatant lie – the nurse had no intention of asking the other staff. This man could be difficult to distract and always liked to feel that the staff were doing something to help him. That is why the nurse offered to go and ask other staff, which she had no intention of doing as the patient’s cases had been hidden to stop him repeatedly packing to go home. Trying to orientate this man could be very distressing for him and tended to make him very angry. The lability of his mood meant that he could become distressed very quickly, and ‘as required medication’ then had to be administered covertly. (Medication issues are explored in more detail in 4.8.1 (p.221). It seemed much kinder, and person centred to adjust the communication to meet his needs, even if this included lying. This interaction was more positive than the first example because, in this case, the nurse validated the patient's distress by offering to find the cases later and offering to ask the other staff if they knew where the cases were. The nurse did this with warmth and genuineness and the verbal communication was believable.

The search for the man's cases was always followed by him continually requesting to go home. The case was in fact in the patient's bedroom, but the door had been locked as he repeatedly packed his case or took his clothes out of the drawers in preparation for going home. He was detained under a Section 3 of the Mental Health Act (2007). When it came to the point of discharge, he would be going to a specialist nursing home rather than to the home he came from and this would not be discussed with him, only his family. However, when he had been at his real home, prior to his admission, he had displayed the same packing behaviour, regularly leaving the house 'to go home'. This sort of behaviour is common in people with dementia. Often, they are in fact looking for their childhood home (Tible et al, 2017).

The most common example of delaying was people promising to return. For example:

Patient; "Er. Er" {Waving hand to stop a healthcare who was walking past}

Healthcare assistant; "[Patient] I'll be two minutes [patient]. I will be back in two minutes"

The healthcare assistant did not return.

This lie is difficult to place. In this instance, it was a blatant lie as the healthcare assistant did not return but, at the time of utterance, it was more likely to be said with the motivation of delaying as the healthcare assistant may well have intended to return. The fact that the healthcare assistant did not return had no consequence due to the patient’s high level of short-term memory impairment. In two minutes, the patient had forgotten that he had asked anyone anything, so he was unaware that the healthcare assistant had not returned.

This type of delaying was used by a whole range of staff groups and always had either an indifferent or positive effect, where the patient accepted the response and was happy to wait for the return of the staff member. The patients generally forgot the interaction with a few minutes of happening because of their very impaired short-term memory. It was never observed to have a negative effect due to the very limited short-term memory of the patients observed:

Patient : “Excuse me ? Excuse me ?” {Beckoning across sitting room}

Pharmacist: “Hi [patient’s name] I’ll be back in five minutes. I just need to go and do something”

Patient: “I need some help”

Pharmacist: “I will be two minutes. You know I always come back and see you”

The pharmacist left the ward.

The patient was sitting in a chair on the far side of the sitting room. The pharmacist put her head through the door and spent a minute just looking at the patients. The pharmacist was very warm and convincing in her replies so they were totally accepted by the patient; however, this could also have been a blatant lie as the pharmacist never intended to return and promptly left the ward. This example was more uncomfortable to observe than the previous one; perhaps because I knew that the motivation was very different. On talking to the healthcare assistant afterwards, they had fully intended to return, whereas the pharmacist had no intention of coming back as she had already said goodbye to the staff. It would have felt more comfortable if the pharmacist had interacted with the patient and found out what they had wanted – it was clearly important to them. After the pharmacist left, I asked the patient if I could help, but they had forgotten what they wanted, so we had a cup of tea.

Below is another example where there was no intent to return:

Domestic; "Just sit there and I will be back in a minute with the paper to do the horses"

The domestic left area.

The domestic wanted to tidy the dining room after breakfast and the patient was walking round the area they wanted to clean. The patient (as discussed extensively in section 4.5.5, p.178) used to look at a newspaper each day with staff to place his bets on the horse racing. The domestic led him through to the lounge and showed him a chair, reassuring him that she would return with the newspaper to do the horses. This was also a blatant lie as this was never their intent given that the promised activity was not part of the domestic's role. It was an activity that she knew staff engaged the patient with. However, it was said with genuineness and the patient accepted what was said without questioning or resisting her guidance. He very quickly forgot the interaction.

Reflection – verbatim from notes.

"I'll be back in two minutes" appears to be a personal phrase, rather than across the board. One or two staff use it regularly.

When reflecting on delaying it was interesting to acknowledge that delaying using some form of “I’ll be back in…” was often teller specific rather than considering who the receiver was. It was generally used by members of staff with less experience, and quite often during medication rounds when they were under pressure to complete the task within a given time.

Not all delaying interactions were positive. In the following interaction, the patient wanted to go home. They were detained on a Section 3 of the Mental Health Act (2007):

Patient: “So I will have to go and get all my things in the morning”

Nurse: “Yes. You are staying here tonight”

Patient: “But I want to go home”

Nurse: “You will have to see a Doctor in the morning first”.

The nurse was trying to delay the patient’s behaviour with the hope that they may forget about going home by tomorrow. If the patient was to leave the ward, a doctor would have needed to see them in order to approve Section 17 leave (MHA, 2007); however, this would not have happened any time soon due to some of the behaviours displayed by the patient. The nurse’s interaction was quite cold, with no real validation or empathy with the patient. This could have been attributable to the fact that the nurse was 11 hours into a 12 ½ hour shift and was clearly tired. The patient had been quite agitated for several hours and trying to rationalise with him often made the situation worse because he could become more elevated from an emotional perspective. The patient walked away but was clearly unhappy. After a few minutes he had forgotten the interaction and was asking questions of other staff members:

Patient: “Are we going to get the cases down?”

Nurse: “We’ll have a look later”

Patient: “I need them now”

Nurse: “We’ll look later on”.

This nurse tried to delay the patient’s behaviour with the hope that he might forget about getting his cases later. He was very persistent. This response was much more empathic in tone and clearly validated the content by agreeing to help to look for them later. The patient walked away as he had in the previous example but appeared much happier about the response. The two examples are very similar in terms of the verbal responses received from the nurses, but the way the responses were delivered were very different and clearly had an impact on how the patient felt at the end of the interaction. With this patient, validation of the content of the interaction as well as the emotion was important in terms of meeting his needs. Validation is discussed in more detail in Chapter 5 (p.256).

The example below is another example where validation was used effectively as part of a delaying interaction.

Patient: “I’ve lost my wallet”

Healthcare assistant: “I’ll look for it later on. Eat your tea for now”.

The healthcare assistant here tried to delay the patient’s behaviour with the hope that he might forget about the wallet by the time he had eaten his tea. The healthcare assistant validated the content of the interaction by agreeing to look for it later. They also validated the anxiety of the patient by speaking in a warm and reassuring tone so that the patient did not doubt that they would look for the wallet after tea. The patient appeared satisfied with the response and ate his tea.

4.7.2 Avoidance

However, as stated earlier, not all examples of avoidance were delaying, as this observation shows:

Nurse; “Come and get your dinner [patient’s name]”

Patient; “Where’s ma mum? I want my mum”

Nurse; “What was she called?”

Patient; “[Mum’s name]”

Nurse; “I thought that was your wife’s name?”

Patient: “I want ma mum”

Nurse; “She’s not here. Shall we go for lunch?”

The patient went for lunch.

This patient regularly spent time looking for family members. Miesen (1990, 1992) identified that older people who develop dementia will at some point in their journey, develop a parent / family fixation. His wife, daughter and grandson were regular visitors. He often became quite focussed on looking for his mum. Initially the nurse (me) focussed on using distraction and validation techniques (Feil, 2002) which initially felt ineffective. However, now reflecting on the situation, perhaps by validating the patient emotionally he was able to subsequently go for lunch. This would be supported by the work of Cheston and Christopher (2019) which says that a parental fixation is in fact an expression of anxiety and is often how a patient will express their need for security. Perhaps the patient’s underlying emotional need had in fact been met, even though he continued to ask for his mum. In this instance, the nurse was avoiding telling the direct truth, as the distress caused by telling him his mother had died many years ago was not justifiable. If he had been told this, it would have been like telling him for the first time, causing a major grief reaction (Spector et al, 2000). Due to his very limited short-term memory, he would have forgotten once his distress had gone but the whole process would be repeated every time he was told. In the second part of the interaction, the nurse resorted to more blatant avoidance when she said, “She’s not here”. This was said with empathy and kindness and carefully constructed non-verbal communication. The nurse’s head was tilted slightly to one side and she shrugged her shoulders. She then used touch to guide the man into the dining room to have lunch. The validation used in the second part of the interaction was much more effective. The patient then sat down to have lunch and quickly forgot about asking for his mum.

Care needs to be taken when using avoidance as a strategy as the person with dementia may feel that the professional carer is ignoring or not listening to them if they do not answer their question or attempt to redirect them (Hertogh et al, 2004). It is often used when staff are trying to avoid what most people would consider to be a blatant lie. This can be particularly useful with patients who have fluctuating memory and may well be able to briefly identify when staff have told them lies, as can be seen below:

Female Patient; “Have you seen [brother’s name]”

Nurse: “No. I’ve just come in”

Patient: “You might have seen him on the way”

Nurse: “No I haven’t seen anyone”

The patient walked away to continue the search for her brother.

The patient was very irritated at the beginning of the interaction. Her brother was younger than her and she had always looked after him. She liked to know where he was; however, it was quite difficult to engage in blatant lies with regards to her brother's whereabouts as he regularly came onto the ward unannounced and if staff had given the patient fictitious information, they may well have got caught out as the patient's short-term memory fluctuated. If the brother arrived when staff said that he was somewhere else, the patient pointed out that they had lied to her, and to her, lying was unforgivable. This could be quite damaging to the staff / patient relationship, although the negative impact tended to be quite brief as she tended to forget in a relatively short period of time. Instead, the nurse chose to try to avoid the conversation specifically about the patient's brother and went for a more generic but equally untruthful answer. The difference with the untruthful response was that it was not about her brother and could not be challenged by the patient, who could not know who the nurse had seen on her journey in. The patient disengaged from the interaction and continued to walk around the ward, looking out of the windows looking for her brother. Her brother did visit later that day.

Some of the avoidance observed felt quite uncomfortable. On one occasion, a specialist nurse came to the ward specifically to observe a patient whose behaviour the staff and other patients considered to be challenging. The specialist nurse subsequently developed a formulation to support the ward staff to meet the needs of the patient more effectively (James, 2011):

Patient: "Hello, what do you do? Have you come to take blood?"

The specialist nurse went to answer the first part of the question but then responded; "No I'm not here to take blood. Have you got good veins?"

{Patient shows her veins}

Patient: “Oh yes, I’ve got good veins”

Specialist nurse; “Oh. I haven’t. I don’t give mine easily {blood}.

The nurse was trying to avoid saying to the patient that she was part of the behavioural support team and had come to observe her (the patient) for fear of causing the patient distress which was likely to be expressed as anger.

Technically, the specialist nurse was not actually lying because she was not there to take blood. However, the patient would be unlikely to be aware of a specialist behaviour nurse’s role, so would not have suspected that there were nurses allocated to reduce behaviour that challenges. The patient equally would not have had any insight to the fact that her behaviour was challenging for both staff and patients around her. In some of the literature this type of lie would be considered as withholding the truth (Elvish et al, 2010). The nurse was avoiding telling the truth about her role, but it was also a very skilled interaction in terms of deflecting and distracting the patient from the original purpose of the interaction. The nurse acknowledged what the patient had said and clearly illustrated that she was listening by picking up the conversation around veins rather than discussing her own purpose. I am unsure why I was so uncomfortable with this interaction, as it was positive in terms of outcome. I think it is difficult when professionals shield or hide their true role or purpose as that then brings up issues of capacity and consent (MCA, 2005). The patient was going to have no real input into the formulation that would be developed to meet her needs (as identified by staff) which goes against my beliefs around patient choice and empowerment. The difficulty in this case was that if the nurse had tried to discuss the patient’s behaviour with them and the impact it was having both on the patient, and those around her, it was likely to have resulted in a complete denial and feelings of distress for the patient. It may also have damaged the patient’s relationship with staff if she felt that she was either being constantly watched or that people were judging her. If behavioural support is considered as an intervention, like medication, then the intervention that was formulated would be delivered covertly. If medication was to be administered covertly, strict guidelines would have to be followed for it to be deemed both ethical and safe (NICE, 2015). There is no reasoning behind why different interventions are treated differently both from an ethical and policy perspective. Both would be being delivered or administered under the auspice of best interest (MCA, 2005) yet one is considered acceptable, the other is not. These apparently simple interactions can be incredibly complex when they are examined on a closer level and there are no easy answers. Medication related issues are covered in more depth in 4.8.1, (p.221).

The interaction below, is in fact very similar in the motivation for avoiding the truth and it involved the same nurse with a different patient. However, it did not evoke the same feelings of discomfort. I think this is because the response is closer to the truth and the patient she is interacting with, was not the one who was specifically being observed at that time therefore would not be subject to a covert intervention as a result of the interaction:

Female patient: “Do you work here?”

Specialist Nurse: “I’m [name]. I come to support the nurses”.

The specialist nurse was trying to avoid saying that they were from the behavioural support team and had come to observe the behaviour of specific patients.

In this interaction, the specialist nurse was technically correct in her response that she had come to support the ward nurses. However, this is also avoidance because she deliberately did not state her job role or title. This patient would have become very upset if they had suspected that she was on a mental health ward or had a mental health issue. She would also have been very upset if it was perceived by others that her own behaviour was difficult. The patient often commented on the behaviour of other patients but had no insight into her own behaviour. Overall, the interaction was much shorter and less elaborate than the previous example.

A lot of the instances of avoidance were in relation to not telling a patient that they were on a mental health ward and this prevents some ethical challenges. People have a right to know where they are and why. However, if that information is likely to cause extreme distress, then there is a strong argument for not telling the patient if it is avoidable. This interaction took place at teatime with the patient sitting at the dining table:

Patient: "Can I ask where we are? Are we in {Local town name}?"

Nurse (me): "Yes"

Patient: "Is this the asylum?"

Nurse (me): "I wouldn't call it an asylum. I would call it [hospital name]

Patient: "So it isn't the asylum?"

Nurse (me): "I would call it [hospital name]. It's very new"

Patient: "So it's not the asylum? I wouldn't want to stay in the asylum".

The patient continued eating her tea and I turned away from her to pour some drinks and disengage from the conversation.

I was avoiding telling the patient they were in a psychiatric hospital, or asylum as they called it and I was very careful to use the name of the hospital as it no longer included the word ‘hospital’. The new title reflected that it was in the countryside and made no reference to it being any sort of health facility. The new hospital still has a similar name to the old one and is on the same site. I used the correct name for the hospital and technically it would not be described as an asylum in today’s language. However, using the patient’s frame of reference, it most definitely is an asylum, and she was detained against her will on a Section 3 of the MHA (2007). She had no understanding or recognition of her detention, despite her rights being read to her on a regular basis and a paper copy of them being left in her bedroom.

The patient was very clear that she did not want to be in ‘the asylum’ and was very focussed on the fact that there was nothing the matter with her. She was quite advanced in her dementia journey and had minimal short-term memory. Her mood could be quite labile, and she had been rapidly tranquilised on a couple of occasions as her behaviour presented a serious risk to her own health. The conversation was generally very light and reassuring, demonstrating to the patient that the nurse understood her anxieties and that no, they were not in the asylum. Whilst it was not comfortable telling lies in this case, I felt very relieved at the end of the interaction that the patient had been appeased and had continued with her tea. I was very conscious of what I was saying and aware that my purpose and motivation was avoidance. I found it very difficult to lie to this level; however, my motivation was that of non-maleficence and not wanting the patient to become distressed and potentially injured. It was very difficult for everyone when this patient became elevated and distressed as she was very tiny and frail but could be very aggressive, throwing herself at the doors which then required physical restraint or rapid tranquilisation. In these instances, the ethical complexities are very difficult for staff.

Withholding information is also referred to in the literature; however, this is generally in relation to giving information to people who do have capacity and it is often around diagnosis or prognosis (Richard, Lajeunesse & Lussier, 2010). In this study, avoidance covered any of the instances of withholding information as in the example below:

Patient: “Where’s [wife’s name]?”

Nurse: “At home in [village name]”

Patient:” Why is she not here?”

Nurse:” You’re in hospital”

Patient: “Why am I here?”

Nurse: “Because you were having a few problems at home”.

During the conversation the nurse tried to avoid telling the patient that he was having his mental health assessed or that he had a diagnosis of dementia. Effectively, they were also withholding information. If the nurse had been truthful with the patient, and he had understood what he had been told, he would have become very distressed. He would quickly have forgotten what he had been told and the scenario would be likely to be repeated in a very short space of time. There was no reason to give him information that would cause him distress and that would very soon forgotten. Several of the examples of withholding information were focused around not identifying the environment as a psychiatric unit or giving people their diagnosis repeatedly. It is important that everyone has a right to know their own diagnosis and at an earlier stage in their dementia journey, all patients had been given their diagnosis. It was about avoiding giving the diagnosis repeatedly, at a point in their journey that it was likely to cause distress. Similar instances were recorded on several occasions as the example below illustrates:

Patient: “Why am I here?” {agitated}

Healthcare assistant: “You are here to be assessed”

Patient: “Assessed? Me?” {loudly}

Healthcare assistant:” There are different levels of assessment”.

