Northumbria Research Link

Citation: Morey, Sarah (2016) Adaptation to patienthood: A grounded theory study on the contributions of Healthcare Assistants towards the patient experience. Doctoral thesis, Northumbria University.

Citation: Morey, Sarah (2016) Adaptation to patienthood: A grounded theory study on the contributions of Healthcare Assistants towards the patient experience. Doctoral thesis, Northumbria University.

Adaptation to patienthood: a grounded theory study on the contributions of Healthcare Assistants towards the patient experience.

Sarah Louise Morey

PhD

2016

Adaptation to patienthood: a grounded theory study on the contributions of Healthcare Assistants towards the patient experience.

Sarah Louise Morey

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

Research undertaken in the Faculty of
Health and Life Sciences.

September 2016

Abstract

Background

The healthcare assistant (HCA) workforce delivers much of the fundamental care across both health and social care and is therefore in a unique position to influence the patient experience. To date, there has been little qualitative research that explores the HCA role from the perspective of the patient.

Research Aim

The research set out to explore, and generate a theoretical understanding of, the role of the HCA from the patient perspective within secondary care.

Research Design

This study explores patients' perceptions of the role of the HCA within secondary care. Ethical approval was granted in May 2014. Data were collected in a large teaching hospital in North East England between 2014 and 2015. Employing constructivist grounded theory, twenty patient interviews were coded and analysed. Three later interviews were added for depth to the findings.

Findings

Four core categories emerged from the data:

- **Expectation**

Participants entered the healthcare environment with varying expectations but told a largely positive story about their experiences, reframing negative episodes within an overall positive narrative. This reframing may indicate participants were indirectly reinvesting in staff for their future care needs.

- **Observation**

Some participants worked out "who was who" through observation, often associating tasks with uniform. Where jurisdiction and performance of the HCA was not as expected, this sometimes made participants more vigilant.

- **Meaningful connections**

Meaningful connections involved comfort and consideration from staff and humorous interactions between participants and HCAs. These connections contributed to the patienthood experience and were employed as a trading strategy, to cement relationships and overcome difficult circumstances.

- **Adaptation**

Participants worked out when to ask for help, recognising their dependency on staff availability and desire not to be labelled a nuisance.

Conclusion

In conclusion, education and development for HCAs that enhances understanding of roles and performance and their impact on relationships with patients would enhance the patient experience.

Implications

Investigation of the negative patient episodes hidden within reframed positive narratives would inform future policy and educational initiatives.

Contents

List of Tables and Diagrams

List of tables

List of Diagrams

List of Boxes

List of Mind Maps

Acknowledgements

Without the encouragement of my long suffering husband Phil, I could not have considered undertaking this level of study. He has been there with me throughout the journey, encouraging and listening to endless ramblings and providing me with a layman’s perspective of considerable insight. Thank you.

To our two daughters Alice and Elinor, thank you for just letting me do this and being there when I needed to be.

To my supervision team, Dr Alison Steven and Reverend Professor Pauline Pearson a huge thank you. The light hand, the endless positive feedback and encouragement. A truly wonderful supervision team that has got the best from me.

To my peers and colleagues, thank you. A diverse group that has inspired me and kept me focussed when things were tough.

To my friends and family, a big thank you for understanding.

Finally, to Jack our wonderful dog, big hugs for providing me with a reason to get out and walk every day, bringing me a greater perspective as I looked out across the Northumberland Coast.

<u>Declaration</u>

I declare that the work contained in this thesis has not been submitted for any other award and that it is all my own work. I also confirm that this work fully acknowledges opinions, ideas and contributions from the work of others. The work was done in collaboration with Newcastle-Upon-Tyne Hospitals Foundation Trust. Any ethical clearance for the research presented in this thesis has been approved. Approval has been sought and granted by the University Ethics Committee (4.5.2014) and NRES (7.10.2014) external committee.

I declare that the Word Count of this Thesis is 85,120 words.

Name: Sarah Louise Morey

Signature:

Date:

> *As I went to attend to Sir Peter Scott after his admission to hospital I asked one of the nursing auxiliaries to come and assist me in making him more comfortable.*
>
> *He sat up in bed, sketch book in hand lost in his own time and space as the activities of the ward unfolded around him. The auxiliary glanced at what he was sketching and said “Oh you’re quite good at drawing aren’t you?” Unknown to the auxiliary was his great ability as a wildlife artist.*
>
> *He looked up and smiled, and did not say a word, but with a wink of his eye there was a suggestion he was happy to let her comment pass. He was happy just being there with us both in that moment….*

I worked on a ward as a newly qualified nurse back in the early 1980s where I relied heavily on the auxiliaries – those currently referred to as healthcare assistants, or HCAs. Often twice my age and with many years of experience behind them I was often struck by their hard work, dedication and cheerfulness when I was often stressed and overwhelmed by the enormity of the responsibility. I owe a debt of gratitude to all those auxiliaries that were the silent army of workers that made significant contribution to my early nursing career and to the patients they cared for.

Chapter 1: Introduction to the study

Chapter 1. Introduction to the study

This introductory chapter is divided into 3 parts. I firstly describe my interest in the role of the healthcare assistant (HCA) and how I came to study this subject matter. I then move onto the background and context for the HCA with the support of relevant literature. This provides the justification for the research area and what contribution this research will make to the existing body of knowledge. I conclude chapter 1 with an overview of the layout and structure of the thesis.

1.1 Orientation

My interest in this area stems from my work in clinical practice whilst studying for an MSc that I completed in 2012. Being interested in the secondary care workforce and the dynamics between healthcare assistants (HCA) and registered nurses (RN), I undertook a mixed methods study to explore the relationship between the two. The results were broadly in line with existing literature and suggested that the relationship between HCA and RN was complex (Spilsbury and Meyer, 2005), with the HCA role subject to much development over time (Allen, 2001; Stokes and Warden 2004; Kessler et al 2010; 2012). RNs also noted a shift in their capacity to deliver bedside care to the patient, delegating much of this activity to the HCA, as also found by others (Chang et al, 1998; Keeney et al, 2005; Spilsbury and Meyer, 2004, 2005; Kessler et al, 2010; Bach et al, 2012).

My continued interest in the role of the HCA was against a backdrop of the Mid Staffordshire Inquiry, (MSPI, 2010) and the subsequent Francis report (MSPI, 2013). The unfolding Mid Staffordshire story and subsequent report brought some of the local issues into sharp focus, with the result that the senior management team was engaged with the output from my MSc in order to gain further understanding of the HCA role from the workforce perspective.

My MSc literature review highlighted a dearth of research on the HCA role from the patients' perspective. I decided to undertake study at doctoral level to pursue this issue further, successfully obtaining a full-time PhD studentship that has led to this doctoral study on patient perceptions of the Healthcare Assistant (HCA).

1.2 Background

There are an estimated 416,000 unqualified care workers currently employed in the UK working within adult health and social care (National Minimum Data Set) (NMDS, 2016). Of HCAs working solely in the acute setting, 85.5% are female and 18.1% are from ethnic minority groups (Health and Social Care Information Centre) (HSCIC, 2016). The number of unqualified care workers reported by NMDS (2016) is lower than Cavendish's (2013) estimate of 1.3 million, illustrating an inconsistent picture of the numbers involved. This may be due to the variety of titles this workforce has been given, which have included Nursing Auxiliary (NA), Nursing Aide, Nursing Assistant and Healthcare Support Worker (HCSW). Many nations also have a nursing workforce that includes an assistant role but, as Kessler et al (2010) point out, the development and evolution of these roles is complex and rooted within nations' own healthcare economy, thereby making direct comparison misleading. Although I draw upon research throughout this study from other countries, I therefore do so with a degree of caution.

The scope of the HCA role is changing in the UK: the Assistant Practitioner (AP) role was first introduced in 2002 (RCN, 2010a), with further developments from the most recent government (Gov. UK, 2015) review proposing a new Nurse Associate (NuA) role that will be implemented in 2016 (NHS HEE, 2016). The HCA workforce therefore has a number of complexities associated with it in terms of the large unspecified numbers working within this role and the change in the scope of the role.

Healthcare provision across secondary and social care has had the nation's attention since the numerous issues at Mid Staffordshire Hospital (MSPI, 2010) and at Winterbourne (DH, 2013b) came to light. Mid Staffordshire is broadly summarised by failings in clinical effectiveness, patient safety and the patient experience (NHS, 2013).

The MSPI (2013) made 270 recommendations, to which the Government responded (DH, 2013b) with a commitment to improved patient experience and quality of care through listening and responding to patients' feedback. A number of other reviews; Cavendish (2013), Keogh, (NHS, 2013), Berwick, (DH, 2013a), and the 6 Cs initiative (NHS England 2013a), were also triggered as a result.

The Cavendish report (2013) endorsed many of the MSPI (2013) recommendations, adding the concept of the Care Certificate (NHS HEE, 2014) to support development of the HCA. The Keogh review (NHS, 2013) was triggered by the mortality figures at the Mid Staffordshire hospital, which prompted a review of fourteen hospitals across the UK with outlying mortality rates.

The Keogh review (NHS, 2013) recommended that staffing levels reflected the acuity and number of patients and were published in a transparent way. Keogh (NHS, 2013) also re-emphasized the importance of patient feedback and of ensuring that this was meaningful for patients.

The Berwick (DH, 2013a) report, triggered by a need for improved patient safety in the NHS, identified the need for a greater presence of patients and carers from ward to board, wherein their voices would contribute to greater depth of understanding of safety issues. Berwick (DH, 2013a) emphasised a no-blame approach to learning from mistakes. In addition, he called for greater transparency and accessibility of data and information around safety issues for all concerned, including the public in general.

A three-year UK nursing strategy called '*Compassion in Practice*' was launched in 2012, to refocus care provision on championing six 'fundamental values' (the 6Cs), which included care, compassion, competence, communication, courage and commitment (NHS England, 2013a). Implementation of the strategy involved six areas of action that included a greater emphasis on working with patients to improve patient care and gain feedback and on ensuring staff have the appropriate skills and competencies to deliver safe and effective care (NHS England, 2013a). The 6Cs appear to have become part of the nursing language, as posited by Baillie (2015), despite a call for a common inter professional framework (MSPI, 2013) of NHS values.

In light of a number of inquiries into poor and inadequate care (MSPI, 2013; NHS, 2013; DH, 2013a), and the reporting of poor care delivery by the media (BBC News, 2007; 2010; 2011a,c; 2012; 2013a,b,c; 2014), the patient experience is clearly refocusing policy makers towards the centrality of the patient. National Institute for Health and Care Excellence (NICE, 2012) has published standards for improving patient experience and the NHS Outcome Framework 2015/2016 (Domain 4) outlines the responsibility that organisations have in *"Ensuring patients have a positive experience of care…"* (Gov.UK, 2014 p15).

Renewed emphasis upon partnership working between patients, their families and practitioners (IOM, 2001) also contributes to patient experience and underpins the DH (2012b) paper "No Decision About Me Without Me." This paper proposes a cultural shift within healthcare that sees patient involvement as part of the day-to-day rather than the exception.

1.3 Justification and focus

Secondary care was selected as the setting for this study in preference to primary and tertiary care for two reasons. Firstly, I had completed my MSc whilst working as a Senior Nurse within secondary care and the beginnings of an idea developed from this work that had explored the role of the HCA from the RN's perspective. Secondly, I was familiar with the context of secondary care and able to navigate my way around the complexities of conducting research within familiar surroundings, despite not having worked in the hosting organisation. It therefore made sense to conduct this research within secondary care, exploring the patients' perspective to complement my earlier MSc research from a staff perspective.

Although there has been much research focusing on the HCA role from the perspectives of the RN, HCA, management and education (see literature review for detail), there is a paucity of qualitative research addressing the patients' perceptions of the HCA role.

The resulting generation of theory from the research process will add to the body of knowledge around the patient experience, understanding and relationship with the role of the HCA. This study will identify areas of further research, the output from which will inform policy makers, organisations and commissioners around developing the HCA role with consideration and understanding of the patients' perspective.

1.3.1 Aims and objectives

The research set out to explore, and generate a theoretical understanding of, the role of the HCA from the patient perspective within secondary care.
The research question was broad to ensure there were no constraints on the generation of the theory (Smith and Biley, 1997). A title for the research was arrived at through an inductive research process following a grounded theory methodology (chapter 4). The details of this inductive process will be addressed fully in the conclusion (chapter 7. Section 7.2)

This research journey began with the following research question and related research objectives:

> *"What perceptions do patients hold of the HCA role and the care delivered and what influences these perceptions?"*

Objectives:

1. To investigate and describe what the patient conceptualises as the role of the HCA.
2. To develop an understanding of what influenced these concepts.
3. To gain an understanding of the interactions between HCA and patient.
4. To explore the meanings of these interactions for patients.

1.4 Thesis structure

The thesis structure is presented as a sequential progression of my academic research journey and is summarised as follows:

Chapter 1 Introduction. In this chapter I have addressed how I came to this area of study and have provided a background and context which has framed this area of interest.

Chapter 2 Literature review. This chapter sets the scene for the context of the patient and the HCA within secondary care. The initial stage of the literature review in chapter 2 was undertaken at the start of the research process. This literature review was added to throughout the period of study that ensured that the issues discussed were up to date. The second stage of the literature review was undertaken after the first stage data analysis took place and as such is incorporated in the discussion chapter (chapter 6) and not in the contextual literature review (chapter 2).

Chapter 3 Theoretical perspectives. This chapter will address the theoretical and philosophical underpinning of my thesis.

Chapter 4 Methodology. This chapter discusses the selection of Constructivist Grounded Theory Methodology (CGTM) in terms of its historical roots, its development and the application to this research. This chapter will include details of participant sampling, data coding and analysis.

Chapter 5 Findings. This chapter presents the findings from the analytical codes and categories that emerged from the data without supporting academic literature. This chapter ends with a brief summary before moving onto the discussion chapter.

Chapter 6 Discussion. This chapter presents a discussion of the findings and theoretical model drawing upon sociological, nursing and wider literature. This approach includes the second stage literature review commenced during the first stage coding and analysis.

Chapter 7 Conclusion. The conclusion then provides implications for practice, research, policy and education leading to suggestions for further areas of research.

Glossary. A glossary of terms is found at the end of the thesis on pages 367-368.

1.5 Reflexivity

My underlying assumptions as researcher were evidenced at the start of the research journey and identification of these assumptions began at the research proposal stage (appendix 1). I employed a reflexive approach to address these early assumptions, which has continued throughout the research journey to help me “check” my position and to ensure openness and transparency, all of which will contribute to quality and rigor (discussed in Chapter 4 section 4.7). In addition, a reflexive diary approach was employed to address understanding regarding decisions made (Etherington, 2004; Dowling, 2006) (see appendix 2 and 3 for evidence). This approach therefore addressed transparency, the limiting of preconceptions and the need to meet deadlines that were dictated by both the funding and hosting organisations.

Rather than explain points of reflexivity throughout my narrative, I have chosen to address the concept of reflexivity within the methodology chapter (chapter 4). So as not to lose flow and sense of this thesis I will therefore signpost to the reader those issues for which reflexivity has been a point of consideration and which will be evidenced within the appendices.

Chapter 2: Literature review

Chapter 2 Literature review

2.1 Introduction

The timing and positioning of the literature review within the research journey for a grounded theory methodology is not without debate and controversy as Glaser and Strauss (1967) identified that the literature review should be conducted following data collection and analysis. I adopted a more contemporary approach (Charmaz, 2006, 2014; Stern, 2007; Ramalho et al, 2015;) involving a two- part literature review, for which there is an introduction and rationale in the following section.

2.1.1 Rationale for the position of the literature review

In line with Glaser and Strauss (1967) and Glaser (1978), carrying out the literature review before undertaking the data analysis may influence how you see the data and they therefore argue that the literature review should be undertaken after the data analysis is completed. This principle was justified by Glaser and Strauss on the basis that it ensured the emerging themes and categories from the data analysis would not be *“contaminated”* (Glaser and Strauss 1967 p 37; Glaser, 1992 p 31) with preconceptions taken from the literature review.

It is therefore argued that by leaving the literature review until later on, one can remain open minded (Glaser and Strauss, 1967; Glaser, 1992; Corbin and Strauss, 2008). There has been much debate around this position, with some authors interpreting this principle as the researcher being a *“tablar rasa”* (Bulmer 1979; Layder, 1998; Dey, 1999) who comes to the research with no preconceived hypothesis (McCann and Clark, 2003a). For a researcher to detach themselves in this way from what they already know, or have known, there is an implicit assumption that the researcher is not adopting a constructivist epistemological view (Ramalho et al, 2015). This issue will be explored later on in chapter 3.

Dey (2007, p176), in later work, modified his initial *“tablar rasa”* interpretation, suggesting Glaser and Strauss’s position did not require complete abstinence from literature. Instead, Dey (2007) suggested that researchers should avoid bringing preconceived views to their area of research, which might otherwise have stifled the development of theory (Charmaz, 2014).

It can be argued that most researchers will already have prior knowledge, experience and understanding of their research area. Corbin and Strauss (2008) posit that it is how one uses these preconceptions, rather than trying to dispense with them, that is important.

In addition, contemporary scholars see the delayed literature review approach as being practically difficult to achieve, as they recognise that some preparatory work prior to commencing study is required (Stern, 2007; Ramalho et al, 2015). The option of delaying the literature review until after data collection was not practical within this doctoral study, as university processes and ethical approval timescales both required an initial review of the literature. Although the literature evidence produced for ethical and project approval was not the full and comprehensive pan-discipline review required for the final work (Charmaz, 2014), it was still necessary to produce a preparatory version.

A pragmatic view on these constraints was therefore taken, with a decision to undertake a literature review in two parts. The initial review was concerned with the contextualisation of the HCA and the patient within healthcare, setting the stage for the research process (Corbin and Strauss, 2008) in line with other qualitative methods of inquiry (Gibbs, 2008; Creswell, 2012). The second part of the review was concerned with supporting, challenging and offering multiple perspectives on the theory generated from the data. This second part is contained within the discussion chapter (chapter 6) and is concerned with exploration and critique of the literature relating to the core categories generated from the data as the process moves towards theory generation. Charmaz (2014) takes Thornberg’s (2012) perspective suggesting that the literature can be used to help sensitise and develop ideas through an abductive process. She adds that critique and reflection are essential to maintain quality with such an approach and that the literature should be woven into the thesis to support or refute the grounded theory.

Separating out the literature into that which informs the context and that which may influence data collection and analysis was not an easy process. It was therefore not practicable to identify a clear cut off point where part one stopped and part two began. There was a balance to be maintained in order to address this tension, which was met by reflexive journaling and critical review of the literature (see appendix 2 and 3). This, in turn, supported preparedness to being open to emerging themes (Charmaz, 2014; Ramalho et al, 2015) as the data analysis commenced.

The presentation of this first stage literature review resembles a theoretical framework. Charmaz (2014) alludes to a blurring of lines between a literature review and theoretical framework for grounded theory studies. My position for this is that the first stage literature review provided a platform or framework for the whole study. As the thesis developed there was an increasing awareness of broader sociological literature, which is contained within the discussion chapter (chapter 5). This journey from first stage literature review to abstraction of data and use of wider literature could be seen as a journey from theoretical framework to conceptual framework, which is also representative of my developmental journey and the process of grounded theory generation.

2.1.2 Literature search strategy

The purpose of the literature review is to make a well argued case for the research and to provide context and background for the area of interest (Machi and McEvoy, 2010).

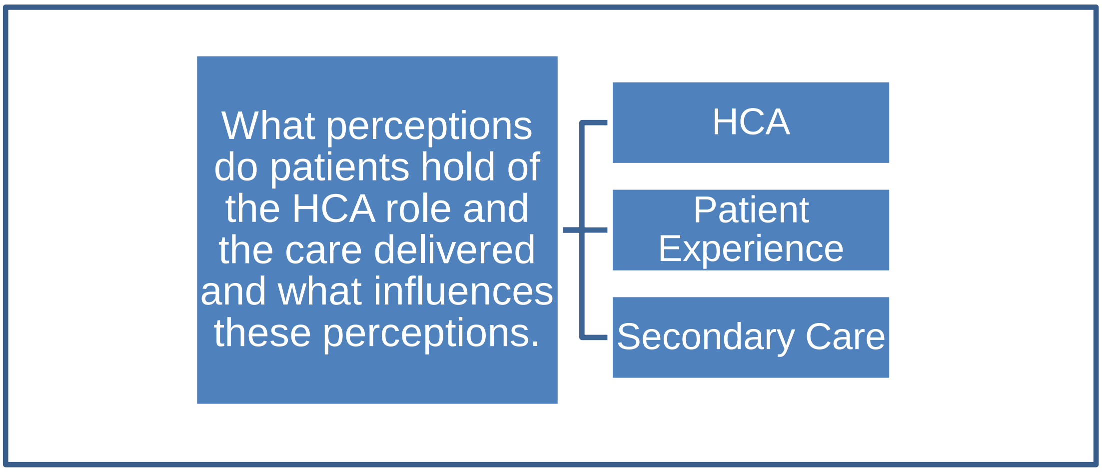
The initial search was focussed around three key areas: the patient, the patient experience within secondary care and the healthcare assistant. These areas were in response to the research question, as illustrated in diagram 1. As the areas are broad and there were time and resource limitations, a clear strategy was required. I adapted Booth et al's (2012) suggestion of a four stage approach: search, appraisal, synthesis and analysis (SALSA), modifying the last two stages for the purposes of this doctoral study.

