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**The experience of health care workers in a dementia care tertiary setting**

**A thesis submitted to the University of Huddersfield**

**In partial fulfilment of the requirements Masters by Research**

**By Abigail Avery**

**July 2018**

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## **Abstract**

The purpose of this study is to explore individual experiences of health care staff when working within dementia tertiary care. The study follows qualitative methods through the use of interviews with nine staff on a one to one basis about what they think, feel and experience daily. Through examining daily routines associated with various positions and roles, this allows for any positives experiences, challenges and recommendations to be discussed from the perspectives of care staff. Therefore, by investigating individual's experiences this enables a greater understanding of what it is like for healthcare professionals working with patients who have dementia in a hospital setting. Staff identified or suggested specific areas that could be changed or improved from their perspective these included: the physical environment, the care environment, education and training and ensuring that staff maintain a good level of health and wellbeing. However, many healthcare staff focused on positive aspects of their work and aim to provide high quality care. Furthermore these outcomes can demonstrate areas for change, which then encourages further research or development in this area of care.

## **Chapter 1 - Introduction and Background**

The purpose of this study was to investigate the individual experiences of healthcare workers when working within a dementia care facility. The study examined how staff managed stressful or pressurised situations and workers own personal strategies to manage their work challenges whilst working on a dementia ward. The individual work experiences of staff were also explored to determine what occurs when working on a dementia tertiary ward. The study investigated, through the use of interviews, thoughts, feelings and emotions associated with employee's personal experiences. The main reasons to conduct this study were from the previous literature research that identified issues and gaps in dementia tertiary care and also personal perceptions and interest within this sector. The study was conducted within a dementia care facility in the North of England and the rationale for conducting this study will be now outlined.

The introduction section will describe and define what dementia is and its effects on a global scale, through to its local impact on individual people, carers and families. Then the focus turns to primary health care interventions, strategies and support for the surrounding community. Followed by the service pathway for dementia care been demonstrated and discussed from initial dementia diagnosis to hospital inpatient admission and palliative care.

The World Health Organisation (WHO) (2016) identified that there are more than forty seven million people worldwide living with some form of dementia. It is estimated that there are around 7.7million new cases of dementia every year due to population ageing, and this number is expected to triple by 2050. It is estimated the worldwide cost of dementia, which is mainly driven by social-care needs, was estimated at US\$ 604 billion. It is recognised unless new effective treatments or care methods are discovered and developed, these costs are set to soar, with costs growing fastest in low- and middle-income countries specifically (WHO, 2010).

It is estimated that the number of people living with dementia in the United Kingdom (UK) ranges from 800,000 to 850,000 and the disease costs the UK economy an estimated £23 billion a year. This cost is expected to double by the year 2040 and this is a significant challenge for society to meet these needs both financially and practically (The Department of Health (DH), 2015; The Alzheimer's Society, 2015). The number of people with some type of dementia is expected to continue to increase and surpass one million people by 2025. According to local area statistics it is estimated that there are as many as 67,630 people

currently living with dementia in Yorkshire and Humber with many people not even having an official diagnosis (Alzheimer's Society 2013).

The term 'dementia' is an umbrella term used to describe symptoms that may include memory loss, difficulties with thinking, problem-solving or communication. For the majority of dementia's the actual cause is unknown, and the likely cause is to be made up of many factors including age, genetic susceptibility, environmental factors, diet and general health. There are many brain diseases which can cause dementia, the most common types are: Alzheimer's disease, Frontal temporal lobe dementia, vascular dementia and Lewy body dementia. For some types of dementia medication is a form of treatment used to slow the progression, other forms of intervention include reduction of certain risk factors such as smoking, high blood pressure or cholesterol. Although there are over one hundred different types of dementia, dementia in its various forms is a progressive and incurable disease, which means the symptoms will gradually get worse over time, resulting in severe cognitive impairment along with potential physical disability. This can have a huge impact not only on the individual but the carer or family members as well. This is because caring for a person with dementia can become gradually more demanding, physically and emotionally over time. In some cases this can impact a carer's own health and well-being if not managed and supported sufficiently. However with the support of a multidisciplinary team the effects of dementia can be managed and the individual can be supported to have a greater quality of life (Harrison-Dening, 2013).

A wide variety of cognitive symptoms can occur in dementia, although the clinical presentation of these symptoms can vary, depending on the disease causing the dementia. Memory loss is the most common symptom, and is a core feature of any dementing illness. This is the most reported issue for patients and families as patients have difficulty learning new information, such as names, dates, lists and details of previous conversations. As the disease progresses the long term memory begins to be affected alongside disorders of thought, perception and behaviour (Holmes & Amin, 2016). Behavioural and psychological symptoms of dementia (BPSD) are common symptoms experienced by patients, these include agitation, aggression, delusions, paranoia and sleep disturbance. These particular symptoms can be difficult to manage and can cause distress to relatives and other supporting caregivers (White, Leurent, Lord, Scott, Jones & Sampson, 2016). In addition some patients will also experience secondary difficulties alongside their dementia; these difficulties are often around mood disorders including depression and anxiety (Holmes & Amin, 2016).

There are an estimated 540,000 carers that support people with dementia in England and one in three people will care for a person with dementia at some point during their life. The term 'carer' is described as someone who supports or looks after a family member, partner or friend who needs assistance either because of their age, physical or mental illness or a disability. A carer is not usually a paid worker or a volunteer however, it is suggested that half of 'carers' are employed alongside their caring role. Around 60,000 'carers' have reduced their working hours to make time for caring for a loved one, whilst another 50,000 have left work altogether (DH, 2015).

Carers for people with dementia experience a level of care burden which has been correlated with adverse social, financial, physical and psychological health outcomes. Although it is believed some carers are able to find feelings of joy, satisfaction or contentment in caring for a loved one (Shim, Barroso and Davis, 2012). There are three main categories suggested for how carers cope and feel when supporting a partner with dementia: positively, ambivalent and negatively. It is suggested that everyone fits generally into one of these categories. Those carers who are more positive about their outlook of caring, were on more loving terms towards a partner and focused on aspects of the relationship they still had, rather than what had been lost. This type of attitude results in carers being less likely to feel the care burden compared with others. Those who are ambivalent report that the relationship they had with the spouse was lost, but they still described satisfaction in being able to care for the spouse. They describe mixed emotions and have difficulty accepting that their partners couldn't reciprocate the relationship. In contrast the carers who refer to negative experiences of caring are suggested to have a poor past relationship prior to diagnosis, which has affected their ability to find positives. The focus was on their own unmet needs rather than their partner's, which in turn resulted in them feeling a significant caregiving burden (Shim et al, 2012).

One of the primary aims of health and social care services is to provide quality care for people with dementia. It is suggested that just a little help for many people makes an enormous difference to those with dementia or to family carers who are encountering difficulty of some description. It is suggested the UK is aiming is to move away from the current 'patchwork services', characterized by inconsistent, incoherent and uncoordinated services with unstable resources. Instead the aim is to work towards a 'network' of services with consistency throughout an individual's journey through the dementia pathway. This moves towards improvements in the quality of life and this is a new paradigm, focused on recovery, crisis prevention and the promotion of well-being (Page, Keady & Clarke, 2007).

The National Institute for Health and Care Excellence (NICE) is an independent public body that provides national guidance and advice to improve health and social care in England. NICE guidance offers evidence-based recommendations on a broad range of topics, from preventing and managing specific conditions, improving health, and managing medicines in different settings, to providing social care and support to adults and children, safe staffing, and planning broader services and interventions to improve the health of communities. They aim to promote individualised care and integrated care (Garcia, McFarlane, Barnes, Sanabria, Alonso-Coello & Alderson, 2014).

A flow chart from NICE (2016) presents a proposed way forward in the UK for supporting patients with dementia. This represents a dementia overview of the ‘dementia pathway’. Starting with identifying the memory difficulties, and then onto assessment which is followed by a diagnosis. Following on from this is post diagnostic support, advice and the implementation of services and support for carers. The final sections of the chart identify interventions, care home admissions, acute inpatient hospitals and then palliative care/end of life at the end of the pathway. This pathway was designed so that a clear approach was in place to support people throughout their journey through dementia and receive appropriate treatment, services and advice (See appendix 1).

Having looked at the scale and burden of dementia and the policy recommendations the next section will focus on the impact of providing dementia care on health care workers.

## **Chapter 2 - Background**

There is increasing evidence that healthcare workers who care for patients with dementia have a demanding role. Reasons such as older adults living longer, the increasing numbers of people having dementia and the level of acuteness in hospital, will inevitably lead to increasing demands and pressures on healthcare workers and the health care system (Edberg, & Hallberg, 2001; Forbes & Neufeld, 2008).

It is estimated that the number of people living in care or nursing homes with a diagnosis of dementia in the UK ranges from 280,000 to 310,000 (Alzheimer's Research UK, 2014; Thraves, 2016). It is estimated that the number of people with dementia living in residential care equates to about a third of all dementia patients and two-thirds live at home. Around 70% of care home residents are currently estimated to have dementia. Individuals with dementia who are currently living in a care home are more likely to go into hospital with potentially avoidable conditions than others of the same age group (DH, 2015). In relation to hospital care statistics, patients who have a dementia are sometimes in hospital for conditions for which, if there wasn't a presence of dementia, they would not need to be admitted. The impact this can have on hospitals is that one in four beds is said to be occupied by individuals who have dementia. In addition to this patients with dementia are more likely to stay in hospital for longer, be readmitted at a later date and are more likely to die than patients without dementia who are admitted for the same reason or health complication (DH, 2015).

These factors are reported and supported globally as approximately 20% of general medical inpatients in Australia have a cognitive impairment either in the form of a dementia or delirium, which is most common in older adult patients. Patients with a form of impairment have a greater length of stay on average in hospital and are more likely to require further treatment in hospital within a month than those without impairment. The costs associated with hospital utilization were significantly higher for those with cognitive impairment due to the requirements of their care needs (LoGiudice, Tropea, Brand, Gorelik & Liew, 2016).

The data suggests how often health care workers are likely to come into contact with a patient who has dementia, therefore the need for an understanding of day to day experiences of working with dementia is essential.

As the numbers of patients with dementia been admitted to hospital increases, this leads to higher costs, longer lengths of stay due to the needs of their condition and poorer health

outcomes. Older adults with dementia are vulnerable when hospitals are unable to meet their specialist needs and their high levels of dependency (Gavin, Kuntemeier, Al-Hammadi, Germino, White & McGillick, 2010).

A UK study on acute inpatients that were admitted to hospital due to their dementia concluded that individuals with dementia are frequently admitted to acute hospitals. As many as 6% of people with dementia are inpatients in general hospitals compared with 0.6% of over-65s without dementia. BPSD accounted for 75% of patient's contributing factors for a patient's stay in an acute inpatient setting. It was also identified that the mean cost of admission was higher for people with BPSD compared to general hospital admissions, which impacts the health service financially (Sampson, White Leurent, Scott, Lord, Round & Jones, 2014).

Therefore if the number of people diagnosed with dementia increases over time, this could then directly affect all areas of the dementia pathway. An increase in the number of people requiring specialist care would result in more health care workers being required to treat, support and assist with the long term care of individuals who have advanced stages of dementia. Subsequently the greater the need for more services the greater financial support would also be required. The increase in patients who have dementia emphasises the requirement to understand what it is like to work within this setting every day as it is suggested to become more common over time, with an increasing requirement for more staff and facilities to meet demand.

Having looked at the impact of providing dementia care on health care workers, the focus will now turn to the current literature available.

### **Chapter 3 - Literature Review**

The reasons for focusing on this topic area are because of a personal interest in dementia tertiary care and what it is like to work within this area, also the increasing number of people who are developing dementia globally. There is also limited research on advanced dementia in tertiary care and what it is like to work within this setting. Having introduced the topic area, the focus can now turn to reviewing the literature. The purpose of the search strategy was to explore the available literature surrounding the provision of care for people with dementia in tertiary care settings.

The main purpose of all literature reviews is to ‘inform practice and policy about what is known, how well established the evidence is on a topic, and which questions go unanswered that need to be answered’. This method has the potential to make changes and affect many people and health care practice (Dodgson, 2017). A literature review can provide a concise examination and discussion of evidence in a particular area of interest and include a range of perspectives and opposing views (Bolderston, 2008). Literature reviews should ‘objectively report the current knowledge on a topic’ and ‘provide a summary of the best available research from previously published studies related to a specific topic’. Researchers also use literature reviews to identify, justify and refine hypotheses and to recognize limitations in previous research so these can be avoided or overcome (Baker, 2016).