Similarly, to the nurse above, the healthcare assistant was trying to avoid saying to the patient that they were in hospital to have their mental health assessed; technically they were also withholding that information.

In summary, avoidance and delaying are ways of not telling the whole truth and therefore, for the purposes of this study are regarded as untruths or lies. Findings suggest that they are generally very effective and can be a generally kind way of sustaining an interaction with a patient, without confronting them with a potentially distressing whole truth. Again, the key aspect of this theme was that how an interaction is delivered is far more important than the actual content in terms of reducing distress and meeting the patient’s needs. The majority of times where avoidance was used, were spontaneous and not care planned. This is a detail which has not been captured in previous studies, regardless of whether avoidance is considered to be a truth or a lie. Avoidance and delaying, in most cases were almost automatic, an instant response to an immediate situation without fore thought or planning. This contradicts previous studies where participants say that they only lie in a conscious manner and in order to reduce distress or meet an identified patient need (Turner, 2016). Again, this demonstrates that the ethnographical methodology employed in this study was able to uncover new information.

4.8 Blatant

In the simplest form, a blatant lie is an untruthful communication, which if successful, will deceive the receiver (remembering that deception only occurs when the lie is believed by the receiver). It is blatant because it is simply a lie in its own right, initiated without prompting by the teller. It is not uttered to go along with the person with dementia or to avoid answering a question. There are no props or external factors involved. It is generally given as a definitive and correct statement, even though the teller knows it to be untrue.

Blatant lies covered a wide range of instances, but there were also four significant subthemes that were identified: medication administration, passing the buck, deferring to a higher authority, and searching for family members. Blatant lies were the biggest overall theme recorded, yet none of the lies were care planned, they were all spontaneous. The issue of spontaneity and unconscious lying will be discussed in more detail in 4.8.4 (p.238).

Blatant was perhaps the most varied theme in terms of response from the patient. The response from the patient relied on how the lie was said as opposed to the content and the motivation of the teller for expressing it. Lies which validated (Feil, 2002) a patient’s feelings or addressed their emotional needs, were generally successful. However, those which either did not address the expressed emotion or were delivered with indifference often either made no impact or had a negative impact. Some of the lies in this category were said glibly and without any real engagement, often when staff were tired or towards the end of a shift. Whilst the intention from staff would not be to cause harm (maleficence), they inadvertently missed an opportunity for beneficence or to make the patient feel differently (NMC, 2018). Spontaneous, unconscious lying has not previously been identified in the literature as previous research has relied on the accounts of carers after the intervention and suggested that decisions about lie telling and deception were conscious interactions triggered by specific dilemmas, often related to confidentiality, managing behaviour and difficult questions (Tullo et al, 2015).

This group of lies has the potential to impact personhood most significantly, particularly when used without previous contemplation or planning which potentially will lead to inconsistency. Motivation for telling the lie was also a key element. If the motivation was to address the needs of the patient it was said with more genuineness and validated the patient’s emotions and usually resulted in a positive outcome for them. If the lie was just said as a retort more aimed at meeting the needs of the member of staff, then it was generally not effective or potentially had a short but identifiable negative impact. In the existing literature, the carers described their motivation for telling lies as being to reduce distress or improve compliance (James et al, 2006), however, this was not always seen during this study and sometimes the lies appeared to form a natural part of the teller’s usual discourse.

There is an argument that says if blatant lies are to be told on a regular basis, they should be consistent (James, 2008) and preferably care planned to ensure this. However, Russell, (2018) disagrees as she feels this has the potential to increase paranoia and suspicion as the person with dementia moves into a world where everyone is colluding and conspiring with each other, but not the person with dementia. The lies that are in this category would generally be very difficult to care plan for, as the interactions that stimulated them were often quite random and inconsistent.

Feil (1992) argues vehemently that people with dementia should never be lied to, and instead validation techniques should be used. Richards (1994) further developed the ideas of Feil and introduced the Integrative Validation approach, a modified version of the Feil original. When studied, a lot of validation therapy can be seen to actually involve not telling the truth, and very much going along with the patient's reality (this was previously discussed in the going along with section, 4.6, p.187). Again, Richards states that patients should not be lied to. However, in the Erdmann and Schnepp study (2016) looking at Integrative Validation Therapy, one of the examples they give to demonstrate unconditional appreciation of and respect for residents, contains a blatant lie. This is never acknowledged by the authors.

Mrs. O.: ''I don't really know, how did I come to be here?''
Geriatric nurse P.: ''I don't know either, beats me. But I 'm happy that you are here.''
Mrs. O.: ''And I'm happy that I'm here''
(. . .) Mrs. O. again: ''How is it that I am now here with you?''
Geriatric nurse P.: ''I don't know either. Let's just enjoy it.''
Mrs. O.: ''I think so, too.''

(Erdmann and Schnepp, 2016, p1190)

The nurse must have known why Mrs O was there. Another concept discussed is congruence and the importance of truth telling, yet this is clearly not how the intervention is applied in practice. The congruence is demonstrated in terms of the emotional intervention but not in terms of the verbal content. I witnessed a similar situation which was handled very differently:

Patient: "Why am I here? I don't know why I am in here"

Healthcare assistant: "I don't know either"

Patient: "Well that's just ridiculous"

The patient subsequently walked out of lounge looking irritated.

All the staff on the ward are in uniform and clearly identifiable and the patient had enough insight to know that someone wearing a uniform would know why she was there and was right in her assumption that it was ridiculous that the staff did not know why she was there. There was minimal engagement from the healthcare assistant who appeared not to want to become involved in a conversation with the patient at that point and responded very quickly to the initial question. The patient was quite labile and could become angry quickly if she did not feel in control. She was detained on a Section 3 (MHA 2007) which she was unable to comprehend. She could understand that she was not going to be allowed off the ward but could not understand why. The healthcare assistant interacted in quite a cold manner, making no attempt to validate the patient's feelings. The healthcare assistant could have perhaps responded by asking "Why? Don't you like it here" and tried to engage the patient in a conversation about her feelings or perhaps engaged her in a different lie such as, "you are only here for a couple of days". This would still have been a blatant lie but would have possibly met the patients' needs more effectively. In this instance, it could be argued that the lie was told to meet the needs of the healthcare assistant. It successfully disengaged the healthcare assistant from an interaction they clearly did not want to have but did not meet the patient's needs.

What it highlights, is that it is the emotional or affective element of an interaction that is significant. It may be more useful to consider validation as a philosophy of care rather than an intervention (Mitchell and Agnelli, 2015). This is illustrated in the following example:

Nurse: “You’re looking very smart this morning”

{Patient responded positively by smiling but the verbal content was unintelligible}

Nurse: “Very smart, dapper”.

The patient was wearing a Tee-shirt and track suit bottoms with no socks or slippers and, whilst clean, was not what most people would have called smart. The comments from the nurse were said engagingly and with great warmth. The interaction did elicit a positive response from the patient, although the patient had virtually no verbal communication. It is more likely that he was responding to the warmth and emotion being expressed rather than the verbal content of the interaction which he was unlikely to be able to have comprehended.

4.8.1 Medication administration

Administering medication involved two nurses dispensing and subsequently administering medication to each patient. The ward was often busy and as this is a time limited task, dictated by the prescription times, staff were sometimes stressed when carrying it out:

Nurse: “Here’s a little drink for you” {Paracetamol}

Patient: “Oh. Oh” {Puts paracetamol to lips}

Nurse: “It’s nice. Have a little drink”.

The nurse’s communication style was key in this instance as it conveyed warmth and caring which encouraged the patient to trust the nurse and take the drink. There was no tension or anxiety from either party. The nurse genuinely wanted the patient to take the analgesia as they were concerned that the patient was in discomfort due to the pain in his hip.

The patient accepted the medication under the guise of ‘a little drink’. At no point was the patient told it was medication. The nurse had a pleasant and encouraging tone throughout the interaction. The patient was often resistant to taking medication but regularly complained about pain in his hip. However, he was unable to associate taking medication with reducing his pain. It had been decided that it was in his best interest to have paracetamol to address his pain levels, but it was never referred to as medication and was given as a syrup rather than tablets.

This type of blatant lie, particularly in relation to people with dementia, presents some ethical challenges. Effectively, the paracetamol was being given covertly. The patient was offered a drink of an unidentified substance. The nurse knew that if she was honest about the drink the patient may not take it, so gave it covertly as ‘a little drink’. This was not care planned or documented and covert medication administration had not been discussed with the family or the multi-disciplinary team. No mental capacity assessment had been made (MCA, 2005) to indicate that a best interest decision could be taken.

The example above (and below) document staff telling lies to patients to get patients to take medication. After a considerable amount of reflection and consideration, I would argue that these examples illustrate medicines being given covertly. The NICE Guideline (2015) is very clear that medication should only be administered covertly in exceptional circumstances, where it is deemed necessary and in accordance with the MCA (2005). These instances have only been identified because of the ethnographic methodology of this study. They have not been previously identified but present a huge ethical dilemma for nursing staff who are unintentionally but regularly administering medication outside the parameters of current legislation (NMC, 2018). It must also be highlighted that the nurses were acting with the best intentions with the intent of beneficence. Recommendations around this practice will be made in Chapter 6 (p.264).

Compliance with medication was heavily reliant on the relationship between the person administering the medication and the patient. Due to the nature of dementia, relationships could fluctuate daily, and depended on the general atmosphere on the ward. In the next instance, a healthcare assistant had been asked to give the patient their medication, under the supervision of the nurse. This decision was taken because the nurse had been the target of the patient's anger earlier in the shift. It was decided not to risk elevating the patient who was now much happier, with the possible consequence that he might refuse to take his medication:

Healthcare assistant: “Here you are [patient]. I've brought you a tipple.

Patient: “Oh”

Healthcare assistant: “A little shot. Just whiskey”

Patient takes medication

Healthcare assistant: “How was that?”

Patient: “Awful”.

The patient was often reluctant to take medication but had always been a whiskey drinker. There was no comprehension that he was being offered an opaque liquid from a medicine pot rather than a golden coloured liquid from a glass. There was recognition that it did not taste right, but he had drunk it by then. Again, I would consider this to be covert medication administration, as discussed previously. The interaction from the perspective of the healthcare assistant was warm and genuine in manner, despite the content being a direct lie. The patient validated the emotion that was conveyed and consequently, took the liquid. The patient made no link between the healthcare assistant and the unpleasant tasting whiskey and within a short period of time, had forgotten that he had taken it. Telling a lie had a positive impact for this patient.

The way an interaction is conducted, in relation to the member of staff is always the indicator as to whether it is more or less likely to be successful. When staff were warm and engaged whilst telling lies, the interaction nearly always resulted in a positive outcome regardless of what was said, as the observation below shows:

A nurse coming into lounge with medication; *"Here are my favourite ladies"* speaking to a group of three patients. Her tone was warm and her fondness for the ladies appeared genuine. This gave a generalised, pleasant message to all the patients as a group.

The nurse then approached one of the patients, smiling broadly and offering a pot containing several tablets; "They are pain killers for your hip"

There was also an anti-psychotic medication mixed in.

Patient; "What's this one?" {Asking about antipsychotic}

Nurse: "It's for your hip" {This was said in a reassuring manner with a kind tone}

There was an element of familiarity with this interaction when the nurse first entered the room. It established a positive milieu before the nurse attempted to carry out the more difficult intervention of administering the medication.

The patient was happy to take analgesia but no other medication. She clearly had some awareness that all the tablets did not look the same. She also knew she had a problem with her hip and was happy to take analgesia to relieve the pain, hence she did not challenge the lie being told by the nurse. It was generally accepted that staff could tell lies to get the patient to take her anti-psychotic medication as she could become very distressed and unwell without it. However, this was not documented, or care planned.

Another situation that was recorded on several occasions was when staff either passed the buck, or deferred to a higher authority:

Nurse: "Here's your painkillers, open your mouth"

The patient responded verbally but not coherently. However, she also made it plain that she did not want to take them.

Nurse; "It's for your knee. Your daughter says you have to have them"

Patient; "No"

The nurse gave a big sigh and dropped her shoulders, clearly conveying her irritation.

Nurse: "Your daughter rang and said you have to have them". This was said in a very firm voice.

The patient then allowed nurse to put tablets in her mouth. The patient then spat them out later. This was a frequent habit of the patient, so a member of staff had *been allocated to observe the patient for a period of time to see if she either swallowed them or spat them out.*

The interaction was brusque, and the nurse appeared tense as she approached the patient. It was often challenging to get the patient to accept medication which the staff found difficult. Consequently, staff often experienced anticipatory anxiety with regards to giving this patient medication. It is very easy to approach the task negatively with a patient who is often challenging, but that approach tends to communicate anxiety to the patient, increasing the chances of them refusing (Feil, 2002). The nurse interacted with the patient in a very matter of fact tone and lacked any warmth or empathy. In this instance, telling a lie did not help to get the patient to take her medication. Equally, lying did not have a negative impact either since, once the medication had been spat out, the patient had forgotten the interaction within minutes. On another occasion, two nurses entered into a deceitful communication that involved deferring to a higher authority, which was again ineffective:

It was morning and the patient had been agitated since coming out of their bedroom. He had been sitting in lounge, shouting, and swearing intermittently. Two nurses approached him with his medication.

Patient: "What are they?

Nurse 1: "Your tablets"

Patient: "What are they for?"

Nurse 1: "All sorts of things"

{This initial untruth was avoidance as she did not want to tell him that it included anti-depressant and anti-psychotic medication}

Nurse 2: "You need to take them, or the doctor will tell me I'm not doing my job."

Nurse 1: "The doctor says you have to have them"

Nurse 2: "I've had mine"

Patient: "What? All of them?" {This was said as the patient looked into a medicine pot with several tablets in}

Nurse 2: "Yes. They make you feel better.

Patient did not take any of the tablets and the frustration of the nurses was evident.

As an observer, this was quite a difficult interaction that, from the outside, always looked likely to fail. The patient was already agitated when the two nurses appeared. They clearly had a purpose and had approached the patient, almost prepared for a battle, which is what they got. The defensiveness from the patient perhaps came from a more emotional level than an actual reluctance to take tablets. The patient had limited ability to process new information so having two nurses, in a communal area, with background noise telling them to do something they were unsure of was unlikely to have a positive outcome. The lies were told with resignation and perhaps irritation rather than with warmth and encouragement from the perspective of the patient. Although the verbal communication of the nurses was said with the best intentions, the way they spoke lacked any warmth or empathy. There was no validation or even acknowledgement of the patient's uncertainty. Again, there was no long-term emotional outcome of the interaction as the patient forgot the incident within minutes; however, the patient's physical health may have been better if he/she had taken the medication. The motivation for these lies is questionable. The nurses wanted the patient to take the tablets as they were prescribed. However, it could be argued that the lies were told to speed up the task to meet the needs of the nurses who were under pressure to complete the task within a given time frame. If they had perhaps reframed their motivation so that the focus of their thinking and subsequent behaviour was based around wanting the patient to take the medication to help meet the patient's needs, they may have approached the task differently. If they had expressed positive and warm emotions as they approached the patient, they may have been able to engage them and give them the medication. A warmer, less confrontational approach was used by a different pair of nurses later in the shift and the patient accepted the mediation without question.

4.8.2 Passing the buck and deferring to a higher authority

Whilst I have categorised the two above examples as blatant lies, which they are in terms of this study, other studies may have categorised them differently. Turner et al.'s (2017) study identified that it was mainly other disciplines 'passing the buck' to qualified nurses, although this was conducted in a general hospital setting. In the current study, there were some occasions where deferring to a higher authority was witnessed and this was always reference being made to a doctor. Passing the buck and deferring to a higher authority are blatant lies, and form sub themes within this key theme. Generally, these two themes were unsuccessful, even when not related to administering medication:

Nurse trying to obtain urine sample from a patient. Pot already in toilet.

Nurse: "Don't flush the toilet when you've finished please as we need a water sample.

Patient: "I'm not giving you one. I'm going to give it in at [GP's]

Nurse: "No, you aren't going to [GP]. Our Doctors need it"

Patient: “I’m not giving you one. [GP] wants it”

Nurse: [GP] rang earlier and asked us to get one.

Patient: “I don’t think so and I’m not”.

The staff suspected that the patient had a urine infection, and it was very important that they obtained a urine sample. The nurse’s tone in the first part of the interaction was light and matter of fact. They had not anticipated any resistance from the patient so had not really planned or considered outcomes other than obtaining the sample. As the interaction progressed, the nurse’s frustration became more evident in their voice and they then resorted to a blatant lie. As the nurse’s frustration rose, the patient became far more resistive and did not provide the sample at that point. It highlighted again that the way healthcare professionals approach people is essential. In this instance, the nurse went into the interaction wanting to obtain the water sample as she needed to send it quickly. She wanted it now. Whilst the purpose ultimately was to meet the patient’s physical healthcare needs, the nurse did not plan the interaction sufficiently so that the communication demonstrated this. Their aim was to get a sample which was meeting their immediate needs, whereas the patient wanted to give a sample to her GP, which was her need. This again highlights the impact that motivation and validation of the patient or otherwise, has on the outcomes of interactions. A pot was left in the toilet and later in the day a sample was obtained as the patient had forgotten the conversation. In this instance, telling lies had no impact on the patient or their behaviour.