Search

Searching the literature was an ongoing process that began at project approval and continued through to the literature that has contributed to the discussion chapter. The following databases and sources were used:

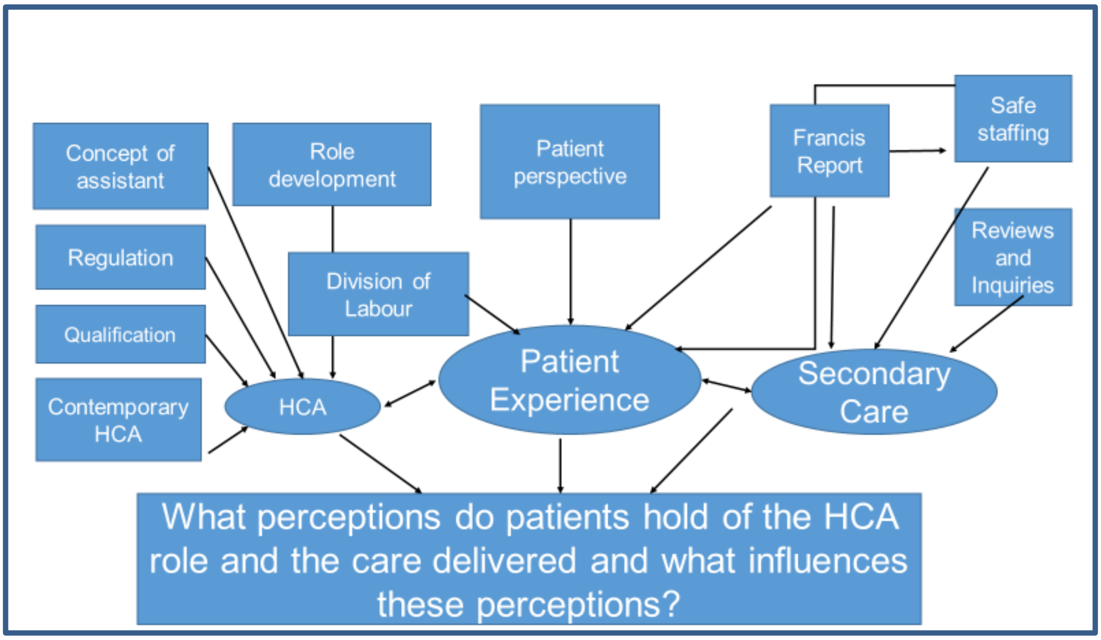
- Web of Science
- Zotec alerts and RSS feeds.
- Google Scholar
- Department of Health
- National Health Service (NHS)
- NHS England
- Gov.UK
- Nursing and Midwifery Council (NMC)
- Royal College of Nursing (RCN)

Diagram 1: First stage literature search.



As the first stage literature review developed, I followed up key pieces of literature through citation searches, as suggested by Booth et al (2012), and other sources of literature including books and policy documents. This approach led to an expansion of the initial literature review, which is illustrated in diagram 2.

Diagram 2: Expanded literature search showing the direction and connections.



- **Inclusion and exclusion**

This first stage literature had the potential to be very broad. There was a necessity to manage the search for literature from a recent history. Taking literature from 2000 onwards provided me with a context from the historical position of the NHS Plan (2000); a white paper that changed the direction of the NHS in terms of increasing relationships between public and private sector, introduction of incidence reporting systems and a narrative around regulation of professions. There were points where literature was searched before 2000 to provide greater understanding of certain areas. Literature from other countries was used with caution as there was an awareness that the healthcare provision, the patient experience and the role of the assistant differs across the globe.

Appraisal

A systematic review of the literature was undertaken with the use of a critical review model (appendix 4). In line with Booth et al (2012), this was to exclude poor quality and irrelevant research.

Synthesis and analysis.

The literature synthesis attempted to bring a different perspective on this study through looking for similarities and differences within the literature regarding particular themes. Booth et al (2012) described this process as rearranging the bricks (existing literature) in new ways, which therefore helps to explain what is already known in addition to identifying any gaps in the literature (Machi and McEvoy, 2012).

This initial literature review contextualizes my study and is structured as follows:

Part 1 Secondary care: begins with a review of the secondary care environment and context. It then continues with a review of significant current issues and concerns impacting on the provision of secondary care, such as length of stay, budget constraints, staffing levels and an overview of a number of inquiries into care delivery ending with a review and implications of the Mid Staffs Public Inquiry (2013).

Part 2 The HCA: explores multiple aspects of the role of the Healthcare Assistant (HCA), from the historical development of the role through to the present day and the division of labour.

Part 3 The patient: explores and investigates the patient within secondary care their experiences and perceptions looking firstly how the patient experience is evidenced through feedback and data. I then move towards exploration of the concept of patient centered care, a review of the factors that shape the patient experience and end the literature review with what is known about the patients' perspectives of the HCA role.

2.2 Part 1 Secondary care

2.2.1 The nature of secondary care

Launched in 1948 and free at the point of delivery (with the exception of prescription charges), the NHS in England deals with 1 million patients every 36 hours (NHS Confederation, 2016). Employing 1.5 million staff, the NHS is within the top 5 employers worldwide (Nuffield Trust, 2012).

It is beyond the scope of this research to produce an extensive history of the NHS, thus a more recent history will provide the context of secondary care within which the patient experiences healthcare today.

The Health and Social Care Act (2012) instigated wide ranging changes to the NHS in England. Recommendations included an increase in patient involvement in the NHS, giving greater statutory powers to the Healthwatch England organisation (Healthwatch, 2016) that listens to the patient and public voice.

The NHS 5-year forward plan (NHS, 2014b) recognised that patients are the experts with respect to patient experience and, as such, the principles underpinning the plan (NHS, 2014b) require patient and public engagement. This engagement is designed to promote greater involvement with service development and design, wherein attention is focussed at clinical and health information delivery alongside a re-emphasis on patient choice (National Voices, 2016). The patient voice is explored more fully in section 2.4.

There is a significant history to patient involvement and choice, however, the patient centred care and choice narrative has increased in recent times. This may be a result of an increased presence of health care charities (iwantgreatcare, 2014; Patient Opinion, 2014) and health care campaigns (Cure the NHS, 2016) coupled with a shift from paternalism towards consumerism (Klein, 2010; Green et al, 2011).

2.2.2 Length of stay

Overnight hospital bed occupancy in England runs between 84% and 89%, despite a near 50 % reduction in bed availability to 137,088 between 2014 and 2015 compared to 1987 (Nuffield Trust, 2016), with the greatest decline seen in mental health, learning disability and longer term care of older people (King’s Fund, 2015b). There has been a corresponding increase in the number of day case beds during the same period (Nuffield Trust, 2016). This change has been driven by calls for more procedures to be offered as day cases rather than overnight stays which, in turn, improves waiting times and patient outcomes (NHS Institute for Innovation and Improvement, 2008a).

Greater efficiency in reducing length of stay for patients resulted from initiatives such as The Enhanced Recovery Programme (NHS Institute for Innovation and Improvement, 2008b). Through early mobilisation and pathway management, patients received improved outcomes and earlier discharge. Few patients now enter hospital the day before surgery, with many organisations utilising day surgery (British Association of Day Surgery, BADS, 2011). Advances in procedure and anaesthetics have enabled day surgery for increasingly complex procedures and could indicate a shift in the acuity and complexity of patients. Thus, patient experiences are different to those of a number of years ago.

Patients are now more likely to be admitted to a pre-operative surgical area prior to their surgery and this is seen as beneficial for patients, reducing waiting time in hospital. This, however, raises issues as the patient enters the ward for the first time immediately following surgery, making orientation and relationship development a challenge to both staff and patient. Bundgaard et al (2011) acknowledge that the nurse in these situations has less time with the patient, and suggest that short stay impacted upon the depth of knowing and the ability of the nurse to adapt to the decreased length of stay. Patients valued those nurses who listened to them and recognised their individual needs and were cautious about asking for help when they observed staff were busy (Bundgaard et al, 2011). Others, however, suggested that it remains difficult to know the patient in short stay surroundings (Mcilfatrick et al, 2006), as nurses face a dilemma between time spent managing the environment versus being there for the patient.

A reduced length of stay within secondary care has benefits in terms of patient outcomes and organisational capacity. What is less certain, however, is the impact upon the nurse patient relationship.

2.2.3 Fiscal and quality issues.

A service provider needs to achieve a fine balance between financial stability and quality of service, with a number of factors impacting upon both areas. The dangers of getting the balance wrong were highlighted recently by Sir David Nicholson who, when giving evidence at the MSPI, said he: *"…was not concerned about Mid staffs as they were in a minor deficit no one raised concerns."* BBC News (2011d).

Reports into poor quality nursing care have highlighted the potential for harm (CQC, 2011; Health Service Ombudsman, 2011; MSPI, 2013; DH, 2013b). Addressing poor quality care, however, comes with increased fiscal cost (Pappas, 2008) that, in turn, impacts upon the continuing financial challenges faced by the NHS. Many Foundation Trusts are already in financial difficulty, with those in deficit forecast to rise from 24% in 2011/12 to 40-50% in 2014/15 (King's Fund, 2016b).

Between 2010 and 2014, hospital activity has steadily increased, with emergency, elective and outpatient admissions growing at a faster rate than the growth in population. The ageing population, coupled with improvements in treatment, may account for the increased activity (King's Fund, 2016b). With healthcare spend increasing in real terms at an annual rate of 0.9% (King's Fund, 2016b), there will continue to be some challenging times ahead for the service providers that may well impact on staffing numbers. At the same time, new and revised models of care will take time to realise fiscal benefits (King's Fund, 2016a).

2.2.4 Safe staffing

Evidence suggests that the numbers, quality and skill mix of staff involved in direct care delivery all impact on patient outcomes (Lankshear et al, 2005; Kane et al 2007; Shuldham et al 2009; Ball et al 2013; Schreuders et al, 2014; Griffiths et al 2015; Twigg et al, 2015). The evidence, however, is inconsistent across authors, suggesting that research results are affected by the heterogeneity of data (Lankshear et al, 2005), variation in patient dependency and staff numbers (Kane et al 2007; Shuldham et al 2009; Schreuders et al, 2014) and measurement sensitivity (Schreuders et al, 2014). In addition, a number of these studies are international (Kane et al 2007; Schreuders et al 2014; Twigg et al 2015), which may make comparison with the UK difficult.

Nurse sensitive outcomes (NSO) are a frequently cited measure by which patient outcomes are determined. They include the following:

- Patient complications (urinary tract infections, pressure ulcers, hospital acquired pneumonia, deep vein thrombosis and pulmonary embolus).
- Length of stay.
- Exploratory measures (upper gastrointestinal bleed, shock, cardiac arrest).
- Surgical complications (wound infection). (International Council of Nurses, ICN 2007)

Lankshear et al (2005) conducted a review of 22 multi-site international organisations and found that the provision of greater staff numbers, in particular of registered nurses, and a richer skill mix was associated with improved outcomes for patients. Schreuders et al’s (2014) Australian study, by way of contrast, found there was no consistent relationship between nurse staffing levels and inpatient complications. In explaining this inconsistency, Schreuders et al (2014) suggested that as staffing levels increase, progressively smaller reductions in negative NSO should be expected. There may therefore be thresholds for staffing levels with respect to specific patient complications. On the other hand, they argue that the measures themselves may not be sensitive enough.

Inconsistency between patient outcomes across different types of complications and nurse staffing levels was also noted by Kane et al (2007), despite an overall association between an increase in RN numbers and a decreased likelihood of mortality and complications. Shuldham et al’s (2009) UK work looked at retrospective hospital data at ward level over a 12-month period. In the lower dependency patient category there was only a weak association between nurse staffing levels and the majority of patient outcomes. Higher dependency patients showed few significant results, although sepsis reduced significantly as the ratio of staff hours increased. In conclusion, the lack of significance and/or consistency in this research area indicates that skill mix, ratio and RN numbers do not appear to have a simple relationship with NSO.

Ball et al’s (2013) study concluded that “missed care”, reported by 86% of RNs (n=2917) interviewed, was as a consequence of reduced RNs per patient, although this varied across clinical areas. They also noted that an increase in HCSW’s (HCA) did not ameliorate missed care, bringing into question the role of the HCA as complement to the RN in these particular aspects of care delivery. Kessler et al (2010) saw the relief and substitute element of the HCA’s role as potentially enhancing quality of care, although they cited McKenna et al’s (2004) concerns around patient safety and quality issues arising from increasing numbers of HCAs and the resultant skill mix dilution.

A recent report from the BMJ (Griffiths et al, 2015) looked at RN, HCSW (HCA) and medical staffing levels, bed occupancy and mortality data from 137 trusts across the UK over a two- year period from 2009 to 2011. They concluded there was an inverse correlation between patient mortality and RN numbers, with no such correlation identified with the HCSW. They went on to suggest that the latter point was of consideration for trusts that operated a policy of substituting HCSW for RNs (Griffiths et al, 2015), which was also cited as a concern by the Safe Staffing Alliance (2016).

The safe staffing agenda has been a concern of unions (RCN, 2010b; UNISON, 2015) and the NMC (2016). NICE published safe staffing guidelines in the wake of the Francis Inquiry (MSPI, 2013) and Berwick (DH, 2013a) but there was a subsequent suspension of this work in 2015 (NICE, 2016). The resultant uncertainty, however, has driven an increased awareness of the issues around skill mix, safe staffing and patient outcomes (Safe Staffing Alliance, 2016).

2.2.5 Reviews and inquiries; a retrospective view

Reports and inquiries into poor, inadequate and substandard care go back many years, with Robb (1967) bringing the plight of vulnerable elderly patients and clients to the attention of the then Wilson Labour Government (1960-1970). Attention on this issue resulted in House of Commons debate (2011; 2012), followed by the first reading of the NHS Reorganisation Bill, 1972 (Health Foundation, 2016a). "*Sans everything. A case to answer*" (Robb, 1967) brought together a collection of media reports and interviews that illustrated some of the substandard and, at times, cruel conditions for, and attitudes staff held towards, elderly patients. Firth (1967) suggests that such care work was subject to poor pay and conditions, with few willing or able to undertake such duties. She suggested that those working under such conditions, with the exception of a few, will fail to care under the strain. Firth (1967) went on to suggest that it should not become a witch hunt against the individual that fails in their duty of care, but that monitoring and improvement led by the government should result in change and improvement. She acknowledged, however, the risk that everything will carry on as before once the headlines have died down. Walshe and Higgins (2002) state that inquiries deployed to investigate service failures and substandard clinical performance do not necessarily bring about change and improvement.

Before reviewing the MSPI (2013), I felt it was necessary to highlight a more recent historical context for what became more than just another report, as suggested by the Guardian (2013)

> *“Where no one who cares about the NHS should….allow these recommendations be glossed over”*

The following section details in chronological order the recent (last 10 years) reports and inquiries.

2.2.6 Chronology inquiries and reviews:

The following inquiries, reports and media responses illustrate the narrative generated within the public domain. This brief chronology may illustrate the backdrop and thus a broader context for some of the patient experiences that are described within the findings chapter (chapter 5).

Date	Review/Inquiry	Content	Media
2007	Maidstone and Tunbridge Wells (Health Commission 2007)	Clostridium difficile outbreak with 90 deaths related to the outbreak. The Healthcare Commission concluded that the relatively low proportion of RN on the medical and surgical wards were a contributory factor towards the outbreak, subsequent management and resulting deaths.	The BBC report: *Hospital bug deaths ‘scandalous’* (BBC 2007)
2011	The Health Service Ombudsmen Report (2011)	Ten investigations into poor and inadequate care for NHS care of older people.	The BBC Report: *NHS ‘failing to treat elderly with care and respect’* (BBC, 2011b)
2010	Francis Inquiry (MSPI, 2010).	Recorded 400 more deaths than expected between 2005-2008 skill mix dilution from 60:40 to 40:60	The BBC report: *Hospital left patients ‘sobbing and humiliated’* (BBC 2010)
2011	Care Quality Commission (2011)	Dignity and nutrition	The BBC report: *Regulator raises elderly care concerns*. (BBC 2011c)

2012	Winterbourne View (DH, 2013b)	Care home in Somerset.	The BBC report: *Abuse footage shocked nation* (BBC 2012)
2013	The Mid Staffordshire Public Inquiry (MSPI, 2013),	Publication of the final report from Robert Francis QC	The BBC report: *Stafford Hospital: 'hiding mistakes should be a criminal offence'* (BBC 2013a) *Francis inquiry into Stafford Hospital cost government £6m* (BBC 2013b)
2013	Keogh Review (NHS, 2013)	Review into the quality of care and treatment provided by 14 hospital trusts in England; overview report	The BBC report: *Will the Keogh review make hospitals safer? (BBC 2013c)*
2014	BBC News (2014) Panorama	BBC News (2014) reported on a recent Panorama programme that filmed abuse within a care home in Essex. Some care staff were either suspended or dismissed pending a full investigation. This home had previously met all of its CQC domains.	The BBC report: *Care home abuse: Staff sacked or suspended.* (BBC 2014)

Table 1: Summary of reviews and inquiries

What has changed since the publication of Sans Everything (Robb, 1967) is the immediacy with which the general public receive “breaking news” broadcast with covert footage and eye-catching headlines that may shape the perception and understanding of both public and patients within the healthcare system.

2.2.7 Review of Mid Staffordshire Public Inquiry (MSPI, 2013)

The Mid Staffordshire Public Inquiry (2013) found that between 2005 and 2008 there were sub-standard conditions for patients attending Mid Staffordshire hospital. Robert Francis QC used the word “appalling” to describe the care that patients suffered during this time and his report made 290 recommendations for improvement. The regulator at the time, the Health Care Commission (HCC), had assessed the organisation as largely compliant, with no concerns raised by the Strategic Health Authority and Department of Health when the trust successfully achieved Foundation Trust status. It was only through the determination of a group of patients and relatives (Cure the NHS, 2016) that the issues finally came to light and an inquiry was ordered. This illustrates the importance of listening to the patients’ voice and the potential consequences of not doing so.

There were apologies from various government leaders as the inquiry was held and results subsequently published.

Within the published results of the Francis Inquiry (MSPI, 2013), one of the 290 recommendations was that organisations need to listen to staff, patients and carers.

> *“Greater attention […] to the narrative contained in, for instance, complaints data as well as to the numbers.” (Francis Inquiry- MSPI, 2013. P90).*

The Cavendish Review (Cavendish, 2013) was published in response to the Mid Staffordshire Public Inquiry (2013) and made recommendations for the training and support of HCAs. There was recognition that the HCA works within complex environments, undertaking increasingly complex tasks that are often not recognised for the significant contribution they make to care delivery. Cavendish (2013) concluded that although roles and job descriptions may vary, support staff should share common core values and knowledge and managers and commissioners need to support such activity.

The Mid Staffordshire Public Inquiry's (MSPI, 2013), subsequent recommendations, which include the government response (DH, 2013a) and Cavendish Report (Cavendish, 2013), have led to a number of HCA related initiatives, including registration and regulation and the development of the care certificate, all of which will be examined in the literature review. An additional recommendation (MSPI, 2013 rec 187) was for all nursing students to spend one year working as a HCA prior to starting their degree course, with a pilot launched across a number of organisations involving 250 HCAs. The subsequent report (Allied Health Solutions, no date) concluded that the programme was conceptually successful for students, HCAs and service providers, who saw a greater diversity of staff applying and moving toward RN qualification. A number of the organisations involved are continuing with the programme (NHS HEE, no date).

2.3 Part 2 The HCA

2.3.1 Conceptualising the assistant role

The assistant role exists across a number of professions, including social work, teaching, police and law, but is deeply embedded within health and social care (Bach and Kessler, 2012). Assistant positions are found in nursing, medicine, allied health professions and medical science. Under New Labour's (1994-2010) modernisation project (DH, 2000a), there was a significant increase in 'assistant' staffing levels in addition to further role development. Kessler et al (2010) suggested the rationale for an assistant role may be threefold, wherein '*assistance'* is provided to any one or combination of the delegator within the profession, the service user and the team.

The NHS Plan (DH, 2000b) justified the need for a number of changes in the NHS from a backdrop of long waiting times for patient treatment and wide variations in service provision across the country. The plan described how the NHS was going to reshape service provision from the '*patient's point of view'* through more flexible ways of working. These included nurses taking on more medical tasks, with resultant delegation to, and investment in, the non-professional roles in order to realise their potential to meet the increasing demand for healthcare. Bach and Kessler (2012) suggest the assistant role has therefore been shaped over time by the need to meet public policy goals.

Developments in the assistant role are a result of drivers that can be summarised as:

- Relief of burdensome tasks from professionals
- Meeting recruitment and retention deficits
- Additional improvements to service (Bach and Kessler, 2012)

The nursing assistant role is generically concerned with multiple aspects of healthcare, from general housekeeping within the clinical area and bedside care through to more advanced roles involving a great deal of technical skill (Kessler et al, 2012). The NMC (2006) provides a definition for the HCA as a subset of the generic Healthcare Support Worker (HCSW):

> *"Those who provide a direct service - that is, they have a direct influence/effect on care/treatment to patients and members of the public and are supervised by and/or undertake healthcare duties delegated to them by healthcare registrants."* (NMC, 2006)

2.3.2 The HCA role development

Nursing care support roles have been part of the healthcare workforce since the time of the Crimean War (1854-1856), where the "pauper nurse" (Dewar and Macleod Clark, 1992), otherwise known as “nurses’ aide” (Stokes and Warden, 2004), supported the nurse in their duties. This nurse aide of the 19th Century morphed into the present day HCA role. The Health Care Act of 1919 recognised nursing as a registered profession (Health Foundation, 2016b) but did not recognise unqualified aides as part of the professional nursing workforce (Kessler et al, 2012). The ‘nursing auxillary’ (NA) role was given formal recognition in 1955 and thus became part of the recognised nursing workforce, although there was still no form of registration or training requirement (Kessler et al, 2010). During this time the NA worked alongside a “qualified assistant nurse” that was designated the status of State Enrolled Nurse (SEN) in 1961 (Webb, 2000).