There are many different types of literature reviews; one of these is systematic reviews. The main aim of systematic reviews is to identify all studies that are relevant to a specific topic or question, then perform a detailed search of the literature and evaluate the findings of the relevant studies. Systematic reviews can be a complex and often time-consuming process, by screening the articles, titles and abstracts this then helps identify relevant studies. Throughout the process all areas of focus such as the search terms used, databases and the criteria for inclusion or exclusion of studies should be documented. These are critical for referencing; tracking progress and potential future replication purposes (Lowe, 2009).

Another type of literature review is a narrative or traditional review: this provides a foundational overview and the significance of a problem addressed in a manuscript. This covers the current literature and illustrates the gap in the research. Another way that narrative reviews the literature is in the form of a stand-alone research article. It critiques and summarizes a body of literature then highlights the main findings of a topic area,

demonstrates any gaps or inconsistencies, and finally directs the reviewer to a sufficiently focused research question (Baker, 2016).

For the purpose of this literature review a systematic approach was used to review the current research rather than a formal systematic review. The term ‘systematic approach’, refers to aspects of a literature review that individually or collectively contribute to its methods being both explicit and reproducible. A systematic approach is associated with terms such as: Transparent, Methodical, Objective, Standardised, Structure and Reproducible. Following a systematic approach allows the overarching structure easier to navigate and interpret a review’s contents. Having a focused research question with a clear and detailed methodology enables others to judge whether the process was appropriate. In addition structured and clear search strategies allow the research to be reproduced or replicated in the future if sufficient detail is provided. A stated inclusion and exclusion criteria enables readers to understand why particular articles have or may not have been included in the literature review. Another consideration is for the requirement for internal validity. Bias in many forms can occur during research, and by demonstrating any pre-research opinions, views or perceptions through the form of reflexivity allows this potential bias to be minimised (Booth, Papaioannou & Sutton, 2012).

The focus of the literature was ‘the experiences of healthcare workers caring for people with advanced stages of dementia in a residential or hospital based setting’. During the literature search the initial search terms used began quite broadly as it wasn’t apparent what specific research had previously been conducted. Therefore, a scoping review was conducted before settling on a precise search strategy, as the main characteristic of this method is that it provides an overview of a broad topic (Moher, Stewart & Shekelle, 2015). Scoping reviews aim to map out the literature of a particular topic area and provides an opportunity for key concepts, current gaps in the research and types of evidence to inform future research (Daudt, Mossel & Scott, 2013). The scoping review informed the systematic approach chosen.

The main search engines that were used were Science Direct, Wiley Online Library, Sage Journals and International Journal of Nursing Practice and Studies was where the search initially began leading to the other search engines being used such as: Cinahl, Medline, Psych Info and Cochrane collection. These are the key databases that concern physical and psychological health. This expanded the search and the range of articles that could be accessed by demonstrating the volume of papers available and recency. Finally, there were

articles and studies which were hand searched through publication reference lists to ensure seminal papers weren't missed.

There were specific areas where the search began such as 'dementia care' which directed the search towards more informative books and journals on the condition rather than events or circumstances around dementia care. From this the search was altered to 'dementia inpatient' and then 'dementia tertiary care' which narrowed the search further. The benefit of doing wider searches initially allowed for other areas of focus to be suggested alongside the initial search terms, such as dementia training and education, staffing perspectives, emotional labour, quality of care and aggression in dementia. These outcomes influenced further searches to be more specific with a set area of interest or focus.

Following on from this, search filters were then applied to exclude certain literature so that only literature which contained full online text could be brought up in the search. This decision was taken for pragmatic reasons so as to focus the search on content that is accessible and detailed. Only literature that had been published in the past ten years or less was permitted to attain research that was the most current. Finally all articles were filtered to ensure they were in English so these could be read. These changes condensed all future searches; this reduced the number of results. This is demonstrated in the table below.

**Table one**

| <b>Inclusion Criteria</b>  | <b>Exclusion Criteria</b>                                  |
|--|--|
| Research based articles.   | Brief or limited access articles.                          |
| Based in nursing residential care homes or tertiary care settings.                   | Articles more than ten years old.                          |
| Patients have advanced/acute levels of dementia.                                     | Non English articles.                                      |
| Include experiences or perspectives of healthcare workers on patients with dementia. | Articles that were vague, short in length or lacked depth. |
|  | Articles that didn't lead to relevant information.         |

To determine whether a piece of literature required further reading or to be included in the literature review it needed to meet inclusion criteria. There were several elements which made up the inclusion and exclusion criteria and various methods to determine whether to include or exclude certain papers. The articles that were present after using the initial filters then had to be based either in a nursing residential care home or tertiary care setting, and the focus was on patients who had advanced dementia. The articles also had to contain experiences or perspectives of healthcare workers from various roles who supported patients with dementia. Finally, the articles had to be research based articles which focused on other studies within this area of interest. On the other hand there were further exclusion criteria which also applied to the articles that remained present after the initial filters. Articles which appeared promising on the initial inspection of the title and abstract which didn't lead to relevant information following a full paper review were also discounted from the literature review.

There are alternative approaches which can be used to assist when searching for articles. Boolean Operators were used throughout the search, phrases such as (and, or, not) are used to combine or exclude keywords in a search, resulting in more focused and productive results. Examples of these are 'dementia and training' and 'dementia and environment'. Proximity Operators (which use with, near and others) can also help when searching to narrow down and focus on a term such as 'aggression with dementia', making searches more specific and producing less results which are more relevant (Ecker & Skelly, 2010).

Another alternative when searching for literature is the use of a wildcard character, this is a single character such as an asterisk (\*), used to represent a number of characters or an empty string. Using 'dementia and staff\*' brought up articles containing various titles in relation to dementia staff including 'staff perceptions', 'staff views' and 'staff experiences' all in relation to the main topic areas. An Additional method when searching for articles was professional grouping. Rather than searching for nursing or nurse or nurses, using 'nurs\*' incorporates all of these versions of searches thus speeding up the process and enabling access to the appropriate literature (Joung & Yang, 2014).

Now the process of searching for literature on dementia care has been discussed the focus turns to discussing the literature that was identified.

## **Chapter 4 - Current Literature**

During the literature search, themes were identified in relation to caring for people with advanced dementia. Advanced dementia is when patients with dementia have further decline in their cognitive abilities such as performing activities of daily living, e.g. eating, dressing and bathing. Those with advanced dementia also struggle to recognise family members, understand language, difficulty swallowing and can have problems with controlling incontinence (Mitchell, 2015).

### **Educational Factors**

When searching literature into advanced dementia, six papers were identified and considered in relation to educational factors and caring for patients with dementia. Four papers that were looked at included studies that used qualitative approaches to explore healthcare staff views and experiences within a dementia care environment. The methods used to obtain the data were mainly semi-structured Interviews (Moyle, et al 2010; Jansen, et al 2017). Alternatively Charter and Hughes, (2012) used focus groups to explore experiences in the workplace. In contrast (Chang, et al 2009) used both methods to investigate education with acute hospitals. The sample sizes varied between all the studies but all had a small number of participants ranging from seven to twenty who were recruited across the four studies. Two were based within the United Kingdom and the others in Australia.

In comparison, a further two papers were also looked at, one based on a qualitative approach using a questionnaire on palliative care for advanced dementia and another which was used a mixed method approach using a combination of focus groups about the training, and quantitative rating scales on practices and attitudes. The qualitative approach recruited a large participant group of 300 care staff (Chen et al, 2017). The nursing staff with greater work experience and training had greater knowledge of end of life care and a more positive attitude towards caring for people with dementia. However, the paper using a mixed method approach was used to test how to give training to healthcare staff. The paper demonstrated the feasibility and practicality of training hospital staff about dementia and its impact on patient outcomes. Training had an immediate impact on reported knowledge, confidence and attitudes with a lasting impact in most hospitals. The paper also highlighted the need for interventions in advanced dementia care and the need for ongoing training and reinforcement to improve care and ensure its sustainability (Gavin et al, 2010).

All the papers supported the need for educational requirements to be improved or increased as this enhances the quality of care. Chang et al, (2009) and Charter et al, (2012) identified that staff wanted more specific education and training around dementia care, this included learning more about the symptoms of dementia, learning about the individual person and also learning from other specialists. Staff education could improve the current situation so that patients with dementia receive care which takes into account their individual needs and human dignity (Moyle, 2010). It is believed improved education would then enable staff to support patients better and enable staff to give a higher standard of care. Specifically further education for those who aren't qualified staff members and those who have less work experience so care standards can be improved and the working experience (Chen, 2017). Through personal development both papers acknowledged the potential risk of personal stress and burn-out amongst staff members, therefore by supporting staff around the difficulties of caring for patients with advanced dementia the less likely they are to experience stress. Further recommendations were that further research is required to investigate employee's management and coping strategies when supporting those with advanced dementia and the need for new ideas to be suggested if care could be improved (Chang et al, 2009).

Overall, the main focus of the literature in relation to educational factors demonstrated the need for more specific learning for employees to ensure that the correct and quality care is given to patients with advanced dementia. Staff recognised their own areas of difficulty or gaps within their knowledge which in their view could be improved on. The focus on development and learning appeared to also correlate with the reduction in reported stress and burn out symptoms.

### **Patient Behaviours**

There were many papers that identified behaviour issues within dementia care although most were for dementia care in general rather than specific to behaviours in advanced dementia care. Four papers were examined around behaviours which are experienced by staff when caring for patients with advanced dementia.

One paper examined the behaviours of patients with dementia through the use of quantitative methods of questionnaires, ratings and scales. These looked at the frequency of certain behaviours such as repetitive actions, wandering and verbal disruption. In addition to the frequency of behaviours observed by staff there was also a scale on how disruptive behaviours were and what causes the most personal distress to staff. The paper investigated

staff opinions and experiences across fifteen care facilities and had 259 questionnaires returned (Cubit et al, 2007).

The most disruptive behaviours identified were verbal disruption, wandering and repetitive actions. Whereas patients physical aggression, verbal disruptions and wandering were identified as causing staff the most personal distress. Other main points identified were that staff younger than forty reported aggressive behaviour more frequently than those staff older than forty years old. In addition the length of time worked in older adult care was also a significant factor; staff who had worked more than five years reported less aggression than those who were new to the role. In contrast some staff seemed to accept or tolerate resident behaviours as it didn't cause them stress as they viewed it as 'part of the job' (Cubit et al, 2007).

In comparison, two papers explored behavioural symptoms of dementia, one regarding immigrant patients and the second on general hospital in patients with dementia. Although both used a qualitative approach to gather data, each took a different method to research this area. Rosendahl et al, (2016) used semi-structured interviews that were conducted on staff and carers. Three main areas were identified in relation to the main challenges and changes for immigrants in care. The patient's new living situation, challenges in communication and the role of the family members as an expert and interpreter for the nursing staff. Findings suggest that family members played a crucial role in the lives of immigrants as they facilitate communication between the nursing staff and the patient allowing the patient with dementia the opportunity to engage in meaningful activity and enabling staff to meet the needs of patients which they previously may not (Rosendahl et al, 2016). A longitudinal cohort study was conducted focusing on all aspects of BPSD on 230 patients with dementia admitted to acute hospital. These were measured alongside other quality indicators. Participants in hospital were very impaired, with 75% having BPSD, and 43% had some BPSD that was moderately or severely troubling to staff. The most common difficulties were aggression, activity disturbance, sleep disturbance and anxiety (Sampson et al, 2014).

Overall, the main focus of literature in relation to behaviours within dementia care was around aggression, repetition, communication and wandering. These symptoms are highly distressing for the person with dementia, other inpatients, their families and acute hospital staff. They increase the risk of adverse events and appear to have a detrimental effect on the quality of medical care received. There is concern that staff may not always be able to

manage the range or severity of BPSD symptoms and that patients and staff would benefit from more specialists psychiatric support (Sampson et al, 2014). The more information staff have in relation to patients with dementia allows them staff to enhance the quality of care and staff can be more specific to an individual's needs (Rosendahl et al, 2016). The majority of staff mentioned that they need more training and support in managing BPSD in people with dementia. In addition to this staff identified the requirement and opportunity to debrief after stressful events. Therefore by having more measures in place will prevent negative effects such as staff sickness, low morale and reduced job satisfaction (Cubit et al, 2007).

### **Environment**

When searching literature into dementia and the environment, four papers were identified and considered in relation to environmental factors within an inpatient or residential unit for patients with dementia.