There were more instances of passing the buck where reference was made to a family member and these were generally more positive in terms of outcome; for example:

Healthcare assistant: “[Patient] come and get your soup”

Patient wanders off

Healthcare assistant: “Come on [patient]. Your [wife] will kick your arse if you don’t have your soup. She will kick your arse.”

Patient turns round towards dining room.

Healthcare assistant 2: “[wife] will kick your arse mind.

Patient goes into dining room and eats soup standing up.

This patient rarely sat down at all, including to eat. He was supported to eat by staff, whilst moving round the ward. The fact that he went into the dining room and subsequently allowed staff to support him to eat was a positive outcome. This also resonated with banter and familiarity as the healthcare assistants used the patient’s frame of reference in terms of the word ‘arse’ which was familiar however, the predominant feature was that it was a blatant lie.

Before starting the research, I had anticipated that there would be many more instances of deferring to a higher authority or passing the buck witnessed. This was also the perception of staff asked in both the Cunningham (2005) and Day et al (2011) study, yet when actual observation rather than personal perception is used to gather data, it was not such a common theme, which highlights the importance of using ethnography for this study.

4.8.3 Searching for family members

Another significant subtheme of blatant lies related to the whereabouts of family members. When patients ask about either a deceased family member or a family member who could not be with them at that time, it was often a pivotal point for them in terms of their emotional or distress levels. A truthful response stating that the person is either dead or not coming is likely to evoke huge distress in the patient (Dening, 2019) and may well lead on to further behaviour that challenges, such as heightened emotional arousal or physical and verbal aggression. In these situations, a blatant lie was often used, generally with a positive effect:

Patient: "Mam. Mam. Where's me mam?"

Healthcare assistant: "She's at home. She's fine."

Patient: "Are you sure?"

Healthcare assistant: "Yes she's at home"

Patient: "Oh".

The healthcare assistant spoke in a very confident and reassuring manner. The reassurance conveyed by the tone of the healthcare assistant placated the patient who seemed satisfied by the answer and did not ask again. Some literature (Miesen, 1990) links behaviour such as searching for a parent to anxiety. This would explain why the reassurance offered by the healthcare assistant was effective as it addressed the underlying need of high anxiety. It was far more likely to be the social construct of the response rather than the actual verbal content of the communication that met the patient's needs. Feil (2012) argues that the anxiety should have been validated without moving into direct lie telling. In this situation, where a patient has very limited cognitive ability a short but effective communication, even if it is based on a lie could be seen to be more person centred and in the best interests of the patient. This patient would often spend time looking for family members, such as illustrated here:

Patient: “Where’s [wife’s name]”

Healthcare assistant: “She’s coming in this afternoon”

Patient: “Are you sure?”

Healthcare assistant; “Yes. She will be in with your grandson”.

The healthcare assistant did not know when wife was next visiting, or with whom. However, her response was very confident and assertive. The patient was particularly close to his grandson and introducing the thought that he would also be visiting, gave the patient something to look forward to. Overall, the response was sufficient to reassure the patient in the short term. The patient appeared satisfied with this answer and went to have a cup of tea. Sometimes though, this patient would challenge the responses he was given:

Patient: “Where’s [grandson’s name]” {Agitated and quite aggressive}

Healthcare assistant: “He’s at home with his mam and dad”

Patient: “Don’t be so fucking stupid. How would you know?”

Healthcare assistant: “[wife’s name] told me this morning. They’ll be back later”.

Initially, the patient challenged the response of the healthcare assistant with a reasonable comment – they would not have any means of knowing where the grandson was. However, the healthcare assistant went on to further embellish the lie by referring to his wife which helped to de-escalate the patient. The patient’s wife had not and would not be in. The healthcare assistant knew the patient very well and knew that a reference to their wife was likely to diffuse the situation even when their first response was challenged. The patient would not remember whether their wife had visited, but the thought that she had would make him feel better regardless. The fact that the healthcare assistant continued with the conversation with absolute conviction, helped maintain the genuineness and flow of the interaction which further validated the underlying anxiety, which was likely to be the real unmet need, rather than actually needing the presence of their wife at that point. If the healthcare assistant had changed the direction of the conversation at that point, it may have raised further suspicion or anger in the patient, putting the relationship in jeopardy in the short term. It would be unlikely to have a lasting impact on the relationship, even if it had deteriorated in the short term as the patient had very limited memory. This again highlights that the way an interaction is delivered is more important, than what is said. The high level of genuineness validated the patient and resulted in the lie having a positive outcome in that the patient then appeared to relax and went to sit in the lounge.

This can also be illustrated by another example when a healthcare assistant was challenged about a blatant lie:

Patient: “It’s like jail in here”

Healthcare assistant: “No”

Patient: “It is. Everything’s bloody locked”

Healthcare assistant: “No it’s not”

Patient: “Well open the bloody door then”

Healthcare assistant: “Do you have a key?”

Patient: “No. You do”

Healthcare assistant: “No I don’t have a key”

Patient: "Yes you bloody do. You've just come through it" {Raising his voice. Walks off}.

This patient had some limited short-term memory and used to watch the ward staff very carefully. He often challenged staff when he thought they were being untruthful although it did not appear to affect the relationship as he forgot the interaction soon afterwards. He could become quite elevated and emotional in the short term if he did not get what he wanted, which was usually the door to be opened or access to his cars which no longer existed and had been sold by his family several years ago. The response from the healthcare was quite challenging and did not make any attempt to empathise with the patient or validate his anxiety. As a result, there was a short sharp exchange that resulted in negative consequences for the patient, although they did not last long.

The variability of this patient's memory made telling lies to him much more complex and ethically challenging. During interactions, it was important to try and minimise the emotional response from him and staff often responded to him spontaneously as he could be relentless in his search for his car and suitcases. The searching behaviour often started after tea and in the early evening when staff were tired and weary. The consequence of this was that sometimes they responded to them in quite a flat tone, without validating the underlying anxiety, resulting in an ineffective communication:

Patient: "Where's my car?"

Healthcare assistant: "It's at home"

Patient: "Are you sure? Why?"

Healthcare assistant: "It's outside your house"

Patient: “Well I hope it is, for your sake”.

In this instance, the patient then walked away with the interaction having apparently made very little impact on them. The healthcare assistant had clearly told a blatant lie but again was also avoiding facing the patient with the outright truth, knowing the consequences of going down this route. The motivation for the lie telling in this instance was to meet the needs of the healthcare assistant – to disengage from what could become a potentially difficult and volatile interaction.

On occasions, visitors to the ward would respond with lies to patients who they did not know. This could sometimes be negative as they rarely validated the receiver’s emotions. On these occasions, it was important for staff to pick up the interaction and then validate the patient’s emotions or unmet need to prevent situations from escalating:

Patient: “Where’s [wife’s name]

Visitor: “She’s at work”

The visitor answered almost automatically and very quickly with little feeling.

Patient: “Where’s [wife’s name]

A healthcare assistant quickly picked up the conversation when the same question was asked again.

Healthcare assistant: “She’s at home”

Patient: “You’re lying. She’s not. She’s at work.”

Healthcare assistant: “She’s at home doing your washing.

Patient: “She’s cheating on me”

Healthcare assistant: “No she isn’t. [wife’s name] loves you

The healthcare assistant responded with a much more reassuring tone that went some way to validating the patient’s anxiety.

4.8.4 Spontaneous lies

Spontaneous lies present a real challenge to currently published literature because most definitions of lying reflect an intention to deceive or lie (James et al, 2006, Tuckett, 2004). In this study, on occasions (as detailed earlier) when healthcare professionals just responded with a lie in an almost automatic or unconscious way, there was no real intent other than responding to the patient in some way or disengaging from the conversation. On these occasions there was little emotion attached to the responses and sometimes they were effective but at other times were responded to with indifference. Isenberg (1964) is one of the few, early authors that support the notion that people can lie without having the intention to deceive and the validity of their work has had many challenges over the years (Jones, 1986). Carson, Wokutch and Murrman (1982) cover the middle ground by talking about the teller realising rather than intending, that their statement is likely to deceive others, but again, this definition is challenged as being inadequate in the literature (Jones, 1986). There were examples of spontaneous lies in all categories. The example below is from ‘going along with’:

Patient {Shouting}; “Bread bread get my bread”

Healthcare assistant: “OK. It’s in the fridge. I will go and get it now”

The healthcare assistant walked out of one door and came back through another, sitting down in a different chair. As soon as the healthcare assistant was out of sight the patient stopped shouting. There was no recognition when they came back into the room. The lie did meet the patient’s needs in that they stopped shouting so it could be assumed that they were less distressed, but there did not appear to be any other real impact. The lie was spontaneous but effective.

Patient at the table after tea: “Where’s my gin and tonic?”

Healthcare assistant: “You’ll get one later”

The healthcare assistant walked away. There was no real consequence or outcome to this lie that was an example of avoidance and delaying. The healthcare assistant responded appropriately if untruthfully to the patient and walked away. No further requests were made by the patient.

Patient (M) starts to shout at another patient (M)

Patient: “Who’s he? Get him out. Get him out”

Nurse: “He’s a visitor. He will be going home shortly.

The nurse carefully guided the patient who was shouting away. The person being shouted at was another patient and was not going anywhere. The nurse had said the first thing that had come into her head that was likely to have diffused the situation, which it did. By the time the patient had been guided away, he had forgotten the altercation which had culminated in a blatant lie. Despite the nurse’s response being spontaneous it was said with confidence and reassurance.

There were many instances of spontaneous lies, often expressed with no real intent or motivation. As stated at the beginning of the section, this is new knowledge. In previous studies staff have justified telling lies or deceiving people on the basis of they only said them to reduce a patient’s distress or meet a patient need. This would indicate that they only lied as part of a conscious reality. The observed reality is that people regularly lie, almost subconsciously. The lie is expressed as part of the pattern of their normal conversation. It will not have been identified in previous studies as they have asked people what their perceptions of what they said, whereas this study observed and recorded what was said. This has implications for practice in terms of the fact that there are high levels of lying in practice, that have not been acknowledged or recorded and appear to have little impact the patients, but non the less, contravene the Code (NMC, 2018).

In summary, blatant lies is the largest and most diverse theme with some definable subthemes. By using ethnography, the study found that blatant lies are used spontaneously and frequently by staff. The motivation in some cases is difficult to define by observing the interactions and in these instances, lies seem to be unconsciously used as an instant and automatic response to a situation. This is new knowledge which has not been identified in previous studies but is very significant. It contradicts many previous studies where staff have said they only tell lies with purpose and as a conscious act.

If people are unaware that they are lying, it becomes very difficult to explore and reflect on the ethics of the interactions. Validation and motivation (conscious or sub consciously) remain key elements in terms of whether a lie is successful. That is why it is important to have a defined taxonomy for practitioners to start reflecting on interactions to help them identify when they have potentially told lies, but not previously realised. The subsequent development of the Lie ARM (Affective Reflection Model) in Chapter 5 (p.258), enables practitioners to reflect more deeply on their interactions and consider the affective domains that underpin their interactions and influence the outcomes.

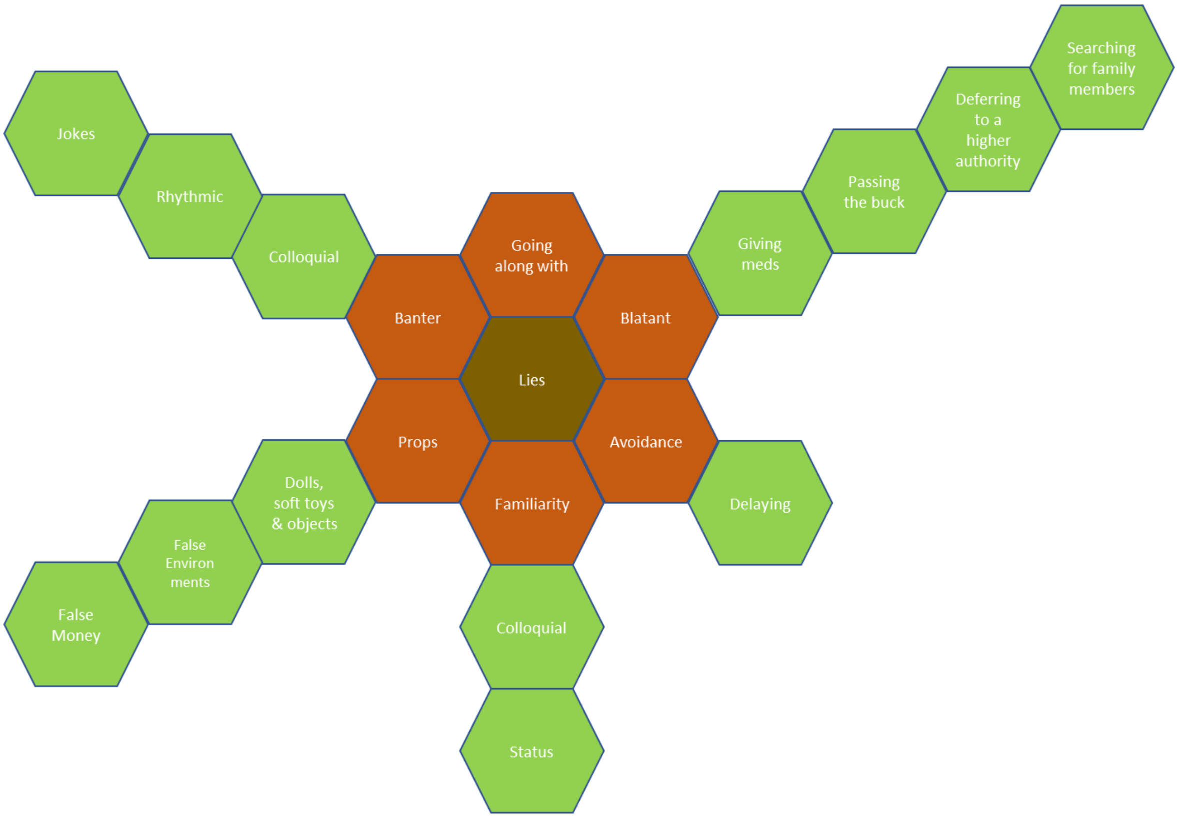
4.9 Taxonomy of lies

The six key themes have formed the basis taxonomy which was the first aim of the research. The sub themes were then added to make it more comprehensive. It is important to acknowledge that the development of the taxonomy was not done in vacuo but evolved from extensive reflexivity and detailed examination of the observational field notes and daily reflections (Snow et al, 2003). The significance of this strategy is explored in section 4.10 (p.245) which considers the daily reflections that occurred alongside the actual data collection and what they added to the study. When the taxonomy is viewed in the form of the model, it is important that this represents a visual guide that is fluid. The themes were generated on the assumption of the healthcare professional's truth, rather than that of the person with dementia, as the healthcare professional's truth is more likely to shared by those around the person with dementia.

In this study, anything that is not the wholetruth is considered to be a lie. The lies have been categorised according to a taxonomy rather than a spectrum as referred to in much of the literature (Williamson and Kirtley, 2016). This is because lying is subjective, and it is very difficult to consistently allocate the level of lying or truth that is being expressed. Also, the purpose of a taxonomy is to bring a level of definition and objectivity to the subject. It is a way of classifying things into related groups, based on common factors, often in descending order rather than scale.

The placing of the categories on the model is arbitrary as no category has more significance or priority over another. Some lies told will fit into multiple categories, but in terms of classification, there was always one element of the untruthful part of the interaction that was more prominent, and the lie was categorised in terms of the largest or most significant element. For example, in props when discussing the use of soft toys there was quite often an element of going along with the patient's reality, but the main focus of the lie was around the use of props, hence its theme and subsequent sub theme.

Figure 9 Taxonomy of Lies



Central to the taxonomy is lies. In terms of this study, everything that is not the wholetruth, is deemed to be a lie, and would fit in the central theme. All lies can then be allocated to one of the six key themes, based on its predominant feature. Whilst it is acknowledged that some lies have elements of more than one theme, there is always one which overrides the others. The arms of the taxonomy illustrate the subthemes, that exist within the 6 main themes. All the data collected during this study, fits into one of the six key themes, or sub themes.

In summary, six themes of lying were identified using an ethnographic methodology. Some of these themes, such as banter have not been identified as lying in previously published work. Other themes such as familiarity have been redefined. However, after observing and recording them, the themes and subthemes identified are definitely untruths and therefore lies. Some lies have also been grouped together as a subtheme, such as delaying was always observed to be an avoidance of the truth.

One of the significant findings was the use of spontaneous lies across all categories, which again brings new knowledge to the topic. Previous studies identified that lying was a conscious and purposeful activity. However, using ethnography has identified that many lies that are told are unconscious, and in some cases, serve little purpose. Some lies were also told without deception. In some previous studies, deception has been an essential part of classifying something as a lie.

Many of the lies that were witnessed could be considered or classified as therapeutic. That is, they met the needs of the patient in some way, such as lowering distress, maintaining a relationship, or supporting a level of social interaction. Some lies had no observable impact and in a small number of cases, they caused irritation for the receiver. This negative response was always short lived due to the limited short-term memory of the receiver. After observing such a wide range of untruthful interactions, it has become clear that the key elements of whether a lie results in a positive interaction for the patient, is how and why it is said. Motivation and validation on the part of the teller are the indicative elements as to whether the lie is likely to be effective or therapeutic. They demonstrate empathy and understanding which help to meet the needs of the patient. This is true for people even with advanced dementia, as the ability to experience and feel emotion remains long after cognitive reasoning has diminished. These affective domains were used to develop the Lie ARM (Affective Reflection Model) and will be explored in Chapter 5 (p.258).