The term HCA has been recognised since 1986 (Waldie, 2010), when the government used it in the following documents, “Project 2000: A new preparation for practice” UKCC (1986) and The NHS plan: A plan for investment, a plan for reform, DH (2000b). When Project 2000 came into being (UKCC, 1986), the training and education regime of the student nurse changed from an apprenticeship model in which they were included in workforce establishment, to one where they attended HEIs (UKCC, 1986) and were assigned supernumerary status when in the clinical area during training (UKCC, 1986). With the student nurse no longer part of the clinical establishment, the impact on staffing numbers was addressed through the introduction of the HCA. The HCA was viewed as a local, more flexible role that worked alongside the NA which thereafter gradually absorbed into the HCA role. At this time organisations responded by deploying their HCAs as part substitution for the student nurse (Kessler et al, 2010) and, in addition, the State Enrolled Nurse (SEN) was phased out. This resulted in the workforce having only one form of registered nurse; a Registered Nurse (RN) who provided supervision for the HCA and mentorship for the student nurse.

The European Work Time Directive (EWTD, 1998) saw doctors’ working hours reduced, with a major influence on how healthcare service was delivered. Organisations responded by delegating some tasks originally undertaken by the junior doctor, for example catheterisation, cannulation and phlebotomy, to the RN (Kessler et al, 2010). The Wanless report (2002) then looked at the staffing resources required for health care delivery in the future. Advances in medical technology and the changing health needs of the population were identified as impacting on the number of staff and skill mix across the health economy, with a consequent requirement for an increase in the number of doctors. The shortfall in doctors at the time was noted and it was suggested that some of the RN activity could be delegated to the HCA, thus releasing the RN for more medical duties and relieving pressure on the doctors. A subsequent shortfall in RNs was identified by Wanless (2002) with a potential solution of an increased HCA workforce projected to be an increase of 74,000 over the following 20 years from the date of the report resulting in a change of skill mix.

Faced with a shortage of RNs and an understanding that a diluted skill mix could negatively affect patient outcomes, the RCN (2004), in their report "The future nurse: the RCN vision", identified a need to bring the HCA closer to the RN workforce in order to better complement the RN role. The RCN (2004) acknowledged the HCA role contributes to patient care but the nature of its contribution is different to that delivered by the RN. Kessler et al (2010) also suggested the co-production element of the HCA role as one that may be able to offer the patient something different in contrast to the RN patient relationship. Co-production from Kessler et al's (2010) perspective is argued as both adding to patient care and supporting the RN.

A later discussion paper (RCN, 2007a) recognised that much nursing care is delivered by HCAs and that there is a need for organisations to support the development of the role. It is worth noting at this point that there was concern about the HCA duties being largely seen as task orientated, resulting in a more fractured delivery of care rather than a holistic approach (MIDRIS, 2001). Others recognised the significant contribution the HCA made to care provision (Hogan and Playle, 2000). These differing views can be partly explained by the immediate context for the HCA being dependent upon the culture of the healthcare setting (Chang et al, 1998).

The following table (table 2) is adapted from Kessler et al (2012) to illustrate the various categories, classification and derivations of the HCA role currently seen in the workforce. Cavendish (2013) recognised the complex nature of this role in terms of identification, responsibility and role demarcation; concepts that will be explored later on in the literature review.

Table 2: HCA role titles and duties

HCA category	**Role/duties**
Auxiliary	Low skilled routine housekeeping not directly involving the patient
Caring	Semi-skilled patient centred
Technical	Higher skill clinical intervention
Medical	High skill complex clinical intervention

Recent pronouncements from the UK government (Gov. UK, 2015) have identified the need for a new role of Nurse Associate (NuA), a post positioned between RN and HCA with the potential to gain foundation degree status through access to higher education.

This role has gained approval for introduction within health and social care (NHS HEE, 2016). The AN role has been criticised as a possible solution for the shortage of RNs (UNISON, 2016), although others see it as a useful bridge between the RN and HCA with the potential to offer a route of access towards full registration as a RN (HEE, 2015).

The AN role is very early on in its development however it adds another layer to the care workforce that will need to respond to its introduction. With the HCA workforce little understood (Bach et al, 2012) there is an imperative to understand more fully role development and career trajectory of the AN to RN and the impact on workforce and patient experience.

2.3.3 HCAs' qualifications and career trajectory

During the early 2000's the NHS Career Framework was developed, providing a hierarchical structure for the support/assistant roles from grade 2 to grade 4 of the NVQ[1] framework that was previously not in existence. Grade 2 was purely positioned as a support role, with the Senior HCA at grade 3 and the assistant or associate practitioner at grade 4. Through agenda for change (AfC[2]) (DH, 2004), grades were replaced by equivalent bands, with band 4 identified for the Assistant Practitioner (AP) role. This was seen by the RCN (2007a) as an opportunity for organisations to support the introduction and development of the AP for support workers across healthcare. AP status provides the HCA with access to education at HEIs, where they can achieve a foundation degree. This does not, however, necessarily meet the entry requirements onto a pre-registration degree. In addition to there being limited numbers of band 4 roles, the AP role also has potential career limitations (Skills for Health, 2015).

As mentioned, more recent developments have seen the role of Nurse Associate (NuA) proposed (December 2015) by the UK Government (Gov. UK, 2015), with implementation in 2016 (NHS HEE, 2016).

There are no nationally recognised minimum educational standards required for employment as an HCA, with Cavendish (2013) reporting that only 39% of surveyed providers required 2 as a minimum. The NHS careers website (NHS Careers, no date) suggests that some employers require a BTEC or National Vocational Qualification (NVQ) qualification in healthcare to be recruited into the role, while other employers themselves will offer training towards CACHE[3] (Council for Awards in Care, Health and Education)

---

[1] *NVQ: National Vocational Qualification that covers health, social care and education.*

[2] *AfC: Agenda for Change was introduced in 2004 as a single pay system for all NHS workers with the exception of medical staff, dentists and some senior managers.*

[3] *CACHE: Council for awards in care health and education. Designed to meet the vocational qualification needs of today's workforce.*

(CACHE, no date) qualifications as part of the HCA's learning and development plan once recruited (NHS Careers, no date). The CACHE qualification allows for participants to study flexibly at their own pace and leads to awards in health and social care.

More recently, as reinforced by Cavendish (2013), the UK government mandated Health Education England to develop '*A Fundamental Care Certificate*', now known as the *'Care Certificate'* (NHS HEE, 2014). It was piloted during spring/summer 2013, with implementation across all health and social care organisations by March 2015. The certificate is managed and delivered at a local level, with standards being set centrally across 15 domains by NHS HEE (2014). Organisations are to use it as part of the induction programme for new starters, which is recommended to take place within the first 12 weeks of commencing employment. The Scottish Government (2009), however, piloted a project between 2006 and 2009 that addressed minimum standards for the HCA and, as a result, induction standards have been mandatory in Scotland since 2010 (NHS Scotland, 2010a,b).

A recent report from The HSJ (2014), however, suggested that a quarter of new HCAs did not receive any initial training before commencing work in the clinical area. Those organisations providing initial training demonstrated a lack of consistency in content and duration (HSJ, 2014). This gives rise to patient safety implications (RCN, 2007b) and the concern that differing levels of ability and aptitude amongst HCAs may lead to significant inconsistencies in delivery of care (McKenna et al, 2004).

2.3.4 Regulation of HCA

An NMC commissioned report (Griffiths and Robinson, 2010) explored the risks arising from an unregulated workforce and the considerations necessary to become regulated. The authors identified different motives behind the views articulated by the various parties. For example, in 2011 the NMC chief executive suggested regulation has the potential to prevent RNs previously struck off from returning to work as a HCA (NT, 2011) and that regulation has the potential to avoid *“a ghastly national disaster”*. The Chief Executive of the NHS at the time responded by suggesting that education and training was more appropriate than registration of the HCA workforce. In addition, the then Health Secretary for the Conservative government (Gov. UK, 2011) spoke at the 2011 NHS Employers Conference, outlining plans to bring in minimum training standards and a code of conduct for HCAs and HCSWs that went some way to address the situation of regulation and standardisation. He also presented the government’s position on registration for the HCA workforce, stating that registration for a significant number of largely low paid individuals would be costly for the individual and would not guarantee a safe workforce. He instead encouraged organisations to ensure they employ the right staff and educate and train them appropriately. These debates were articulated against a backdrop of the initial publication of the Francis Inquiry (MSPI, 2010).

The Mid Staffordshire Public Inquiry (MSPI, 2013) focussed the nation’s attention on nursing, recommending that the healthcare support workers should operate under a national code of conduct with agreed standards, underpinned by education and training (rec no: 210, 211). The UK government’s initial response was a continuation of their earlier position (Gov.UK 2011) while re-emphasising the need to refer staff who have been involved in causing harm to the DBS (disclosure and barring service) to prevent them working in another organisation. The response also stated that education and training should aim to provide safe and effective care within a culture of care and compassion, monitored by the CQC[4] (DH, 2013b).

2.3.5 The HCA contextualized today

The complexity of the HCA role has been impacted by a number of drivers that need to be understood in terms of the relationships between workforce, end users, policy formation and the requirements of the NHS. Kessler et al

---

[4] *CQC: Care quality commission an independent regulator for health and social care services.*

(2010) describe the HCA role development in response to these drivers as resulting in a workforce that is partly relief and substitute for the RN, a co-producer contributing to the provision of healthcare and an apprentice for further training and education. Kessler et al (2010) claim that these areas have developed as a result of the direction that public policy has taken for the HCA and the wider workforce within healthcare.

The concept of ‘relief’ was described by Kessler et al (2010, p22), as:

> *“the use of the HCA has been to relieve nurses of ‘routine’ or ‘burdensome’ tasks”.*

These routine and burdensome activities include washing, feeding and bed making, which are variously described as ‘fundamental care’ (Spilsbury and Meyer, 2005) and ‘basic care’ (Pearcey, 2008). Giving equal voice to both RN and HCA, Bach et al (2012) noted that the HCAs embraced the caring aspects of their role, valuing the interactions with patients, previously noted by Spilsbury and Meyer (2005). For the RN however, this delegation to the HCA is seen as a ‘loss’ to the RN role and consequently ‘devaluing basic care’ (Spilsbury and Meyer, 2005). The RN’s perception of ‘devaluing’ the provision of care, together with the language used to describe such tasks as ‘burdensome’, does little to bring a sense of unity between patients and carers of all positions. There is potentially a disconnect between the value the patient places on having these care tasks carried out sensitively and the value that public policymakers have placed on bedside duties and the HCA and RN roles (Kessler et al, 2010).

The patient has also noted a change in those who were delivering bedside care (Hancock and Campbell, 2006). Patients reported the HCA as being increasingly available and involved in their care, with the RN correspondingly less so (Hancock and Campbell, 2006). Anderson (1997) and Chang et al (1998) describe the assistant role introduced at this time as relieving the RN of tasks, allowing the RN more time with the patient. There appears to be a very different situation today, however, where it is recognised that the HCA continues to deliver much of the bedside care (Kessler et al, 2010, 2012; Cavendish 2013).

Kessler et al (2010) describe a shift to increased accessibility and availability of the HCA for the patient. This increase is suggested as providing a unique contribution to provision of healthcare, which is classified as ‘co-production’. Spilsbury and Meyer (2005) state that the ‘relief’ of the RN from her duties by the HCA could be seen more in terms of a co-dependency, whereby the RN and the HCA are dependent on each other for successful fulfilment. This co-dependency is not without problems, as transference of information from the HCA to the RN depends on both individual relationships and a functioning formal system of information transfer (Spilsbury and Meyer, 2004, 2005). There is potential for communication breakdown and incomplete transference of information both across and within teams, which may result in compromised patient safety. Co-dependency also requires clear role demarcation, whereas Spilsbury and Meyer (2005) found evidence of the opposite in their research. As an example, RNs needed extra support in more technical tasks only at certain times, with the resultant support activity then withdrawn from the HCA when not required. Spilsbury and Meyer (2005) call this lack of role demarcation ‘exploitation’ and point to legal implications for both the HCA working beyond scope and practice and the RN when delegating such duties in situations where the workforce is not educationally supported.

2.3.6 Division of labour

Role development of the HCA, as described in the previous section (section 2.3), illustrates the extent to which it has been shaped by social, technical, economic and organisational change (Allen, 2001; Kessler et al 2010). Change, coupled with development of healthcare roles, has in turn impacted upon the division of labour more generally, which will be explored within this section.

The concept of division of labour relates to Durkheim’s work “*The Division of Labor in Society*” (1933, first published 1893) that addresses how division of labour emerges when communal societies develop into more complex specialised societies and the consequences of such.

More contemporary work from Allen (2001) draws on the work of Durkheim (1933), Abbot (1988) and Hughes (1984), suggesting that all three share the following perspectives:

1. For those that work there is meaning for the activity.
2. Developments and change are subject to social, economic and /or technological influences.
3. These changes will shape the system of work and reshape occupational boundaries.
4. Tasks take a different course as new tasks enter and others leave through obsolescence or delegation.
5. Occupations evolve and inter-relate with each other.

Allen’s (2001) work has a particular significance for my own area of interest, acting as a point of reference for theories around job description, role activity for the HCA and the tasks undertaken, all of which are addressed within this section of the literature review. From my own personal and professional experience, coupled with my further understanding of the theories around division of labour, I wanted to make clear my own position and understanding prior to continuing my research (see appendix 1).

In many organisations, job descriptions are often only loosely based on reality, with employees engaged in activities that are not necessarily listed within the formal role descriptions and vice versa (Abbott, 1988). This is evidenced in Spilsbury and Meyers’ (2005) work, in which negotiation of extra tasks outside of job descriptions was shaped by availability of resources. The HCA undertook tasks outside of their job description when there was a shortage of staff with the jurisdiction to perform those tasks, with clear implications for safety (McKenna et al, 2004) and for the RN’s accountability (McKenna, 2004; Spilsbury and Meyer, 2004; Keeney et al, 2005). When suitably qualified resource became available, however, this activity reverted back to the RN. Abbott (1988) suggested that boundaries around roles and responsibility can disappear in overworked organisations, which may further affect the disparity between the job description and the activity of the employee. In addition, there is often dissonance between the work the employee ‘thinks they do’ and the work they ‘actually do’ within organisations (Hughes, 1984), adding to blurring of roles and responsibility at both an organisational and individual level. Bach et al (2012) identified two opposing perspectives articulated by the HCAs. Some HCAs suggested they often worked alone or with other HCAs, whereas others identified team working in which all were equal. This suggests wide variation in the supervisory and delegatory environment within which the HCA works.

Hancock and Campbell (2006) identified that recognition, boundaries and development of both RN and HCA roles lacked clarity and that these issues needed to be addressed from a local and national perspective to ensure that the quality of care delivered is safe and appropriate. This lack of clarity was more recently confirmed by Cavendish (2013), who found a confused landscape for the HCA within organisations, including numerous job descriptions in the workplace. The Mid Staffordshire Public Inquiry (2013) reported that there is a need to delineate more clearly between the role of the RN and the role of the HCA (rec no 207) for the benefit of patients. This was reiterated by Cavendish (2013), who suggested that greater clarity would assist patients in navigating their way around the various staff roles.

Some tasks or roles within healthcare are seen as ‘dirty’ and of low value, related to the physical, moral or social aspects of such work. Smith (2012) suggested that within the contemporary setting, the HCA is seen as the lowest member of the nursing hierarchy, performing much of the personal care and, as such, associated with ‘dirty’ work. Bach et al (2012) did, report situations in which RNs delegating unpleasant tasks to the HCA recognised the inequitable distribution of tasks. Allen (2001) noted that the HCAs resented the lack of preparedness of some RNs to undertake such “low value” tasks, which contrasted with situations where RNs were prepared for such tasks and viewed them as investing in their team relationships. Allen

(2001) also noted that, in the absence of lower skilled staff, the RN will ‘pick up’ these ‘dirty’ tasks, including portering and clerical duties.

Allen (2001) identified that, although the hierarchy is present within the clinical environment, at an individual level the RN is less concerned with maintaining their position within the hierarchy, instead wanting to ensure patients’ needs are met whatever their role and responsibility. Allen (2001, p77) suggest the RN is in conflict between the professional view of delivering “hands on care” versus the managerial view of delegation to the HCA so as to undertake other “professional duties”. In reality, however, as the RN’s career progresses he/she becomes further removed from these tasks, delegating them to lower paid workers and so reinforcing the prestige of the RN role and the concept of ‘dirty’ tasks as being lower in the hierarchy (Bach et al, 2012). Kessler et al (2012) suggested that this shift is unfair and degrading, as the HCA undertakes tasks that have been associated with the RN for a lower remuneration. There is hope, however, for the HCA in the form of an apprentice pathway to RN, as many of the HCAs articulated a long-held desire to become a RN (Kessler et al 2012; NHS HEE, no date). This may well be a point of further discussion as the new AN (NHS HEE, 2016) role is designed to move toward RN registration in comparison to a lack of commitment to realise such an opportunity for the existing HCA position.

2.4 Part 3 The patient

2.4.1 Valuing patient experience data

The patient voice is now recognised as important in ensuring improved patient experience and outcomes (NHS England, 2013a), evidencing a renewed focus on the importance of user views (Mockford et al, 2012). The survey methods employed by the NHS are predominately quantitative and include the NHS’s (2014b) annual national survey that, in collaboration with the CQC and Picker Institute (2016), seeks to gain feedback from a number of recent inpatients. In addition, patients are given the opportunity to respond to the ‘Friends and Family Test’ (NHS England, 2013b), a ‘real-time’ feedback tool that openly publishes data online for comparison between healthcare providers.

There has been criticism, however, about such feedback mechanisms and their reliance on a quantitative approach to represent the complex reality of the patient experience (Patient Experience, 2013). Patients are now asked to provide further information and suggestions for improvement, with organisations accessing this feedback to inform service improvement initiatives (NHS England 2013b). The reduction of patient views, perceptions and understandings that occurs with quantitative surveys illustrates the need for a deeper understanding of the complex nature of the patient experience. There are a number of other organisations providing services for patient and public feedback, including Patient Opinion (2014), iwantgreatcare (2014) and NHS Choices (2014). The King's Fund (2015a) survey asks the public more generally about their satisfaction with the NHS, with the result remaining fairly consistent at about 40% satisfaction. These findings, however, are broad and describe trends that summarise and reduce the patient experience in a way that may obscure poor experience.

Patient experience data are used as an indicator of quality and performance for healthcare systems both nationally and internationally (Lombarts et al, 2009; DH, 2014), and as a means of monitoring clinical effectiveness and safety (DH, 2008, 2012b). This combination of information is used to inform policy makers, alongside more general performance monitoring of healthcare providers (Giordano et al, 2010). Local services seeking improvement (Coulter et al, 2009) may also utilise patient experience data. Despite criticism, some suggest this data will provide commissioners and patients with insight into the service (Fung et al, 2008) provided by the organisation.

The recent history of incentive improvement for the NHS brought about targets for a number of issues, for example, waiting time targets as outlined in "The NHS Plan" (DH, 2000a). Although on the face of it the targets did evidence improvement for A&E waiting times, trolley waits and elective waiting times, doubts were raised about how robust these improved figures actually were. Bevan and Hood (2006, p521) described how service providers may "*hit these targets but miss the point"* as gaming comes into play, in which they focus on the target area to the detriment of other areas. Lack of consistency across providers in what parameters were being reported, coupled with the enforcers' collusion in not looking too closely if the reports were improving, is potentially evidenced by the published figures not matching patient reports from independent surveys. Additionally, there are unintended consequences of performance measurement and monitoring whereby organisations will prioritize incentivised measured elements of care over other elements of care that are not measured (Smith, 1995) but are of equal or greater value. The Mid Staffordshire Public Inquiry (2013, p4) identified that Mid Staffordshire hospital had "*a culture of doing the systems business- not that of the patients"* and he therefore concluded that organisations need to listen to staff, patients and carers so as to *"foster a common culture shared by all in the service of putting patients first."*

Patient complaints and quality of service are linked, a relationship that is recognized in international literature (Cowan and Anthony, 2008; Jonsson and Øvretveit, 2008; Hsieh, 2010), with formal complaints considered by the CQC as part of their inspection programme (CQC, 2014).

Causes of complaints are often identified as failure to take account of a service user's perspective coupled with communication failure (Coulter, 2002). Junior staff, with their significant patient contact, are at the forefront of patient complaints and yet the process of investigating, interpreting and reporting on complaints is often undertaken by small groups of more senior staff (Allsop and Mulchay, 1995). This communication disconnect is further complicated where there is a difference between what is known informally at ground level from staff, patients and carers and what is reported officially (Waring and Bishop, 2010). This problem, explained as a failure of communication in which information is erased, distorted or missed as it travels towards the official reporting system, further compounds the difficulty in accessing the authentic patient voice (Waring and Bishop, 2010).

There is an ontological difference between the official reporting language of management, which is quantitative, predictive and generalizing, and the local language that is narrative based and explains a particular situation. It is difficult to translate the latter into the former (Hill, 2004; Yanow, 2004) and thus the “ward to board” concept of bringing information from ward level to the board room has considerable challenges, suggesting there is further work to do in ensuring the patient experience is acknowledged. Martin et al (2015) describe the difficulty for organisations in utilising complaints data, which they classify as ‘soft’ intelligence. The authors suggest that, rather than reducing the data for clarity and uniformity, managers need to bring a sense of “disruption” to the data to “hear” the multiple voices that are otherwise obscured by the more systematic, traditional approach.

Post Francis (2013), a review of NHS complaints systems and processes Clwyd and Hart (DH, 2013c) concluded that service users complain if they have experienced poor information provision, a lack of compassion, a lack of dignity and care, poor staff attitudes and a lack of resources. In addition, they identified that some patients felt “they were a problem or a burden rather than being cared for” (DH, 2013c, p16). Service users also felt confused, fearful and frustrated with respect to the complaints system.

Mockford et al’s (2011) systematic review attempted to identify literature that evidenced the impact of public and patient involvement in the NHS and health services within the UK. The inclusion of patients within studies is not without its difficulties, but Mockford et al (2011) concluded that there is a need for greater understanding of the contribution from the narratives and experiences of service users. Tsianakas et al (2012a) further added that, although time consuming to collect and analyse, there is a depth to patient stories and narratives that would otherwise be missed by survey alone but will bring greater understanding of the patient experience.