Two papers investigated factors which can influence care given to patients with dementia; using qualitative research methods, then by using semi-structured interviews, each study discussed this with care staff (Borbasi et al, 2006; Hadjri et al, 2015). The studies interviewed a similar range of participants (n = 22-25) and asked them about factors which influenced care. The themes identified initially focused on the built environment, organizational factors, and the ideal or current dementia care management. Environmental issues such as the footprints of buildings, equipment, sociocultural implications such as language barriers, and economic issues like funding good staffing levels can impact on the quality of care for those with dementia, even though professionals aim to give the best practice. (Borbasi et al, 2006). In contrast, (Hadjri, Rooney & Faith, 2015) identified themes around the level of care required by a resident, the atmosphere of a home, design and quality of the home. The design of the physical environment is an important factor and can enhance behaviour, cognition and comfort for people with dementia. This has the potential to contribute to the well-being and functionality of people with dementia. Both these studies support the idea of environment having an impact on patients with dementia. It is recommended that management need to focus more on the needs of the client group and the health professionals than the needs of the institutes. They describe a system under pressure, including a lack of time and additional training also emerged as important aspects necessary to meet the care needs of patients with dementia (Borbasi et al, 2006; Hadjri et al, 2015).

Another paper explored environmental factors using the qualitative method of focus groups, with purposive sampling (n = 15). This study took place within two care facilities in Canada, and aimed to explore staff's perception on the physical environment and how this may affect resident's behaviour, wellbeing and staff job satisfaction. Two main themes occurred as a result of this study; these were that a supportive physical environment contributes positively to both quality of care staff interaction and residents quality of life. In contrast to this, an unsupportive physical environment contributes negatively to residents' quality of life and thereby makes the work of staff more challenging. The key areas of environment which had an impact were: comfort, familiarity, and organized spaces which had positive impacts. Negative factors included stimulation overload, safety risks, wayfinding challenge, and rushed care. This study demonstrates that a properly designed physical environment is beneficial to both staff and patients and potentially could result in better care and help the well-being of residents (Lee, Chaudhury & Hung, 2016).

A further paper took a different approach to investigating the physical environment, by exploring how the environment can enhance care and additionally identify potential design opportunities to maintain quality of life for those with dementia (Mobley, Leigh & Malinin, 2017). Specialized nursing care units (SNCU) with the United States examined relationships between the physical environment and the behaviour of residents and staff. A mix method combination of quantitative and qualitative approaches was used to collect data through a spatial inventory, staff e-survey, and behavioural observations. Data indicated SNCU designs have the potential to support care significantly, and some physical conditions could be improved by simple design interventions, suggesting some staff may lack awareness about how the physical environment could improve the quality of life for patients. Additionally to obtain staff perceptions, a survey was used to gather ratings of environmental features and attributes to gain an understanding of how staff perceives the relationships between settings and behaviours. Therefore by linking design features and best practices with observed behaviours is a framework of the role environmental design features play in coping and stress for people managing dementia (Mobley, Leigh & Malinin, 2017).

Overall the literature on the environment and dementia care was consistent and suggested the need for a suitable dementia specific environment is required within a hospital or nursing home settings. A suitable and appropriate environment allows for the best and most appropriate care to be given to patients. On the other hand some of the literature also

identifies the impact physical environment can have on care staff as well as patients, and this should also be considered by those who are in charge of the institutions.

### **Staff Wellbeing**

When searching literature into dementia and staff wellbeing, five papers were identified and considered in relation to how staffs are when working within an inpatient or residential unit for patients with dementia. Four papers approached this area by using the qualitative method of questionnaires (Schmidt, Dichter, Bartholomeyczik & Hasselhorn, 2014; Duffy, Oyebode & Allen, 2009; Park, 2010; Bassal, Czellar, Kaiser & Dan-Glauser, 2015). Two of the qualitative papers used questionnaires to explore the impact on nurses general health, burnout and work ability while caring for people with dementia and collected a large number of views ranging from 245 (Schmidt et al, 2014) to 305 (Duffy et al, 2009). The outcomes suggest that workers are dissatisfied and this causes substantial work stress, high levels of emotional exhaustion and depersonalization which indicates burnout. Age was also a key factor with burnout and the older staffs were less likely they are to experience burnout. This implies older staffs have developed emotional resilience and are more likely to manage stressors at work, although younger members of staff may need more support in their work environment. These findings suggest employers need to address these levels of burnout, especially as this may impact on the quality of their work in caring for older people with dementia.

Another two papers focused more on the emotions experienced during caring for people with dementia using questionnaires. The papers recruited a varied amount of participants due to one being a pilot study, ranging from 43 to 267 (Bassal et al, 2015; Park, 2010). A rating questionnaire measured the frequency of emotions experienced at work alongside what emotion regulation strategies were used when experiencing emotional exhaustion. It was suggested that caregivers experience positive emotions more frequently than negative emotions, and the more positive emotions experienced leads to better physical and mental health. In addition caregivers who experienced more negative emotions reported poorer physical and mental health and were more likely to feel emotional exhaustion (Bassal et al, 2015). In contrast to this, Park (2010) investigated stress levels and attitudes experienced by nursing staff within dementia care. Nursing assistants reported higher stress levels than nurses when caring for patients with dementia who present with aggressive behaviours, whereas nurses reported higher stress levels when they experienced a lack of resources. The findings in this study showed a need for specific educational programs for staff to enhance

their dementia care knowledge, alleviate stress, and finally change positively their attitudes towards families of patients (Park, 2010).

The final paper used a qualitative and quantitative mixed method approach of interviews and observations to explore the experiences of nursing staff and patients about the care given to people with dementia in acute hospitals. Findings suggest that people with dementia found the delivery of care and the experience of being in hospital distressing. It was acknowledged that nurses strive to give good care but are not always able to facilitate or achieve this. This study concluded that innovative methods of developing practice are implemented and evaluated and that further research into this subject needs to be undertaken (Cowdell, 2010).

These outcomes are supported that when caregivers support people with dementia, the caregiving process is emotionally draining by nature (McCarty & Drebing, 2003).

Additionally, when measuring work related wellbeing factors such as health, both physical and psychological care is often considered as important subcomponents of well-being (Danna & Griffin, 1999). Further research should be done using a qualitative approach so strategies can be developed to combat burnout and turnover. If policies and standards are established to improve care levels in long term care institutes, such as staffing levels, these can then help support and reduce stress in the work place (Park, 2010).

Overall, there is some literature evidence around staff experiences within dementia hospital care, there are certain areas and recurring themes appearing in several literature articles. These main themes include environmental aspects, behaviours, training, education and staff morale. These reasons stated above suggest a gap within previous research. These studies suggest a possible need for improved working conditions for those caring for people with dementia as it impacts both the patient and worker which could cause further complications and health issues. The literature identified the physical environment as a significant area that causes stress and burn out.

When establishing the quality of the literature a Critical Appraisal Skills Programme (CASP) was used in the critical appraisal of research. There are many critical appraisal tools; the qualitative research checklist was specifically chosen to look at the trustworthiness and relevance of an article. There are three main areas which are questioned within the qualitative research checklist, these are: the validity of the results, what are the results, and do the results help locally. To enable these questions to be answered ten subcategories of analysis are included on the qualitative checklist (Nadelson & Nadelson, 2014; CASP, 2017).

The literature found was a mix of both quantitative and qualitative studies with a mix of questionnaires and focus groups being the preferred method of choice. The literature conducted was mainly fairly small in scale and most research was conducted on a single site. Most literature discovered has fairly substantial depth and detail. The main focus of these articles was around caring for people with dementia within a nursing home setting rather than a hospital setting. However, it appears there is a lack of studies in dementia tertiary care and the experiences of staff within this setting. In relation to the content of the literature, there were more papers, both research and opinion based, focusing on areas such as the physical environment, behaviours of dementia and education and less in relation to specific areas of staff wellbeing or support strategies. Most of the literature studies included had sufficient detail of the process and the design of the research but some papers are missing some elements of detail. This then can makes it unclear what the strengths and limitations of some articles are. Furthermore, some of these articles do suggest further improvements and identify gaps within their own studies and how to enhance their research further. There is a lack specifically of one to one research focusing on individual experiences where staff can express personal views in a setting away from other employees. However, previous literature can allow for some indication as to what areas could be discussed in future studies.

## **Chapter 5 - Methodology & Methods**

Having looked at the current literature identified during the search process this then informed which approach and method was used for the study. The main aim and objectives of the study are outlined below:

Aim: To explore the experiences of health care workers within a dementia tertiary setting.

Objectives:

- To explore thoughts, feelings and the emotions of staff's individual experiences while working on a dementia ward.
- To identify any challenges staff experience within the dementia tertiary care and how they manage these challenges.
- To identify additional support strategies for staff to manage their current work challenges.

### **Research design**

When conducting a piece of research a researcher must decide which method is most suitable to conduct their investigation, by deciding whether to conduct a quantitative or qualitative piece of research. The term 'quantitative data' is described as variables of interest where relevant data can be collected. The main type of information gathered from quantitative data is information that may be counted or in a numerical form. In a quantitative design, research tends to be more structured and controlled. The primary data collection methods are: questionnaires, observations, self-report and measurements (Polit & Beck, 2008). Qualitative research is described as social and behavioural research, based on unobtrusive field observations that can be analysed without using numbers or statistics (Hageman, 2008). This method means investigations can be conducted in greater depth and this allows for rich data to be gathered. Qualitative research is more loosely structured allowing for beliefs, feelings or behaviours to be expressed in depth. The main advantage of using qualitative research is it allows the research to analyse naturalistic environments (Merchant & Van der Stede, 2006). In addition to this, qualitative studies are able to examine more complicated research without compromising the data gathered. This approach then allows for greater flexibility when conducting research (Berg, 2003). Qualitative research is the most suitable method for investigating staff perceptions within dementia care as this approach allows for greater flexibility and the opportunity for rich data to be gathered regarding individual experiences.

The focus then turns to what research design should be used to conduct the study. There are three main qualitative research designs, and each of these designs will be discussed. The three main designs are ethnography, phenomenology and grounded theory. Ethnography is described as the study of social interactions, behaviours, and perceptions that can occur within specific groups, teams, organisations, and communities. The main aim of this design is to obtain rich insights into individual views and actions, as well as the surrounding environment. This is gathered through the collection of detailed observations and interviews, often by means of an investigation on a small number of participants. There is an emphasis on participant observation and the advantages for the researcher, and being able to immerse themselves within a setting. However, using this process means the data takes a long time to collect, therefore long term access to the research site is paramount. Overall, the unpredictability of this approach requires the researcher to be flexible, patient and persistent in their work as this can be disrupted due to site circumstances (Reeves, Kuper & Hodges, 2008).

Grounded theory is a form of qualitative research developed by Glaser and Strauss and its main aim is to generate theories regarding social phenomena and to develop a greater level of understanding (Lingard, Albert & Levinson, 2008). Grounded theory examines six areas of the social processes: causes, contexts, contingencies, consequences, covariance's and conditions. Grounded theory relies on theoretical sampling and this involves recruiting participants who have varied experiences within an area of interest. The researcher continues to recruit participants to the sample until they have reached theoretical saturation, when the complete range of constructs that make up the theory is fully represented by the data (Starks & Trinidad, 2007). It is suggested that a researcher shouldn't primarily rely on just one data collection technique. Therefore by using several data collection methods techniques such as interviews and observations, this creates a stronger research design. However, grounded theory research can be a time consuming process and this requires access to the area for a lengthy period of time (Polit & Beck, 2008).

'Phenomenology has been described as both a philosophical movement and an approach to human science research' (Dowling, 2007, p. 131). When looking to develop a deep understanding of a lived experience a researcher needs to become immersed in the phenomenon (Earle, 2010). Phenomenology is defined as the method to describe and understand the lived experience of an individual (De Chesnay, 2014). This is based on the

philosophical work of Edmund Husserl and Heidegger where the approach is used to explore and understand people's everyday experiences (Polit and Beck, 2008).

These three different types of qualitative research design approaches were considered when deciding on how to conduct the study. However, with the study being a generic qualitative study I elected to use generic qualitative inquiry methods to obtain participant data.

A generic qualitative inquiry investigates participant's subjective opinions, attitudes, beliefs, or reflections on their experiences, of things in the outer world. This approach can be used as the methodological approach when the research question requires a qualitative methodology. In addition this method can be used when the researcher has pre-knowledge or pre-understandings about the topic that they want to describe from the participants' perspective. A generic qualitative study's data collection method, aims to gather information from a representative sample of people about real-world events, processes, or experiences. The focus is to acquire a broad range of opinions, ideas, or reflections from a well-informed sample in attempt to obtain rich information about the topic (Percy, Kostere & Kostere, 2015).