4.10 Reflection and reflexivity

After every shift I completed a written reflection as soon as possible after finishing. The reflection initially was to help me debrief and assimilate how I felt about being on the ward, both as a staff nurse and as a researcher. The reflections have provided some interesting insights into when lying occurs and in some cases indicate what the underlying motivation or trigger may also be. Some of the things I reflected were very much around my frustrations as a clinician, in a researcher's role. There were days where I observed things that whilst were not reportable in terms of levels of care, could certainly have been improved but I declined from intervening as I was trying to maintain my role as a participant observer and did not want to exert any power or influence very less experienced members of staff that may have potentially affected my relationships in the team or jeopardised the research. This was clearly identified in some of my daily reflections from both areas.

Reflection – verbatim from notes. First shift on a period of data collection.

It was very strange going onto the ward. The staff were receptive and warm. There were several staff I knew which was nice. The nurse in charge after tea was a former student. Some of her interactions were unnecessary and provoked an already distressed patient. It was very difficult to be there in the role of participant observer as I felt I was not able to discuss this with her, particularly as she had generated significant data today.

Reflection – verbatim from notes. Last day after a period of data collection.

Very relieved to finish this period of data collection with only scratches and bruises. It has been increasingly difficult to collect data with the rising violence on the ward. Safety has had to be the first priority, so some lies have been missed and some forgotten.

As you become more ‘participant’ it is harder to maintain ‘observer’ status. Particularly that of accurate observer.

Whilst this level of internal conflict was not a constant or even regular theme, it certainly existed. Drake and Harvey (2014) talked about the conflict of the researcher / participant role not only being quite difficult but also emotionally demanding, which was my own experience. I think my sensitivity to this was heightened by the fact that I was unable to join the team as a novice. From joining the wards, I was assigned the role of expert, or initially that of potential critic (Hammersley and Atkinson, 2019). It was this perception that perhaps pushed me more directly into the role of complete participant, as my observer / researcher role was often overlooked and forgotten by the staff (Junker, 1960). The role of complete participant is unusual when data is being collected overtly. Often, for a researcher to be completely accepted within a community, they have to conceal their identity (Zempi, 2017). However, I was able to do this effectively as in one way, I was already a member of the group I was going to study (Holdaway, 1982). I was already a senior nurse and recognised as such, although I had not previously worked within the two teams I joined. The team’s expectations were that I would be able to join and execute my role as an experienced nurse without issue, which I was able to do. Some commentators suggest that complete participation is the ideal standpoint to carry out ethnographic research (Hancock, 2018).

It must be acknowledged that being a complete participant or insider, was not without its challenges. As a complete participant I was involved in the existing social and professional practices that existed on the ward, to a much greater extent than I would have been had I identified myself for example as an observer-participant. In some cases, documented below, this undoubtedly reduced opportunity to collect data, especially when the ward was volatile (Hammersley and Atkinson, 2019). That said, I feel that if I had adopted any other researcher role, I would have missed more opportunities to collect rich data and the subsequent reflexivity would have been much less productive. By being a complete participant, I was also able to explore the context and motivations of interactions with the study participants to help develop the reflexivity. Lewis and Russell (2010) argued that there are less risks adopting insider roles or ‘going native’ when it is done in environments where the community is that of established reflective practitioners (such as large public health organisations). I was also aware of the risks of over rapport with people. I had to be conscious of not aligning myself with one staff group or another, for example, healthcare assistants or qualified nurses, or making stronger affiliations with the subgroups within them. This could have potentially influenced the data collected as staff relations and socialisations had a big impact on levels of communication within the ward and are discussed further on in the chapter (p.248).

One of the main findings of my daily reflections was the significance that staff relationships and the milieu of the ward had on communication and how it manifested during a shift. This was not only in relation to collectable data but in in terms of more general communication between staff and patients and between the staff themselves.

4.10.1 Staff relationships

An unexpected finding of the study was the effect that the social structure and personal dynamics of the staff team had on the amount of data that was collected. If the staff all got on and liked each other there tended to be much more conversation between staff, and staff and patients. This was amplified if any of the staff were particularly outgoing or cheerful in their outlook. Consequently, on those shifts there was more data collected.

Reflection – verbatim from notes. Lots of data today due to a regular agency healthcare assistant who generally lifts the mood of the ward as she is very bubbly and bounces off other staff so lots of banter with patients.

In complete contrast to this, yet on the same ward later in the week.

Reflection – verbatim from notes. Ward had a very odd feel today, largely due to the mix of healthcare assistants. Two of the healthcare assistants work very differently and this was very obvious. There was very little chat and no banter between staff, or between staff and patients resulting in no data at all by the end of the shift. I reflected on this with the ward manager as this had never happened before. I decided to stay on for an extra hour as the afternoon staff were coming on and staff were changing between male and female sides. Then got 10 items I an hour! Atmosphere completely lifted and with that people became much more spontaneous and chattier.

The following day.

Reflection – verbatim from notes.

More data collected today. More newly qualified staff who make more effort to communicate with each other so more banter evident.

As this is the first observational study about lie telling, there is nothing in the current literature that identifies or explains this phenomenon. However, there are many studies that consider the role of interpersonal relations within the healthcare team and the impact that has on more general communication (Lee and Doran, 2017). Many of these studies are in relation to communication and patient safety. Initially these two areas may not seem to be connected, but if communication styles change according to the team dynamic, this has the potential to be reflected in the behaviour or responses of the patients. If staff communicate less or ineffectively to each other, and this is mirrored in their communication to the patients then safety might become an issue as staff may not deescalate or interact to meet the patients' needs as well as they could.

If the people who are on shift perform as a group, rather than a team then there is less cooperation and communication between them (Cahill et al, 2018). Most of the literature discusses teams and teamwork in relation to the completion of a task and in many of these cases, communication within teams has been developed and improved with the inception of checklists and briefings (de Vries, 2009, Lingard et al, 2008). However, in terms of this study, the communications were influenced by much more social relationships. Where the communication became purely professional in nature, it tended to be shorter, more specific and task driven. There was not a general chatter or discourse outside of this. The communication became limited to functional speech, directing care. Where staff were on duty that had strong social relationships, that is they were also friends, quite often outside of the work arena, they spoke much more frequently and on a more social level about things such as family and nights out. This often formed the basis of gentle teasing and humour. Where this happened, staff would include patients in the conversation, asking about their families or activities at home. This resulted in more data being collected across all categories, and particularly in relation to banter. This could be attributable to the more jovial and social atmosphere that was created. This would be supported by research carried out with sports teams where it is known that social cohesion is a necessary element for a team to succeed (Cahill et al, 2018). In order to achieve social cohesion, the team ‘spirit’ must be developed and is based on emergent states, including cognitive, attitudinal, motivational and emotional states. As identified already in the study, attitudes, emotion and motivation are key elements as to whether a lie will have a positive effect and will be explored further in Chapter 5 (p.258).

4.10.2 Ward Milieu

The levels of aggression seemed to play a significant part in how much communication there was. The more potential there was for aggression, the less communication and subsequently data was observed. This applied to both areas.

Reflection – verbatim from notes. This reflection covered the last 4 shifts of a period of data collection.

This week has been very difficult with limited data collected. One patient remains in seclusion with two members of staff. There is one patient on within arm’s length observations and two others on 15-minute observations. Due to the business of the ward, there is less banter. People are very stressed about the levels of aggression and the risk of being injured. As a result, there is a lot of tension. This is impacting on how people communicate. There is far less joviality and banter. Much of the shift is focused on meeting patient's basic needs. And maintaining safety for both staff and patients.

Whilst there have been less identifiable and distinct lies recorded, there has been a noticeable increase in the amount of going along with, particularly in terms of sentence fragments and nonverbal communication. This tends to feel more like validation than lying as it is on a more emotional than cognitive level.

Reflection – verbatim from notes. This was a shift towards the end of the period of data collection.

Shift was busy due to one male patient being very aggressive. Whilst I was sitting with him in PMVA (physical management of violence and aggression) arm holds (2 staff to 1 patient) the patient kicked another patient in the groin. They had been physical with each other earlier in the week. The patient who had been kicked instantly threw a cup of juice back. It hit the patient, me and the healthcare assistant holding the other arm. It was very intimidating, and staff removed the second patient.

Not much data collected due to high risks on shift. Constant risk management.

The middle period of data collection generated significantly less pieces of data – 65 compared to 84 during the first period and 103 during the third period. This is most likely attributable to the high levels of aggression and subsequent tension during the second period. I recorded this as an issue in my daily reflections on several occasions.

Reflection – verbatim from notes.

Ward had a very odd atmosphere on arrival for shift. Major incident between two men. Staff clearly stressed and distressed. Very little data collected today as shift was simply a case of trying to maintain safety and firefighting. Communication was focused on ‘do this’, ‘move here’ and ‘put the chair down’. Very difficult environment to exist in.

Reflection – verbatim from notes.

Difficult to collect data in this environment. Not sure if I am not hearing in the chaos, or if it is not there because people are simply firefighting.

The literature identifies that both physical and verbal aggression in patients causes an increase in staff stress and distress (Miyamoto et al, 2010). When severe aggression is displayed, as it was at times on both wards, although more consistently during the second period of data collection, it is significantly more stressful for staff (Rodney, 2000). When patients display aggression, it takes more staff intervention to maintain a safe environment which then creates time pressures for the staff. In a study by Caris-Verhallen et al (1999) they identified that the amount of time pressure experienced by staff limited the amount of affective communication that happened between staff and patients. The more social discourse around lifestyle and feelings also became limited. It must be noted that the study was carried on older people living in a nursing home but who did not have dementia. They also noted that nurses smiled less when they were under pressure of time, and this was apparent when the wards were busy due to aggression. Given the level of emotional validation people with dementia can derive from their interactions with staff (Richards, 2010). It is highly likely that this type of ward milieu reduces the instances of lie telling but also decreases the amount and quality of communication generally. In environments where there is high expressed emotion (expressed as aggression), communication is not prioritised by staff (Stans et al, 2013) and interactions become limited to task-orientated topics and largely occur during nursing care activities (Williams, 2009). The lack of communication can cause an even greater risk of agitation and aggression (Downs and Collins, 2015). There is no previous literature that documents the impact of the ward milieu on lie telling as this study is the first to acknowledge the phenomenon directly.

Reflection

When the wards were very busy my role as a researcher became secondary to that of a nurse. As a complete participant, and registrant (NMC, 2018) I had to prioritise the safety of patients and staff ahead of my desire to capture data. This meant that on occasions I became involved with interventions to deescalate situations, making it difficult to both remember and subsequently record any observed data. The tension between participant and researcher has been well documented in the literature (Hammersley and Atkinson, 2019) and whilst it was not a big issue during this study, it could be frustrating at times when I knew I had missed items of data.

4.10.3 Ability to recognise data

There were some days that I became concerned that perhaps I was not recognising all of the available data. Sometimes this was because of the large volume of data observed in a short space of time.

Reflection – verbatim from notes.

Difficult to remember data as it came in flurries when staff giving medication out, many lies told in a couple of minutes.

At other times, the ward environment made it difficult to observe interactions. This was a particular issue when the wards were noisy.

Reflection – verbatim from notes.

Only two lies today although I think there was a third, but I forgot it.

Sometimes the ward is so noisy, I cannot hear the interactions between staff and patients.

It also became difficult to recognise lies. Some lies are told so frequently and as part of normal conversation, sometimes it is not until you reflect on an interaction that you realise that a lie had been told. This is very much reflected in previous studies where a limited range of lies are documented as sometimes people will not realise, they have lied (James, 2015).

Reflection – verbatim from notes.

The more you hear lies repeated, the harder it is to actually hear and subsequently record them.

Reflection – verbatim from notes.

Continues to be hard to recognise when untruths are told. Perhaps this is what makes ethnography difficult? The more continuously you are exposed to something the more it becomes ‘normal’ and does not register.

On two occasions today, staff had interacted with patients and then said, ‘there’s one for your book’. They both appeared pleased to have contributed to data and then wanted to discuss whether they had told a ‘true lie’. One was blatant, the other probably / possibly banter or perhaps just familial.

This reflection also acknowledges that some staff were very keen to be recognised as having told lies. Hammersley and Atkinson (2019) identify that both member- identified as well as observer-identified data may be used in some circumstances. However, I only used data that I had directly observed to avoid recording the perceptions of others as to what had been said, which has been done in previous studies. In the two cases mentioned above, I did actually witness the interactions, so I was able to record them and then discuss the outcomes and context with the tellers.

In summary, by using ethnography for this study, the many layers of each interaction were observed and examined. That has not been possible with previous studies that have used alternative methodologies. By doing this I was able to uncover and describe interactions as they happened, rather than relying on what people think they say or do which challenges some of the previously published literature. It also allowed me to access the context in which the interactions happened, to help to explain the phenomenon further. By using reflexivity, I was able to explore the complexity of the phenomenon and consider the intricate and elaborate relationships between attitudes and behaviour, which helps to contribute to the trustworthiness of the data (Gerrish and Lacey, 2010).

One of the key points observed is that staff socialisation with each other and the subsequent relationships has a significant impact on the type of communication used, not only between staff, but between staff and patients. It can be argued that patients still received care that met their basic needs, regardless of staff mix, communication was observed to be more positive and social when the staff team were more communicative and friendly with each other, even if this did result in more lies being told.

The other significant point was around the milieu of the ward and the impact it has on communication. As anxieties and tensions rise in the staff, there is less social interaction and communication returns to a more limited and task orientated level.

The use of reflexivity, over time began to identify themes which I would not have recognised by looking at the data in isolation, which is one of the benefits of ethnography (Hammersley, 1990). The impact of teller motivation and attitude or genuineness has emerged as a key theme in relation to outcome of an interaction. What was also clear that these two key areas had much more significance than the actual verbal content of the interaction. The most important things underpinning a positive interaction are genuineness on behalf of the teller and their ability to validate the emotion of the receiver. These are all impacted by staff relationships and what is going on in the environment. The themes of validation and motivation, in relation to patient outcomes are explored further in Chapter 5.

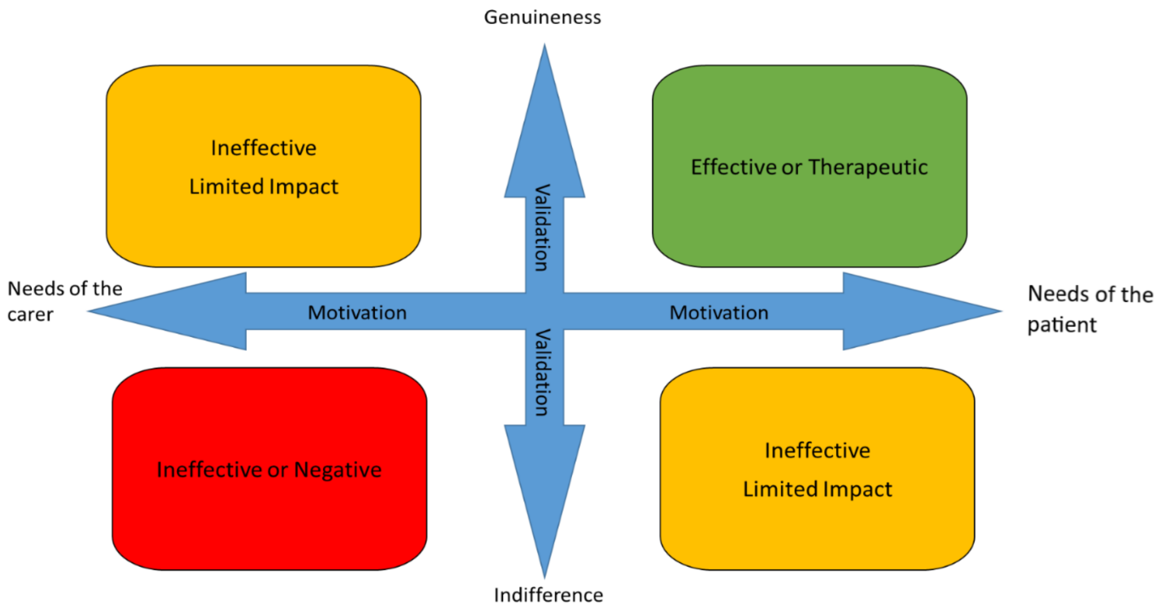
Chapter 5

5. The Lie ARM (Affective Reflection Model)

This chapter introduces the Lie ARM (Affective Reflection Model) which has been developed as a result of the findings of this study.

My study observed and documented the outcomes of the range of lies being told in practice. I have used this knowledge, together with findings from previous literature, to create the Lie ARM model, which can be used to help to both predict the likely effect of pre-planned lies and consider the impact of lies already told. It will also direct users to reflect on their own skills in terms of how they conducted the interaction and examine their motivation for doing so.

Figure 10 The Lie ARM (Affective Reflection Model)



The affective domains of validation, genuineness and motivation have reoccurred throughout the research. The impact they had on interactions was apparent during every interaction regardless of the lie being told and were the main influencers with regard to patient outcomes. Each of these themes are covered to varying degrees in the literature but have not previously explored in combination when considering lie telling.