2.4.2 Patient centered care

Patient centered care is a concept of increasing importance within healthcare (Shaller, 2007) that is central to quality and dependent upon personal, professional and organisational relationships (Epstein and Street, 2011). Epstein and Street (2011) argue that there is often misunderstanding regarding what the term means, with the result that superficial attempts at patient centeredness may add to the patient experience but not necessarily to patient centered care. Shaller (2007) suggests six elements that define patient centeredness; sharing knowledge, collaboration, involving family and friends, consideration for the spiritual dimension of care, respect for needs and preferences and accessible information.

The extent to which organisations achieve patient centeredness depends partly on leadership from management in implementation and communication, from top to bottom, of the organisation’s vision (Shaller, 2007).

Engels (1977) posited the biomedical model, derived from an underlying principle that complex phenomena stem from a primary cause, as the dominant healthcare model in the western world. Patient centeredness, however, is difficult to position within the biomedical model.

The biopsychosocial model (BPSM) (Engels, 1977, 1980), by way of contrast, is a metatheory that addresses the social, psychological and behavioural aspects of physical health. The BPSM rejects the idea that health is absence of disease, defining health in terms of physical mental and social wellbeing, as well as physical dysfunction and disability (Stone, 1979, Ware 1992). The subjective experience of illness is therefore an important health indicator and Engel (1977, 1980) highlighted the importance of the patient experience of illness in shaping the clinical expression of the disease.

Locating patient centeredness within the BPMS model (Engels 1977,1980) has the potential to bring benefit to the overall patient experience through improved quality and outcomes.

2.4.3 Qualitative research into the patients’ perspective

In an attempt to gain further insight into patients’ perceptions of their own lived experience, I turned to the literature for research that tells narratives from the patients’ own voices.

As patient perceptions of care have already been studied within the patient satisfaction literature (Coughlin, 2012), I researched more broadly to seek greater understanding of perceptions of being a patient within the environment of secondary care. I collated the literature and categorised it into the following themes.

- Environment

The built environment of secondary care is where patients may attend outpatients during the day or may become inpatients for varying lengths of stay. The environment therefore becomes the temporary residence (Spichiger, 2009) for patients during these episodes. Douglas and Douglas (2003) carried out fifty individual semi-structured interviews across four directorates of one organisation to seek out patients’ perceptions of their temporary residence. They found that patients felt vulnerable when the environment was not conducive to promotion of self-care and lacked privacy. Their use of the phrase ‘patient friendly’ was not directed specifically at staff or at the residence itself, but was more to do with the overall feel of the space they were residing in. Patients within the elderly directorate wished for greater social engagement with others and the authors concluded from this that special design would contribute to all of the participants’ concerns.

- Health and Illness

Patients’ condition and health also impacts upon their experiences. Spichiger’s (2009) study explored terminally ill patients’ experiences of being in hospital, in which patients describe their experience within the hospital along a continuum from ‘heaven’ to ‘prison’. As some patients’ worlds began to reduce due to their terminal condition, they sometimes felt trapped within the ‘prison’ whereas the description of ‘heaven’ was ascribed by some to situations where their diagnosis had been made and they could finally deal with their pain and previously unmanaged symptoms.

- Service Improvement

Literature that seeks the experiences of patients to facilitate service improvement has also helped illuminate the patient experience more generally. Tsianakas et al (2012b) reported patients within breast and lung cancer care that described feelings of neglect in situations where staff missed an opportunity to bring psychological support and feelings of vulnerability when they were inpatients in non- specialist areas. Vulnerability was also apparent for those patients who experienced a lack of continuity with respect to the staff caring for them, resulting in sporadic relationship building. Interestingly, the participants understood and tolerated long waiting times if caused by another patient requiring increased attention.

2.4.4 Patients' perspectives of the HCA

Within the UK since 2000, a number of empirical studies have been undertaken that explore perceptions and understandings of the HCA role from the perspective of healthcare staff; the RN, the student nurse and sometimes the HCA themselves (Pearcey, 2000, 2008; Bowman et al, 2003; Ormandy et al, 2004; Spilsbury and Meyer, 2004, 2005; Hancock and Campbell, 2006; Payne et al, 2007; Alcorn and Topping, 2009; Butler Williams et al, 2010; James et al, 2010;). These studies have limited input from the patients' perspective; those that do have included patients as part of a wider study, leaving the patients' voice somewhat reduced. In an attempt to bring depth to the discussion around the patient perspective on the HCA there are three studies (Keeney et al, 2005; Hancock and Campbell 2006; Kessler et al, 2010) to date that address this perspective and will therefore be explored more fully in this next section.

Kessler et al's (2010) large study across four trusts found that staff and patients had different perceptions regarding the identification of staff and their roles. Patients often used the generic term 'nurse' to describe or recall staff, with some stating there was difficulty in differentiating the various roles. The patients in Kessler et al's study (2010) were past patients: some were interviewed within a focus group setting and others through a survey approach. The perspective of past experiences may therefore be different to the lived experience.

The survey did, however, indicate that the vast majority of patients could identify the various roles, using the different uniforms as the most common way of identifying staff. Patients' condition and capacity impacted upon their ability to identify staff. Patients who could identify the staff reported much higher levels of satisfaction with their experience, although some staff participants articulated that they felt patients were not really concerned with roles.

Keeney et al (2005) interviewed inpatient maternity patients (n=6), which constituted a smaller and more specific patient group than that of Kessler et al (2010). Keeney et al (2005) also identified that these patients were generally satisfied with the care provided by the HCA. Hancock and Campbell's (2006) study sought the views of 12 'expert' patients on the HCA development programme within one organisation. The criteria of 'patient expert' was fulfilled through high frequency of admission to the ward or hospital and thus being known to the HCA's manager. Caution should be exercised with respect to the responses from patients within this study as their frequent attendance may have been likely to continue beyond the point of interview and thus there may have been a reluctance on their part to disclose their true feelings and experiences with candour. In addition, the patients were asked to comment on HCAs who were undertaking training and education to enhance their role and thus their views may not necessarily be taken as being representative for all HCAs within that organisation.

Patients across all studies noted that the HCA was more involved in their care than the RN, who was engaged with other duties (Keeney et al, 2005; Hancock and Campbell 2006; Kessler et al, 2010). Kessler et al's (2010) study suggested that the duties performed by the RN were the more important ones. The patients mentioned 'not bothering' the RN with simple things but instead calling on the HCA for support. We are left uncertain as to what these 'simple things' were, although the patient survey findings rated care from both RNs and HCAs highly. The RN scored higher as being someone to confide in, suggesting that patients valued the time spent communicating with the RN. The quality and quantity of contact time between the patient and HCA/RN was difficult to establish from the focus group and survey data for Kessler et al’s (2010) study. Field notes taken by Kessler et al (2010) suggest, however, that the RN may spend an average of two minutes less than the HCA at each contact episode. This may well have influenced patients’ perceptions and subsequent recall of events. Further exploration of these different perceptions would have illuminated a much deeper understanding of what the patient values from the nursing team with respect to contact episodes.

Kessler et al (2010) suggested the surveyed patients were cautious and less certain about their relationship with the HCA and the quality of care in comparison to the focus groups, who were less cautious. This may suggest that the surveyed participants were more comfortable delivering a less positive view of the HCA. The researchers are at pains to say, however, that caution is needed when drawing conclusions from these differences. Keeney et al (2005) found that patients were mostly satisfied with the care that was delivered by the HCA, with some adding that there were certain duties relating to their assessment that they would not be happy with the HCA performing.

These three studies (Keeney et al, 2005; Hancock and Campbell 2006; Kessler et al, 2010) illustrate there are significant gaps in the literature addressing the role of the HCA from the patients’ perspective. Each one offers insight from either a past patient perspective (Kessler et al, 2010) or from a small speciality patient group (Keeney et al, 2005) or from a purposively selected patient group (Hancock and Campbell, 2006).

2.5 Chapter Summary.

Secondary care faces many challenges within contemporary healthcare, not least the balancing of quality of care and the patient experience against increasing fiscal pressures. Recent reports into poor or substandard care (The Mid Staffordshire Public Inquiry, 2013; DH, 2013b) have seen a refocus towards understanding and capturing the patient experience. This data informs the public (Fung et al, 2008), policy makers (Giordano et al, 2010), and commissioners (Coulter, 2009) on service provision, however this is often from a quantitative, reductive position.

The HCA role has developed in a number of ways and in response to multiple agendas that has resulted in the HCA delivering much of the bedside care (Keeney et al, 2005; Hancock and Campbell, 2006; Kessler et al, 2010, 2012; Cavendish, 2013). This has impacted upon the division of labour in the clinical setting, where the RN is now seen as less available to the patient then the HCA (Hancock and Campbell, 2006). Furthermore, although there has been much research focussing on the HCA, RN and student nurse, there is a paucity of research literature addressing in depth the patients’ perceptions of the HCA role.

Chapter 3 Theoretical Perspectives

Chapter 3 Theoretical perspectives

3.1 Introduction

This chapter will address the philosophical perspective underpinning my research strategy, which in turn informed the theoretical perspective of symbolic interactionism (SI) and postmodernism (illustrated in diagram 5). Early on in this research process, I identified that Constructivist Grounded Theory Methodology (CGTM) would be the most suitable methodology to support my research objectives and question. In the following chapter on methodology (chapter 4), I will explain the rationale for selecting CGTM alongside Situational Analysis (SA) (Clarke 2005) as a heuristic device to support reflexivity and elements of data analysis.

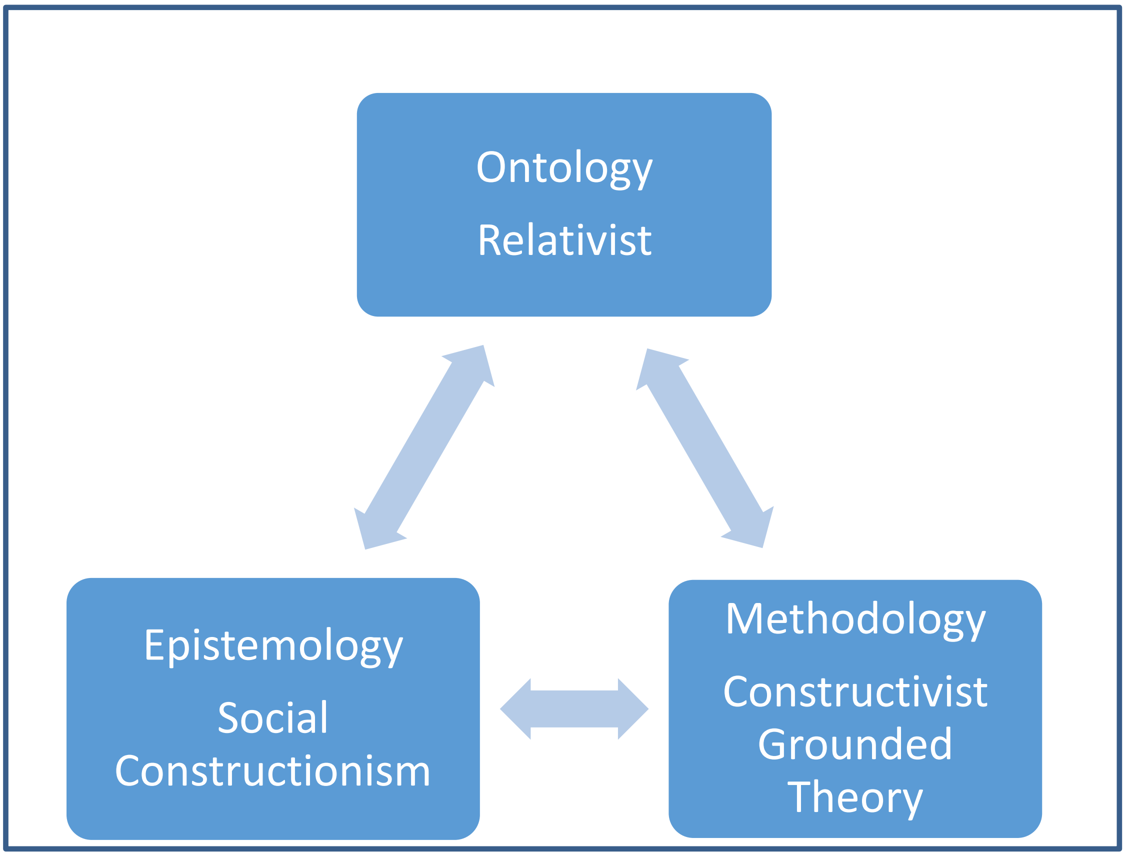
The selection of CGTM was considered in a two stage approach; methodology and epistemological perspective (McCann and Clark, 2003b).

In stage one, the aim of this study was to explore the patients' perceptions of the role of the HCA, an area where there was a paucity of research. Birks and Mills (2011) suggest that grounded theory is an appropriate methodological choice where little is known on the area of research and where theory generation is a desired outcome.

Stage two involved identifying the positioning of CGTM within a constructionist epistemological perspective, in which there is an understanding that individuals make sense and meaning as they interact with the individuals and objects of their world (Crotty 1998; Blaikie, 2007).

The constructionist stance proposed by Charmaz (2006; 2014) also informed this decision. As such, a dynamic process began between methodology and epistemology to understand more fully the congruent relationship between a constructionist epistemological perspective and CGTM. This is illustrated in diagram 3.

Diagram 3: The research paradigm represented as a cyclical decision making process.



The following sections will detail the philosophical, ontological and epistemological positions, how these relate to the theoretical perspective and justification for the research design in answering the proposed research question. As part of this process, my world view will be evidenced (Holloway and Wheeler, 2010; Welford et al, 2011), which will add to the strength of the research design (Mills et al, 2006).

3.2 Philosophical perspective

In the post positivist era of qualitative research, I recognised that I came to my research journey from a number of standpoints and preconceptions shaped by my social, clinical and historical experiences (illustrated in appendix 1), some of which was known and some was not (Mills et al, 2006).

I also felt that I was not able to leave these behind or separate myself from them in an objective way. Smith and Hodkinson (2005) describe the attempt at objective neutrality for the researcher as ill founded. They further suggest that a relativist stance is the only option in a post-modern world where we move from discovery to constructing. Constructing is shaped by preferences and judgement's which are informed by social and historical influences (Smith and Hodkinson, 2005) congruent with my beliefs and understandings of my standpoint and subjectivity.

3.2.1 A relativist ontological perspective:

Relativist ontology is congruent with social constructionist's epistemology (Crotty, 1998; Denzin and Lincoln, 2005b p184; Mills et al, 2006) and with postmodernism (Blaikie, 2007). Mills et al (2006) suggest that a relativist ontological view is one where there is recognition of multiple realities shaped by context.

There are however multiple relativist ontological positions (Stanford University, 2015) that require explanation with Blaikie (2007) suggesting that simple distinctions need elaboration for clarity.

My interpretation of a relativist ontological perspective is one where the external world exists in relation to our thoughts, where there is no existence of the external world independent of our thoughts. What we think of as real is real because we think of it as real. The external world consists of representations that are the creations of the individual's mind (Blaikie, 2007). As humans we live in a world of shared interpretations where different circumstances, situations and cultures are likely to have different constructed views of social reality and thus are relative (Crotty, 1998).

There are however criticisms of a relativist ontology with Hammersley (1992) questioning the usefulness of multiple accounts as each is worthy of consideration. Andrews (2012) adds that no one account takes precedence over another. Smith and Hodkinson (2005) suggest this position may lead to a research position of "anything goes" unhelpful and potentially chaotic. They do however dispute the notion of anything goes suggesting that we all make choices and are inclined to one option over another and as such relativism offers us a way of recognising the limitation of uncertainty (Smith and Hodkinson, 2005).

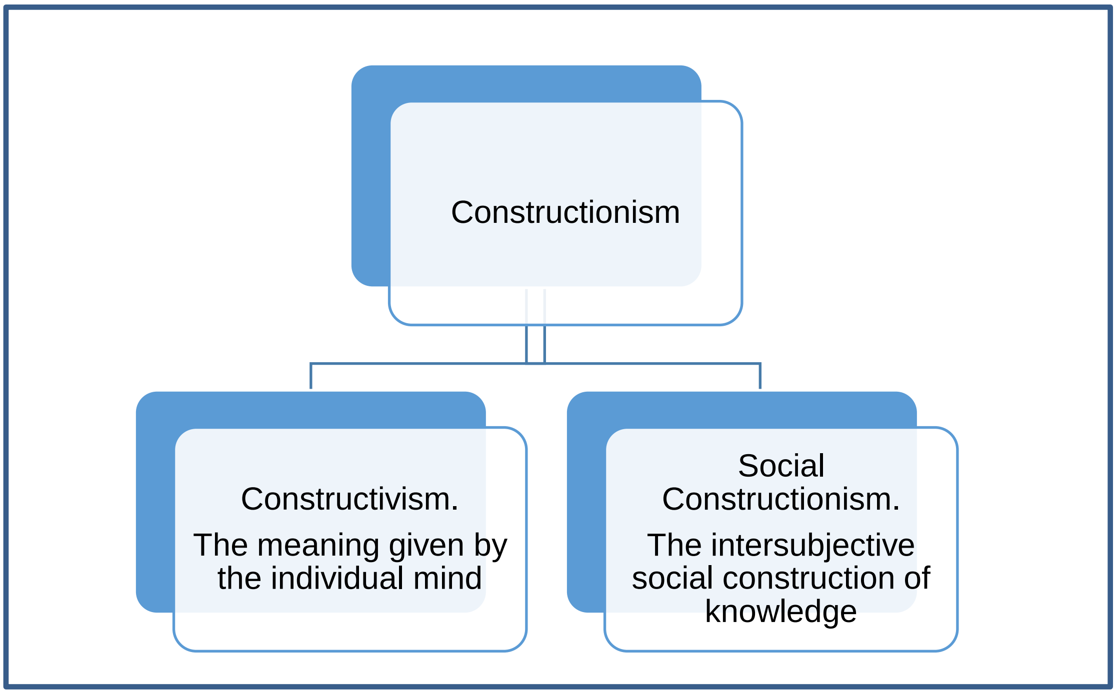
3.2.2 Epistemology

Epistemology is concerned with the theory of knowledge, what knowledge is and how as humans, “we know what we know” (Blaikie, 2007 p18). Denzin and Lincoln (2005b p22) posit that epistemology is “what is the relationship between the inquirer and the known” concerned with, the subjective nature between researcher and participant and co-construction of meaning (Denzin and Lincoln, 2005a p 184). By describing my epistemological position, the lens through which the research subject was approached is captured (Lipscomb, 2008; Kelly, 2010).

It is worth clarifying some of the language I have used at this point with particular reference to constructivism and social constructionism as these are often used interchangeably (Gergen and Gergen 2004; Andrews, 2012). The difference between constructivism and social constructionism under the collective term constructionism that is worth referring to at this stage is noted by Blaikie (2007) and Gergen and Gergen (2004) and summarised in diagram 4.

Social Constructionism has a recent history as it has developed over the last 30 years and is closely linked to post modernism (Andrews, 2012). Social constructionists see knowledge as created through the interactions individuals have (Schwandt, 2003) and is the outcome of people having to make sense of their encounters with the physical world.

Diagram 4. The hierarchical description of constructionism. Adapted from Blaikie (2007, p22) and Gergen and Gergen (2004, p8)



Social constructionism is used to refer to the influence the social world has on the individual’s perception, meaning making and understandings (Gergen, 2009). He suggests that what we understand as real is socially constructed; events happen but the meaning associated with that event is socially constructed through the interactions we have with others. If social constructionism is accepted then there are implications for what we take for granted (Gergen and Gergen 2004; Gergen 2009), “nothing is real unless people agree that it is” (Gergen 2009, p4). For the social constructionist there is a rejection of the constraint of history or tradition and openness to the possibilities of meaning and how meaning is created (Gergen, 2009)

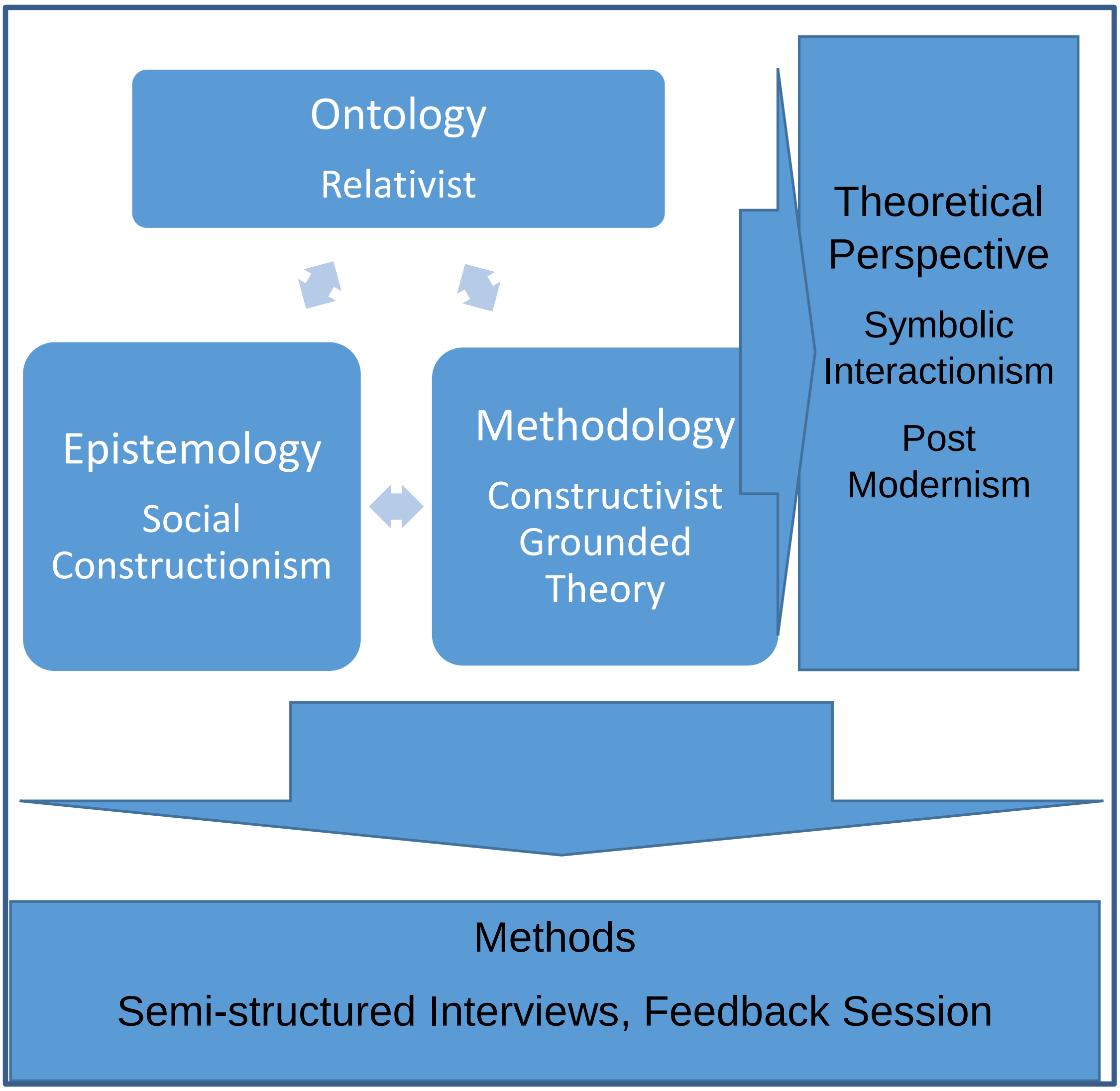
For clarity, I have used the following terms in this work, constructivism is used to describe the individuals position in terms of how the individual mentally constructs meaning (Blaikie, 2007). When referring to GTM (Charmaz, 2014), the term constructivist will be applied. When describing my epistemological position, I will however refer to constructionism as in social constructionism.