Generic qualitative methods was deemed to be the most appropriate option to obtain new information by following an inductive approach aiming to generate meanings from data and identify patterns and these then form conclusions. Also a generic approach allowed for a specific representative sample to be interviewed in a particular area of interest and participants experiences and thoughts could be explored.

When conducting this study, 'Healthcare Workers' which is a generic term used to cover a wide range of professionals who are working to support the needs of patients were interviewed. The study included interviews with staff from various National Health Service (NHS) banding levels to gain a broader perspective of what it is like to work on a dementia ward. The focus was on tertiary care environments because this area includes patients who require the highest level of care due to their poor level of health. The participant sample aimed to include Support Workers at Band 3 level, Health Practitioners Band 4, Nurses and Occupational Therapists at Band 5 and 6. All participants must have worked on the dementia wards for at least one year or more and they were approached due to having sufficient experience on the wards over a period of time. This aimed to produce an accurate reflection on working life which is applicable to other hospital wards.

In addition, those interviewed had various qualifications depending on their profession, although all contribute to the care of individual patients within a multi-disciplinary team. The study was in the format of a qualitative piece of research to explore health professional's thoughts and experiences whilst working within an acute dementia hospital. The criteria for admission to the two dementia wards was for those 65 years and over and patients would be detained under the Mental Health Act (2007) Section 2, although there may be some exceptions to this depending on circumstances.

### **Sampling**

Purposive sampling is a non-random method to ensure that particular participants within a category are represented in the final sample of a project. The rationale for using a purposive strategy is that the researcher assumes, due to their prior knowledge and understanding of a topic area, that certain participants may have a different or unique perspective on the area of focus (Robinson, 2014). This method of recruitment is described as a selection of participants within a given area of focus or interest which allows for the most knowledge to be collected (Guarte & Barrios, 2006). This sample method assists in obtaining all the relevant information which other techniques may not (Collins & O'Brien, 2011). Purposive sampling was the preferred method to recruit participants within dementia hospital care. As the participants work within the focused area of interest and staff all work different shift patterns. This method enables the best chance to recruit the required sample.

There were two methods considered before deciding how to collect the data from the participants; through the use of focus groups or through interviews. The first method considered was through the use of focus groups. Focus groups are a research technique collecting data through group interaction on a specific topic which is determined by the researcher. This process is an active interaction among participants to explore individual's views and opinions. However, there are some limitations which can affect the practicality of using focus groups. A focus group is usually more difficult to organise than other methods and this can create issues with bringing participants together at the same time (Jayasekara, 2012). This particular limitation was the reason for not choosing focus groups as the research setting would not be able to facilitate a group of staff leaving the ward.

The method chosen to obtain the data from the participants was through the use of interviews. Interviews are the most common approach when attempting to collect qualitative data. Qualitative research interviews are where the researcher is interested in collecting "facts", or

gaining insights into or understanding of opinions, attitudes, experiences, processes, behaviours, or predictions (Rowley, 2012). This technique of collection ‘encourages the interviewee to share rich descriptions of phenomena’, this then allows the interviewer to analyse and interpret the data as they want, using their own methods. In addition, it is also suggested that the main purpose of interviews is to contribute to knowledge, both conceptual and theoretical and it is based on the meanings that life experiences hold for the interviewees (Dicicco-Bloom & Crabtree, 2006). This was a key aspect in the research as it is based on health staffs individual experiences therefore interviews was the most appropriate method.

Prior to approaching the participants an invitation letter was sent to all staff who have worked on the dementia wards for a period of one year or more inviting each employee for interview. The letter also included the participant information sheet and consent form so that staff could read them prior to being approached (see appendix 3, 4 and 5). On the day of recruitment prior notice was given to those who were on shift as this was to enable maximum participation. The participant group criteria included healthcare staff from the dementia wards from various positions and roles, ranging from band 3 to band 5 who have worked on the dementia wards for a minimum of twelve months. Each staff member who met the criteria for interview was then approached individually on the days of the interviews with an aim to recruit between ten to fifteen participants. Once the sample of participants was gathered they were then interviewed and sample size was aimed to recruit a number of participants from each role and banding position. The participant group were any healthcare workers who consented to take part in the interviews and were able to participate in the given time over a set period of weeks. Management staff and students were excluded from the interviews, because the research focus was on frontline staff.

The concept of reaching saturation can be problematic in qualitative research for those who use it as a means to determine sample size. Saturation means that no more additional data is being found. Additionally, researchers see similar results, reports or comments on a repeated basis. The researcher then becomes confident that the particular category has reached saturation. However there is the risk of presuming saturation has been met too quickly when that may not be the case, it is likely that the analysis could lack criticality and complexity (Nelson, 2016). For this study it would be difficult to establish if saturation was achieved.

The interviews were conducted in a private meeting room within the hospital building to help ensure maximum participation and provide a safe, secure and accessible setting for all

participants. The interviews were conducted on a one to one basis using a semi-structured format, which is the most common type of interview type. Semi-structured interviews take on a variety of different forms, with varying numbers of questions, and varying degrees of adaptations of questions in order to accommodate the interviewee (Rowley, 2012). The main goals of semi-structured interviews are to gather systematic information about a set of central topics (Wilson, 2014). The interview questions and guidelines were set prior to the interviews taking place (see appendix 6). This format also allowed for some exploration for when new issues or themes emerged throughout the interview. There is flexibility with semi-structured interviews as to how many fixed questions are asked during an interview and depending on the responses given, this can then be adapted. The benefit of using semi-structural interviews are when there is some knowledge about the topic or issues under investigation, but further details are still needed (Wilson, 2014). This allows the researcher to investigate what staffs individual experiences were whilst working on a dementia inpatient ward, and each participant had the opportunity to share their individual thoughts, feelings and experiences. This allowed for any comments or additional points to be explored within the interview.

### **Management Access and Approval**

To gain access to the site facility written confirmation was required from the Site Manager, subject to all other ethical checks being approved and regulated. Then the School Research and Ethics Panel (SREP) approval was sought. This involved an application detailing all aspects of the research and contained all documentation which would be used as part of the research study. Once SREP approval was obtained the application for the Integrated Research Application System (IRAS) was then subsequently completed. The IRAS form was then submitted to the NHS Health research authority (HRA). Permission was then given for the research study to proceed and organise with Site Manager (see appendix 7.0). A one to one meeting between the site manager and the researcher took place as well as a telephone consultation between the manager and supervisor regarding the outline of the study, proposals and addressing any concerns.

## **Chapter 6 - Ethical Considerations**

### **Consent**

The study required University ethics approval, NHS Trust approval and management approval before undertaking any research. Therefore consideration needed to be demonstrated regarding awareness on what issues might arise. Ethical considerations need to be thought about and addressed before research is conducted. However, even though many ethical issues can be predicted, often some occur during the research process itself (Wiles, 2012). Informed consent is one of the key principles which underpin research; it involves informing participants exactly what they would be participating in, with clear information so that they can make their choice whether or not to participate. The main areas of informed consent are: what are the aims of the study, the reasons why it is been conducted, what the participants would be doing in the study, what would be the outcome with the results, if they are any risks involved and finally if there is any possible benefits from the outcome of the results (Wiles, 2012). Informed consent was obtained and collected through a formal letter. Prior to been approached on the day, potential participants were sent the consent form, then handed this on the day with further time to consider their participation before being requested to sign the consent form.

### **Confidentiality**

Most researchers raise the importance of issues regarding the confidentiality of research data and that retaining the confidentiality of participants data is paramount. Although in health care, it is identified confidentiality is not an absolute given and so it is important for researchers to understand their legal boundaries with regards to what is divulged during research, such as when interviewing the participants (Tense Stiles & Petrila, 2011). All participants in the research were informed that what they discuss would be in confidence, although if risks were identified about themselves or others this could then be rescinded. Participants were also informed that some of their direct quotes may be used throughout the written research or discussed with my supervisors through the process.

### **Storage of data & Anonymity**

Anonymity in practice is information on the identity of the research participants such as name, age, gender etc. This personal data should be removed from the final research reports.

In addition by anonymizing research participants this has an influence on the overall quality of research (Vainio, 2012).

When conducting the interviews an MP3 player device was used to document the audio recordings of each participant and these were then transferred to an encrypted memory stick before being transcribed on a password protected computer. The recordings on the MP3 device were then stored in a lockable drawer and the information was deleted once the recordings had been transcribed. The transcription does not include any information which could lead to the possible identification of individuals as the participants views remained anonymous, as well as the location of the study site. Participants were able to read their own transcript and have the opportunity to request any particular parts of the material to be removed up to the point of analysis. The transcripts will be kept for a minimum of five years. Finally, participants were reminded that they had the right to withdraw at any time until the submission of the research.

### **Risks and burdens**

It is suggested that while most qualitative research has minimal risks, certain sensitive issues when discussed could be potentially distressing (Wiles, 2012). There was a risk that the research interview may discuss issues that neither the researcher nor the participant was prepared to discuss. These issues can be exacerbated by the very nature of the qualitative interview questions themselves. This may lead participants to disclose sensitive information about themselves or others that could have been problematic (Smythe and Murray, 2000).

If the participants became distressed during the interview through the recall of negative experiences currently or previously endured whilst at work, the participant could choose to either terminate the interview or withdraw from the study at any stage. If not the interviewer would pause the interview, allowing participants time to compose themselves before continuing. Any further support required after the interview would be directed to the site manager and NHS counselling service if necessary. The researcher received individual support by receiving regular supervision with supervisors throughout the process and after each interview. These principles must be adhered to so that the risk of harm to the researcher or participant is minimised.

## **Chapter 7 - Data Analysis**

Thematic analysis (TA) is a method for identifying, analysing, and interpreting patterns of meaning or ‘themes’ within a piece of qualitative data. TA has systematic procedures for generating codes and themes from qualitative data. Codes are small sections of data that demonstrate an area of interest which are potentially relevant to the research question. Codes help enable the development of themes or patterns within data, these help organise and report the researcher’s analytic observations. The aim of TA is to identify and interpret key concepts guided by the research question (Clarke & Braun, 2016).

Thematic analysis was used in my study to identify any common themes that may occur from the data. The data was transcribed from the recordings into written transcripts so it could be analysed. When interviewing and transcribing the data a researcher must be aware of non-verbal communication and paralinguistic aspects such as pitch, tone and voice intonation as these inform the interviewer of themes and opinions alongside the verbal content (King and Horrocks, 2010). When identifying themes within the study’s transcript key words or phrases which were repeated throughout an individual’s interview were recorded. During the study, by identifying key emotions or feelings both positive and negative whilst writing up the transcripts, this can assist in the analysis process. This process focused on using coding to decide which parts of the transcripts were relevant to the main question. Once specific codes were identified, they were then grouped together into similar opinions, feelings and emotions that have some common meaning. Finally, from these codes the overarching themes from the study were then developed. It is suggested the researcher should not speculate on what individuals have meant from the transcripts but they should identify the recurring themes which have been suggested throughout. Therefore, by using this method it enables the researcher to conclude across all the interviews any similarities or differences between individuals but also ensuring rigour (King and Horrocks, 2010).

The software which was used to assist in analysing the data was called Nvivo®. This is a qualitative data analysis (QDA) computer software package. The software is designed for qualitative researchers who work with detailed text or information where deep levels of analysis are required either with small or large volumes of data. Nvivo® is designed to help organize and analyse data such as interviews, to speed up the analysis process and help connect the data and establish links. The term ‘Nodes’ are a main component of Nvivo® and are what would be more commonly referred to in research literature as codes signifying

themes and subthemes. 'Nodes' provide storage areas for coded text where data is stored as an area of focus and it is allocated to a certain node and helps to identify recurrent themes. Nvivo® also contains tools to enable researchers to examine the data in various ways in a timely manner through the use of queries where a researcher can ask questions of the text, such as the frequency of a term or phrases supporting a specific area. These can be presented in lists, diagrams or charts (Houghton, Murphy, Meehan, Thomas, Brooker & Casey, 2017).

## **Chapter 8 - Rigour**

There are a range of methods in place to ensure rigour for qualitative research. These include coding using computer programs to assist qualitative data analysis, recording data objectively and comprehensibly, and transcription techniques of conversation analysis. None of these techniques are said to solve all the problems of reliability and validity indefinitely but they can advance these causes in research reports (Seale & Silverman, 1997). These techniques help establish a qualitative account of people working within an acute dementia care setting and gain a true reflection of their experiences.