5.1 Validation

Validation and its significance was explored in Chapter 2 (p.11) as part of the literature review. Within the literature there is a consensus that validation is an important and positive strategy for communicating on a verbal and emotional level, with people with dementia (Feil, 1992, Richards, 1994). However, the proponents of validation as a therapy argue that it is based on truth. Whilst validation is an essential part of communicating with a person with dementia, the findings of my study demonstrate that validation is often based on untruths; i.e., lies. In order to be able to use validation techniques effectively, healthcare professionals need to be able to demonstrate empathy and genuineness. Validation was chosen as part of the model, rather than empathy because the significant action on behalf of the teller is demonstrating their empathy by using validation. A person can be empathic without necessarily demonstrating it. It is the demonstration of that emotion that was significant in the observed interactions.

Genuineness and lying initially appears to present a level of dissonance, which would be the case if the model was addressing content. However, the Lie ARM specifically looks at the affective elements of the interaction. A person can be genuine in terms of their affective domain, even if what they are saying, is not representative of their own truth. It is that genuine empathy for the person with dementia that makes the validation effective. If a person interacts with indifference, it will not have a positive effect on the receiver, as was demonstrated in the study.

5.2 Motivation

The motivation for an interaction involving telling a lie is very important in relation to whether it is likely to be successful. If the motivation is to meet the needs of the patient, it is more likely to be successful or generate the required response by the teller. If the motivation is to meet the needs of the nurse or carer, it is far less likely to be effective. For example, if a healthcare professional tells a lie because they are busy and need to complete a series of interventions quickly, it is unlikely to be positive because the personal motivation is likely to reduce the genuineness that the lie is said with and will not adequately validate the patient's emotions. If the lie is said because the goal of the healthcare professional is to meet the needs of the patient to the best of their ability, they will be genuine in their interaction and will validate the patient's emotions. Motivation was also highlighted as a key factor in telling a 'good lie' in a study by Casey et al (2019), who identified motivation as being important not only to carers, but by people with memory problems who at some point may well be the receivers of untruths. The Casey et al (2019) study found that reducing emotional distress overrode any other ethical concerns and made lie telling justifiable.

In the case of banter and familiarity, the motivation as such is difficult to identify, as it is often linked to the usual social discourse of the teller. However, because of this, they are generally delivered with a high level of genuineness, meaning that they nearly always have a positive outcome.

5.3 Using the Lie ARM

The model has been developed to help professional carers to reflect on lies that have been told, or that they are considering using, in conjunction with the Taxonomy of Lies defined in Chapter 5. It also potentially has a role with informal or family carers who need support to reflect on lie telling to a person with dementia. As identified by Green (2015) it is important to know the person with dementia well before considering using lies as an intervention. I would argue that the context in which the lie is to be used is also important as this helps people to examine their motivation in more depth. Prior to this study, the literature had highlighted that the therapeutic value of lying is rarely monitored or confirmed (Sperber, 2014).

If a team is proposing that a lie be used as a regular intervention for a person with dementia, they can explore it using the Lie ARM. They need to consider what the motivation for using the lie is. This will help them to consider whether they are intending to lie under the auspices of best interests. If they are, this will then prompt them to follow the guidance in the Mental Capacity Act (2005). It will also prompt them to consider how they will validate the emotions of the person with dementia and ensure that they are being genuine in their interactions. This may need further exploration for individuals as part of their clinical supervision process to ensure that they have the skills to deliver a consistent intervention.

The Lie ARM can also be used retrospectively by individuals or groups, to reflect on a lie that has already been told. It would be helpful to discuss the untruth initially, in terms of the taxonomy. By having that initial discussion around the theme that the lie is part of, will help people to reflect more deeply on the motivation for using it and the level of validation used when delivering it. The lie may have had a positive, negative or indifferent outcome. By examining the interaction in detail, they may be able to identify the elements which made it positive, negative or ineffective which will be helpful in planning further interventions.

It is important that in the future the taxonomy and Lie ARM are evaluated in practice by a range of healthcare professionals. This will form the basis of my future study.

Chapter 6

6. Conclusions and Recommendations

This study has generated new knowledge in relation to telling lies to people with dementia. The study was carried out in NHS clinical environments, with formal carers. The study was unique in its approach, using ethnography to observe what is happening rather than exploring the perceptions of what people think happened. This has generated new, and at times unexpected data which will help to develop and improve care for people with dementia.

The original purpose of the study was to undertake a critical analysis of the concept of lying in clinical practice, in the context of people with dementia, with the aim of answering the following questions:

- What lies are told in practice?
- Who tells lies in practice and why?
- What effect does lie telling have on people with dementia?
- Can the impact of telling lies be predicted?

Each of the above questions will be addressed individually and there will be discussion around whether the study was able to answer them. The recommendations for practice and future research will be made following this.

6.1 Conclusions

6.1.1 What lies are told in practice?

A broad spectrum of lies was observed being told in practice which were sub divided into six key themes and a range of subthemes, forming the taxonomy.

For the purposes of this study, and the debate it generates, anything that is not the wholetruth is regarded as a lie. A sliding scale of levels of lying was not considered since it is too subjective and difficult to measure as the verbal content of the lie only forms a small part of the overall interaction and subsequent outcome.

Whilst the taxonomy helps to identify the type of lie told, it does not capture the difference between planned and spontaneous lies. The observation of spontaneous lies is a significant addition to existing knowledge and is key to identifying why people lie and is summarised below. Previous studies asked people retrospectively what lies they had told, and in all studies, participants said that they told lies to reduce distress or meet the needs of the patient, identifying them as a conscious action. This study observed interactions that did have reducing distress as the motivation; however, there was also many spontaneous and unconscious lies that were not pre-planned or premeditated and appeared to occur as part of usual discourse, which were not told with the purpose of reducing distress.

6.1.2 Who tells lies in practice and why?

Lies were observed being told across all staff on the wards, regardless of role. Nurses, doctors, healthcare assistants, ancillary staff and visitors to the ward were all observed telling lies. Most lies were recorded from nursing staff and healthcare assistants, but this is attributable to them having the greatest amount of patient contact rather than those groups using a greater percentage of untruths or lies in their discourse.

Using the Lie ARM model will be particularly helpful to support healthcare professionals to reflect on their practice and help them to consider when they have lied spontaneously. This difference between spontaneous and planned lying is a strong indicator of the under-pinning motivation for delivering it. Planned lies were motivated towards meeting the needs of the patient and had positive outcomes in all observed cases. Spontaneous lies had a less consistent outcome. This was because in some cases, there was no identifiable underlying motivation for their occurrence, they simply occurred as part of the teller's usual discourse and were not relative to the potential response of the receiver. Where the primary motivation was to meet the needs of the nurse, the lie generally had a mildly negative or no observable impact. In the cases where there was a negative impact, it did not last long due to the limitations of the patients' short-term memory.

6.1.3 What effect does lie telling have on people with dementia?

The main argument for not telling lies to people with dementia is that telling lies may potentially damage trust and the therapeutic relationship if they are recognised (Schermer, 2007). On a very limited number of occasions, lies told by staff were challenged by the receiver or patient, but they were not seen to have a negative impact for more than a few minutes and there was no observed impact on the relationship with staff. This outcome is supported by theory of mind reasoning which is discussed extensively in Chapter 2.

In this study, many lies were found to have either a positive outcome, i.e., they could be considered therapeutic, or they had no observable effect, they just happened as part of conversation. The outcome of the lie was dependant on the motivation and genuineness of the teller and whether they validated the emotions of the person with dementia. This again is supported by theory of mind reasoning which identifies that people with dementia can maintain functioning in the affective domains, even when they have very impaired short-term memory (Gregory et al, 2002). There were very few instances when an untruthful interaction had any negative effect. This was unlikely to be because of the lie being told and was much more attributable to the way it was delivered, and the motivation behind it.

6.1.4 Can the effectiveness of telling lies be predicted?

Yes, using the Lie ARM model developed as a result of this study, although this will require future research (7.2.3) to validate its use. However, to predict something, you have to know it is going to happen. This research has demonstrated that often lies are not premeditated and therefore an outcome cannot be foretold. If a lie is being discussed so that it becomes incorporated into a regular plan of care, it would be good practice to reflect on the proposed intervention in relation to the Lie Arm, so the likelihood of it being beneficial or otherwise can be explored. It will also help to identify what elements or behaviours will be required to be demonstrated by staff to make the lie therapeutic and ensure consistency.

6.2 Limitations of the Study

- The data for the study was collected by one person as a complete participant observer which provided both new and unique knowledge. Informal conversational interviews and discussions also took place as a means of contextualising data and checking out observations. However, it would have been useful to subsequently carry out more structured interviews or focus groups with participants to discuss the daily / weekly findings and gather more information about their awareness of when they were telling lies, and their views on their motivation.

- There is a limitation of qualitative research with regard to the non-generalisability of the findings. However, in this study, every precaution has been taken to be transparent and reflexive so that the reader can make a judgement about my influence on the study. The outputs, i.e., the taxonomy and the Lie ARM ca have their validity tested in other environments in the future,

- The data analysis was carried out solely carried out by the researcher, so it could be argued that the interpretation is limited. However, the emerging findings were discussed in depth with the supervision team, which did support checking and trustworthiness of the analysis.
- People with dementia themselves were not involved in the development of the study. Consulting service uses, patients and the public has been shown to be beneficial to the development of research studies (Gove et al., 2018) It would have therefore been useful to consider the views and opinions of people with dementia and their families when developing and designing the study.

6.3 Recommendations

6.3.1 Practice

- The starting point of any relationship should be truth. However, in cases where using the truth is likely to cause distress or harm to the person with dementia, lie telling can be an effective strategy when it is done with best intentions of staff and has the best interests (MCA,

2015) at its core. This has been endorsed by the Mental Health Foundation Report (Williamson & Kirtley, 2016) which supports using ‘untruths’ with people with dementia. The principles of non-maleficence and beneficence should override a blanket instruction for honesty as the welfare of the person with dementia should always be the overriding purpose of any intervention. Lie telling should be considered as a useful strategy for supporting people with dementia.

- Staff should regularly reflect on their practice in relation to lie telling. It would be useful to do this in groups using the taxonomy to identify regular patterns of lie telling in practice and then explore the identified lies using the Lie ARM.

- The issue of spontaneous lies should be discussed on a regular basis. It would be helpful to monitor the occurrence of these in teams and the subsequent impact on patients. Staff need to become more aware of when they are engaging in this practice.

- If lies are being used with best intention, rather than best interest, for example, in the case of medication administration, teams should address this in line with covert medication policy. The issues identified in relation to medication during this study will be discussed with the Trust so that they can ensure staff are working within the covert medication policy.

- The makeup of staff teams should be considered in relation to socialisation and the subsequent impact on communication in terms of personality as well as skill mix.

- There should be heightened awareness within teams about the impact the ward milieu has on staff communication and behaviour.

- There should be increased education with regard to the moral, ethical and practical issues of telling lies to people with dementia. Lies should be talked about more in general, to reduce the stigma and emotional impact of the word lie, and the language used around lying and deceit.

6.3.2 Policy

- In light of the issues and observations raised in this unique study, I would ask the NMC and the GMC to revisit their policies and directives in relation to honesty and truth telling. I would advocate that whilst truth should always be the starting point, the codes should also add a caveat similar to the one linked to confidentiality, i.e., the truth should always be the starting point, except when the truth is likely to cause distress and is not in the best interest of the patient, in which case, a lie should be used. It is this lack of flexibility or caveat under current guidelines that can lead to difficulties for staff who feel that they should not tell lies ever, even if it is in the best interests of the patient, as it would be going against the professional codes. This would need to be assessed and documented for each patient.

- I would also ask the Alzheimer’s Society to look again at their guidelines on telling lies and consider advocating their use in some cases, where the truth is likely to cause distress and is not in the best interest of the person with dementia.

- The Government also needs to review the current NICE guidelines in relation to people with dementia and endorse the use of lies where it is in the best interest of the person with dementia.

6.3.3 Future Research

- The taxonomy needs to be tested fully to see if the results are replicated using further ethnographic studies in order to show that it is a valid tool for categorising lies that are told to people with dementia, across a range of settings.

- The Lie ARM in conjunction with the taxonomy needs to be tried in practice by a range of healthcare professionals and its impact evaluated, both in relation to being a predictive tool and a reflective tool. It is planned that this will be done initially in the UK and Singapore.

- The issue of spontaneous lie telling needs to be explored in more depth, given that this is the first time it has been identified. Further ethnographic study will need to take place as spontaneous lies are difficult to identify other than by observation.

- Further studies into all aspects of lie telling need to be initiated using both an ethnographic methodology to ensure that what is happening in practice is captured in to improve practice and ultimately the care outcomes for people with dementia, and a phenomenological approach to understand the lived experience of those telling lies, and those receiving them.

- In future studies, people with dementia should be involved in the research process from the beginning as ultimately, the outcome of further research has the potential to influence care they may receive.

Appendices

Appendix 1

PHD01 - Participant Invitation Letter

Faculty of Health and Life Sciences
G215, Coach Lane Campus West
Northumbria University
Newcastle upon Tyne
NE7 7XA

Participant Invitation Letter

Wholetruth, untruths and lies: A two stage ethnographical study of communicative interaction between professional caregivers and people with dementia.

Invitation to Participate

You are invited to take part in a research study as part of my Doctoral studies. Before you decide to take part it is important for you to understand why this research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything not clear to you or if you would like more information please do not hesitate to contact me. Once you have read this information please take time to decide whether or not you wish to take part.

Thank you in advance for taking time to read this document.

I am a Senior Lecturer in Mental Health at Northumbria University. I am a registered Mental Health Nurse and Specialist Practitioner in Older People's Mental Health. I am currently undertaking a piece of research as part of my Doctoral studies. I am writing to you to ask if you would be willing to take part in this research.

During my research I will be working on the ward, as a staff nurse as part of the nursing team. I will be observing how staff communicate with patients with dementia. I am particularly interested in documenting instances where we tell either untruths or sometimes tell lies to patients. This is something that goes on regularly in all practice areas caring for people with dementia and is generally done with the aim of reducing the distress of the person with dementia, or getting them to participate in an activity such as eating or drinking. Lots of research has been conducted asking carers and professionals their views and stance on this sensitive matter, but there has never been a study which has actually recorded what is said and then looked at the outcomes for patients. In order to carry out the research, it is important that nothing is changed or altered in relation to the care currently being given.

In the first part of the study, I will be solely looking at who is saying what in order to create a taxonomy or scale looking at the range of communications from whole truth through untruth to lie. Participants will be completely anonymous and no details other than their professional role will be documented. In the second part of the study I will return to the wards, again working as a staff nurse and then start to record patient responses to different types of communication. This will help to guide and improve future practice.

If, after reading the “Participant Information Sheet”, you decide you would be happy to take part, please read and sign the enclosed `consent to take part` form. The signed consent form can either posted to me at Northumbria University using the reply-paid envelope provided (no stamp is required) or left on the ward for me to collect. Please note that only signed responses will be used.

If you have any questions please contact me at Northumbria University. You can contact me by telephone on 0191 2156713 or by e-mail at jane.murray@northumbria.ac.uk

Thank you for considering taking part in this study. I look forward to hearing from you.

Yours sincerely

Jane

Jane Murray, MSc, BA(Hons), FHEA, RMN,

Senior Lecturer, Mental Health

Room G215, CLC East,

Faculty of Health and Life Sciences

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Telephone : 0191 2156713 Email : jane.murray@northumbria.ac.uk

Principal Supervisor

Dr Mick Hill,

Principal Lecturer / Director of Post Graduate Research

Co-Founder – Northern Hub for Veterans and Military Families Research

Faculty of Health and Life Sciences,

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Northumbria University,

Newcastle upon Tyne,

NE7 7XA

Telephone: 0191-2156623 Email: michael.hill@northumbria.ac.uk

Appendix 2

PHD02- Participant Information Sheet

Faculty of Health and Life Sciences
Coach Lane Campus
Northumbria University
Newcastle upon Tyne
NE7 7XA

PARTICIPANT INFORMATION SHEET – Wholetruth, untruths and lies: A two stage ethnographical study of communicative interaction between professional caregivers and people with dementia – phase 1.

Invitation to participate

You are invited to take part in a research study as part of my Doctoral studies. Before you decide to take part it is important for you to understand why this research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything not clear to you or if you would like more information please do not hesitate to contact me. Once you have read this information please take time to decide whether or not you wish to take part.

Thank you in advance for taking time to read this document.

What is the purpose of the study?

The purpose of the study is to to establish and record the range of untruths and lies that are being told by professional carers in clinical practice using an ethnographical methodology. It will also create a taxonomy of untruth and lies being told by professional carers in clinical practice.

This means that the study is looking at how professionals communicate with people with dementia and when do they tell the wholetruth, untruth and lies, as part of that persons care. This is something that goes on regularly in all practice areas caring for people with dementia and is generally done with the aim of reducing the distress of the person with dementia, or getting them to participate in an activity such as eating or drinking. Lots of research has been conducted asking carers and professionals their views and stance on this sensitive matter, but there has never been a study that has actually recorded what is said and then looked at the outcomes for patients. I will be observing how staff communicate with patients with dementia and making notes of instances where we tell either untruths or sometimes tell lies to patients. In order to carry out the research, it is important that nothing is changed or altered in relation to the care currently being given.