Relativist ontology and the epistemology of constructionism allow for the possibility of multiple realities within any social context. This acceptance of multiple realities was congruent with the research paradigm.

3.3 Theoretical perspective

My position regarding theoretical perspective was drawn from Crotty (1998) and Blaikie (2007) who propose that the philosophical stance of the researcher informs the methodological process. I recognised that the theoretical perspective is in itself informed by underpinning epistemology and ontological positions, outlined in diagram 5.

Diagram 5: Situating the theoretical perspective and the research paradigm.



My research took the position of a combined theoretical perspective of symbolic interactionism (that remains an underpinning principle of Charmaz's (2014) GTM) with post modernism, as recognised within Clarke's (2005) work on SA. Charmaz (2014) suggests that a combined theoretical perspective adds to the researcher's theoretical insights and addresses concerns around preconception.

3.3.1 Symbolic Interactionism.

Symbolic interactionism (SI) is a theoretical perspective that underpins many qualitative methodologies. The term stems from the pragmatist ideas of Mead and Dewey (Blumer, 1969; Crotty, 1998). The foundational aspects of GTM are inextricably linked with SI, which is concerned with issues around language, communication, relating to others, how we relate to others and community (Blumer, 1969). Charmaz (2014) asserts that the complementary combination of Grounded Theory as a method and SI as a perspective has potential as a "*theory-methods package"* (a phrase coined by Clarke, 2005). Charmaz (2014) goes on to describe how SI can be used as a theoretical perspective that aids the researcher to be receptive to meanings and events in the research study. To evaluate this, I explore SI's contribution within GTM.

Blumer's (1969) seminal work on SI is concerned with three premises:

- Human actions are based on the meanings that are attached to <u>things</u>.
- The meanings of the <u>things</u> one encounters come from the social interaction between oneself and others, akin to social constructionism.
- An interpretive process is at play as humans encounter these <u>things</u>.

The "*things*" Blumer refers to can be classified into "objects" relating to 3 areas. In the present study, for example, the following are illustrations of the objects within the social world of the in-patient or out-patient.

- Physical objects e.g. beds, lockers and call bells.
- Social objects e.g. HCA, RN, Drs, partner/spouse, visitors, and friends.
- Abstract objects e.g. care, ethics, professionalism, values and principles.

It is also a point for consideration that these objects may have meaning at an individual level or at a collective level. Blumer (1969) talks about the meanings individuals may have for objects, for example, ‘the bed in bay 6’ will have a very different meaning for the patient who is about occupy that bed as their base in hospital compared to the nursing team, who may view it as an object that helps them manage the moving and handling requirements of patients. The ability to see how objects are viewed by the individual supports the notion of the researcher entering the participants’ world, recognising their differing views, perceptions and understandings alongside the researcher’s own position, an approach that is congruent with a constructivist paradigm. The emphasis that SI places on objects has supported my understanding and application of Clarke’s (2005) SA approach, which will be discussed later in this chapter.

Holton (2007) discussed Glaser’s (2005) view on SI as a theoretical perspective. Glaser (2005) was concerned about the potential to limit GTM to the one lens of SI, which may in turn influence data collection and subsequent analysis, resulting in a less creative abstraction of the data. Glaser (2005) went on to say that GTM as a general methodology should be supported by an epistemological stance appropriate for the area of study.

It is worth noting, however, that Milliken and Schreiber (2012) suggest that SI provides a series of “windows” through which the researcher can view and explore the area of study. In this study I took the stance of Milliken and Schreiber (2012) in viewing GTM and SI as inextricably linked, but not to the exclusion of other theoretical and philosophical perspectives that may overlap and contribute.

3.3.2 Postmodernism

GT and its theoretical underpinning of SI can be seen as positioned within a postmodernist philosophy (Clarke, 2005). The following narrative explores how I came to conceptualise postmodernism in relation to GTM from both Charmaz's (2014) and Clarke's (2005) perspective and the underpinning relationship of SI.

Encompassing more than just science and philosophy, postmodernism is a widely-used term within other disciplines such as art, literature and architecture (Crotty, 1998; Crook, 2001; Blaikie, 2007). To understand postmodernism one needs to look to modernism to situate the "*post"* or "*after*" (Blaikie, 2007; Seale 2004). Modernism is seen as the outcome of the Enlightenment, the intellectual movement of the seventeenth and eighteenth centuries, which saw superstition and myth challenged by reason, generalised truth and the stability of meaning, with progress seen as a consequence (Alvesson, 2002). Postmodernism, however, challenges the view of generalised or absolute truth (Seale, 2004) and the epistemic underpinnings for such views, e.g. basing itself in an epistemology where there is uncertainty, ambiguity (Crotty, 1998; Bryman 2012) and plurality (Crook, 2001).

Crotty (1998) describes postmodernism as a continuum that has emerged from modernism and therefore has a relationship to modernism. Willmott (1992) stated that attempting to define postmodernism is futile as the movement views standardisation in contrast to the very nature of the understandings of postmodernism. While accepting that postmodernism is difficult to define, I understood that postmodernism, as a concept, encapsulates the complex changing nature of contemporary society. The broad global explanations and grand theories have been supplanted by an understanding that knowledge or theory is constructed, not fixed or permanent but of the time (Clarke, 2005).

Alvesson (2002) suggested that there is a difficulty for the researcher exploring postmodernism when clarity is needed regarding the application of postmodernism as a philosophical stance, or alternatively when searching for postmodern phenomena. In selecting SA as a postmodern advancement to GTM in this present study I have committed to a philosophy of accepting uncertainty and ambiguity. This is in line with what Alvesson (2002) describes as a “soft interchange” between philosophy and the postmodern period being more appropriate for certain approaches of social research. Caution is required in this approach, as noted by Alvesson (2002), as there is a possibility the researcher is so concerned with language used in representation that it constricts and constrains the diverse phenomena being explored.

3.4 Chapter summary

In summary, a combined theoretical perspective of SI located within postmodernism has been selected. With the selection of Charmaz’s (2014) constructivist approach to GTM, and drawing upon Clarke’s (2005) SA as a heuristic device to assist in bringing out these complexities, I am confident that there is congruence throughout the research design and approach.

The next chapter will attend to the historical beginnings of GTM by addressing the context of the emergence and subsequent divergence and development of GT as a methodology.

Chapter 4 Methodology

Chapter 4 Methodology

4.1 Introduction to methodology

This chapter incorporates the historical and theoretical principles that underpin GTM and SA. Bryant and Charmaz (2007) state that it is necessary for the researcher to evidence their understandings of GTM with more than mere reference to the original work, which is that of Glaser and Strauss (1967). The reader will be led through each point of consideration with reference to the original GTM (Glaser and Strauss, 1967), subsequent divergent GTM perspectives (Glaser, 1978, 1992, 1998, 2002, 2005; Corbin and Strauss, 1990, 2008; Strauss and Corbin, 1990, 1998, 2008) and then towards a more contemporary approach (Charmaz, 2006, 2014) adopted for this doctoral study. I opted to use Charmaz's (2014) contemporary GTM, which is underpinned by a constructivist paradigm that recognises multiple social realities and co-construction of those realities between researcher and participant.

Reflexivity is necessary to ensure there is transparency throughout the research process around researcher position and the decisions made, which in turn adds to the quality of the research (Alvesson and Sköldberg, 2009). I draw upon SA to support this transparency through reflexivity detailed at the end of this chapter (section 4.7) and in relevant appendices.

4.1.1 Historical context of Grounded Theory.

Grounded theory has its beginnings in the work of Glaser and Strauss (1967), who proposed that theory could be *"discovered*" from the data by a process of systematically gathering and analysing data (Glaser and Strauss, 1967): an inductive process of data collection (Bryant and Charmaz, 2007; Morse, 2001).

A positivist paradigm dominated the 1960's research climate, in which statistical, quantitative research methods prevailed (Bryant and Charmaz, 2007) and where value was placed on objectivity and on replication of results and outcomes. The researcher was assumed to be a passive objective observer, generating facts about a single, external world (Bryant and Charmaz, 2007; Charmaz, 2014). Bryant and Charmaz (2007) claim it is important to understand the context of Grounded Theory development to appreciate the debates that have formed part of the subsequent divergence and development of GT as a methodology

Glaser and Strauss came from differing backgrounds: Glaser had experience in quantitative methods and Strauss studied within the Chicago School, where traditions of pragmatism, symbolic interactionism (SI) and ethnographic study were commonly followed. They collaborated on their research, advancing the principle of developing theory by beginning with data and moving through levels of abstraction, rather than testing existing theories (Charmaz, 2014). By doing so, they addressed the criticism that qualitative research offered only description and were able to show that the theoretical concepts generated were from, and thus located within, the data (Charmaz, 2014). Within this approach lies the paradox: by addressing the criticisms of positivists, and in trying to position GTM as a significant alternative to the prevailing statistical quantitative inquiry, Glaser and Strauss (1967) arguably located GTM within the positivist ontological view that there is a reality out there waiting to be discovered.

The heritage of Strauss contributed to GTM, wherein the pragmatist underpinnings of SI attested to people making sense of their worlds through construction and interaction. This position was in contrast to the belief of a unitary, testable truth that prevailed at the time (Bryant and Charmaz, 2007). The paradox of GTM's positivist derivation within underpinnings of pragmatism has remained a subject of much debate. It is addressed in detail by contemporary researchers like Charmaz (2006, 2014) and Clarke (2005), who seek to reposition the methodology within constructivist and postmodernist thinking.

4.1.2 Situational analysis.

The principles of situational analysis (SA) (Clarke, 2005) were an important consideration for my research. I did not adopt the data analysis process described in Clarke's (2005) approach but instead used some of the underpinning principles to add an additional dimension to the research process. SA aims to capture the complexities inherent within research, with Clarke (2005) suggesting that not attending to such complexities may lead to a reductionist view and over-simplification. She described attending to differences or variances within the data (Clarke, 2005) to reinforce the notion of complexity rather than reducing negative or variant cases in favour of commonality. In addition, SA helps articulate the "sites of silence" (Clarke 2005 p85), i.e. that which is not articulated through the data but the researcher believes is there (den Outer et al, p 2013). Clarke (2005) proposed that there are no grand narratives to be generated from applying SA, but that the theory derived will explain a particular situation or area that cannot be generalised in a qualitative sense.

This process helps bring marginalised perspectives to the fore, which in turn supports the notion of multiple perspectives within SI. Clarke (2005) stated that within GT in its most basic and earliest form (Glaser and Strauss, 1967), the context for the research activity was not stressed, although Strauss did attend to this in later work (Strauss, 1987 p 77-81). He described the need to achieve a balance for contextual or situational data, so as to inform but not overwhelm the interactions (Strauss, 1987). Clarke (2005) concerned herself with the discourse that surrounds, and has influence on, social worlds and with the non-human elements that exist within our situatedness and the resultant complexities.

Clarke (2005) described her development of GTM in ways to "*push it around the postmodern turn"*, one of which involved map making to support the analytical stage of research. This method underpinned a different approach for my research where maps, although not used for data analysis, were adapted and used throughout the research process.

The use of these maps had the ultimate aim of opening up my mind to the situatedness of the participants' worlds before data collection commenced. Through grounded theory and the cyclical nature of constant comparison, these maps were revisited prior to each interview. The two main cartographic approaches detailed below were adapted from Clarke (2005):

- Situational maps, which lay out human and non- human elements, discursive and other elements, framed within the research inquiry and the analysis of the relationships among them.
- Social worlds/arena maps, which lay out the collective actors and the key non-human elements and discourse interpreted at a meso level.

I used SA as a heuristic device purely to challenge preconceptions, beliefs and understandings around preparatory research activity (articulated within this chapter under Phase 1 Preparation for Field Work, section 4.2). The application of SA in this way contributed to my reflexive approach which was captured through a mapping process of situation and social worlds, articulated in section 4.6.

4.1.3 Constructivist Grounded Theory Methodology (CGTM) and the decisions made.

Charmaz's (2006, 2014) model of CGTM captures the inductive nature of classic grounded theory methodology (Glaser and Strauss, 1967) along with other tenets of CGTM, but seeks to be more flexible as an approach, acknowledging the co-construction of data between researcher and participants. Co-construction is an approach whereby the researcher gives voice to the participants through a co-production process, congruent with a constructivist epistemology (Denzin and Lincoln, 2005 p 184). Co-construction is a point of departure from traditional grounded theory (Charmaz, 2006, 2014; Bryant and Charmaz, 2007), and sits in contrast to the Glaserian (1978) stance of a "reality" emerging from the data (Mills et al, 2006).

Despite the diversity of GT’s philosophical assumptions, there are a number of central components that contribute to each version (McCann and Clark, 2003b). McCann and Clark (2003b) suggest that each version of GTM places different emphasis on each assumption. These central components are detailed below in relation to where each is located, and described within this and previous chapters:

- Conducting the literature review (Section 2.1.1 & 4.6.3)
- Memo writing. (Phase 2)
- Construction of analytic codes and categories from the data (Phase 3)
- Constant comparison of the data at every stage (Phase 3)
- Theoretical sampling (Phase 2)
- Theoretical sensitivity (Phase 3)
- Quality and rigour (Section 4.5)

The following sections will address each of these components within the three research phases detailed below, exploring their origins and development and justifying their use within this research activity. The three research phases were undertaken concurrently, in line with GTM, and were as follows:

- **Phase 1 Preparation for field work**. This addresses the preparatory stage of this research and includes positioning the literature review, the ethical approval process, and the participant recruitment strategy.
- **Phase 2 Conducting the field work**. This addresses data collection, memo writing, the research settings and the research relationship.
- **Phase 3 Working with data**. This addresses the analytical process, constant comparison, rigour and reflexivity.

4.2 Phase 1 Preparation for field work

4.2.1 Ethics

Ethical approval from University ethics and IRAS (2013), NRES (2011) (NREC Ref 14/EE1151) required that data collection was to take place within the outpatient department and a number of inpatient wards across the two sites of the one organisation. In addition, local organisational policy dictated the registration of projects and areas of study with the research and development office. Additional requirements from the hosting organisation necessitated a DBS (2013) certification and completion of their Good Clinical Practice module (appendix 5).

4.2.2 Research Sites

The rationale for selecting only one organisation centred on the need to develop a deep understanding of the patients’ perceptions, rather than undertaking a broad generalisable study, for which a multi-centred approach would have been more suitable. A number of clinical areas within the organisation were identified as suitable sites for the conduct of the research, including general surgical wards and outpatients.

The research was conducted across two hospitals within the hosting organisation and involved outpatient (OPD) and surgical inpatient areas across both sites. Access to participants was in line with the ethical approval process. Relevant gatekeepers and stakeholders were involved early on to ensure smooth progression and early identification of potential issues. The organisation’s Director of Nursing arranged for me to attend and present my proposed research to the Matrons’ meeting prior to data collection in order to meet them and answer any questions or concerns they had. Matrons from OPD and Surgical services were happy for me to work with them and their team. The organisation employs 13,500 staff, has 1,800 inpatient beds and manages 1.3 million patient contacts annually. Accessing a greater number of clinical areas and departments would, however, have potentially led to a less well focussed study. OPD and surgical inpatient services enabled access to patients requiring surgery and to those who were recovering from surgery.

4.2.3 Voluntary Informed consent and autonomy

On introducing myself and explaining the research to potential participants, I provided a letter of explanation, an information sheet and an informed consent form (appendices 5.1, 5.2 and 5.3). Potential inpatient participants had 3-6 days to consider their participation before I returned to gain their consent. This approach was modified, in line with ethical approval, for potential participants within OPD as there was no opportunity for the 3-6 day period. Mindful of not delaying appointments, I approached potential participants prior to their appointment and they decided after their clinical appointment whether to take part.

Where appropriate to ensure autonomy of decision, documentation was read out to potential participants to provide them with necessary information prior to deciding whether to take part or not (Beauchamp and Childress, 2009). Ethical principles require that the researcher must not employ coercion with, or undue influence on, participants and thus verbal consent was obtained at every contact point. It was made known to participants that they were under no obligation to participate and that they had the right to opt out if they no longer wished to take part, with no effect on any health service that they were receiving or in the future. Mental capacity, with reference to the MCA (2005), was also considered to ensure that consent was gained only from those participants who had capacity. The nurse in charge within each area assisted with the appropriate selection of participants, ensuring they had capacity.

4.2.4 Data protection

All data collected was stored securely in locked storage and on an encrypted memory stick. To ensure both confidentiality and privacy for participants, paper and electronic data were anonymised. Once the raw data containing participants' personal information was anonymised, they were destroyed as per the Data Protection Act (1988). Information cannot be given to a third party without the consent of the participant, in order to maintain privacy (DH, 2005). The participants were informed of their right of access to information stored about them.

4.2.5 Adverse effects

Health and safety was maintained at all times across the clinical areas to ensure the safety of myself as the researcher and participants. Due to the nature of this research, there were limited burdens and costs to participants. Some participants may have found certain aspects of the research process distressing, in which case the responsibility for freedom from exploitation (Polit & Beck, 2008) sits with the researcher, as detailed in the DH research governance framework (DH, 2005 sections 3.5.1 and 3.6.3).

It was recognised that inpatients were in a more vulnerable position than the general population and may have found some discussions upsetting. I therefore carefully observed each patient during the interview process to ensure their wellbeing and was prepared to discontinue if further interaction would have led to distress (DH, 2005 section 3.5.1).

For ongoing support, patients were provided with information on the organisation's patient advocacy and liaison (PALs) procedures. Telephone numbers were provided, where appropriate, for professional support and follow up services. I ensured that no participant was anxious or worried at the end of an interview by employing a short debriefing process once the interview was complete and the audio recording was switched off.

I explained to participants that any information received in the course of the research that could potentially cause harm could create a conflict of interest for myself. The consideration of beneficence was therefore addressed, wherein the risk-benefit was to be assessed by myself and the supervision team. Protocol was developed and made available to the participants that ensured I was obliged to report any information or action from the interview that might lead to potential harm to the participant or others (DH, 2005 section 3.5.1). This would have been the only situation in which confidentiality might have necessarily been breached, with the information required to be reported first to my research supervisors.

4.2.6 Introduction for the clinical staff

I visited the clinical areas that supported the research activity between three and six days prior to undertaking each of the patient interviews. I informed staff about the aims and objectives of the research, as a result of which staff were able to identify me and conduct their work activity without concern. A letter of introduction was made available for the patients, carers, visitors and staff that outlined the proposed research (appendix 5.1). This early visit also provided contextual information for the research around clinical speciality, size and location of the area and familiarisation with the surroundings.

The initial visit to inpatient areas generally prompted the nurse in charge to identify suitable patients willing to take part, which allowed them time to make a decision, and to whom I gave information leaflets (appendix 5.2) before I left. The three to six day ‘thinking time’ period had implications, with some patients either discharged home or transferred to another clinical area. I did not follow up those patients, as approval was only applicable to the clinical areas identified by the hosting organisation.

This approach was employed for all clinical areas and continued for all ten inpatient interviews. The remaining ten participants, plus the three who participated in the feedback session, were interviewed within the OPD setting, for which the ‘thinking time’ period was reduced. Staff assisted in identifying potential participants, who were approached before, and asked to interview after, their appointment. This allowed for a short period of time in which they considered the request. The assistance of staff in the selection of suitable participants may be criticised as having the potential to skew the data and, although this was recognised as a possibility, initial purposeful and theoretical sampling helped to mitigate this risk.

4.2.7 Exclusion criteria

The exclusion criteria applied to all areas and were as follows:

- Patients under 18 years of age (participation of minors was not deemed appropriate for this doctoral study).
- Patients who did not have capacity (to comply with Mental Capacity Act, 2005).
- Patients admitted to accident and emergency (so as not to potentially interrupt patient treatment in an emergency situation).
- Patients admitted to medical or surgical emergency assessment areas (as above).

4.2.8 Delays to the ethical approval process.

The initially proposed data collection was planned to commence during October 2014 but was delayed by NHS R&D requirements. Once these requirements were met, data collection commenced in November 2014.

4.3 Phase 2 Conducting field work and data collection

4.3 Recruitment

4.3.1 Purposive and theoretical sampling strategy

Participant sampling for GT in this study was initially purposeful but then moved to theoretical sampling as categories and theories emerged and developed, in line with McCann and Clarke (2003b).