There are specific criteria for determining the trustworthiness of qualitative research and this was introduced by Guba and Lincoln in the 1980s when they proposed the terminology for achieving rigour. Reliability, validity, and generalizability were changed to dependability, credibility, and transferability. The strategies for achieving these areas were defined and then introduced. The first is credibility (internal validity), which includes prolonged engagement, persistent observation, triangulation, peer debriefing, negative case analysis, referential adequacy, and member checks. Then the transferability of research (external validity, or generalizability): which includes detailed description so the original findings can be applied to another context or setting. Dependability of research (reliability) is attainable through credibility, the use of overlapping methods, replication and the use of audit trail. Finally there is Confirmability (Objectivity) can be achieved by using strategies of triangulation and the audit trail (Morse, 2015).

### **Establishing Credibility**

Rigour can be achieved by following certain principles, and to achieve credibility there are several methods that can be followed. Prolonged engagement is where a researcher spends sufficient time in the field to learn or understand the culture, social setting, or phenomenon of interest. This requires spending adequate time observing various aspects of a setting, speaking with a range of people, and developing relationships and rapport with members of the culture (Lincoln & Guba, 1985). During the study, the process interviewed various staff members from a variety of different roles and positions over a period of time. Through the means of recruitment, orientation about the wards running became apparent, because of previously working within this care environment this then enabled a good level of rapport with some staff to be present from the start. Therefore by being reflective and acknowledging my perceptions and views, new unforeseen outcomes could be established.

In addition to prolonged engagement the purpose of persistent observation is to identify those characteristics and elements in the situation that are most relevant to the problem or issue being pursued and focusing on these in detail. Prolonged engagement provides scope to gain a broad view, whereas persistent observation provides depth and detail (Lincoln & Guba, 1985). This is the reason why in my study that semi structured interviews were chosen, the questions could then be adapted dependant on participant responses. This gave the opportunity for me as the interviewer to gain all relevant information in as much detail as possible with the option to explore further areas of interest from the responses given.

### **Establishing Transferability**

The technique which was identified to establish transferability is known as ‘thick description’. This is the ability to create a rich, contextualized description of an event to increase verisimilitude and transferability of the findings (Creswell, 2012; Merriam, 2009). Thick description is as a way of achieving a type of external validity. Therefore, by describing a phenomenon in as much detail as possible allows the researcher to begin to evaluate the extent to which the conclusions identified are transferable to other settings, situations and people (Lincoln & Guba, 1985). This level of description is a detailed account of field experiences in which the researcher makes explicit the patterns of cultural and social relationships and puts them into context (Holloway, 1997). For the purposes of this study using interviews with open ended questions achieved thick description as this allowed the researcher to explore and gain more depth during the interview exploring individual’s thoughts, feelings and experiences of working with people with dementia.

### **Establishing dependability**

The use of external audits is a method used for determining whether dependability has been achieved when conducting research. External audits provide an opportunity for an outsider to challenge a researcher’s views, the process and the findings of a research study. This feedback can also lead to additional data gathering and findings (Lincoln & Guba 1985). This was achieved during my study in the form of receiving regular supervision with two supervisors who questioned each step of the method and process and sought justification of any choices that were made. In addition to this discussions around the results and outcomes took place, with shared views and interpretations presented and reflected upon.

## **Establishing Confirmability**

The techniques for establishing confirmability are an essential component of rigour and qualitative studies. An audit trail can be used: a transparent description of the research steps taken from the start of a research project to the development and reporting of findings. These are records that are made and kept during the research process and after it has been completed (Lincoln & Guba, 1985).

Categories are used to develop an audit trail. It begins with raw data which includes field notes and documents, analysis products and data reconstruction, synthesis products including themes and definitions. The final report should include findings and connections to existing literatures. It should also include methodological notes on the method, design and procedures on how the research was conducted and include justification for the approach and how to ensure rigour (Halpern, 1983). Finally the inclusion of Instrument development information which is pilot forms such as consent forms and participant information sheets and schedules is essential (Halpern, 1983). It is important that the research path is set out and the rationale for all these decisions is made clear (Lincoln & Guba, 1985). These documents, forms, notes and a detailed description of the study process are all included throughout the thesis.

## **Reflexivity**

Reflexivity is a method to establish confirmability, the perspective or position of the researcher shapes all research quantitative, qualitative and even laboratory science (Lincoln & Guba, 1985). In addition to a researcher's background, their history and position affects what they choose to investigate, the angle of investigation and the methods most suited to the purpose and the framing and communication of its conclusions (Malterud, 2001). A reflexivity section allows the researcher to explore their own expectations and opinions on the outcomes and by acknowledging this then helps ensure rigour.

Reflexivity is also a major component to ensure quality control during qualitative research. Researchers have to understand the potential impact of their characteristics and experiences, on the outcome of what they are investigating. The benefits and challenges of reflexivity are outlined by three main components and these include when the researcher shares the experience of study participants, when the researcher moves from the position of an outsider to the position of an insider in the course of the study and when a researcher has no personal familiarity or experience with what is being studied (Berger, 2015).

Preconceptions are not the same as bias, unless the researcher fails to mention them. The understanding of the researcher's views and beliefs can be an issue, but steps can be taken to minimise the risk of bias. When designing research, having multiple investigators helps challenge and contest beliefs, values and assumptions (Malterud, 2001). On reflection I acknowledge that there is potential to have researcher bias as each individual has their own views and perceptions of this experience. During this research process regular supervision from two supervisors supported these discussions and challenged any preconceptions to help minimise bias.

Prior to conducting this study, I was previously employed by the study site as an occupational therapy assistant at a Band three level for a period of six months. During this time I gained an 'insider perspective' within the dementia tertiary care environment, although I have been away from the study site for over two years. This previous position informed my choice of study and this then helped to formulate some of the questions used during the interview process. Although I knew some of the people I interviewed, this was only in a professional capacity.

Whilst conducting the study the perceived position in the hierarchy during interview stage could have had an impact on participants and their responses in either a positive or negative way. This could have resulted in the interviewer being viewed as under qualified or inexperienced due to prior role, age, appearance or relevant academic background. Alternatively this could have made me more approachable to participants and they may have been more open and willing to divulge personal views or opinions. These elements had the potential to alter individual responses to answering the questions, either by participants giving socially desirable answers, minimal responses or alternatively allowing the participants to be more open. Furthermore by having previously worked within the study environment this also helped facilitate access to the study site and the participants for the time required to complete the study. Therefore by monitoring reflexivity and such possible effects can enhance the research's findings and the credibility of the results.

A reflexive journal can also help ensure rigour where the researcher makes regular entries during the research process. In these entries, the researcher records methodological decisions and the reasons for them, the logistics of the study and reflection upon what is happening in terms of one's own values and interests. Many believe that this is a valuable tool and it is essential to briefly report on manuscripts as best as possible. This should focus on how one's

preconceptions, beliefs, values, assumptions and position may have come into play during the research process (Lincoln & Guba, 1985). During the study process reflections were completed after each interview to make note of key areas, points made and personal reflections on the process and the method itself.

## **Chapter 9 - Findings**

During the research process twenty-seven healthcare staff from a northern care inpatient facility, were approached to participate in the study. As a result of this nine individuals agreed to participate in the study. Those who participated in the study ranged from having two years' experience to over twenty-two years of service. All participants were from various positions, roles or banding levels. A participant data table is included to represent the participant data (see appendix 8.0).

When using the Nvivo software the transcript data was imported onto the software then the data could begin to be coded. When reading through the transcripts, selected phrases of data around common comments, views or opinions were grouped together and created into a Node. Initially twelve different nodes were created focusing on areas such as: environment, training, positives, challenges, behaviours, dementia, support methods, qualities, memory, and enjoyment, promote/help and time. This was because initially it wasn't fully apparent what the main themes were. To establish what the overarching themes were each Node was then looked at in turn and the elements of some Nodes began to overlap and link together into four common overarching themes.

The first theme that was identified from the data was elements of the physical environment, as participants frequently referred to elements around their place of work. Data that was identified with the use of Nodes included areas such as *'the building isn't suitable for dementia'* referencing to the footprint of the building and wards. Followed by other physical factors such as *'no natural light'* where several participants made reference to the wards been dark, dull and enclosed with participants implying that this had a negative impact on patients as well as the staff. This was followed by half of the participants making comments in relation to the facility *been 'non dementia friendly'* or *'not purpose built'* for people with advanced dementia. Two participants continued on from this and made reference to *'purpose built buildings and facilities'* and the need for these to be reintroduced as these were previously *'buildings purpose built for dementia in the community'* and participants believed this would address many aspects of the environment previously identified by participants. In contrast to this most participants did acknowledge that the physical environment had improved recently through the *'refurbishment and new furniture'*, *'great contrasting colours'* and *'new kitchenette that promotes people's independence'*. These aspects of the environment were recognised as positive changes for the ward and a marked improvement. Overall the

frequency and similarities of the data referring specifically to the physical environment of the ward established this as one of the overarching themes from the data.

In conjunction to this several Nodes were grouped together to form the theme of the environment of care, this includes patients behaviours, challenges such as staffing levels, time and resources. These areas are all factors which can influence staffs ability to care for patients and how care is provided within the care setting. This included the difficulties surrounding the client group itself such as behaviours associated with dementia *'there's different behaviours with dementia, they are more demanding'* alongside the patient group and the job been *'a really difficult job, it's really hard'*, *'psychologically hard, it's really physically hard'*. Staff referred to aggression as a difficult aspect of the patient group and this been a challenge to overcome and work with. When patients become irritated or violent this presented a difficult challenge for staff, they spoke about situations where *'you could be punched, spat at and grabbed inappropriately'*. This type of challenge can result in staff having to use various restraint methods which were described as *'always a downward element of the job'*. This implied that staff felt this aspect of their role was a negative part of the job and that they would rather avoid this type of interaction if possible.

The time constraints of working with patients with dementia were referred to by half of the participants during the study. Staff reported that that the role requires a lot of time, *'everything takes longer'* and *'it is hard to manage my time'*. Staff identified that they required more time to perform certain tasks as *'it can be difficult to run and ward when you spend so much time doing medication'* or other tasks. There was a consensus around *'everything just takes longer in this role'* and *'you do have to spend more time with people'*, and it takes more time to explaining things to people with dementia because of the client group's difficulties. Staff accepted that due to the nature of the condition it takes them a lot longer to complete tasks which usually could be done quicker with other service user groups. In addition time was also spoken about in the sense of staff having time for themselves *'so I can take a lunch break'* to allow for staff to have sufficient rest periods. Finally, staff also requested that they wanted more time so that they could spend quality time with patients and time to *'try and make them feel special'* even though participants acknowledged that they can't always do this because of the demands of the role.

The final Node identified as part of this theme was in reference to challenges such as staffing numbers *'Lack of staff usually happens if we've got a high level of observations'*. Staff

expressed that this was a frequent occurrence on the ward for patients to be observed although this can compromise how many other staff are freely available on the rest of the ward. *'It's—it's the heaviness of the close obs'* this was a main focus by the staff. Other participants referred to staffing issues been more down to sickness levels amongst the team. *'Sometimes you can have a lot of sickness on the ward and it can impact on the care'* this aspect was suggested that it happens time to time, although the approach to this situation was contrasting *'You look at the board and you think, oh right, we're two staff members down'*. There was a sense throughout all the interviews that staff seemed to just get on with things and that *'It's just autopilot'*. According to staff even when then numbers are what's expected in relation to staff patient ratio, it's not always as straight forward as that as the patient group's needs are always changing. Staff also identified that there is a current reliance on a *'lot of agency staff and they don't always turn up'*, this then impacts on the overall staffing levels. Some non-qualified participants suggested that more qualified staff should be in the numbers as they believed this would reduce their own stress and support others colleagues better. All these Nodes which were identified in the data combine and link to the overarching theme of the environment of care.

Team work and support was another area that was identified as an overarching theme as there was reoccurring data from all participants regarding the team as a whole. Several participants made reference to the team, *'we do it as a team'*, *'we are a very good team'* and *'we work with each other and really help each other'*. It appears that there is a culture of team support within the hospital working environment and there was a feeling that help in any form is available to staff when necessary. The participants mentioned several forms of support methods during the study which staff can access if required. There was an emphasis on the fixed support arrangements and procedures *'we have regular supervision'*, *'once a month both clinical and management'*. Participants also acknowledged that this support is occurring more frequently, *'it's a lot more regular recently'* staff acknowledged this as a positive improvement. Staff can also approach their managers whenever they need *'we can just walk into their office, their always approachable'*. A further method of support that was identified was the support of the psychology team, *'we have a meeting with them on weekly basis as well, so we can talk to them'*. Participants did state that the increase in the support offered had made a significant difference over recent months and they felt *'really well supported'* compared to previously where certain supports weren't as frequent or in place. Overall,

participants identified many methods to support them whilst caring for patients with dementia and many commented on the improved and varied support options available to them.