This is phase 1 first of the study and I will be solely looking at who is saying what in order to create a taxonomy or scale looking at the range of communications from whole truth through untruth to lie.

Why have I been asked to take part in the study?

You have been chosen because you are either currently working on a ward which supports people with dementia and their family and friends, or your relative or friend is currently an inpatient on a ward which has been selected to participate in the research study.

Do I have to take part in the study?

No. It is entirely voluntary to take part in this study.

It is therefore up to you to decide whether to take part or not. Any questions you might have can be answered by me (the researcher) or any of my research supervisors (see below for contact details) and if you do not want to take part your decision will be respected. At any point in the study you are still free to withdraw at any time and you do not need to give a reason for this. Your information will be kept anonymous and confidential throughout the process and discarded confidentially if and when required. There are no consequences if you decide that you do not want to participate in the study.

If I do want to take part what happens next?

Along with this information sheet you will also receive a study invitation letter which has my postal and email address on it. If you wish to help with this study please complete the attached consent form and either post it back to me in the prepaid envelope, or leave it on the ward for me to collect. Alternatively, you can email me and I will send you a consent form electronically.

What are the possible benefits of taking part?

There can be no assurances of direct or immediate benefits to you if you contribute to this study. However, the information you provide will help to increase understanding of how professionals communicate with people with dementia. This helps to increase knowledge and insight in this area, which in turn helps to develop practice and ultimately improve patient care.

What are the possible disadvantages and risks from taking part?

The collection of data will not impact on patient care as I will be working part of the nursing team, in my already established role as a registered nurse. For professionals agreeing to take part, they may be more aware of the content of their communication, and may reflect more deeply when they are aware of having told untruths or lies. This is not perceived as a disadvantage but may raise emotion in some people as the topic can be quite emotive, even though we know it exists in regular practice.

Please note that as an NMC registrant I have a duty of care to patients and service users receiving care and treatment (NMC 20015). As such, if any issues of safeguarding or poor practice are revealed during discussion, appropriate policy will be adhered to in order to ensure the needs of patients and staff are adequately met.

Where will be the research take place?

The research will take place on the ward where you work or your friend or relative is an inpatient.

Will my taking part in this study be kept confidential?

Yes. All information will be stored confidentially, securely and anonymously within locked filing cabinets for any handwritten notes and password protected computer software for digital recordings or typed files. Your name will not be recorded and place of work will not be traceable. Codes will be used to ensure you cannot be directly linked back to the communication observed. Only your professional role will be recorded. The doctoral study is due to be completed by February 2021. Once all data has been analysed and the PhD completed all data will be confidentially destroyed 3 years after the official point of completion. Only the main researcher can directly access the data.

What will happen to the results of the research study?

At the end of the study, all participants will be sent a summary report of the findings and if specifically requested, a full report can be forwarded. It is intended that the findings will be disseminated to the ward teams, via the Trust, as appropriate and through journal publication and conference presentations. The research findings will also be written at length within the PhD thesis produced to support the Doctorate study. With your permission, anonymised examples may be used to illustrate the study’s findings. You will not be identified in any report or publication arising from the study.

Who is organising and funding the study?

The study is being conducted by Jane Murray, a Senior Lecturer in Mental Health at Northumbria University. She is a registered Mental Health Nurse and Specialist Practitioner in Older People’s Mental Health. The research is being conducted as part of her Doctoral studies which have been funded and supported by Northumbria University.

Who has reviewed the study?

Ethical approval has been granted from the ethical review boards at the Faculty of Health and Life Sciences at Northumbria University, as well as the Research and Development Department within the NHS Trust within which you work or your relative or friend is being cared for. No research will be undertaken without appropriate ethical approval.

For further information about this study please contact:

Jane Murray MSc, BA(Hons), FHEA, RMN

Faculty of Health and Life Sciences,
G215, Coach Lane Campus East,
Northumbria University,
Newcastle upon Tyne,
NE7 7XA

Telephone: 0191 2156713 Email: jane.murray@northumbria.ac.uk

Thank you in advance for your interest in this study & for taking the time to read this.

Additional Points of Contact:

Principal Supervisor;

Dr Mick Hill,
Principal Lecturer / Director of Post Graduate Research
Co-Founder – Northern Hub for Veterans and Military Families Research
Faculty of Health and Life Sciences,
H203, Coach Lane Campus East,
Northumbria University,
Newcastle upon Tyne,
NE7 7XA

Telephone: 0191-2156623 Email: michael.hill@northumbria.ac.uk

Appendix 3

PHD03

Study title	Wholetruth, untruth and lies: A two stage ethnographical study of communicative interaction between professional care givers and people with dementia.	For additional information about the research, please refer to the Participant Information Sheet or contact the research supervisor for further details.
Purpose	To find out more about certain communication strategies used with people with dementia, specifically looking at whole truths, untruths and lies.	**Research Supervisor Details:** Dr. Mick Hill, Principal Lecturer / Director of Postgraduate Research Co-Founder - Northern Hub for Veterans and Military Families Research Northumbria University - Faculty of Health & Life Sciences Room H023,Coach Lane Campus (East),Coach Lane, Newcastle-upon-Tyne NE7 7XA Tel: 0191-2156623 Professor Ian James PhD., MSc., BSc., C.Psychol Trust Lead Challenging Behaviour Consultant Clinical Psychologist Hon. Professor University of Bradford Community Services Akenside Offices Campus for Ageing and Vitality Centre of the Health of the Elderly, NTW NHS FT (Formerly Newcastle General Hospital) Westgate Road Newcastle upon Tyne, NE4 6BE Tel: 0191 2336161
How	Observation of staff talking to patients.	
Participation	Ethical approval has been granted. Participation is optional Observation – anyone can opt out at any time.	
Researcher & Funding	Main researcher – Jane Murray as part of her doctoral studies.	

Front of card

Back of card

Appendix 4

PHD04 – Participant Information Poster for Observation

There is research currently taking place in this area

Please be aware that there may be research occurring within this inpatient area.

What is the study called?

Wholetruth, untruth and lies: A two stage ethnographical study of communicative interaction between professional care givers and people with dementia.

Why?

The research is being done to find out more about certain communication strategies used with people with dementia, specifically looking at whole truths, untruths and lies. We know from existing research that carers and professionals tell lies to patients, usually with the aim of reducing distress. However, there is no accepted definition of what constitutes a lie or deception.

Who?

The research is being carried out by Jane Murray who is a qualified mental health nurse and specialist practitioner in older peoples' mental health. She will be working as a staff nurse as part of the ward team whilst observing the communication of staff on the ward with their patients. It will not affect the care giving process.

Your Rights

Full ethical approval has been granted by Northumbria University and NTW Foundation Trust, however, if you do not wish communications with your friend or relative to be included in the study, please let either Jane Murray or a member of staff know.

Who do I contact?

If you have any further questions, please refer to the participant information sheet or contact:

Dr Michael Hill, Principal Supervisor : 0191 215 6623

michael.hill@northumbria.ac.uk

Appendix 5

PHD05 - Informed Consent Form for Observation

northumbria
UNIVERSITY NEWCASTLE

Faculty of Health & Life Sciences

INFORMED CONSENT FORM

Project Title: Wholetruth, untruths and lies: A two stage ethnographical study of communicative interaction between professional caregivers and people with dementia.

Principal Investigator: Jane Murray

please initial
where applicable

I have carefully read and understood the Participant Information Sheet.	☐
I have had an opportunity to ask questions and discuss this study and I have received satisfactory answers.	☐
I understand I am free to withdraw from the study at any time, without having to give a reason for withdrawing, and without prejudice.	☐
I agree to me being observed by the researcher in my daily activities on the ward and I agree that notes can be taken based upon behaviours observed by the researcher.	☐
I agree to the use of anonymous extracts and results from the study to be published in reports and journals, and for findings to be shared through presentations.	☐

I understand that by taking part in this study I may be exposed to situations that may generate some psychological distress that may become apparent during and / or after the study has finished. I accept the small risk of me experiencing psychological distress as part of this research.

☐

I agree to take part in this study. ☐

Signature of participant.. Date....………………..   (NAME IN BLOCK LETTERS)..………………………
Signature of researcher.. Date....………………..   (NAME IN BLOCK LETTERS)..………………………

Appendix 6

PHD08 Version 4.

02.03.2018- Consultee Information Sheet

Faculty of Health and Life Sciences
Coach Lane Campus
Northumbria University
Newcastle upon Tyne
NE7 7XA

CONSULTEE INFORMATION SHEET – Wholetruth, untruths and lies: A two stage ethnographical study of communicative interaction between professional caregivers and people with dementia – phase 1.

Introduction

Your relative/friend has the opportunity to be a passive participant in some research that is being carried out on the ward. It will not affect their care in any way.

We feel your relative/friend is unable to decide for himself/herself whether they wish to be a passive participant in this research.

To help decide if he/she should be part of the study, we would like to ask your opinion whether or not they would want to be involved. We ask you to consider what you know of their wishes and feelings, and to consider their interests. Please let us know of any advance decisions they may have made about participating in research. These should take precedence.

If you decide your relative/friend would have no objection to being a passive participant in the research, we will ask you to read and sign the consultee declaration attached to this information leaflet. We will then give you a copy to keep. We will keep you fully informed during the study so you can let us know if you have any concerns or you think your relative/friend should be withdrawn.

If you decide that your friend/relative would not wish to be a passive participant, it will not affect the standard of care they receive in any way.

If you are unsure about taking the role of consultee you may seek independent advice.

We will understand if you do not want to take on this responsibility.

The following information is similar to that which would have been provided to your relative/friend.

PARTICIPANT INFORMATION SHEET – Wholetruth, untruths and lies: A two stage ethnographical study of communicative interaction between professional caregivers and people with dementia – phase 1.

Invitation to participate

Your friend or relative has been invited to be a passive participant in a research study as part of my Doctoral studies. Before you decide whether your friend or relative should take part it is important for you to understand why this research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything not clear to you or if you would like more information please do not hesitate to contact me. Once you have read this information please take time to decide whether or not you wish to take part.

Thank you in advance for taking time to read this document.

What is the purpose of the study?

The purpose of the study is to to establish and record the range of wholetruth, untruths and lies that are being told by professional carers in clinical practice using an ethnographical methodology. It will also create a taxonomy of wholetruth, untruth and lies being told by professional carers in clinical practice.

This means that the study is looking at how professionals communicate with people with dementia and when they tell wholetruths, untruths or lies, as part of that persons care. This is something that goes on regularly in all practice areas caring for people with dementia and is generally done with the aim of reducing the distress of the person with dementia, or getting them to participate in an activity such as eating or drinking. Lots of research has been conducted asking carers and professionals their views and stance on this sensitive matter, but there has never been a study that has actually recorded what is said and then looked at the outcomes for patients. I will be working as part of the staff team, observing how staff communicate with patients with dementia and making notes of instances where we tell either the whole truth, untruths or sometimes tell lies to patients. All notes will be made out of sight of patients. In order to carry out the research, it is important that nothing is changed or altered in relation to the care currently being given.

This is phase 1 first of the study and I will be solely looking at who is saying what in order to create a taxonomy or scale looking at the range of communications from whole truth through untruth to lie. The active and passive participants will be completely anonymous.

Why have I been asked to take part in the study?

Your relative or friend is currently an inpatient on a ward which has been selected to participate in the research study.

The study is observing staff and recording what they say. However, within this process, your relative / friend will also be observed when staff communicate with them, making them passive participants; therefore, it is important to gain their views or the views of the consultees in relation to the research. No data will be recorded about patients or staff. They will be completely anonymous.

Does my friend or relative have to take part in the study?

No. It is entirely voluntary to take part in this study.

It is therefore up to you to decide whether your friend or relative should take part or not. Any questions you might have can be answered by me (the researcher) or any of my research supervisors (see below for contact details) and if you do not want to take part your decision will be respected. At any point in the study you are still free to withdraw on behalf of your friend or relative at any time and you do not need to give a reason for this. All information will be kept anonymous and confidential throughout the process and discarded confidentially if and when required. There are no consequences if you decide that you do not want to participate.

If you do want your friend or relative to take part what happens next?

Along with this information sheet you will also receive a study invitation letter which has my postal and email address on it. If you do wish your friend or relative to be part of this study please complete the attached consent form and either post it back to me in the prepaid envelope, or leave it on the ward for me to collect. Alternatively, you can email me and I will send you a consent form electronically.

What are the possible benefits of taking part?

There can be no assurances of direct or immediate benefits to your friend or relative if they contribute to this study. However, the information they provide will help to increase understanding of how professionals communicate with people with dementia. This helps to increase knowledge and insight in this area, which in turn helps to develop practice and ultimately improve patient care.

What are the possible disadvantages and risks from taking part?

The collection of data will not impact on patient care as I will be working part of the nursing team, in my already established role as a registered nurse. For professionals agreeing to take part, they may be more aware of the content of their communication, and may reflect more deeply when they are aware of having told untruths or lies. This is not perceived as a disadvantage but may raise emotion in some people as the topic can be quite emotive, even though we know it exists in regular practice.

Please note that as an NMC registrant I have a duty of care to patients and service users receiving care and treatment (NMC 20015). As such, if any issues of safeguarding or poor practice are revealed during discussion, appropriate policy will be adhered to in order to ensure the needs of patients and staff are adequately met.

Where will be the research take place?

The research will take place on the ward where you work.

Will my taking part in this study be kept confidential?

Yes. All information will be stored confidentially, securely and anonymously within locked filing cabinets for any handwritten notes and password protected computer software for digital recordings or typed files. Your name will not be recorded and place of work will not be traceable. Codes will be used to ensure you cannot be directly linked back to the communication observed. Only your professional role will be recorded. The doctoral study is due to be completed by February 2021. Once all data has been analysed and the PhD completed all data will be confidentially destroyed 3 years after the official point of completion. Only the main researcher can directly access the data.

What will happen to the results of the research study?

At the end of the study, all participants and consultees will be sent a summary report of the findings and if specifically requested, a full report can be forwarded. It is intended that the findings will be disseminated to the ward teams, via the Trust, as appropriate and through journal publication and conference presentations. The research findings will also be written at length within the PhD thesis produced to support the Doctorate study. With your permission, anonymised examples may be used to illustrate the study's findings. You will not be identified in any report or publication arising from the study.

Who is organising and funding the study?

The study is being conducted by Jane Murray, a Senior Lecturer in Mental Health at Northumbria University. She is a registered Mental Health Nurse and Specialist Practitioner in Older People's Mental Health. The research is being conducted as part of her Doctoral studies which have been funded and supported by Northumbria University.

Who has reviewed the study?

Ethical approval has been granted from the ethical review boards at the Faculty of Health and Life Sciences at Northumbria University, as well as the Research and Development Department within the NHS Trust within which you work or your relative or friend is being cared for. No research will be undertaken without appropriate ethical approval.

For further information about this study please contact:

Jane Murray MSc, BA(Hons), FHEA, RMN

Faculty of Health and Life Sciences,
G215, Coach Lane Campus East,
Northumbria University,
Newcastle upon Tyne,
NE7 7XA

Telephone: 0191 2156713 Email: jane.murray@northumbria.ac.uk

Thank you in advance for your interest in this study & for taking the time to read this.

Additional Points of Contact:

Principal Supervisor;

Dr Mick Hill,
Principal Lecturer / Director of Post Graduate Research
Co-Founder – Northern Hub for Veterans and Military Families Research
Faculty of Health and Life Sciences,
H203, Coach Lane Campus East,
Northumbria University,
Newcastle upon Tyne,
NE7 7XA

Telephone: 0191-2156623 Email: michael.hill@northumbria.ac.uk

Appendix 7

PHD09 IRAS 227508 Version 1. 21.01.2018 - Consultee Declaration form for research conducted under the Mental Capacity Act 2005

northumbria
UNIVERSITY NEWCASTLE

Faculty of Health & Life Sciences

CONSULTEE DECLARATION FORM

Project Title: Wholetruth, untruths and lies: A two stage ethnographical study of communicative interaction between professional caregivers and people with dementia.

Principal Investigator: Jane Murray

please initial
where applicable

I [name of consultee] have been consulted about [name of potential participant]'s participation in this research project	☐
I have carefully read and understood the Consultee Information Sheet.	☐
I have had an opportunity to ask questions and discuss this study and I have received satisfactory answers.	☐
In my opinion he/she would have no objection to taking part in the above study.	☐

I understand that I can request he/she is withdrawn from the study at any time, ☐

without giving any reason and without his/her care or legal rights being affected.

I agree to my friend / relative (please delete as appropriate) being observed by the researcher in their daily activities on the ward and I agree that notes can be taken based upon behaviours observed by the researcher. ☐

I understand that relevant sections of anonymised data collected during the study

may be looked at by responsible individuals from Northumbria University and

Northumberland Tyne and Wear Foundation Trust ☐

where it is relevant to their taking part in this research.

I agree to the use of anonymous extracts and results from the study to be published in reports and journals, and for findings to be shared through presentations. ☐

I agree to their GP or other care professional being informed of their participation in the study. ☐

Signature of consultee..…………………

(NAME IN BLOCK LETTERS)...……………………………………

Relationship to participant……………………………………………………

Date....…………………………………………………………………………

Signature of researcher..……………..

(NAME IN BLOCK
LETTERS)...……………………………….