Charmaz (2014) strikes a note of caution that this may result in early closure of the data. She suggests supporting theoretical sampling with memo writing and employing a sufficiently systematic process to identify gaps in the data and develop meaning for categories. This process, of theoretical sampling combined with memo writing, was therefore employed to ensure a sound, congruent methodological approach to GTM (Corbin and Strauss, 2008). The demographic details of the patients who were interviewed is illustrated in appendix 6 and also in chapter 5 section 5.1.

Purposive sampling

The initial stage of participant recruitment was conducted in the OPD where, over the course of each day, I interviewed between two and three participants. In an ideal situation, each interview would have been transcribed and analysed but this was not possible due to time and access limitations. Where possible, I had a break between each interview, during which I could reflect on what had gone before and make additional notes and memos to add to the subsequent interview. Recruitment for this initial phase followed the original inclusion criteria. As these participants were part of the patient community, they were able to provide insight into the research question.

Theoretical sampling

Theoretical sampling is a fundamental principle of GTM and was employed to add to the rigour and quality of the research. Charmaz (2014) posits that theoretical sampling is an approach in which emerging categories, that look promising but lack depth, can be added to through sampling and development of properties within the categories until no new properties emerge. Charmaz (2014) adds a note of caution that theoretical sampling is sometimes poorly evidenced and also misinterpreted as initial sampling. The difference between initial and theoretical sampling is illustrated in appendices 7a (initial sampling strategy) and 7b (theoretical sampling strategy).

4.3.2 Face to face patient interviews

Charmaz (2014) suggests that intensive interviewing, whilst needing to be culturally appropriate, is suitable for GTM data collection as the researcher is using the research method for construction of the data and analytical control. Intensive interviewing is a process Charmaz (2006; 2014) uses throughout her work, whereby open-ended questions from the researcher seek to elicit in-depth responses from the participants about their experiences, perspectives and meanings.

A general semi-structured interview guide provided an element of support for the initial interview process, with subsequent interviews utilising the theoretical sampling approach (Charmaz, 2014); a process that continued until data saturation was reached. Charmaz (2014) suggests that data saturation needs to be congruent with the researcher's epistemological position and the analytical level aspired to. She proposes that if there are too few interviews, the emergent categories may not reach data or theoretical saturation. This will potentially result in the study lacking the ability for further exploration and depth. She conversely posits that substantial amounts of data are, of themselves, not necessarily sufficient to ensure quality. I was therefore mindful to apply Charmaz's (2014) guiding principles of intensive interviewing within the semi-structured interview guide to ensure that data collected was congruent with a constructivist perspective of co-construction and with quality issues detailed in the earlier section.

The initial semi-structured interview guide was drawn up as required for IRAS and NHS ethical approval (appendix 5.5). I was careful to point out during the ethical approval process that these questions were only a guide and that, through an iterative process, they would evolve and develop as the research process developed. Following two pilot interviews, (not included in the data analysis) a revised interview guide was drawn up (appendix 5.6) addressing issues that arose during the pilot. This was further developed and refined as interviews progressed, as illustrated in appendix 5.7. The guide supported me in working through particular areas of each interview (Seale, 2004), allowing me to take some control (Kvale, 1996; Charmaz, 2006) and direction but also allowing participants to tell their story and thus open up their subjective world (Charmaz, 2014). I took Charmaz's (2014) approach, with the design of a number of open ended questions that were congruent with the research question and the potential experience of the participant. Reflexivity and memoing was used throughout for transparency.

The interview is a well-documented method for data collection, with claims that it is the most commonly used data collection tool in qualitative research and often used in preference to other data collection methods (Silverman, 2000). The dominance of the interview within society has led to criticism of its use within qualitative research. Silverman (1993) viewed the interview as being ubiquitous in everyday life and coined the phrase ‘interview society’ to describe the phenomenon. The phenomenon is evidenced by the use of interviews in the mass media (Atkinson and Silverman, 1997; Silverman 1993), with some also claiming that social researchers may endow the interview with more than it is able to reach (Sandelowski, 2002). In addition, there may be an assumption that the interview is relatively straight forward as an approach (Kvale, 1996; Fontana and Frey, 2005), as the rules and roles for the interviewer and interviewee are recognised within everyday life. The semi-structured interview, however, allows for a more flexible approach in which the interviewer can refer to a framework of questions that are more responsive to the individual answers than a structured interview (Bryman, 2012). Morse (2001) concurs, proposing that data generated from semi-structured interviews are superior, in terms of the story generated, to other forms of data collection, which only provide a small snapshot of the story.

Interviewing within the social sciences lacks any prescribed, standardised approach. Given the familiarity of the interview in everyday life, the early stage researcher may assume simplicity and thus underestimate the task ahead (Kvale, 1996). I was therefore mindful of such assumptions and employed the method of face-to-face, semi-structured intensive interviewing to ensure that the approach was congruent with GTM and my epistemological perspective, as described earlier.

There is, however, a view that semi structured interviews may force the data (Glaser and Strauss, 1967) - an issue with GTM that has been present since its early beginnings. Morse (2001) stated that the semi-structured interview is an aid for an early career researcher and is a very different approach to employing strict schedules and guides. I was therefore aware early on that data forcing posed a real threat to the quality and rigour of the study. How I managed this is illustrated in appendices 3.1-3.4, 5.5-5.7 ,9,11,13 through a reflexive approach.

Recording the interviews provided me with an opportunity to take notes, in which expressions, eye contact, body language and artefacts present in the interview space were recorded (appendix 8). Described by Sandelowski (2002) as more than recording the interview, this wholeness of approach that the interviewer invests within the interaction allows for greater understanding of the participants' lived experiences. This, in turn, supports the analytical approach of SA (Clarke, 2005) through mapping out these observations within the situatedness of participants' responses.

Audio recording each interview ensured a full and accurate record of the dialogue. Glaser (1998) refused a recorder (tape) during interviews, claiming that recording denies the researcher the developing skill in note taking. Morse (2001) criticised this approach, pointing to difficulty in using the patients' voice through direct quotes, with Schreiber (2001) reporting note taking as a distraction leading to valuable narrative from the respondents being missed. This critique resonated with me and I therefore employed the voice recorder to 'do the work' whilst I took notes during the interview that added to the situatedness and subtleties. I felt this best suited the interview style and allowed greater freedom within a more holistic approach to the interview interaction.

Fontana and Frey (2005) suggest that the written and spoken word are open to interpretation and misrepresentation by the researcher and the participant, even when using the most carefully planned and worded questions. To ensure any misrepresentation was reduced to a minimum, two pilot interviews were conducted using an initial interview guide that was informed by a combination of the research question, reflection on my researcher position and an initial literature search.

The interviews were transcribed separately, with silences, delays and subtle nuances noted within the transcripts. The subtleties of transcription are often neglected or overlooked but Ochs (1979) claims they are central to generating theory. This approach was therefore employed for all interviews, during the course of which I critically evaluated my interview style, listening and observational skills, presentation of questions and the use of silence, to ascertain if there were points for improvement in the quality of each subsequent interview (appendix 9). Although adopting this approach of transcribing and reviewing each interview was time consuming, as noted by Glaser (1998), listening back ensured both familiarisation with, and immediate immersion in, the data.

Given the growing acceptance that it is unrealistic to achieve neutrality in interviews, researchers are increasingly concerned with co-construction between researcher and participant in the interview itself (Finlay, 2002). I therefore continued to review and reflect upon interview techniques to seek continual improvement in my role of interviewer and to work more reflexively as the interviews progressed. Evidence of this reflexivity can be seen in appendix 9. The use of continual reflexivity throughout my data collection and subsequent analysis is covered in depth in section 4.7 of this chapter. It helped to evidence my position within the study and the part that I played in all aspects of the research process.

As a Registered Nurse, I recognised that I had a “position” within the research process. With limited experience as a patient, I adopted an *“outsider”* stance in the research process with respect to any *“inside”* knowledge of the patient perspective. Some participants, however, also worked within the healthcare professions, so for them I could be seen as an *“insider”*, as Bonner and Tolhurst (2002) state that many researchers will be *“insiders”* (part of the social group they are investigating). Allen (2004) states that the “*insider/outsider”* position will shift and change throughout the research process, with Ganga and Scott (2006) describing how changes in the wider society will also affect researcher positionality. Fontana and Frey (2005) concur and suggest that interviewing techniques are not without influence from the wider cultural context, and as cultures change and develop so do the interviews. Sandelowski (2002) describes the ideal interview as a “*conversation between equals”* and that there needs to be consideration for where power shifts take place between researcher and participant, with a consequent impact on the narration and subsequent analysis. It is therefore important to remain sensitive and flexible with the interview process and to build in reflexivity (Alvesson and Sköldberg, 2009).

The location of each interview was as follows:

Each time within OPD, I was allocated a room in which to hold the interviews. The rooms were part of the consulting suite and thus provided a confidential space that was free from interruption.

Within the inpatient area, I interviewed all participants at their bedside, their beds being located either in open six bedded bays or in single side rooms. Layout of the six bedded bays is detailed in appendix 10

There are clearly difficulties with the inpatient interviews being conducted in the open bays and a number of reflective points in appendix 11 allude to these difficulties.

4.3.3 Feedback session

On return to OPD in order to conduct the patient feedback session, the Sister/Charge Nurse assisted in identifying potential participants. The initial approach for this feedback session was adapted as there were issues associated with recruitment of participants and their subsequent return to OPD. This initial plan and the subsequent alteration is included in appendix 12a, alongside a piece of reflective writing that explores the potential issues around the need for a different approach.

The patient feedback sessions aimed to see if the findings from the patient interviews resonated with past patients’ experiences. Thus, a number of ‘interviews’ with participants from the OPD setting were to be conducted, with the aim of employing a discursive, explanatory approach in bringing findings, quotes and themes to individual participants. The individual one to one approach was necessary as constructing a group was not practicable. The limitations of this approach were noted by Seale (2004), who described the particular importance of interviewing within focus groups to elicit a more interactive and dynamic platform for data collection than can be achieved with one to one interviews. He also described some of the skills the researcher should employ to ensure participants can voice their views freely without dominance, providing space for difference whilst at the same time focussing on the aims and objectives of the researcher.

Acknowledging the principles of focus group interviewing, I therefore adapted my one to one interview style towards a more discursive, focussed, attentive approach where I was looking for agreement, additional thoughts and perspectives but also for areas where the participant refuted what I had suggested. I used quotes from the previous participant interviews that had been coded and themed to discuss findings with participants. An example of one of the themed and coded quotes is provided in appendix 13.

The audio recordings were then transcribed and I read through them a number of times to identify aspects to add to the analytical process of data coding.

4.3.4 Observation.

Charmaz (2006, 2014) pointed to the potential for supplementary data collection through observation and surveys, which are complementary to the interview process within a Grounded Theory approach. Glaser (1998, 2002) proposed that *'all is data',* in as much as the research design should not exclude these approaches for fear of limiting the data and thus the theory. Direct observation was not planned as a data gathering opportunity, however, contextual information from observation was included in this study. Sandelowski (2002) sounded a note of caution with respect to the qualitative researcher who considers the interview as representing the totality of facts, instead urging researchers to take account of the material world, employing a comprehensive observation of the body with the body. Researchers were urged to engage with the body and all its senses to achieve this, the result of which would be *"full-bodied"* qualitative research (Sandelowski, 2002), and I was thus mindful of using observation techniques throughout the interview.

Complementary to Clarke’s (2005) work on situatedness, I employed all senses during the interviews to ensure maximum benefit for the construction of the context and situation of the data gathered. Appendix 9 illustrates the notes that I made, and added to, during a particular interview.

4.3.5 Memo writing.

I employed a number of strategies, all congruent with a CGT methodology, that support the principles of openness and transparency. Journaling played a large part throughout my research, in which Woolgar and Ashmore’s (1988) dialogical “second voice” approach (as described later on page 93) was utilised via hand written notes. For data outputs where I lacked depth of understanding, reading around the subject helped to ensure my critical questioning of the situation. Memoing during data collection and analysis formed an additional written record of the decisions made. In addition, supervision meetings helped to develop my critical voice, which then informed the dialectical journaling.

In their original work, Glaser and Strauss (1967) described memoing as a useful process that can be employed during data collection through the taking of field notes, which add to the data gathered from participants’ responses. Memoing can also be used to provide narrative related to data coding, whereby coding memos help to track, and provide rationale for, the coding decision/s. It is suggested that codes have the memo attached in order that, when the process of writing theory starts, context and rationale is achieved via the memos, which in turn supports the emergent major themes of the theory being generated (Charmaz, 2014)

The process of memoing, and its development over time, is evident in both Glaserian and Straussian work, with contemporary contributions (Clarke, 2005; Lempert, 2007 p245-264; Birks and Mills, 2011; Charmaz, 2014) reinforcing the necessity of memoing. Glaser (1978; 1992; 1998) reiterated the importance of memoing for the coding stage of the research process and was critical of situations where this was lacking, arguing that the researcher would then be writing mere conceptual description. Glaser (1998) cautioned, however, that memoing is difficult, as the researcher needs to be free to capture their own thoughts and conceptualize ideas. Lempert (2007, p245-264) suggested that, whilst memoing itself is a simple activity, the thinking behind the process requires skill and practice, which can be a challenge for the novice researcher. Strauss and Corbin (1998) continued to emphasise the necessity of memoing and produced a detailed account of the different types of memos within their later work (Corbin and Strauss, 2008).

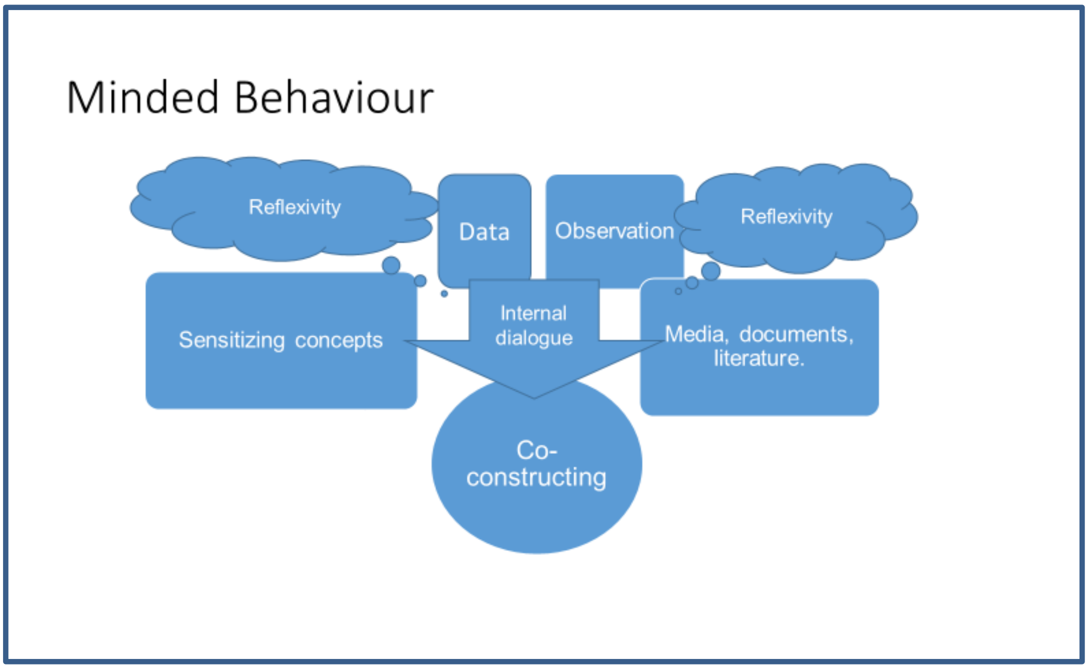
Lempert (2007) described how she memoed and referred to the literature whilst undertaking analysis, but with an awareness of the potential of forcing data into pre-existing categories. She described this process as adding to the questions she needed to ask herself about the data, opening up and sensitizing herself to others' work and theories. This mirrors the approach used in this doctoral study when considering the first stage literature review and the broad reading around the subject, although I was mindful not to bring about early closure by forcing data into preformed ideas (Glaser and Strauss, 1967). By adapting Clarke's (2005) cartographic approach to data analysis; memoing alongside other forms of reflexivity, including discussions and debates with fellow doctoral students, supervision, conference attendance and presentations, I felt that I had built into a reflexive stance into the research activity (appendix 3). Reflexivity is addressed in section 4.7 of this chapter, but has been used alongside memoing to provide for deeper questioning of my positionality, response and development.

4.3.6 The spoken word

Data gathered within this GTM study consisted primarily of spoken words exchanged between myself as researcher and the participants. I also used written recording of the nonverbal signals, as interpreted by myself, and my written observations of the social world being studied. Language was clearly central to this research process (Milliken and Schreiber, 2012) and therefore the language selected ultimately shaped the research. Charmaz (2014) stated that alongside language, the emotions of both participants and researcher will affect the research relationship. I attended to these concerns through a reflexive approach, which is detailed at both a theoretical and practical level in section 4.7 of this chapter.

Diagram 6 illustrates how GT methodologists take into account perspectives other than those elicited from participants, such as researchers' observations, sensitising concepts and material gleaned from literature and other sources such as the media. There is a back and forth process of exploration and analysis of these differing perspectives until the researcher obtains clarity. Milliken and Schreiber (2012) called the internal dialogue that occurs between all these elements 'minded behaviour'.

Diagram 6: Minded Behaviour adapted from Milliken and Schreiber (2012).



Minded behaviour therefore underpinned the research process, providing a constant reminder of the need for openness and transparency (Seale, 2004).

4.4 Phase 3 Working with data.

4.4.1 Data analysis

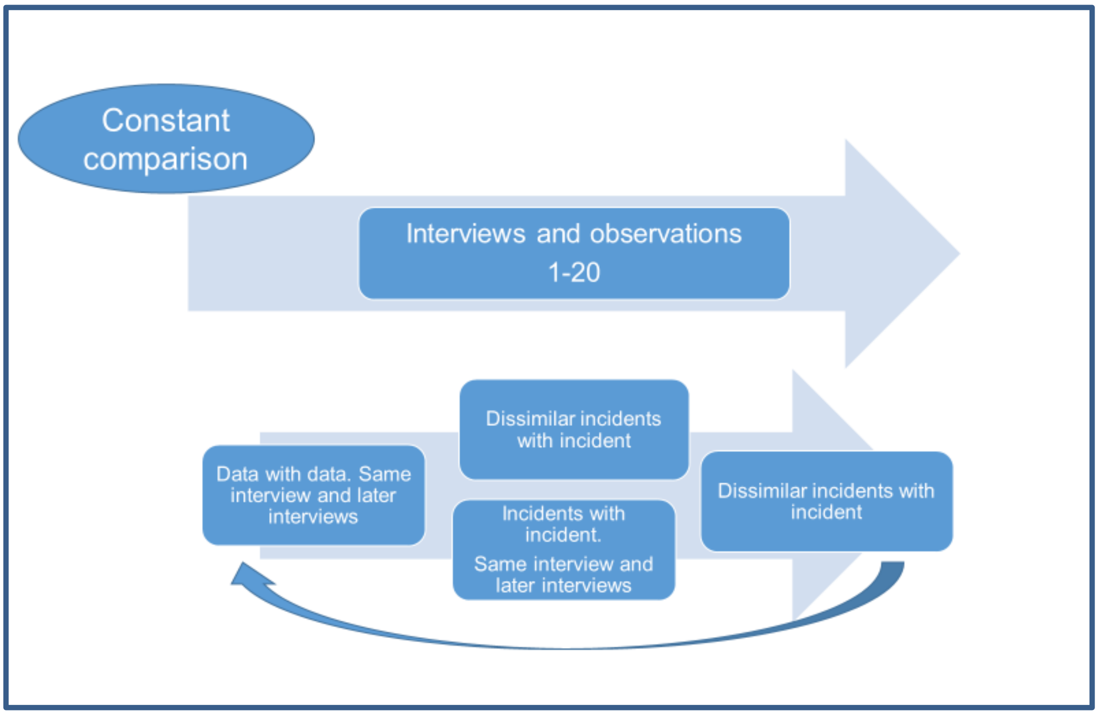
Data analysis took place throughout the data gathering activities of the patient interviews; a process referred to as constant comparative analysis (Glaser and Strauss, 1967; Glaser, 1992; Corbin and Strauss, 2008). Data analysis is not without its challenges and the researcher needs to continue remaining open, reflective and reflexive during this stage (Alvesson and Sköldberg 2009; Charmaz, 2014). If not, there is a danger that codes and categories may be forced into preconceived ideas (Charmaz, 2014). Approaches that I utilised in this respect are referred to within this chapter under quality and rigour and within section 4.7 of this chapter.

4.4.2 Constant comparison.

This approach has the ultimate objective of developing familiarity with the data to support the theoretical properties of the categories generated (Glaser and Strauss, 1967). Charmaz (2006, 2014) described the various dimensions of constant comparison, whereby the researcher compares data from later interviews with data from earlier interviews, and data from within each individual interview. Corbin and Strauss (2008) concur and add that this approach has the potential to uncover different aspects of the area under study. Diagram 7 illustrates the sequential process undertaken for this doctoral study at a macro level, with micro level data analysis described in more detail within appendix 13.

Constant comparison involves making comparisons at every stage and every level of data analysis (Charmaz, 2014). It has remained a major foundation for GTM right through from the original work (Glaser and Strauss, 1967) to more contemporary methodologists (Charmaz, 2014). Glaser and Strauss (1967) advocated using constant comparison alongside theoretical sampling to support theory generation in a cyclical process, generating output that remains close to the data and guides the researcher (Holton, 2007) towards emergent theory. As the categories emerge through constant comparison methods, the researcher can then see if the data continues to support emerging categories through further development of their properties and parameters. I adopted Charmaz's (2014) and Holton's (2007) approach to constant comparison, as detailed in Diagram 7.