The final theme identified was around staff education and training as there was a key focus on professional development and continuing learning from many of the participants. When discussing training on the dementia ward some participants had completed '*NVQ's*' or '*Sterling Training*' which '*looks at different types of dementia, medications and more awareness in dementia*'. Participants suggested that these courses were beneficial and useful in their work, '*you have a real understanding of dementia*'. However some staff experienced '*situations where it was felt that others need more awareness of dementia, even though they may have worked with in this setting for years*' suggesting experience doesn't necessarily mean that staff wouldn't benefit from further learning or development. Participants with more experience that had attended further learning courses commented that the '*training had been really enjoyable*' and '*useful and helped me understand more*'. Participants identified that the '*patient group needs are changing, and the needs of patients require more specialist equipment*' therefore participants were identifying the need for further training in specific areas and acknowledging that they require further education or training to enhance and develop their skills. There were other suggestions regarding areas of training which staff felt they would benefit their current needs such as '*dementia care mapping*', '*university courses*' or '*palliative care*' as palliative carer has been a more frequent situation that staff are experiencing. Further training, would equip staff with the skills and confidence to manage these situations more specifically as the service requirements change and develop.

The analysis of the data represented the perspectives of staffs own individual experiences within dementia tertiary care. Alongside these themes, each participant reverted back to the same main aim which was to give the best care, accepting the challenges, wanting to make a difference and delivering person centred care. Throughout the interviews all participants expressed both positive aspects of the role and the challenges whilst working within dementia care. All of these themes will now be discussed further in the main discussion section.

## **Chapter 10 - Discussion**

This section examines the four overarching themes in further detail and these themes will then be compared to the current literature. By comparing the themes and outcomes of the research to the current literature any similarities or differences can be identified.

### **Physical Environment**

The responses from this study support some previous research studies in relation to physical environment and the role this plays within dementia care. The physical environment was a key theme mentioned throughout all of the interviews and this was also demonstrated in the literature. The interviews focused on environmental aspects such as the building footprint, layout, space and lack of natural light. These aspects were suggested to have an impact on both how the staff feel whilst providing care alongside how patients feel and experience care within the ward setting. These factors were recognised in previous literature which supported the significance of the built environment, organizational factors, care management, resources, sociocultural and economic issues can have an impact on the quality of care that can be given to patients with dementia (Borbasi et al, 2006; Hadjri et al, 2015; Lee et al, 2016). The literature also identified similar issues with an unsupportive physical environment, where this can contribute negatively to patient's quality of life and thereby could make work more challenging for staff (Lee et al, 2016). These challenges can have an impact the quality of care staffs are able give regardless of how much they attempt to achieve good care (Borbasi et al, 2006).

In contrast there were some positive environment changes which a small number of participants acknowledged during the interviews regarding recent improvements with better colour contrasts, design, lighting and better kitchen facilities have made patients and staff happier whilst working on the dementia wards. The current literature supports the idea of the physical environment can have a positive impact with care environments, as it can enhance behaviour, cognition and provide comfort for people with dementia (Hadjri, Rooney & Faith, 2015). In addition, other literature suggests that if the environment is completed appropriately with any unsuitable aspects of the environment been removed or changed this would also have a positive impact for the quality of staff care interaction and patients quality of life (Lee et al, 2016).

However, there was some contrast from the previous literature from some participants during the study who had been working on the dementia ward for a greater number of years. The longer the years of service the more participants referred to specifically designed buildings and facilities and the need for these to be reintroduced within the community as they believed these were more appropriate for the patient group. The participants that suggested these types of facilities were more positive about these been more suitable for the client group from their previous experiences, and these comments were often linked to terms such as more dementia friendly or more suitable for people with dementia. Environmental designs have the potential to support care significantly, and some physical conditions could be improved by simple design interventions or environmental design features play in coping and stress for people managing dementia (Mobley, Leigh & Malinin, 2017).

In conclusion both the literature and current research identify the need for a greater focus on the needs of the client group and the health professionals than the needs of the institutes. However the study highlights that more specifically designed hospital wards specifically designed for patients with dementia which the literature didn't make direct reference to. However the study supports all previous literature that the environment impacts both the staff and patients significantly.

### **Environment of care**

Another area that was raised during the study by participants was a variety of elements which can affect the care environment. These included patient behaviours was a significant challenge mentioned during the interviews with the. Previous research suggested that aggressive behaviours cause the most stress and burn-out for staff (Cubit, Farrell, Robinson & Myhill, 2007). Whereas later research expanded on this point, that patients in hospital can be very impaired and experience BPSD, these behaviours are severely troubling for staff (Rosendahl et al, 2016). Literature identified the most common difficulties experienced were aggression, activity disturbance, sleep disturbance and anxiety. Alongside these behaviours it was suggested that patients and staff would benefit from more specialists psychiatric support (Sampson et al, 2014). These behaviours were acknowledged in this study as staff suggested these experiences resulted in restraint which was a negative aspect of the staffing role. However in contrast, during the study staff didn't make reference to specialist support, the majority of staff mentioned alternative methods for support. These included more qualified staff, higher staff numbers, training and support in managing BPSD in people with dementia.

In addition, further literature suggested that health care assistants experience greater levels of stress than nurses or those in other qualified positions. This implies that staff who are employed at lower level bandings or who aren't qualified are more likely to find patients with dementia more challenging due to their behaviours in comparison to those who are qualified (Park, 2010). This opinion was also supported in this study as those who were not in qualified positions referenced more frequently to terms like *'hard'*, *'challenging'* and *'really difficult'* compared with those in qualified positions who spoke more generally about the behaviours referring to *'it's part of the dementia'* or *'we know they don't mean to be aggressive'* and that qualified staff seemed to tolerate behaviours a lot more than those in non-qualified positions.

Another aspect in relation to the environment of care identified in the interviews was the level of staffing when working with patients that have dementia. This was a common challenge for most staff across all positions, but different circumstances and examples were given regarding this area. This was recognised by previous literature, which if the staffing of qualified staff was at a higher level the less likely other staff would experience stress within the workplace (Park, 2010). However, there was not much previous research that has focused on the impact of staffing levels and the effect this may have on staff and patients with dementia. Overall, during this study staff acknowledged that staffing can be problematic but rather than the focus been on how it effects them, the focus was on the patients and the quality of care. The participants wanted to give the best care and there was an emphasis on aiming to do the job properly. However this requires good staffing levels on a regular basis for this to be achieved.

The final aspect of the care environment raised by participants in this study was the issue of 'time', this was a significant factor in which participants believed needed addressing in terms of the staff requiring more time to perform certain and fulfil the requirements of their jobs. Overall, all the staff's main aim was requesting more time to promote independence, choice and provide options for their patients to make them happy, feel special and make them be as comfortable as possible. There was limited research that focused on time, and when literature investigated this element it was in relation to long shift periods and this leading to burnout and stress, although this was not the main focus, there was a need for more time to the job role and to deliver good care and therefore could help with staffs stress levels (Hughes & Jennings, 2008).

## **Training and Education**

The participants who were working on the dementia wards also recognised education and training as an important requirement whilst caring for patients with dementia. During the study participants stated that they wanted to further their professional development and continuing learning. There was some staff that had received dementia specific training either in the form of degrees or courses prior to or during their time working on the dementia wards. Participants suggested that these courses were beneficial and useful in their work as they helped them overcome challenges in their daily work. The current literature supported the benefit of further training and this can have an immediate impact on staffing knowledge, confidence and attitudes, with a lasting impact in most hospitals. By receiving ongoing training and the reinforcement of methods to improve care this can ensure its sustainability (Gavin et al, 2010).

Staff of varying amounts of experiences had undertaken further training and even those who had worked with this area for many years still found certain trainings beneficial, suggesting experience doesn't necessarily mean staff wouldn't benefit from further learning or development. On the other hand there were other participants that identified that they didn't have any specific training or learning relevant to dementia care. Participants from the study believed further training would equip staff with the skills and confidence to manage these situations, and more specifically as the service requirements change and develop. Staff identified certain areas that they wanted to acquire more knowledge or skills around dementia symptoms and care and this is also supported by literature (Chang et al, 2009; Charter et al, 2012).

Overall, the literature papers all supported the need for education to be improved or increased as this enhances the quality of care (Chang, et al 2009; Moyle, et al 2010; Gavin et al, 2010; Charter and Hughes, 2012; Jansen, et al 2017; Chen et al, 2017). In contrast to the study, literature suggested not only do participants promote the need for more knowledge, skills and self-improvement; this also reduces the chance of staff becoming stressed or burning out as they can cope better with behaviours or communicate about pain issues (Chang et al, 2009). However, the study differs in its view as participants didn't suggest training helped prevent staff with their stress. In fact their focus was to support the needs of the patients better and give quality care, this can be achieved by understanding the person with dementia and what their needs are. Furthermore the literature on education predominantly focused more on staff

who aren't qualified or who are employed in lower banding positions as requiring more development. Although this is disputed during the study as participants believe everyone could benefit from further training and made no reference to this point.

### **Team Work and Support**

The final theme identified by participants was team work and support, the consensus across the board was that staffs feel well supported at work and receive support regularly and can access various things to ensure they are supported. Several participants made reference to the team specifically which suggests there is a culture of team support within the hospital working environment. There was an emphasis on the fixed support arrangements, such as that staff feel able to approach their managers as and when they require.

Previous literature however focuses on the causes of requiring specific support in the work place, such as stress, burn-out, dissatisfaction and negative emotions resulting in staff needing support (Duffy et al, 2009; Park, 2010; Schmidt et al, 2014; Bassal et al, 2015). The literature suggests that nursing assistants reported higher levels of stress than nurses when caring for dementia that present with aggressive behaviours, whereas nurses reported higher stress levels when they experienced a lack of resources (Park, 2010). Other literature refers more generally, stating that nurses seek less help or support than staff in other positions (Hughes & Jennings, 2008). Although the results of the studies analysis suggest support is consistent and regularly accessed by all staff and many made reference to times where they sought support individually regardless of their position. Additional literature identified staff requiring further support when they experienced dissatisfaction whilst at work as this causes substantial work stress, high levels of emotional exhaustion and burnout (Duffy et al, 2009; Schmidt et al, 2014). Although during this study staff never made reference to been dissatisfied in their job, but acknowledge difficult experiences or some stress at times.

There were some new methods that had recently been implemented on the dementia wards which hadn't been identified in the current literature. Participants spoke about the psychology team, and the weekly protected time which staff can attend a meeting to discuss anything they want from difficulties to just taking things through. The increase in the support offered over recent months has made a significant difference according to staff.

On the other hand, in contrast to traditional support methods participants did have alternative ways to support themselves directly. They were variations in individual's personal methods

of managing their own stress or difficulties when working on a dementia ward. The methods included having brief moment off the ward, writing a list for when they get back the next day, time think things through and reflection periods. Participants seem to benefit from both personal methods of support alongside the structured support implemented by the workplace.

## **Chapter 11 - Strengths and Limitations**

The strengths of the research process consist of the study using a qualitative approach, this aimed to gather large detailed amounts of rich data to gain thick description. Through the use of a qualitative inquiry this was the most appropriate method to investigate what it is like working on a dementia ward. The sampling method was purposive allowing for individuals to be approached on the day as they were available allowing for the best opportunity to gain participants and capture a variety of views. The data was collected through the use of semi-structured interviews, which allowed the researcher to explore participant's experiences in greater depth. The semi-structured questions allowed for any unexpected responses or themes to be pursued further when they arose, yet still acquired certain main pieces of data. Furthermore, an additional strength of the study was that the participants were of mixed positions and banding levels, allowing for the researcher to explore various views and opinions across the board. Doing this ensured that there was greater potential to reach saturation and gain wider perspectives.

The scale of this research may have been limited in the depth due to the research been conducted on a single site and because there was a small number of participants involved within the study. There are the issues around potential experimenter bias and this refers to experimenter's often unintentional disposition to obtain a specific or certain result that they are looking for, even when the result does not necessarily reflect the truth. However through an external review, external reviewers would be able to spot imperfections or biased views (Strickland & Suben, 2012). In context with this study two separate supervisors' challenged and discussed any possible preconceived ideas which were acknowledged previously in the reflexivity section. This helps reduce the potential for experimenter bias.