Date.....………………………………………………………………………

Appendix 8

Minutes of Staff Meeting Ward 1, 8th February

Present; Jane Murray, Clinical Manager Older Peoples Inpatient Services, Ward Manager, Pharmacist, Psychologist, Lead Occupational Therapist

Prior to the meeting the proposed documents to be used with participants and consultees had been circulated. PHD01, PHD02, PHD03, PHD04, PHD05, PHD08 and PHD09. Paper copies were also provided at the meeting.

Jane introduced her research. Some staff have been involved in previous discussions. Jane then gave feedback from her attendance at the REC in December and highlighted the issues that were raised by the committee, in particular the concerns raised about the word ‘lie’.

The attendees highlighted that the term ‘lie’ is already in regular use on the ward. When patients are admitted staff discuss the potential use of lies with the patients’ family and it is used explicitly in care plans where necessary.

It was identified that families rarely had an issue with potentially using lies as a therapeutic intervention. On occasions some families had discussions around when and why they would be used, but it was not considered an issue as they are only used in the best interest of the patient.

It was stated that using the term ‘lie’ was important as it was part of the transparency of the care given and highlighted the honesty and candour of the work carried out.

The attendees were very positive and enthusiastic about the research. The importance and potential benefit of the research and resulting taxonomy were highlighted.

Account of Ward 1 Carer's Meeting 24th February

Carer

Health care assistant

Health care assistant

Jane Murray - researcher

Prior to the meeting the Ward Manager had circulated the proposed documents to be used with participants and consultees. PHD01, PHD02, PHD03, PHD04, PHD05, PHD08 and PHD09. Paper copies were also provided at the meeting.

Discussion around the project. The carer said he thought it was very important and did not have any issues with the wording, as that was the reality of living and working with people with dementia. It was more important to tell lies and reduce a persons distress than keep telling the truth and causing upset.

The health care assistants did not have any issues with regard to the word lie, as lies are discussed openly with the families as part of the 72 hour review. The carer clarified that this discussion had taken place with him with regards to his wife's admission, at that point.

No one felt that the wording on the documentation needed to be changed.

Account of Ward 3 Governance Meeting 7th March

Present; Jane Murray, Consultant Psychiatrist, Clinical Nurse Lead, X2 Student Nurses.

Prior to the meeting the Ward Manger had circulated the proposed documents to be used with participants and consultees. PHD01, PHD02, PHD03, PHD04, PHD05, PHD08 and PHD09. Paper copies were also provided at the meeting.

I explained the purpose of the research and the concerns that had been raised by the REC. Consultant Psychiatrist was the most vocal and did not feel any alteration needed to be made to the wording. All other attendees were in agreement. Lying is discussed with families during the initial 72 hour assessment period and in the Teams experience, generates very little or no opposition. Feedback from families is that lying is acceptable to reduce distress or to benefit the patient.

The team expressed their enthusiasm for being involved in the project and stated that they are looking forward to the results and the taxonomy that it generates.

Account of Ward 3 Carer's Meeting 7th March

After the meeting, I was able to meet with a carer whose husband is on the ward and who has Alzheimer's disease. I discussed the project and the paperwork with her at length, specifically asking her about the word lie. She said that whilst it is an uncomfortable word, she felt it had to be in the title of the research, as that was part of what the research was looking at. She then reflected on instances where she has told blatant lies to her husband and the effect that it had on both of them. The effect on her husband was always positive, but it was something she found difficult to do. She welcomed any sort of research that was going to add to the body of knowledge that underpinned the care given to people with dementia.

Account of Staff Meeting on Ward 2 on 9th March

Present for Marsden; Jane Murray, Acting Ward Manager, Staff Nurse

Also in attendance; Ward Manager, other ward, Clinical Lead, other ward, Clinical Lead, other ward

The Ward Manager had circulated the paperwork to the staff team and asked for feedback. She felt the responses were positive and no one had felt that the wording needed to be changed. The staff from the other wards had asked to come to the meeting to see if their wards could be involved with the research. Whilst this is not likely as part of stage 1, I will consider them for involvement in stage 2 of the study (which will require separate ethical approval). Staff nurse also stated that as lies were used as part of planned care, they were discussed with families on admission and she felt that this rarely caused an issue. Families usually identified that they had been involved in telling untruths and lies to reduce distress, as their relative progressed on their journey with dementia.

Account of Carers Meeting on Ward 2 on 20th March

Only one carer attended. Her husband had recently been admitted to the ward. Mary said that she had no issue with the word lie being used and felt very strongly that staff should tell lies in the right context – particularly when it was to reduce distress.

Staff had spoken to other carers and circulated the documents. The feedback from the carers was that the use of the word lie was not an issue and therefore they did not feel the need to meet with me.

Account of 2nd Carers Meeting on Ward 2 on 20th March

No carers attended.

Appendix 9

Northumbria University
General Risk Assessment Form

Date: 10.02.2017	Assessor: Jane Murray	Location:3 wards in NTW Foundation Trust
Area/Activity:	Assessment title: Participant observation as part of an ethnographical study.	

Item No.	Activity/equipment/materials, etc.	Hazard	Persons at risk	Severity	Likelihood	**Risk Rating** H 20-36 M 12-18 L 1-10	Control Measures Required	Final Result*
1	Observation of professional carers communicating with patients who have moderate to severe dementia on inpatient units in NTW Foundation Trust. Communications containing untruths will be recorded as part of an ethnographic study.	The observation and data collection presents no hazard, however, the presence and purpose of the researcher may prompt participants to reflect on their own practice which could elicit an emotional response.	Staff who are being observed	1	2	2 (L)	Due to the nature of the study (observing usual and regular practice) the risk of harm is very low. The risk that exists would be in relation to emotional or psychological distress rather than injury. The fact that the study is being conducted may make people more aware of their own practice and the concept of truth and	1x2= **(L)**

							lies can elicit strong emotions in people. All staff have access to clinical supervision as per the Trust policy, where issues can be discussed. They can also discuss and reflect with the researcher if they wish. If staff felt they needed further, ongoing support, they have access to the Trust Occupational Health service. Staff can alos opt out of the study at any point.	
			Patients who are observed	1	1	1 (L)	The risk to patients is minimal as the researcher will be working in the role of a staff nurse, delivering care in line with the care plans and the rest of the nursing team. It is the staff who are	1x1= 1 (L)

							communicating who are actually being observed, but the patients will be aware of the researchers presence as a nurse. Due to the level of memory impairment experienced by the patients they will be unable to retain information given about either the researcher or the study.	

Northumbria University – Risk Assessment Form

To be completed by the person undertaking the risk assessment

Name: Jane Murray Job Title: Senior Le

Signature: Date: 10.02.2017

To be completed by the Line Manager

I consider this risk assessment to be suitable and sufficient to control the risks to the healt the tasks and any other person who may be affected by the activities.

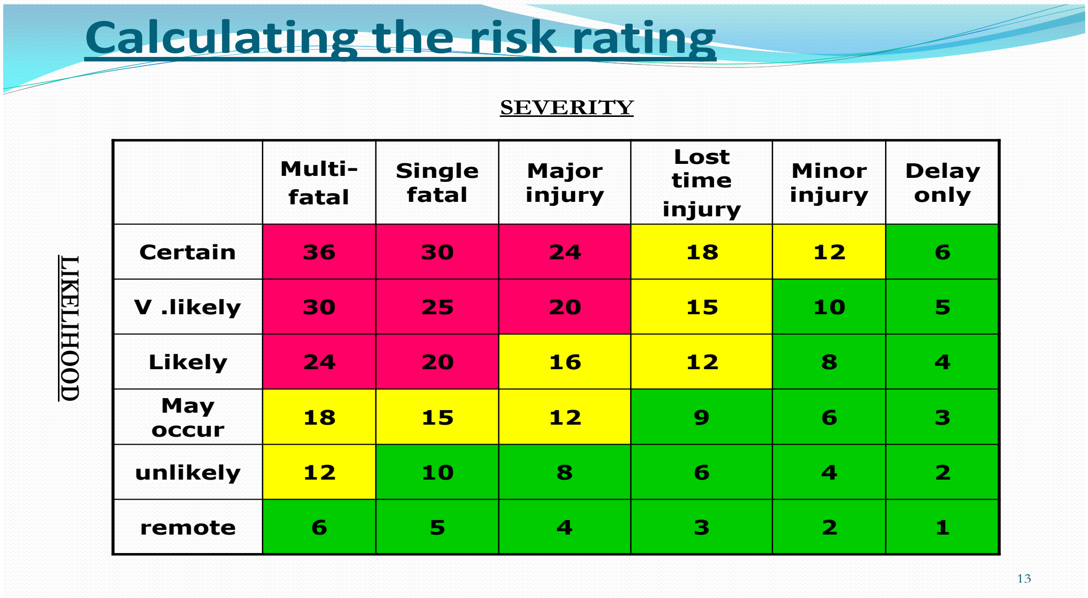
Name: Job Title:

Signature: Date:

NB – If Line Managers do not agree that the risk assessment is suitable and sufficie reviewed.

Risk ratings = likelihood x severity

LIKELIHOOD		SEVERITY	
Certain/imminent	= 6	Multiple fatalities	= 6
Very likely	= 5	Single fatalities	= 5
Likely	= 4	Major injury	= 4
May occur	= 3	Lost time injury	= 3
Unlikely	= 2	Minor injury	= 2
Remote	= 1	Delay only	= 1



Calculating the risk rating

SEVERITY

LIKELIHOOD

	Multi-fatal	Single fatal	Major injury	Lost time injury	Minor injury	Delay only
Certain	36	30	24	18	12	6
V .likely	30	25	20	15	10	5
Likely	24	20	16	12	8	4
May occur	18	15	12	9	6	3
unlikely	12	10	8	6	4	2
remote	6	5	4	3	2	1

Appendix 10

Northumbria University
General Risk Assessment Form

Date: 10.02.2017	Assessor: Jane Murray	Location: NTW Foundation Trust
Area/Activity: PHd Data Collection	Assessment title: Risk assessment working as a staff nurse with people with dementia	

Item No.	**Activity/equipment/materials, etc.**	**Hazard**	**Persons at risk**	**Severity**	**Likelihood**	**Risk Rating** **H 20-36** **M 12-18** **L 1-10**	**Control Measures Required**	**Final Result***
1	Working as a band 5 staff nurse on three wards in NTW Foundation Trust	Some patients can become aggressive due to their illness	The researcher	3	5	15 (M)	• The researcher is a qualified mental health nurse and specialist practitioner working in this field of nursing. • The researcher will undergo the two day Trust induction course so that she is aware of policies etc in relation to the	2x3= 6 **(L)**

							management of violence and aggression • The researcher will undergo RIO (electronic patient management system) training to ensure that she is able to access all relevant Trust policy and patient notes so that she is aware of any potential dangers and how the care plans advise that those people should be supported most effectively • The researcher will undergo the 5 day Prevention of Violence and	

							Aggression Training required by the Trust. The refresher course will be undertaken each year of data collection in line with Trust policy. • The researcher will wear a personal alarm at all times on the ward, in line with Trust policy. • The researcher will discuss any concerns about safety with the relevant ward managers.		

Northumbria University – Risk Assessment Form

To be completed by the person undertaking the risk assessment

Name: Jane Murray Job Title: Senior Le

Signature: Date: 10.02.2017

To be completed by the Line Manager

I consider this risk assessment to be suitable and sufficient to control the risks to the healt
the tasks and any other person who may be affected by the activities.

Name: Job Title:

Signature: Date:

**NB – If Line Managers do not agree that the risk assessment is suitable and sufficie
reviewed.**

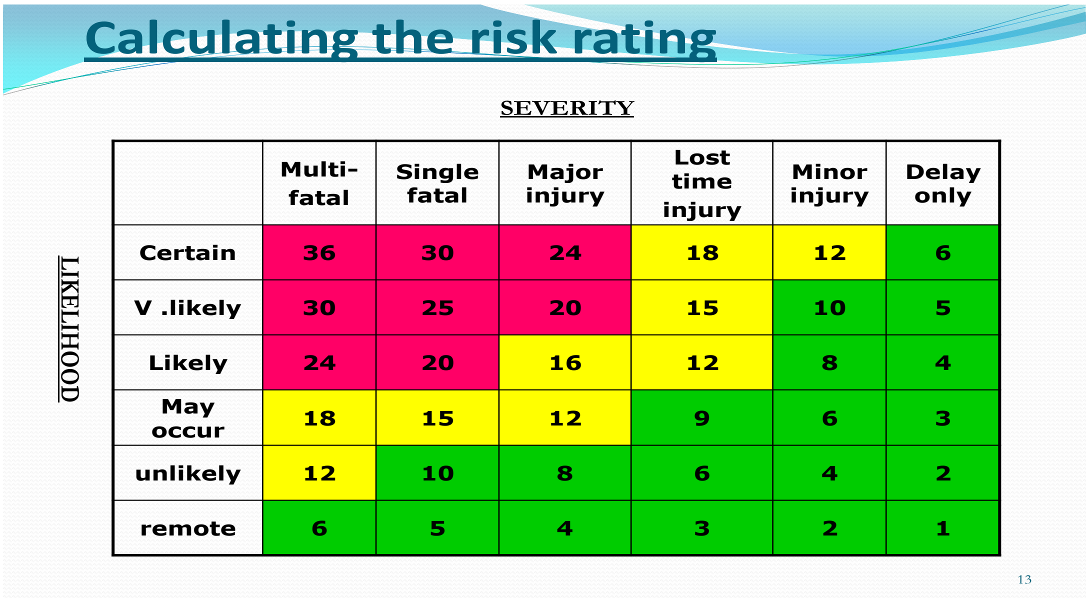
Risk ratings = likelihood x severity

LIKELIHOOD

- Certain/imminent = 6
- Very likely = 5
- Likely = 4
- May occur = 3
- Unlikely = 2
- Remote = 1

SEVERITY

- Multiple fatalities = 6
- Single fatalities = 5
- Major injury = 4
- Lost time injury = 3
- Minor injury = 2
- Delay only = 1



Calculating the risk rating

SEVERITY

LIKELIHOOD

	Multi-fatal	Single fatal	Major injury	Lost time injury	Minor injury	Delay only
Certain	36	30	24	18	12	6
V .likely	30	25	20	15	10	5
Likely	24	20	16	12	8	4
May occur	18	15	12	9	6	3
unlikely	12	10	8	6	4	2
remote	6	5	4	3	2	1

Appendix 11

Transcription of Data for Wholetruth, Untruth and Lies

Ward 1

1.1	Patient (F); “Who is the manager?” Nurse (F): “[name] is but she is busy on the telephone.” Patient; “Well that’s very convenient” {Patient remained quite agitated all afternoon}
1.6	Patient {shouting}; “Bread bread get my bread” Healthcare; “OK. It is in the fridge. I will go and get it now” {Healthcare walks out of one door and comes in another and sits in a different chair}.
1.9	Patient at the table after tea; ”Where’s my gin and tonic?” Healthcare; “ You’ll get one later”
2.1	Patient (F); “Why am I here? I don’t know why I am in here” Healthcare (F); “I don’t know either” Patient; ”Well that’s just ridiculous”
2.4	Patient (F) just returned from acute hospital and was weepy and vocal. “Who’s side are you on? Mine or yours?” Nurse (F); I’m not on anyone’s side. I’m here to help you. To make you well. Patient has advanced dementia and will not recover.
3.2	{Nurse (me) trying to obtain urine sample from a patient. Pot already in toilet.} Nurse (me); “ Don’t flush the toilet when you’ve finished please as we need a water sample. Patient; “I’m not giving you one. I’m going to give it in at [GP’s] No, you aren’t going to [GP]. Our Doctors need it” I’m not giving you one. [GP] wants it Nurse (me); [GP] rang earlier and asked us to get one.

	Patient; “I don’t think so and I’m not”
3.3	{Patient becoming aggressive. Had been asked to sit down. They were hitting and kicking.} Patient; “Has she gone? I hate her” to healthcare but referring to nurse who was doing observations. Healthcare; “She’s not coming back. Don’t worry”
3.4	{Nurse giving out medication} Nurse; “Here’s your painkillers, open your mouth” Patient responded but not coherently Nurse; “It’s for your knee Your daughter says you have to have them ” Patient; “ No” Nurse; “Your daughter rang and said you have to have them” Patient allowed nurse to put tablets in her mouth. She spat them out later.
4.1	Patient (F) had been vomiting and was physically unwell. Specialist nurse (M) came onto ward. Nurse; “How are you?” Patient; “ Oh, I’m fine” Nurse; “Can I borrow you for two minutes please?” Patient; “Oh yes” {It was always going to be considerably longer than this.}
5.3	Patient (M); “Where’s [wife]? Healthcare; “She’ll be in about 10am. She always comes in around then. Patient; “Oh” Accepted comment. Wife only comes in occasionally and it is always the afternoon.
5.5	Patient (M) agitated since coming out of bedroom. Sitting in lounge. Shouting and swearing intermittently. Two nurses came with medication. Patient; “What are they? Nurse 1; “Your tablets”

	Patient; “What are they for?” Nurse 1; “ All sorts of things” Nurse 2; “You need to take them or the doctor will tell me I’m not doing my job.” Nurse 1; “The doctor says you have to have them” Nurse 2; “I’ve had mine” Patient: “What? All of them?” Nurse 2; “Yes. They make you feel better. Patient did not take any of the tablets.