Diagram 7: showing stages and process of constant comparison. Adapted from Charmaz (2014) and Holton (2007)



4.4.3 Construction of analytic codes

Glaser and Strauss (1967, p105) described the coding process, for which the researcher codes incidents within the data "*into as many categories of analysis as possible.*" They went on to state that constant comparison of incidents for categorisation in turn generates theoretical properties of the categories. The descriptions of these categories can come from either the researcher's words or words abstracted from the data.

Glaser (1978) applied the process of open coding, line by line analysis and memo writing to support the theoretical ideas that emerged; an activity that it is suggested has data verification, correction and saturation ‘built in’ if conducted appropriately (Glaser, 1978). He also stated that continued open coding in as many ways as possible, coupled with constant comparison, would lead to emergent categories and saturation. Strauss and Corbin (1990) also conducted open coding as their initial stage but incorporated the development of categories in terms of properties and dimensions at an earlier stage than for Glaser’s approach. Glaser (1978) was critical of categorisation at this earlier stage, suggesting that this may “force” the data. Walker and Myrick (2006) were concerned with the timing of categorisation and therefore concurred with Glaser (1978) in part, although they also recognised the value of applying dimensions during data analysis. Charmaz (2014) also suggested that line-by-line coding is a suitable approach when the researcher is looking at detailed observation that, in addition, will help the researcher see the familiar in new light.

Data coding, as described by Charmaz (2014), is the link between data collection and generation of theory, which helps to shape and give structure to the analysis. The principles of GTM coding take the certainty of the participant’s narrative towards the analytic through an interpretive approach (Charmaz, 2014).

Adopting a constructivist grounded theory approach (Charmaz, 2014) to coding and analysis, I worked through the three phases of initial and focussed coding suggested by Charmaz (2014). I then brought the data back together in the development of links and relationships, a process she described as being different from axial coding. Axial coding, as described by Corbin and Strauss (2008), works alongside open coding, rather than as a separate activity. It is a coding stance that incorporates conditions and context (Strauss and Corbin, 1990) and therefore supports the researcher in moving through the data and relating concepts to each other, thus making connections. Strauss and Corbin (1990) asserted that this approach helps the researcher think systematically in dealing with complexity. Charmaz’s

(2014) approach was a little different, as she suggested that axial coding is “procedural” (Charmaz, 2014, p148) and may therefore “impose” a framework that inhibits or enhances the researcher’s view and understandings. She herself adopted a more emergent process, one that resonated with my grounded theory approach. Evidence of coding and analysis for this doctoral study is contained within appendix 13.

4.4.4 Initial coding.

I transcribed and read through each interview, a process that helped to bring me closer to the data and to ensure accuracy (Easton et al, 2000) of the transcriptions. I explored the use of data software for management of large volumes of data, for example NVIVO, however, I felt that this would bring distance between me and the participants’ voices that I felt I needed to hold onto at every level. Saldaña (2013) recognised that manipulating a software package during coding for the early career researcher can be daunting and may divert the researcher’s efforts into software management rather than data coding and analysis. I therefore decided upon a manual process where, with the use of excel, I could exercise a degree of management when memoing my first impressions and determining what the initial codes may be. This process was undertaken for each interview separately, with acknowledgement that subsequent interview coding could have been influenced by codes that went before, although employment of constant comparison helped to mitigate this risk. Charmaz’s (2014) principles of coding proved to be a solid foundation as I moved through the coding and analytical process summarised below on page 84:

Box 1: Principles of coding, Charmaz (2014 p120).

- Remain open
- Stay close to the data
- Keep codes short, simple and precise
- Preserve actions
- Compare data with data
- Move quickly through the data

Coding was initially achieved through chunking large pieces of narrative, something that Saldaña (2013) called “lumper” coding. He described the difference between “lumping” and “splitting”, wherein the latter generates large amounts of data and codes. Although each approach has advantages and disadvantages, utilising the pragmatic approach of manipulating more manageable pieces of data and subsequent codes I lumped all data as a first stage process (see appendix 13 screen shot 4).

Charmaz (2006) adds a note of caution if not undertaking line by line analysis, suggesting this may result in researcher preconceptions shaping the analytical process. I therefore re-examined the data responses on a line by line basis, recoding as I went. Charmaz (2014) stated that the researcher at this stage needs to ask questions and formulate meanings and suggested an approach, summarised in box 2 (page 85), that helps researchers identify actions and process within the data:

Box 2: Questions I asked of the actions identified in the data, adapted from Charmaz (2014 p 127).

- What process is at issue here? How can I define it?
- How does this process develop?
- How does the participant act whilst in this process?
- What does the participant say about feelings and thoughts through this process? What does the behaviour indicate?

Gerunds

Charmaz (2014) described the presence of numerous gerunds in the transcription as evidence of an in-depth interview. Each transcript was therefore mined for gerunds, firstly in an attempt to identify the depth of each interview and secondly to provide an understanding of the *actions* that participants were experiencing. Where an interview was rich with gerunds, I compared it with ones that had less in order to identify how I could have approached the interview differently. Reflective writing and memoing assisted in developing an improved interview technique.

In vivo codes.

Charmaz (2014) described the use of in vivo codes for 3 purposes:

1. General terms that “everyone” knows (*the extra mile; heart of gold*),
2. An innovative term that captures meaning or experience (*they know what they are doing*),
3. Insider shorthand specific to a group that reflects their perspective (“*don’t be scared to………”*; “*Oh don’t worry about it….”*).

She goes on to say that in vivo codes help to preserve the participant’s responses but only if they are treated appropriately in the coding process.

They will otherwise be lost or else not become grounded within the data. Mindful of this point, I made certain that the in vivo codes were ‘kept alive’ throughout the coding process: revisiting them through the constant comparative process also supported this.

Coding individual incidents helped me to see patterns and differences within participants’ experiences and perceptions. By comparing incidents together, ideas emerged that were then compared to earlier incidents, helping to identify properties of the emerging codes. Charmaz (2014) suggested that through comparison of dissimilar incidents, a greater degree of insightfulness may develop. This approach proved useful at points during coding and analysis where I was “stuck”, struggling for the insight or the ability to see the significance of these incidents.

4.4.5 Focused coding

Focussed coding was employed as the second stage of analysis, from which frequent or important initial codes emerged that were viewed as more significant. These codes developed a conceptual dimension greater than initial codes. Charmaz (2014) noted that the movement from initial towards focussed coding requires more than mere selection. She described how she used these conceptual codes to revisit earlier initial coding for significance and frequency and to “sift” through large amounts of data in order to assess for adequacy of these codes. My use of this technique was not linear: I used it to go back to earlier topics throughout the coding process whenever I needed to reassess codes in a new light, unpick and check any preconceptions or for codes that I had missed. This approach, which also helped to condense the data for greater manageability, is evidenced in the memos that run alongside the analysis see appendix 13 for examples.

Progression from initial to focussed coding was facilitated by transferring the codes onto individual cards. This further analytical process assisted with collation and making sense of the outputs whilst also stimulating and challenging the generation of thought (Graue and Walsh, 1998). I was aware of the potential for transcription error when using ‘incompatible’ systems; to address this, initial codes were checked and rechecked for representation in the card system, ensuring none were missed or overlooked.

4.4.6 Theoretical sensitivity and theoretical coding

Other divergences in GTM concern the term ‘theoretical sensitivity’. This term, as described by Glaser and Strauss (1967), is a two-part concept. It relates firstly to the level of insight the researcher has around the area of study and secondly to what the researcher knows in theoretical terms and how that knowledge is used in the research process. Therein lies the dilemma the researcher may have, as at one and the same time they need to be close to the research process whilst also needing to consider the data from a distance and in conjunction with theoretical knowledge. Glaser (1978) promoted a less well-defined concept of theoretical sensitivity, with the researcher immersed in the data, letting the data “speak” and only using neutral questions alongside constant comparison of the data. Strauss and Corbin (2008) were more directional about the relationship the researcher, with their own prior knowledge and understanding, has to the data and how that relationship is used to immerse oneself within the data to best present the views articulated by the participants. They employ a number of techniques for data analysis, all of which they claim increase theoretical sensitivity. These include flip flop and waving the red flag, questioning and analysis of words and phrases. I have adopted many of these techniques to aid theoretical sensitivity.

Charmaz (2014) and Glaser’s (1978) position on prior knowledge is from differing perspectives. Charmaz (2014) noted that the researcher’s prior knowledge may have some influence on theoretical codes, while Glaser (1978) posited that the researcher needs to know many theoretical codes to aid initial coding through to how they are related and theory generation. This difference became apparent to me through the initial coding process, as I recognised there were some theoretical areas about which I was less knowledgeable and those that I had the potential to close early. As I read more widely to address some of these gaps and concerns, I continued to memo and add to reflexivity to ensure coding was not forced or preconceived, critically reviewing the emergent codes.

4.4.7 Data saturation and data sufficiency

Data saturation, which relates to the stage where nothing new is heard (Stern, 2007) from the data, is a critical consideration within GTM for establishing the quality of the research. Charmaz (2014) talked about the significance of research objectives, whereby a modest study may reach saturation rather more quickly than one that is more ambitious. At a practical level it is therefore difficult to say how many interviews will reach saturation for a given research situation. It was with this in mind that I gained ethical approval for up to thirty participant interviews and a further thirty participants for the feedback sessions. This number was established through a combination of the literature (Charmaz, 2014; Stern, 2007) and advice from other grounded theorists who were aware of this doctoral study’s purpose.

Charmaz (2014) also posited that there is a difference between data saturation, wherein the researcher hears nothing new from participants, and theoretical saturation of the emergent categories. The former may appear early on if the researcher is working within a repetitive process of data collection, whereas the latter is dependent on the analysis stage of constant comparison (Holton, 2007).

4.5 Quality and rigour Issues.

Within the quantitative research tradition, the quality and rigour of research output is often measured in terms of validity and reliability. Given the diverse ontological and epistemological underpinnings of qualitative research, the use of validity and reliability to determine quality and rigour is not necessarily suitable (Seale, 2004). There is much debate about quality issues from the qualitative perspective, therefore it is necessary for the researcher to evidence the quality of the work through numerous approaches that need to be congruent with the research paradigm (Seale, 2004). Corbin and Strauss

(2008) state that each qualitative methodological approach should have its own judgement criteria for quality.

Koelsch (2013) posed the question as to how the researcher evidences quality. Seale (2004) listed various ways in which a researcher can evidence quality. I will discuss the rationale for the evidence I have provided for this doctoral study in the following section:

4.5.1 Member checking

The term member checking, or ‘member validation’ (Seale, 2004), refers to a variety of different approaches that claim to determine credibility of data and findings. These methods include: establishing validity and accuracy of the transcription, in which transcripts are returned to each participant for checking, and adequacy of analysis, wherein the final report is evaluated by the participants (Bloor, 1997; Seale, 1999).

Seale (1999) suggested that the motivation for a researcher to undertake member checking is to ensure they have captured a persuasive account of the respondent’s perspectives. Lincoln & Guba (1985) described member checking as the most important aspect to establish credibility for the qualitative researcher. Forbat and Henderson (2005), however, were critical of member checking as a means of ensuring transcription accuracy as participants, often inexperienced in reading the spoken word transcribed verbatim, may feel overwhelmed by the number of hesitancies, silences and grammatical inaccuracies in their speech. The researcher would therefore have to decide how to incorporate the participants’ feedback having undertaken member validation. Some have argued that participants, by amending or clarifying their responses from the initial transcription, add to their individual voice (Grundy et al, 2003).

Through the constructivist perspective, there is recognition and understanding that the co-creation of data and subsequent analysis is inherent in the process (Charmaz, 2006). I acknowledge this co-construction and, as such, recognise that the resulting theory is derived from an interpretation of what the participant is saying.

The practical challenges of this doctoral study meant it was not possible to return participants’ transcriptions of their interviews or to present to them the finished thesis. More importantly, I viewed this approach as incongruent with the epistemic perspective of constructivism in which each voice, each view and each perspective is to be considered (Forbat and Henderson, 2005), along with the context or situatedness (Clarke 2005) of that captured moment.

A different form of member checking was used in this research, utilising feedback sessions with new participants in which I presented emerging themes and findings to be critiqued, confirmed, refuted and added to (see appendix 12b for sample questions and quotes from feedback sessions). The output from these sessions helped to identify if further themes had emerged and whether additional interviews were necessary to achieve data saturation. In support of this approach, Charmaz (2014) acknowledged the usefulness of member checking and she also described how researchers may adapt this principle to suit the research.

4.5.2 Search for negative instances

Clarke (2005) cautioned against oversimplification and searching for commonalities in isolation, and instead suggests a focus on difference, contradictions and ‘messiness’ of the area under study. She achieved this by adopting a rigorous and consistent approach to data capture and analysis, recording and memoing the resulting complexities through cartography and making links and connections. Using this approach has helped me to look at these complexities in new ways and not to dismiss outliers or negative cases that may have otherwise received little or no analytical treatment.

4.5.3 Produce well-grounded theory

The use of methodological notes (MN) (Corbin and Strauss, 2008), a process known as ‘auditing’ (Seale, 2004), illustrated the decisions made within the coding process and contributed to reflexivity. By attending to the theoretical understandings articulated within this section and their practical application within the methods section, I hope to have achieved well-grounded theory. Applicability in qualitative research can be achieved by ‘thick’, detailed description of the setting, with which the reader can ‘apply’ the research setting to their own situation (Lincoln and Guba, 1985), gaining understanding of the context and settings of the inquiry whereby future corroboration may be possible. Carlson (2010), by way of contrast, described qualitative research inquiry as being unique, with replication across different settings therefore not a concern. Whichever position is taken, rich and thick description will ensure the reader makes some form of connection with the findings and is able to judge transferability to their own situation.

4.6 Reflexive approach

This section will explore reflexivity from my perspective as an early career researcher and how Clarke’s (2005) work on SA supported me in developing a heuristic device for reflexivity during the entire research journey. Woolgar and Ashmore (1988) noted that reflexivity within social science, despite being seen as problematic, was recognised as necessary, although little attention was paid to its application. They described their use of a dialogic approach, whereby the researcher engages in a dialogic ‘second-voice’ position that challenges assumptions and, if written down, assists the researcher in providing evidence of their reflexivity. There is an assumption however that the researcher is knowledgeable about the ‘second-voice’ position and the subject under dialogic debate. I addressed this through supervision meetings, presentations at conferences and networking across the research community (appendix 14). This enabled a dialogue between opposing positions and shifting perspectives to be maintained throughout this study.

Bolam et al (2003) cautioned that qualitative researchers need to move away from prescriptive methods in reflexive activity. They suggested a need to be creative in the development of tools that support the reflexivity process and are responsive to the research paradigm. Exploration of the multiple iterations of GT as a methodology brought me to Clarke's (2005) work on SA, not only as a methodological adjunct to Charmaz's (2006; 2014) approach but also as a heuristic device for reflexivity.

Clarke (2005) suggested researchers avoid using SA prescriptively but instead adapt it for their own unique area of study, which is in line with Bolam et al's (2003) support for reflexive creativity. Clarke's (2005) use of maps and mapping prompted me to think more creatively as to how to capture thoughts and preconceptions as I moved through my study.

4.6.1 Maps and Mapping

The map is an ancient method of representing and communicating large amounts of information (Dodge et al, 2011). The continuous process of mapping is assisted through technological advances, in which the moment is captured but can develop and change as the situation unfolds (Ingold, 2000). Clarke (2005) described the employment of maps and the process of mapping as providing the capacity to capture complexities in a more dynamic way than the written word. Continual mapping was both reassuring and empowering for me a researcher. I was able to see my decision trajectory, which supported the notion of personal and academic development and advancement and in turn informed my research output.

The application of mapping provided me with an audit trail of decisions and developments at various stages. Clarke's (2005) work on 'situation' and 'social worlds' brought me towards a position of greater criticality in terms of questioning and challenging my own preconceptions. This criticality helped in sensitising me when opening up the situation and social worlds at a macro, meso and micro level. In line with a CGTM (Charmaz, 2006, 2014), this approach brings the researcher's preconceptions to the fore, including what is taken for granted by the researcher in terms of themselves, the area of research and the wider context.

The application of SA in the research process was used to support and evidence the following:

- managing positionality
- the literature review
- preparation to enter the field.

This approach had the ultimate aim to ensure the research addressed issues around quality and rigour and to do justice to the multiple perspectives from the research participants' complex worlds. Evidence for managing positionality, the literature review and preparing to enter the field is provided within appendix 3.

4.6.2 Managing positionality

Based on my initial position, I developed a mind map to bring my thoughts, beliefs and understandings from my previous clinical experience and early researcher activity to the fore. The map was annotated with journaling notes to add to the awareness of self. In order to evidence my positionality, and to bring a degree of reflexivity to the process, I engaged a dialectical "second voice" approach, as articulated by Woolgar and Ashmore (1988), that assisted in challenging beliefs and views held. I was aware that this activity was about identifying the position I began the research process from, to bring about challenges to those long held beliefs that may have reduced or limited the research activity.

This map was then analysed in order to make sense of where these thoughts were placed in terms of Clarke's (2005) suggested elements at a macro, meso and micro level. More detailed self-analysis followed, in which links and relationships between these elements were explored as I progressed and gathered more information. A level of tension had started to emerge between what I had begun to research and understand, and what 'was known' from my past clinical experience. By bringing these tensions to the fore I, started to see what would shape and continue to shape the direction of the research activity. The activity of mapping out this process of ‘opening’ up, which continued throughout the research, brought greater clarity and challenge. It uncovered areas where there was a need to seek out further understandings and addressed transparency through the ongoing process of mapping.

The employment of maps and mapping can help the researcher to identify whether they are an insider or outsider. Moore (2009) described the insider researcher as having a position within the social group being studied, with the outsider researcher not having such a position. There is, however, a recognition that this binary distinction is not always clear cut and that it may be more appropriate to see the researcher’s position in terms of their physical and psychological distance from the area of study (Ritchie et al, 2009). Kirby (2007) embraced his unique prior knowledge and experience and used it to position himself as a “contextual researcher” with “experiential alertness”, whilst also noting caution that this should not obscure what is of significance in the data. This approach alludes to a researcher who is contextually aware and thus, through the interactions between researcher and participant, co-constructs a unique story. Through my own experiences in clinical practice, I was experientially alert and contextually aware, and this approach therefore resonated with me. It added to the richness and depth of the area of study, although I was always mindful of this obscuring the data analysis process.

4.6.3 The literature review

The analysis of social worlds is embedded within symbolic interactionism (Blumer, 1969). The researcher enters the area of research and attempts to make some sense of it through asking a number of questions, many of which are prompted by the initial contextual literature review (see appendix 3.1).

The literature review demonstrated the confusing landscape for the HCA in terms of roles, responsibilities and job descriptions. It was therefore important to be clear about these differences across clinical areas in the study and to ensure clarity about the overall roles and responsibilities and strategy for the HCA within the organisation. Job descriptions for individual areas also formed part of the context of the study and the introduction stage of the research sought to gain understanding and clarification of the various roles and responsibilities of the HCA. Examples of the pre data collection work and analysis conducted by myself for the consideration of the participants' social worlds is evidenced in appendix 3.1-3.4.

4.6.4 Preparation to enter the field

Prior to data collection, I started with a messy/working cartographic representation that mapped out the contextual elements already understood from my known experiences within an acute clinical setting (appendix 3.2). This was in part to ensure that I opened up thoughts, beliefs and understandings prior to the data collection activity and to address these through a reflexive approach (appendix 3.3). Appendix 3.4 shows how this messy map then progressed to a map showing the relationships and links that I had identified post pilot interview. Reflexive activity was employed at each stage of the mapping process and assisted by presentations at national and international conferences (appendix 14), which enabled the maps and research ideas and views to be opened up to a wider audience. This situational map (appendix 3.4) continued to evolve and, once each stage was completed, the next stage established relationships and links between the elements. Each map was annotated both before data collection and following each participant researcher interaction. Mapping the preparation and activity of data collection and the associated challenges and opportunities supported the principles of theoretical sampling within grounded theory that were addressed in section 4.3 of this chapter titled recruitment.

4.6.5 Summary

This concludes the methodology chapter where I presented both the theoretical and practical applications of constructivist grounded theory for this study. Before proceeding to the next chapter it is timely to indicate this was the point where I refocussed and evaluated the research aim, research question and research objectives. This iterative process is detailed in chapter 7 section 7.2.

Chapter 5 Findings

Chapter 5 Findings

This chapter brings together the findings from the 20 individual participants interviewed between October 2014 and August 2015, and from the 3 participants who took part in the feedback element of the data collection process during September 2015.

The first part of this chapter provides information on the participant demographics and is then followed by an introduction to the core categories. The remainder of the chapter presents the findings from this research in each of the four core categories.

5.1 Participant demographics

Participants are referred to by:

a. a pseudonym,
b. the letters P (individual participant) or FS (feedback participant)
c. a participant number, which refers to the order in which individual participants were interviewed or in which feedback session participants contributed to the discussion.

Ten patients were interviewed in OPD plus a further three for the feedback session that was held within OPD; ten patients were interviewed within the ward inpatient area. There were eleven female (ten plus one for the feedback) and twelve male (ten plus two for the feedback session) patients interviewed. The average age for male participants was 60 years with an age range from 39 to 78. The average age for female participants was 70.4 with an age range from 53 to 78. Length of stay for the inpatients ranged from two days to eight and a half months.

Interviews varied in length from twenty-five minutes for Polly (P15) to fifty-five minutes for Jessie (P14). Polly's (P15) interview was shorter than I had anticipated as she was tired and became reluctant to talk after a while. The other interviews lasted between forty and fifty-five minutes each.

Three patient feedback sessions were conducted within the OPD. For example, “Darren P1” was the first participant to be interviewed and “Don FS1” was the first participant to speak at the first feedback session.

Don (FS1), a 58 years old male.

Georgie (FS2), a 29 years old female.

Johnny (FS3), a 69 years old male.