## **Chapter 12 - Recommendations**

This study has demonstrated a need for the working and physical environment to be improved for the staff and patients on the dementia wards. This process would also benefit from staff's recommendations and these should be considered and taken into account if changes are to take place. Although creating a purpose built facility for the ever increasing need for dementia care would appear to be the most appropriate action as this could address a lot of the needs identified during this study. Alongside the physical and practical changes, further training and development are required when working within a dementia inpatient unit. Improved knowledge and understanding of dementia and its symptoms are needed alongside, palliative care training and management of dementia. This would enable staff to enhance their skills and equip themselves to support this challenging patient care group. Embarking on these recommendations would improve the working environment for both patients and staff and in doing so would help support staff, increase morale and assist in facilitating a good standard of care for patients. Further research should investigate individual experiences over multiple sites with a higher number of participants to see if the outcomes demonstrated in this study are site specific or a consensus across this specific area of care. Expanding the number of study sites would enable for the sharing of experiences across dementia hospital services and produce alternative ways of working.

## **Chapter 13 - Conclusion**

Dementia tertiary care is a difficult environment to work within and the amount of people requiring this level of care is going to continue to increase over time. Employees working within this environment identify difficulties whilst going about their daily work in relation to resources, the patient group and facilities. Staff acknowledged and recognised these difficulties and believed these could be addressed if appropriate action was taken. However rather than focusing on the challenging aspects of dementia care, all staff reverted back to what could be perceived as their main aim, which was to give high levels of quality care to the best of their abilities. The motivation and commitment of the staff was demonstrated through their unity and team work ethic. Even though all the staff that were interviewed had slightly different views and opinions on how to improve their individual work life, through increasing staffing levels, training options and environmental adaptations. There was also a suggestion of *'it's just the little things'* that would enhance working life for staff, in the form of a more suitable work life balance when feasible and greater flexibility within the role. Therefore by making some changes or adapting the staff working environment this would improve staff morale and reduce the chance of stress or burnout. This then could assist or support a greater level of care as the staff's views and opinions could be considered and put into practice.

The findings of this study are similar to other literature in relation to some of the challenging factors whilst working within dementia care. Although the perception of the patient groups condition and the difficulties this can cause staff was not a main focus of the study, this was more of an acceptance and acknowledgement. This study did suggest some alternatives to previous literature in relation to team work and that staff recognised this as a significant aspect of how they support themselves and each other. Finally the environment of care was developed during this study where several contributing areas were linked together from the staffing perspectives on what effects their role and job rather than each been a singular separate issue. All these points suggest the need for change or the opportunity for staffs thoughts or opinions to be embraced as their daily experiences of working within dementia tertiary care is complex.

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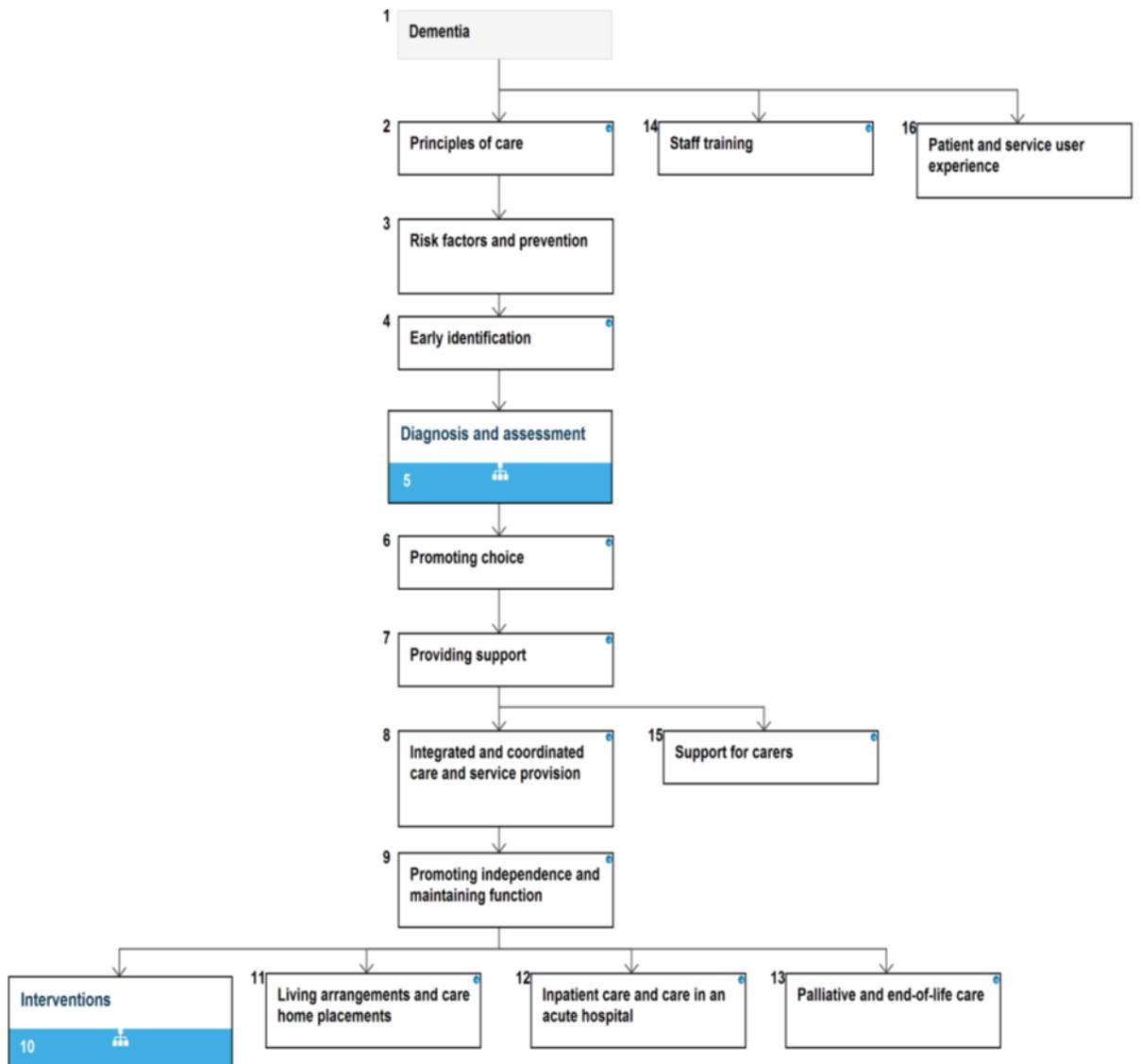
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## Appendix 1

### Dementia Pathway



**Appendix 2 - Table of Literature papers:**

| <b>Author(s) &amp; Year</b>  | <b>Country</b> | <b>Number of Participants (N)</b>            | <b>Research Design</b>  | <b>Main Findings</b>  | <b>Key Themes</b>  |
|--|----------------|--|---|---|--|
| Chang, E., Daly, J., Johnson, A., Harrison, K., Bidewell, J., Stewart, H. & Handcock, K (2009) | Australia      | N = 24                                       | Qualitative, Five Focus Groups & Follow up Interview                  | It's a challenge meeting the needs of residents with advanced dementia. Improved knowledge and skills, and a model of care are needed. This will improve staffs ability to respond to resident's needs.   | Education and Training   |
| Charter & Hughes (2012)  | United Kingdom | N = 7  | Qualitative, Two focus groups   | Continuing staff education is central to the provision of quality dementia care. Staffs express the need to learn about dementia theory, but also practical strategies to deliver good dementia care. Ward-led opportunities to learn about dementia should be available and easily accessible. Improved sharing of information could enable staff to better understand their individual patients' needs. | Training and education   |
| Chen, I., Lin, K., Hu, S., Chuang, Y., Long, C., Chang, C., & Liu, M. (2017)                   | Taiwan         | N = 125 nurses<br>N = 175 nursing assistants | Quantitative, Questionnaire of Palliative Care for Advanced Dementia. | This study indicates the need to provide nurses and nursing assistants with more information about palliative care practice for people with advanced dementia. Particularly nursing assistants, who have less working experience, who have not received palliative and dementia care training, and who have not worked in nursing homes can improve overall nursing staff                                 | Training and education for those less experienced and for palliative care. |

|   |           |  |   |  |  |
|---|-----------|--|---|--|--|
|   |           |  |   | knowledge of and attitudes toward palliative care.   |  |
| Schmidt , S.,<br>Dichter , M.,<br>Bartholomeyczik,<br>S., & Hasselhorn ,<br>H. (2014) | Germany   | N = 305,<br>From fifty<br>nursing<br>homes.                          | Quantitative,<br>Two-wave<br>(2007/2009) self-<br>report<br>questionnaires.                   | Dissatisfaction with the quality of care for dementia residents may constitute a substantial work stressor that negatively impacts burnout, health and work ability. Therefore, NH management should consider the work quality satisfaction of nurses, particularly with respect to dementia care and to identify dissatisfied nurses. Qualitative studies are needed for a deeper understanding of nurses who are dissatisfied. | Work satisfaction levels and the impact on burnout and health. |
| Cubit, K., Farrell,<br>G., Robinson, A.,<br>& Myhill, M.<br>(2007).                   | Australia | N = 259<br>were<br>completed,<br>From fifteen<br>care<br>facilities. | Quantitative,<br>Convenience<br>sample,<br>Questionnaire                                      | Disruption to the daily running of care facilities causes significant staff distress. Repetitive actions or questions by residents along with physically aggressive behaviour cause most personal distress to care staff. Less experienced staff report experiencing more personal distress to resident's behaviours. Future focus should be on orientating and supporting new staff in the residential aged care sector.        | Work environment and its effect on staff distress              |
| Park, M. (2010).  | Korea     | N = 267<br>From ten<br>long term<br>care facilities                  | Qualitative,<br>Caregiver Stress<br>Inventory and the<br>Attitudes About<br>Family Checklist. | The findings showed a need for educational programs for staff to enhance their dementia care knowledge, alleviate their stress, and finally change positively their attitudes toward family. It is important for staff members to develop satisfying and mutually acceptable caregiving roles.   | Alleviating stress by improving Knowledge and education        |
| Borbasi, S., Jones,<br>J., Lockwood, C.,<br>& Emden, C.                               | Australia | N = 25   | Qualitative,<br>Open-ended<br>interviews  | Health professionals aren't always necessarily equipped with the right skills to provide resource intensive dementia care.<br>The need for best-practice principles supported and championed   | Professionals don't always have the skills for                 |

|  |             |        |  |  |   |
|--|-------------|--------|--|--|---|
| (2006).  |             |        |  | by staff from the top of the organization. Innovative models of best-practice for dementia care are required. Lessons should be shared internationally.  | sufficient dementia care.                                 |
| Lee, S., Chaudhury, H., & Hung, L. (2016).                     | Canada      | N = 15 | Qualitative, focus group, from two selected care facilities.                               | This study suggests that a well-designed physical environment can lead to higher morale, closer relationship between staff and residents and work-effectiveness in staff, potentially resulting in better care in enhanced well-being of residents. Specifically, it has shown that a small-scale homelike setting gives dementia care homes more resources to improve quality of life and more supportive work environment for staff.               | Physical environment and the impact on staff and patients |
| Bassal, C., Czellar, J., Kaiser, S., & Dan-Glauser, E. (2015). | Switzerland | N =43  | Quantitative, rating questionnaires measured the frequency of emotions experienced at work | Positive emotions seemed to be more frequently experienced by caregivers, contrary to expectations based on previous studies. Limiting maladaptive coping strategies may simultaneously reduce negative emotions and increase wellbeing. Professional caregivers of Patients with dementia who tend to frequently use expressive suppression and are experiencing low level of positive emotions are the most at risk to also experience exhaustion. | Emotions experienced when caring for dementia patients.   |
| Rosendahl, S., Söderman, M., & Mazaheri, M. (2016).            | Sweden      | N = 9  | Qualitative, semi-structured interviews and all were chosen purposefully                   | The family member played a crucial role in the lives of immigrants with dementia living in a group home by facilitating communication between the nursing staff and the PWD and also by making it possible for PWD to access the cultural activities they wanted and which professional caregivers were either not   | Communication and delivery of good care.                  |