Appendix 12

Appendix 12 Example of data with added context / notes

	Delaying
3.8 (3) (Moved from blatant)	Patient; “Er. Er” {Waving hand to stop a healthcare who was walking past} Healthcare; “[Patient] I’ll be two minutes [patient]. I will be back in two minutes” Healthcare did not return
10.4 (3)	Domestic; “Just sit there and I will be back in a minute with the paper to do the horses” Domestic left area
11 & 12.1 (3)	Patient; “Can I be out?” Healthcare; “Not at the minute” Patient {shouting} “Not at the minute. I’ve been here since 1985” Healthcare; “Ditto” Patient; “Yes but you are paid to be here and I am just locked up” The healthcare was not particular engaged with the patient during the interaction
11 & 12.12 (3) (Moved from blatant)	Patient; “Nurse, I need to go home” Nurse; “Give me two seconds and I’ll come and speak to you” Nurse did not return
11 & 12.13 (3) (Moved from blatant)	Patient; “I need to talk to you. I need to talk to you now” Nurse; “I will be two minutes. I need to finish this” Nurse did not return
13.1 (3) (Moved from blatant)	Patient; “I’ve lost me cases. I’ve got two cases and they’ve gone” Nurse; “We’ll find them later” Patient; “I want them now” Nurse; “I’ll go round and ask all the staff if they’ve seen them” Patient; “Well make sure you do” This had elements of blatant but the key feature was delaying

4.6 (3) (Moved from blatant)	Patient; “Can I go home?” Visitor; “Not at the minute. Drink your tea” Healthcare; “Did you enjoy your visit from your family?” Patient; “Aye” Healthcare; “Are they away to put your horses on?” Patient; “Aye to put my bets on” Family had gone straight home. Key feature was delaying the request to go home
9.4 (2) (Moved from blatant)	Patient; “Nurse, nurse” Nurse is giving out medication; “Hang on a minute, I’ll be two minutes” Does not come back
14 & 15.5 (3)	Patient wants to go home Patient; “So I will have to go and get all my things in the morning” Nurse; “Yes. You are staying here tonight” Patient; “ But I want to go home” Nurse; “You will have to see a Doctor in the morning first” Nurse trying to delay the patients behaviour with the hope that they may forget about going home by tomorrow. Quite a cold interaction. No real validation or empathy. Patient walked away but clearly unhappy.
11 & 12.5 (3)	Patient; “Are we going to get the cases down?” Nurse; “We’ll have a look later” Patient; “I need them now” Nurse; “We’ll look later on” Nurse trying to delay the patients behaviour with the hope that they may forget about getting their cases later. Validation of the content by agreeing to help to look for them later. Patient walked away.
11 & 12.4 (3)	Patient; “I’ve lost my wallet” Healthcare; “I’ll look for it later on. Eat your tea for now”

	Nurse trying to delay the patients behaviour with the hope that they may forget about the wallet by the time they have eaten their tea. Validation of the content by agreeing to look for it later. Patient ate tea.
7.9 (3)	Patient; “Can you help? Some stupid fool has locked number 5 with my two dogs in” Healthcare; “I think the cleaner may have locked it after she cleaned up after them.” Patient; “Don’t be stupid. They are dying and asleep so they won’t have done anything” Healthcare; “I just need to do the laundry then I will come down” Healthcare delaying the point at which she needed to go into the patients bedroom. The dogs are soft toys the patient believes are real but poorly because they don’t move. Quite cold. Not much validation or empathy. Patient walks away muttering under her breath and clearly not happy.
7.7 (3)	Patient; “Are you teaching this morning?” Healthcare; “Not at the minute” Patient; “When are the lessons in here?” Healthcare; “They’’ll be on later” {Patient thought she was in school not hospital} A cold interaction. Patient walked away tutting about the lack of lessons.
5.5 (3)	Patient; “What time am I going home?” Nurse; “Oh just stay here tonight. We’ve got a bed for you” Patient; “Oh” Nurse; “Just stay with us” Nurse avoiding stating that the patient was on a S3 so chose to delay the proposed departure. It was said with warmth as though she genuinely wanted the patient to stay. Patient sat down in lounge.
5.4 (3)	Patient; “I’m worried about [wife]. I keep ringing and she’s not in” Healthcare; “I’m sure she’s fine”

	Patient; "I need to go home" Healthcare; "Have some tea first – in about an hour. Then we'll sort it out" Patient had not rang wife today – sometimes he has been allowed to but tends to get more distressed and upset her. Healthcare delaying in the hope he will forget.
13.2 (3)	Patient; "Where's me stuff?" Healthcare; "Eeeeee. It must be somewhere" Patient; "But I want it" Healthcare; "Well we'll look for it later. It will be somewhere easy" Some validation / reassurance given by healthcare. Patient accepted response and walked away
1.4 (3)	Patient; "Can you show me how to get upstairs please? I need to find my suitcase" Healthcare; "Not at the minute. We'll do it later" Patient; "But I need to go upstairs" Healthcare; "We'll go later. Lets go down here" Patient went with healthcare but clearly not happy and returned to same questioning very quickly. Not much validation / warmth in healthcare's response.
1.11 (1)	Patient (F) {At 6.30pm}; "Well I will go and get my bag to go home. I'm not staying here, I want my own bed" Nurse (me); " Well there's not much happens here after tea. You will need to speak to a doctor tomorrow. There is a party next door we are going to" Patient accepted response from nurse as she likes to party. She was going next door to watch football world cup game with other patients. Ward set out like a bar. Distraction more than validation in the content of this communication.
8.2 (1)	Patient (M); "I need to get to my mother. I do" Healthcare; " Well you need to have your tea and your tablets first, before you go home.

	Patient went to have tea. Accepting of response as it was positive and did not argue with his intentions.

Appendix 13

Health Research
Authority

Yorkshire & The Humber - Leeds West Research Ethics Committee
NHSBT Newcastle Blood Donor Centre
Holland Drive
Newcastle upon Tyne
NE2 4NQ

Telephone: 0207 104 8086

<u>Please note</u>: This is an acknowledgement letter from the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

27 April 2018

Mrs Jane Elizabeth Murray
G215 University of Northumbria at Newcastle
Room G215, Coach Lane Campus East,
Benton, Newcastle Upon Tyne
NE7 7XA

Dear Mrs Murray

Study title: **Wholetruth, untruths and lies: A two stage ethnographic study of communicative interaction between professional caregivers and people with dementia.**
REC reference: **18/YH/0054** **IRAS project ID:** **227508**

Thank you for your letter of 27th April. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 27 April 2018

Documents received

The documents received were as follows:

Document	*Version*	*Date*
Participant information sheet (PIS) [Consultee Information Sheet]	2	27 April 2018
Sample diary card/patient card [Participant Information Card for Observation]	2	27 April 2018

Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	*Version*	*Date*
Copies of advertisement materials for research participants [PH04 Participant Information Poster Version 1]	Version 1	13 March 2017
Covering letter on headed paper [Covering Letter IRAS 227508]	Version 2	20 March 2018
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Public and Employers Liability Letter]	1	20 March 2018
IRAS Application Form [IRAS_Form_03042018]		03 April 2018
Letters of invitation to participant [PHD01 Participant Invitation Letter]	2	19 March 2018
Other [PHD06 IRAS 227508 Observation of staff and Patients Risk assessment form]	1	10 February 2017
Other [PHD07 IRAS 227508 Risk of Violence and Aggression]	1	10 February 2017
Other [PHD09 IRAS 227508 Consultee Declaration Form]	1	21 January 2018
Other [PHD10 IRAS 227508 Response to the REC 8th December 2017]	1	19 March 2018
Other [PHD11 IRAS 227508 Minutes of Staff and carers meetings]	1	20 March 2018
Other [PH12 Unfavourable opinion from the REC]	1	21 December 2017
Other [Employers Liability Certificate 227508]	1	20 March 2018
Other [Professional Indemnity Insurance IRAS 227508]	1	20 March 2018
Participant consent form [PH05 IRAS 227508 Participant Consent Form]	2	19 March 2018
Participant information sheet (PIS) [PHD02 IRAS 227508 Participant Information Sheet]	2	19 March 2018
Participant information sheet (PIS) [Consultee Information Sheet]	2	27 April 2018
Research protocol or project proposal [Protocol Research proposal]	2	20 March 2018
Response to Additional Conditions Met		
Sample diary card/patient card [Participant Information Card for Observation]	2	27 April 2018
Summary CV for Chief Investigator (CI) [Jane Murray CV Nov 17 Version 1]	Version 1	17 November 2017
Summary CV for supervisor (student research) [CV Mick Hill Nov 17 version 1]	Version 1	17 November 2017
Summary CV for supervisor (student research) [Ian James CV Nov 17 Version 1]	Version 1	17 November 2017

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

18/YH/0054 **Please quote this number on all correspondence**

Yours sincerely

Christie Ord REC Manager

E-mail: nrescommittee.yorkandhumber-leedswest@nhs.net

Copy to: *Mr Simon Douglas, Northumberland, Tyne and Wear Mental Health Foundation Trust*

Appendix 14

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

Mrs Jane Murray
Phd Student
University of Northumbria at Newcastle
G215, Coach Lane Campus East
Benton
Newcastle Upon Tyne
NE77XA

Email: hra.approval@nhs.net
Research-permissions@wales.nhs.uk

27 April 2018

Dear Mrs Murray

HRA and Health and Care

Study title:	**Wholetruth, untruths and lies: A two stage ethnographic study of communicative interaction between professional caregivers and people with dementia.**
IRAS project ID:	**227508**
REC reference:	**18/YH/0054**
Sponsor	**Northumbria University**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

How should I continue to work with participating NHS organisations in England and Wales? You should now provide a copy of this letter to all participating NHS organisations in England and Wales*, as well as any documentation that has been updated as a result of the assessment.

*'In flight studies' which have already started an SSI (Site Specific Information) application for NHS organisations in Wales will continue to use this route. Until 10 June 2018, applications on either documentation will be accepted in Wales, but after this date all local information packs should be shared with NHS organisations in Wales using the Statement of Activities/Schedule of Events for non-commercial studies and template agreement/ Industry costing template for commercial studies.

Following the arranging of capacity and capability, participating NHS organisations should **formally confirm** their capacity and capability to undertake the study. How this will be confirmed is detailed in the "*summary of assessment*" section towards the end of this letter.

You should provide, if you have not already done so, detailed instructions to each organisation as to how you will notify them that research activities may commence at site following their confirmation of capacity and capability (e.g. provision by you of a 'green light' email, formal notification following a site initiation visit, activities may commence immediately following confirmation by participating organisation, etc.).

It is important that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details of the research management function for each organisation can be accessed here.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within the devolved administrations of Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) has been sent to the coordinating centre of each participating nation. You should work with the relevant national coordinating functions to ensure any nation specific checks are complete, and with each site so that they are able to give management permission for the study to begin.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your nonNHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including: Registration of research

- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

I am a participating NHS organisation in England or Wales. What should I do once I receive this letter?

You should work with the applicant and sponsor to complete any outstanding arrangements so you are able to confirm capacity and capability in line with the information provided in this letter.

The sponsor contact for this application is as follows:

Name: Mrs Samantha King
Tel: 01912437108
Email: samantha.king@northumbria.ac.uk

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **227508**. Please quote this on all correspondence.

Yours sincerely

Isobel Lyle | Senior Assessor
Health Research Authority
HRA, Room 1, Jarrow Business Centre, Rolling Mill Rd, Jarrow, NE32 3D
T: 0207 972 2496
Hra.approval@nhs.net or Isobel.lyle@nhs.net
www.hra.nhs.uk

Sign up to receive our newsletter HRA Latest

Copy to: *Mrs Samantha King, Sponsor contact, Northumbria University at Newcastle*
Mr Simon Douglas, R&D contact, Northumberland, Tyne and Wear Mental Health Foundation Trust

List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	*Version*	*Date*
Copies of advertisement materials for research participants [PH04 Participant Information Poster Version 1]	Version 1	13 March 2017
Covering letter on headed paper [Covering Letter IRAS 227508]	Version 2	20 March 2018
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Public and Employers Liability Letter]	1	20 March 2018
HRA Schedule of Events [HRA Assessed]	Version 2.0	05 December 2017
HRA Statement of Activities [HRA Assessed]	V1.0	05 December 2017
IRAS Application Form [IRAS_Form_03042018]		03 April 2018
Letters of invitation to participant [PHD01 Participant Invitation Letter]	2	19 March 2018
Other [PHD06 IRAS 227508 Observation of staff and Patients Risk assessment form]	1	10 February 2017
Other [PHD07 IRAS 227508 Risk of Violence and Aggression]	1	10 February 2017
Other [PHD09 IRAS 227508 Consultee Declaration Form]	1	21 January 2018
Other [PHD10 IRAS 227508 Response to the REC 8th December 2017]	1	19 March 2018
Other [PHD11 IRAS 227508 Minutes of Staff and carers meetings]	1	20 March 2018
Other [PH12 Unfavourable opinion from the REC]	1	21 December 2017
Other [Employers Liability Certificate 227508]	1	20 March 2018
Other [Professional Indemnity Insurance IRAS 227508]	1	20 March 2018
Participant consent form [PH05 IRAS 227508 Participant Consent Form]	2	19 March 2018
Participant information sheet (PIS) [Consultee Information Sheet]	2	27 April 2018
Participant information sheet (PIS) [PHD02 IRAS 227508 Participant Information Sheet]	2	19 March 2018
Research protocol or project proposal [Protocol Research proposal]	2	20 March 2018
Sample diary card/patient card [Participant Information Card for Observation]	2	27 April 2018
Summary CV for Chief Investigator (CI) [Jane Murray CV Nov 17 Version 1]	Version 1	17 November 2017
Summary CV for supervisor (student research) [CV Mick Hill Nov 17 version 1]	Version 1	17 November 2017
Summary CV for supervisor (student research) [Ian James CV Nov 17 Version 1]	Version 1	17 November 2017
227508, 18.YH.0054 Ack of Add Conds 27.04.18		27 April 2018

Summary of assessment

The following information provides assurance to you, the sponsor and the NHS in England and Wales that the study, as assessed for HRA and HCRW Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England and Wales to assist in assessing, arranging and confirming capacity and capability.

Assessment criteria

Section	Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	No comments
2.1	Participant information/consent documents and consent process	Yes	No comments
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	A statement of activities will act as agreement of an NHS organisation to participate. The Sponsor is not requesting and does not expect any other site agreement.
4.2	Insurance/indemnity arrangements assessed	Yes	No comments
4.3	Financial arrangements assessed	Yes	No application for funding has been made. No funding is being provided to NHS organisations in England (refer *Statement of Activities*)
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	No comments
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments
5.3	Compliance with any applicable laws or regulations	Yes	No comments
6.1	NHS Research Ethics Committee favourable opinion	Yes	No comments
Section	**Assessment Criteria**	**Compliant with Standards**	**Comments**
	received for applicable studies		

6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

Participating NHS Organisations in England and Wales

This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.

This is an Educational study where a single NHS organisation is being asked to facilitate the research which is being undertaken by the Student and is, therefore, an 'all site activties' site 'type'.

The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England and Wales in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation.

If Chief Investigators, sponsors or Principal Investigators are asked to complete site level forms for participating NHS organisations in England and Wales which are not provided in IRAS or on the HRA website, the Chief Investigator, sponsor or Principal Investigator should notify the HRA immediately at hra.approval@nhs.net. The HRA will work with these organisations to achieve a consistent approach to information provision.

Confirmation of Capacity and Capability

This describes whether formal confirmation of capacity and capability is expected from participating NHS organisations in England.

Participating NHS organisation(s) in England and Wales **will be expected to formally confirm their capacity and capability** to host this research.

- The sponsor should ensure that participating NHS organisations are provided with a copy of this letter and all relevant study documentation, and work jointly with NHS organisations to arrange capacity and capability whilst the HRA assessment is ongoing.
- Further detail on how capacity and capability will be confirmed by participating NHS organisations, following issue of the Letter of HRA Approval, is provided in the *Participating NHS Organisations* and *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* sections of this appendix.
- The Assessing, Arranging, and Confirming document on the HRA website provides further information for the sponsor and NHS organisations on assessing, arranging and confirming capacity and capability.

Principal Investigator Suitability

This confirms whether the sponsor's position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England, and the minimum expectations for education, training and experience that PIs should meet (where applicable).

The Sponsor has confirmed that a Local Collaborator is required at site to facilitate the research. The Sponsor does not require assistance to identify a Local Collaborator.

GCP training is not a generic training expectation, in line with the HRA/HCRW/MHRA statement on training expectations

The Researcher has current registration with the Nursing & Midwifery Council as a mental health nurse.

The participating NHS organisation is being asked to support accessing an honorary contract, Access to Trust induction and Access to PMVA training

HR Good Practice Resource Pack Expectations

This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken.

The Researcher is expected to obtain an honorary research contract from the single participating NHS organisation on the basis of a Research Passport. These should confirm enhanced DBS checks, including appropriate barred list checks, and occupational health clearance. If the research was to extend beyond the single NHS organisation then a Letter of Access would be required for subsequent organisations.

Other Information to Aid Study Set-up

This details any other information that may be helpful to sponsors and participating NHS organisations in England in study set-up.

☐ The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.

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