|  |                                   |                             |  |  |   |
|--|-----------------------------------|-----------------------------|--|--|---|
|  |                                   |                             |  | able to recognise as needed or could not deliver.  |   |
| Jansen, B., Brazil, K., Passmore, P., Buchanan, H., Maxwell, D., McIlfatrick, S., Morgan, S., Watson, M. Parsons, C. (2017). | Northern Ireland & United Kingdom | N = 14 (13 female & 1 male) | Qualitative approach, semi-structured interviews with healthcare assistants<br>Participants' average length of caring experience was 15.4 years. | Assessing and managing pain in dementia is a priority in provision of end of life care for people with dementia. HCAs provide the majority of direct care to these patients, and as a result are often well placed to recognise problems as they arise. This study highlights the potential for non-qualified healthcare staff to contribute meaningfully to a critical and complex area of dementia care. Supporting, educating, training and upskilling these staff to improve the quality of care and care experience for people with dementia and their families. Critical to this is changing perceptions and the stigma of the HCA role. | Pain management and end of life care and the impact of non-qualified staff can have. Education and training for all staff involved with care. |
| Sampson, E., White, N., Leurent, B., Scott, S., Lord, K., Round, J., & Jones, L. (2014).                                     | United Kingdom                    | N = 230                     | Longitudinal cohort study, assessed for BPSD at admission and discharge.<br>Measures of care quality, length of stay, adverse events & mortality | This study demonstrated a high prevalence of behavioural and psychiatric symptoms in people with dementia in the acute hospital, particularly aggression and activity disturbance. There is a need for staff to have access to specialist psychiatric advice and support or liaison services for older people. The findings support concerns about inadequate staff numbers for such dependent and vulnerable patients. The majority of acute hospital nurses want more training and support in managing BPSD.   | Behaviours of patients with dementia and staff support networks in its management.  |
| Moyle, W., Borbasi, S., Wallis,  | Australia                         | N = 13                      | Qualitative, Convenience   | People with dementia are not always provided with care that takes into account their individual needs. Finally, staff education  | Environmental and staff   |

|  |                |   |   |  |  |
|--|----------------|---|---|--|--|
| M., Olorenshaw, R., & Gracia, N. (2010)  |                |   | sampling , Interviews   | and training is of prime importance, and in particular it must go beyond education of individuals to facilitate positive organisational change.  | education to deliver person centred care.  |
| Cowdell, F. (2010)   | United Kingdom | N = 11  | Observations and interviews   | Nurses appeared to strive to give ‘good’ care but were constrained by organizational and environmental factors and a lack of the support and education needed to provide person-centred care. Staff showed a lack of empathy and tended to work within an embedded habitus. To develop practice there is a need to engage with staff on emotional and intellectual levels.                           | Environment factors and education for person centred care to engage with staff.  |
| Gavin, J., Kuntemeier, B., Al-Hammadi, N., Germino, J., White, M., & McGillick, J. (2010). | America        | N = 397 individuals at 4 community hospitals and attended 8 training sessions.<br>N = 34 Completed full process | Qualitative, Pre-test, focus groups about the training. Quantitative, rating scales, Immediate test followed by the Post-test (120days) | Training hospital staff about dementia and its impact on patient outcomes. At baseline, there was low knowledge and confidence in the ability to care for dementia patients. Training had an immediate impact on knowledge, confidence and attitudes with lasting impact in 3 of 4 hospitals. The need for ongoing training and administrative reinforcement in order to sustain behavioural change. | Training improved knowledge, confidence and attitudes of staff in the long term. |
| Mobley, C., Leigh, K., & Malinin, L. (2017).   | America        | N = 6 Health staff<br>N = 9 patients were   | Mixed Qualitative, spatial inventory tool, Direct   | The researcher conducted a total of 27 different observations. A total of 224 (72%) instances were categorized as behaviours suggesting adaptation–coping, and 85 (28%) were categorized as behaviours suggesting maladjustment–stress. The three most   | Physical environment role in adaptation–coping and stress                        |

|   |                |                    |   |   |   |
|---|----------------|--------------------|---|---|---|
|   |                | observed           | observations and e-surveys  | frequently observed behaviours were communication, strolling, and social integration.   | for people dealing with dementia  |
| Hadjri, K., Rooney, C., & Faith, V. (2015). | England        | N = 22<br>Managers | Qualitative, Semi-structured Interviews   | Findings suggest that there are three interconnected themes emerging from participants' experience of managing a care home where some residents have dementia. These themes are concerned with the level of care required by the resident, the atmosphere of a home, and the design quality of the care home.   | Environment, atmosphere, Training of carers emerged as an important aspect to care for residents. |
| Duffy, B., Oyebode, J., & Allen, J. (2009). | United Kingdom | N = 245            | Qualitative research, A cross-sectional survey design was employed using multiple questionnaires. | The study suggested that staff had moderate levels of burnout and many were emotional exhausted with work. Age appeared to play an important role within burnout, as older care staffs were less likely to experience feelings of emotional exhaustion. These findings suggest employers need to address these levels of burnout, and services need to recognize the stressors that care staff are under and to help improve staff feelings of self-efficacy at work. | Burnout among care staff for older adults with dementia.  |

### **Appendix 3**

#### **Cover Letter**

Dear employee,

You are being invited to take part in a study on ‘The lived experience of healthcare worker’s caring for people with dementia’.

I am an MSc student based at the University of Huddersfield and I am interested in exploring individual’s experiences when working in a dementia care setting.

I have included an information sheet and consent form which explains the aims of the study in more detail along with this letter. I aim to conduct these interviews throughout November.

Thank you for taking time to read this letter.

Regards

Abigail Avery

Appendix 4 - Consent Form

*University of*  
**HUDDERSFIELD**  
Inspiring tomorrow's professionals

**Title of research project:**

**The lived experience of healthcare worker's caring for people with dementia.**

**It is important that you read, understand and sign the consent form. Your contribution to this research is entirely voluntary and you are not obliged in any way to participate. If you require any further information contact me or any of my supervisors.**

**I have being fully informed of the nature and aims of the research.**

**I consent to take part in it.**

**I understand that I have the right to withdraw from the research at any time without giving any reason.**

**I give permission for my words to be quoted and used (by use of pseudonym).**

**I understand that the information collected will be stored at the University of Huddersfield securely for no more than the period of study.**

**I understand that no other person than the researcher and supervisors will have access to the information provided.**

**If you are satisfied that you understand the information provided and are happy to take part in the project please put a tick in the box aligned next to each sentence the print and sign the document below.**

**(One copy to be given to participant and other retained by researcher).**

**Signature of researcher**

\_\_\_\_\_

**Print Name:**

\_\_\_\_\_

**Date:**

\_\_\_\_\_

**Signature of researcher**

\_\_\_\_\_

**Print Name:**

\_\_\_\_\_

**Date:**

\_\_\_\_\_



**The lived experience of healthcare worker's caring for people with dementia.**

**INFORMATION SHEET**

You are being invited to take part in a study about your experiences of working within a dementia care setting. Before you decide to take part it is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with me if you wish. Please do not hesitate to ask if there is anything that is not clear or if you would like more information.

**What is the study about?**

The purpose of this study is to identify how healthcare workers experience working within a dementia tertiary care setting. In addition how individual's health and well-being are managed and supported whilst in the work place by explore thoughts, feelings and emotions of staff individual experiences.

**Why I have been approached?**

You have been asked to participate because you currently are working in the NHS as an employee who works on the dementia admission wards and has being for a period of 12 months or more.

**Do I have to take part?**

It is your decision whether or not you take part. If you decide to take part you will be asked to sign a consent form, and you will be free to withdraw at any time up until the analysis write up is complete and without giving a reason.

**What will I need to do?**

If you agree to take part in the research you will be asked to take part in an interview on a one to one basis using a semi-structural format. The interview will then be carried out in a private meeting room on site and should last between 30minutes and one hour in duration. I will use an MP3 to document the audio recordings and these will then transferred to an encrypted memory stick before being transcribed on a password protected computer.

**Will my identity be disclosed?**

All information disclosed within the interview will be kept confidential, unless you indicate that you or anyone else is at risk of serious harm, in which case I would need to pass this information to my supervisor. However some direct quotes could be used during analysis but identifying data will be anonymised.

**What will happen to the information?**

All information collected from you during this research will be kept secure and any identifying material, such as names will be removed in order to ensure anonymity.

It is anticipated that the research may, at some point, be published in a journal or report. However, should this happen, your anonymity will be ensured, although it may be necessary to use your words in the presentation of the findings and your permission for this is included in the consent form.

**Who can I contact for further information?**

If you require any further information about the research, please contact me on:

Name: Abigail Avery

E-mail – [abigail.avery@hud.ac.uk](mailto:abigail.avery@hud.ac.uk)

Telephone – 07808708191

Further contacts: Research and Development Lead (NHS): Email

University Supervisor: Professor Philip Keeley - [p.n.keeley@hud.ac.uk](mailto:p.n.keeley@hud.ac.uk)

University Supervisor: Dr Andrea Denton [a.denton@hud.ac.uk](mailto:a.denton@hud.ac.uk)

## **Appendix 6**

### **Interview Questions/Guidelines**

Thank you for coming,

Go over consent form/information sheet and reasons for conducting the interview.

How are you? How's today being?

Ask personal data questions: Interview number, age, gender, years of service, position and qualifications.

1. Can you tell me about your daily routine at work?  
    Could you describe in as much detail as possible?
2. What aspect of your job do you enjoy the most and why?
3. What is the best thing you have achieved whilst working on the dementia ward?
4. Do you have further examples of this?
5. You mentioned that....how did you feel about it?  
  
    I would now like to introduce a new topic,
6. What aspect of your work do you find the most challenging on the dementia ward?
7. Can you expand on this further? Or do you have further examples of this?
8. Do these challenges impact you at all?
9. What are your strategies to cope or manage these challenges?
10. What support or help do you receive when faced with challenges at work and do you find these support methods useful?
11. What would make work life better or help you?
12. What is it about you that get you up every day to come and work within a dementia care environment?
13. Thank you for answering the questions, is there any questions or thoughts you have on what I have said?

## **Appendix 7 - HRA Approval Letter**



**Health Research Authority**

Miss Abigail Avery  
26 Broadlands Court  
Pudsey  
LS289GE  
Professor Philip Keeley  
Department of Health Sciences  
University of Huddersfield  
Queensgate  
Huddersfield  
HD13DH

Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)

16 September 2016

Dear Miss Avery

### Letter of HRA Approval

**Study title:** The lived experiences of healthcare worker's caring for people with dementia in a tertiary care setting.  
**IRAS project ID:** 201317  
**Sponsor** University of Huddersfield

I am pleased to confirm that HRA Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

#### **Participation of NHS Organisations in England**

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

*Appendix B* provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical 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 and further information about working with the research management function for each organisation can be accessed from [www.hra.nhs.uk/hra-approval](http://www.hra.nhs.uk/hra-approval).

### Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

### After HRA Approval

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.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the [HRA website](#), and emailed to [hra.amendments@nhs.net](mailto:hra.amendments@nhs.net).
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the [HRA website](#).

### Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at <http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/>.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

### User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please email the HRA at [hra.approval@nhs.net](mailto:hra.approval@nhs.net). Additionally, one of our staff would be happy to call and discuss your experience of HRA Approval.

#### HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

Your IRAS project ID is **201317**. Please quote this on all correspondence.

Yours sincerely

Thomas Fairman  
HRA Assessor

Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)

Copy to: *Dr Catherine O'Halloran, University of Huddersfield, (Sponsor Contact)*

*(Lead NHS R&D Contact)*

*Professor Philip Keeley, University of Huddersfield  
(Academic Supervisor and Chief Investigator)*

**Appendix 8 - Participant Data:**

| Participant Number | Gender:<br>Male (M) or<br>Female (F) | Position:<br>Nurse (MHN)<br>Health Support<br>Worker (HSW)<br>Therapy Staff<br>(T) | Banding<br>Level | Age Range: |                     |
|--------------------|--------------------------------------|--|------------------|------------|---------------------|
|                    |                                      |  |                  | 18-25      | Years of<br>service |
|                    |                                      |  |                  | 26-35      | 1-5                 |
|                    |                                      |  |                  | 36-45      | 6-10                |
|                    |                                      |  |                  | 46-55      | 11-15               |
|                    |                                      |  |                  | 56+        | 16-21               |
|                    |                                      |  |                  |            | 22+                 |
| 1                  | F                                    | HSW  | 3                | 36-45      | 1-5                 |
| 2                  | M                                    | HSW  | 3                | 46-55      | 11-15               |
| 3                  | F                                    | MHN  | 5                | 26-35      | 1-5                 |
| 4                  | F                                    | HSW  | 3                | 46-55      | 22+                 |
| 5                  | M                                    | MHN  | 5                | 26-35      | 1-5                 |
| 6                  | F                                    | HSW  | 3                | 46-55      | 16-20               |
| 7                  | F                                    | T  | 3                | 36-45      | 1-5                 |
| 8                  | F                                    | T  | 5                | 26-35      | 1-5                 |
| 9                  | F                                    | T  | 6                | 26-35      | 6-10                |