Where participants refer to a member of staff by name these have been changed to a pseudonym to ensure confidentiality

Further detail on each of the participants is disclosed within appendix 6.

Each section of the findings chapter has additional data from the FS participants that confirms or adds another dimension to the findings.

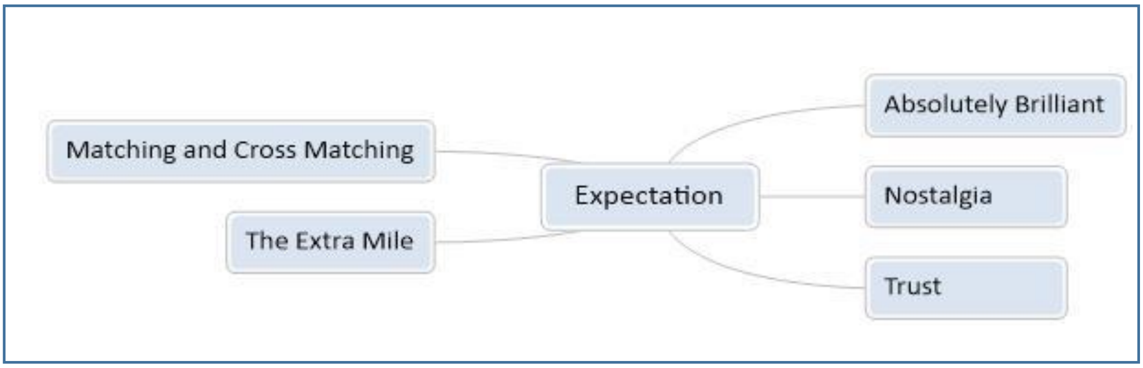
At this point it is worth noting that the age and length of stay of the participants was likely to influence their responses, how they gave meaning and interpreted their experiences. It was with this in mind that there was a broad age range and length of stay recruited to add breadth to the demographic.

5.2 Introduction to core categories

Each one of the participants is represented within this chapter to a greater or lesser degree. It is worth noting that many participant responses did not specifically refer to the healthcare assistant (HCA), often using “*the nurse”* as their reference point. Some responses were more specific, using terms such as “HCA”, “auxillary” or nurse. Although the research question relates specifically to the patients’ understandings of the HCA, the participants’ interactions were not exclusively with the HCA. I have therefore included narrative and comments about all nursing roles, where appropriate, and where necessary indicated which role the participant is referring to. The participants sometimes referred to themselves or other as “patients”. In describing their narratives, I have chosen to refer to them as “participants”, although when observing some of the clinical interactions which took place I have also referred to them as “patients”.

The findings will be presented within each core category, **expectation**, **observation**, **meaningful connections** and **adaptation**. As each core category is introduced the focussed codes that sit underneath will follow. I also illustrate the findings with some personal memos made through the coding and analysis stage.

5.3 Core category 1: Expectation



Mind Map 1: ***Core Category 1. Expectation.***

As a core category, “expectation” details how participants narrated a very positive view of a number of organisational aspects related to their knowledge or experience. These aspects included staff, the ward and OPD areas, the organisation and the NHS as a whole. Their belief in these organisational aspects was often formed prior to their admission as a patient and provided participants with a feeling of security that was often unwavering, despite more recent experiences that may have indicated otherwise. Participants drew on their own non-patient experiences to help them navigate through their patient hood and to make sense of the new world they found themselves a part of.

5.3.1 Absolutely brilliant

‘Absolutely brilliant’ refers to the broad generalised narrative that many participants used to describe the organisational aspects noted above and their overall experiences. It became apparent through the analysis process that these broad statements often overshadowed or masked contrasting, often deeper or more specific understanding and experience. Many participants expressed positive views early on in the interviews, with their narratives later moving on to indicate a disconnect between their broadly positive attitudes and some of their more negative experiences.

The positive local and national reputation of the NHS organisation provided some participants with a degree of comfort and reassurance. This was best illustrated by Ali (P20):

> *“Friends told me I was coming to the best, the elite. I did not know this before my admission as I had come over from Australia. I felt comfort in that before I came in knowing that there was an elite reputation. They have treated me superbly.”* Ali (P20)

Stanley (P8) commented on the organisation, taking the broad perspective that everyone knew what to do and how to do it. He was reassured by the efficiency of the staff he was directly in contact with, extrapolating this experience to an organisational level:

> *“…it seems to be a well- oiled machine.”* Stanley (P8)

Recalling events from the past, Gary (P19) also took comfort and reassurance from the positive health outcomes which both he and his mother had experienced as patients in the past. This positivity was present throughout his interview, even though he separately described his own direct concerns about staff during his present inpatient stay:

> *"… definitely, especially for what they've done for me and, you know, my Mum was in a couple of weeks before me and what they done for her and that."* Gary (P19)

In a similar way to Gary (P19), Mary (P11) and Idris (P9) had an enduring faith in the NHS despite being let down by some personal experiences:

> *"I have a lot of faith in hospitals I have been in a few times and I have always been so well looked after, errm I have a lot of faith in them. It's just these odd little times that nurse lost the professionalism of it."* Mary (P11).

> *"Yes I think people do pick it up and think there is something wrong with the NHS. And I err I don't see that there is much wrong with it. I think we are very fortunate I regard myself as very fortunate because otherwise I would be dead quite bluntly."* Idris (P9)

Freda (P12), herself a retired nursing home HCA, may have used her experience and knowledge of the role to inform her perspective of a collective confidence with the staff:

> *"Yes there is a big confidence with the staff that's in here."* Freda (P12)

Freda (P12) clearly possessed some insight into what the caring role entailed and knew some of the pressure points for staff. She watched and observed how these were managed and was reassured by what she saw. She also took comfort from observing staff working continuously, and in so doing may have conflated working continuously with effectiveness:

> *"Well the nurses and the care assistants that are here are tremendous they work nonstop and I mean they work tremendously well. They have always got time for people they have an explanation if you're not too sure they will explain to you. They never look as if they are trying to rush out even though they never stop you know."* Freda (P12)

Judy (P16) described how busy her clinical area was and how the HCAs were more visible to her simply because of their duties on the ward, although her sense of connectedness with them was compromised by the work pressures:

> *“Well I don't know if it’s because they [HCA] had the time because they were the ones who were very, very busy, very busy doing a lot of like the beds and everything generally but yet they were around on the Ward. … I didn’t have any complaint whatsoever about the care and the professionalism but I just I think which is the usual thing is that they’re just so really, really busy that they haven’t really got time…”* Judy (P16).

Francis (P13) provided the perspective of having had numerous hospital stays; her latest admission had already been nearly eight months long. She articulated an overall positive view of all the staff, qualifying this view by explaining that her expertise as a longer stay inpatient meant she would know if there were any problems:

> *“Yes. I can't fault anybody. There’s not even one I can say, ‘*oh, I don’t want to see that one’*, you know. They’ve just all been so good. And when you spend as much time as I have, you know.”* Francis (P13).

Idris (P9) and Ivan (P6) both gave positive views regarding the nursing care they had received. Ivan (P6) identified one HCA in particular whom he believed warranted a personal recommendation:

> *“Without exception. The nursing care I received myself was beyond reproach. There was no complaint about it at all.”* Idris (P9)

> *“… like the one we have here; she is brilliant.”* Ivan (P6)

As participants' interviews progressed, their overall positive views were sometimes tempered with more negative or equivocal experiences. Jane (P5) initially vocalised an overall positive view of the staff but then went on to suggest that some staff were not as friendly as others. This was not expanded upon by Jane, despite numerous prompts throughout the interview to explore this shift in her view:

> *"Yes erm well there are all very, very good."*
>
> *"Well they are all very friendly… "*
>
> *"They are very considerate and* ***most*** *[*my emphasis*] of them are very, very friendly."* Jane (P5)

Despite initially providing a broadly positive view of staff and the HCAs, Jessie (P14) and Catherine (P18) each identified a problematic member of staff. Jessie (P14) was troubled as to how she was going to manage one staff member for the duration of her inpatient stay and Catherine (P18) also had concerns about a particular member of staff. Both of them managed to isolate their negative experiences from the remaining positive experiences:

> *"On the whole of my experience in here, there's only been the once that I've felt vulnerable the next night."* Jessie (P14)
>
> *"They were all really very good. I think… I mean I've had really good experience in the [hospital] from everybody, except for once…"* Catherine (P18)

Johnny (FS3) stated his overwhelmingly positive views on the care he had received across a number of hospital stays:

> *"I am in and out [hospital] all the time…the care is just outstanding…I have heard other people but I have never come across it."* Johnny (FS3).

5.3.2 Matching and cross matching

Participants often used their own non-healthcare experiences to help them ‘match’ against, navigate through and make sense of the new world of healthcare they had begun to inhabit. As participants recalled interactions they had with staff, they also used their own experiences to ‘cross match’ in assisting the recognition of qualities demonstrated by particular staff. Others thought about the HCAs and the career trajectory they could follow with education, enabling them to transition to nursing should they want to. Some of the participants were, or had been, working within a variety of healthcare settings, giving them an inside or more intimate knowledge of this new social world they were now inhabiting as patients.

Molly (P2), with a wry smile, told me of her contribution to healthcare:

> *“Ohhh a very special job, I was a bed maker.”* Molly (P2).

Freda (P12) was more candid, explaining her previous role as an HCA in a residential home and identifying the similarities with the role of the HCAs caring for her as a patient:

> *“The role of the health care is precisely in the words health care. You check everybody’s health and what care is needed to go with it. Everything has to be written down and kept records of. It is very important, very important that you get on with the person you are talking to. You don’t talk down to them you don’t talk over them.”* Freda (P12).

Participants who had not worked within healthcare often used their working lives to make sense of their patient experiences. Colin (P3) used his extensive working knowledge of team work and leadership, together with his understanding of positive personal qualities within his own working environment, to identify, associate and form an understanding of his clinical experiences:

> *“Every industry and every profession has got a different urm priority if you like…But, err, I can tell when I have got a team member who is interested and who’s not interested, erm they ask the right questions and say the right thing. You know if they are interested or not.”* Colin (P3).

Colin (P3) ‘mapped’ across the attitudes and behaviours valued from his own work environment to those he came into contact with as a patient that enabled him to make value judgements on individual members of staff. Colin (P3) described an HCA who had arranged for him to receive some emotional support from the chaplain and valued the fact of being interested in him as a person whilst also recognising the contribution that individual members of staff make to the team effort:

> *“She had the right mentality to…. you know, with me. You’re are a close knit team when you’re away, were all in the same boat… my management now...it’s basically getting them to err to pull together and identify, so if someone is letting their chin down…. there is more to it than just the treatment somebody needs, or the operation, and for her to identify that as a junior I thought was pretty good I thought, as no one else was interested… I am very aware this is a huge hospital here and everyone plays their part.”* Colin (P3).

A different work ethic between healthcare and other sectors was also evident when Anthony (P7) told of a time when a HCA remained after her shift had finished to help give out breakfast. He applied his view of the working world he had inhabited to work out the issues around this act:

> *“I’d have got me breakfast half hour late, I am sorry I am a union man she’s breaking the rules should not have done that.”* Anthony (P7).

Anthony’s (P7) view may have not been held by others, but if the HCA had upheld the principle of not working beyond the end of her shift, this could have impacted on others who may have been less keen to have their breakfast delayed. This provides an illustration of the complexities of differing perspectives.

Stanley (P8) also used his knowledge of his working world to seek out the familiar and to identify any possible differences in how he might manage the clinical area:

> *"It is…. but I think it could be a critical thing to do as well I mean everyone thinks they do their job better than everybody else so erm thinking along those lines and the way I did my job thinking that everything was done properly errm and then you transfer it to here. One of the things I have thought about is would I manage this ward any different to the Sister?"* Stanley (P8).

Catherine (P18) also reflected upon her working world, and in particular the bureaucracy she faced, empathising with those staff whom she saw as suffering from bureaucracy:

> *"I thought it was quite bureaucratic. I thought every time I've been in there's been loads and loads of paperwork and I come from a bureaucratic kind of thing and I know what that must feel like and I feel that it's a bit upsetting for them that they've got to plough through all this stuff."* Catherine (P18).

Catherine's (P18) working life was in public service management and she used her past experience to identify a number of processes she saw as unnecessary:

> *"No, I meant generally in the Health Service and the way that I thought that the Nursing staff were doing things that I didn't think they ought to be doing. I said, 'if they kitchens want that, they should be up here doing it, shouldn't be the Nursing staff,' even the Health Assistants shouldn't be doing that sort of thing, which I thought was so unnecessary."* Catherine (P18).

Catherine (P18) used her knowledge of systems and organisations to unpick what was happening, concluding that some jobs are not necessarily best undertaken by the nursing or healthcare staff.

Ivan (P6) cross-matched his prior knowledge of employment requirements to identify the motivations for getting qualifications and also used his grandson's recent college and work experience to help him understand the workplace for the HCA. He also recognised that access to University was not always possible, as the HCA may be limited by their circumstances notwithstanding their capability:

> *"… they have if they want, a job that can go further… I mean a health care can become a nurse of course she can, she can go to Uni… there are certain situations for people if they haven't got support from home how can they afford to do it, they just CAN'T afford to do it to spend time to go to University".* Ivan (P6).

Idris (P9) also recognised that, despite access to education being more available, a support network would still be a necessary requirement for an HCA wishing to study:

> *"I was fortunate…. I grew up when education was less universal than it is now……. I had a father who supported me."* Idris (P9)

5.3.3 Nostalgia

'Nostalgia' describes how participants recalled events, people or circumstances with affection and fondness. They recalled individuals, teams of staff and feelings of nostalgia that related to both meso level (clinical areas) and macro level (organisation) from both past and current experiences. This nostalgic view often shaped their ongoing experience, resulting in either a reinforcement of view or a disconnect between expectation and their reality. This latter point is illustrated by Molly (P2), who had an expectation of her impending admission shaped by her experience a number of years previously as an HCA (a role known at that time as an “auxiliary”). The reality fell short of her expectations, both in terms of environment and her relationship with the RN. However, it was the HCAs themselves that did meet her expectations based on what she recalled from her time as an auxiliary:

> *“Yes, yes I was very disappointed because I used to work at [hospital] and I thought there wasn’t another hospital like it…Well when I thought it was going to be* ‘oh so lovely’ *like I remembered it when I worked there. Like you go into a six bay you know and the nurses are going to be coming in and out and the auxiliaries and whatever. I was on this horrible, well you saw very few nurses they were always in a hurry to do something else, but it was always the auxillary nurses that did what you asked them…”* Molly (P2).

There was a sense of resignation from Idris (P9) as he recalled a time when he was familiar with the workings of a hospital, contrasting his previous strong knowledge to his current lack of knowledge:

> *“Vaguely, I used to know way back in the ice age. I knew perfectly well. I don’t know now… I can only think that things had been better with the old style. I knew when there was Matrons who were Gods [laughter] and err, all the cleaning and tidying was done by the nursing staff….”* Idris (P9).

Looking back, Idris (P9) recalled how his experience and understanding of the previous ways of working had been reassuring. This nostalgic understanding of times past that seemed to him to be an improvement on current practices was, however, in contrast to the care his wife received and that he described as “quite perfect”, For Idris (P9), the personal experience and the connectedness he felt with staff was the main way in which he made sense of his perceptions of a different time: a time when saw things as being better than they are now.

Gary (P19) held onto his previous experience as a sort of talisman. He saw no reason to doubt the medical teams and had faith in the logic that ‘they did it before they will do it again’:

> *“You know, when I found I was coming here again I was saying, ‘*Oh good they saved my life 20 year ago*.’”* Gary (P19).

Colin (P3) provided nostalgic recollections of two HCAs from an earlier experience who were memorable for being, as he saw it, pivotal for his recovery:

> *“It turns out that I knew the two ladies that looked after me ….it wasn’t until I got out of hospital that I met Bella I said ‘*I’ll tell you something you were the only two that were interested’ *and they were. They was the only two who, that kept us going, a bit of dignity and all of that and I told them both and said ‘*much appreciated’ *and I told Rosie this year ‘*If it wasn’t for you and Bella I would not be sure where me head would be at this moment*.’”* Colin (P3).

Colin (P3) is reminded annually of the impact the two HCAs had upon his recovery when he sees one of them at an event they both attend outside of the organisation:

> *“I see her every year. So every time I see her I haven’t forgotten.”* Colin (P3).

Participants also described more recent experiences that were developing into nostalgia. Stanley (P8) recalled the RNs and HCAs that were part of his care before a team changeover, looking back and reflecting:

> *“You sort of build up a confidence and rapport with the first group…”* Stanley (P8).

Jessie’s (P14) nostalgic view involved one particular HCA during her recent inpatient experience. This relationship had both an immediacy and a lasting effect upon Jessie (P14), with the HCA continuing to contribute to Jessie’s (P14) experience:

> *“She knew exactly how I felt, and she used to say to us, ‘*you know, Jessie, you’ll get better*’… and to hear her so calm saying that, and think I can do it, I’ve got to do it…She still does, yes.”* Jessie (P14).

The environment also appeared to contribute to participants’ views of past events. Catherine’s (P18) nostalgic view was of a small specialist inpatient area that she attended before being moved to a general area:

> *“The little private place that’s cool and air-conditioned and wonderful and then I was in a kind of general Ward after that…but they didn’t have enough people on the Ward I don't think.”* Catherine (P18).

5.3.4 The extra mile

‘The extra mile’ describes the things staff do that go beyond participants’ expectations. These things included the care and consideration shown to them when participants recognised their dependency was greater than anticipated. Also included were physical things or tokens that meant staff had thought about them beyond their immediate needs. Additionally, the special connection some participants made with certain members of staff and how those connections transcended the everyday routine bringing the participant something special.

Some participants recognised the heavy demands their conditions placed on staff. Jessie (P14) told me of the physical dependency she was dealing with and acknowledged that the repetitive need to get to the bathroom was burdensome for staff assisting her. She spoke specifically about the HCAs in her narrative, as they were the ones who helped her manage her day-by-day, hour-by-hour needs:

> *"Well, I'll tell you what it is… because of the medication I take, I have to go to the toilet about ten times for a wee all the time…I try to do as much as I can, but it's like I know I can rely on them and their caring is unreal. Their caring is, I mean, it's as if they're your mother and couldn't care less whatever you want they'll do, the caring is unreal*." Jessie (P14).

As Jessie (P14) described the care she received, it came across as if she felt it was extraordinary; above and beyond what she expected. The maternal aspect is also worth noting as Jessie (P14) clearly regarded the care as being offered unconditionally: whatever happened, the HCA would be there for her.

In contrast, Polly (P15) felt the ward staff in general did not exhibit any elements of care towards her. It is worth noting that these two participants were on the same ward and were interviewed within an hour of each other:

> *"But they haven't got the patience… Well, they ignore you as they walk past and you can shout."* Polly (P15).

Polly (P15) was mobile and relatively independent and thus had less call on staff time than Jessie (P14) who, by comparison, was hooked up to drips and drains and thus had restricted mobility. At the time of interview, Polly (P15) was waiting for social care to organise her discharge home. Her family visited a few times per week but it appeared that she might be lonely and in need of human contact. She was also located at the far end of the ward, whereas Jessie (P14) was located right next to the nurses' station due to her clinical needs. These contrasting narratives of Polly (P15) and Jessie (P14) illustrate that there is a continuum of both actual and perceived care.

Francis (P13) described how staff went above and beyond the call of duty and how she felt both when she was given her guardian angel token (a small trinket or charm representing an angel like figure) by her specialist RN and when an HCA gave her some beauty samples. The giving of these tokens is discussed within the section 'tokens of friendship' but it equally demonstrates the extra mile that some staff go to and the feelings that this invoked in Francis (P13):

> *"I was choked; you know…"* Francis (P13).

Gary (P18) also described a token of friendship, with an HCA bringing in a radio for the bay to listen to the football. He was appreciative and felt good about the effort she had gone to, contrasting her care and effort with the actions of some temporary agency staff who also worked on the ward:

> *"Because we were on about the football match and that we couldn't get it on the radio and that here and she just says that she'll bring her dad's radio in in the morning and brought in a radio for me…Good, nice, you know, they're helpful, a lot of them are helpful that are here permanent but I think that some of the agency, a lot of them are okay, but a couple of the agency ones just don't really care, you know?"* Gary (P18).

Judy (P16) described the observations she made when an HCA came back to visit her mother once she had transferred to another ward. The effort in doing so was beyond any responsibilities for the HCA's formal role. The HCA did something extraordinary in Judy's (P16) eyes:

> *"because it was there, the care, it was beyond just the basics, it was real love and the attachments they have to these people was…"* Judy (P16).

Idris (P9) was adamant that the extra noteworthy and special things staff did and he valued could be lost within a system of process and targets that doesn't recognise such activities:

> *"No, no, I think if we lose that we will lose something very precious."* Idris (P9).

Don (FS1) recognised there were things staff did beyond what was expected but didn't have an expectation that they would happen to him. Georgie (FS2) recalled a time when the HCA went to find her partner who had walked out during a long wait for Georgie's surgery:

> *"I wouldn't expect them... It's a pleasant surprise if it would happen."* Don (FS1).

> "*and she physically went round looking for him because she knew how distraught he was and I thought that was lovely... beyond their job description…I thought it was really nice."* Georgie (FS2).

5.3.5 Trust

The concept of 'trust' became apparent as a focussed code during the analysis process. Some of the participants' experiences of trust were broader than their interactions with the HCA and I have therefore included these episodes as patients are not cared for by HCAs in isolation from other healthcare professionals. It is these broader interactions that also helped shape some of the perceptions and views of the participants with respect to the HCA. Participants also used the word 'faith' in their narratives and this has been coded under trust within the context of the narratives. There is a difference in how I have interpreted faith, which has a more spiritual meaning underpinned by belief, as compared to trust, which is about a confidence based on logical expectation or evidence and proofs.

Anthony (P7) was clear that, from a patient's perspective, care is built upon trust at every level. Trust itself is built, as described by Anthony (P7), by the staff performing their duties to the best of their ability within the organisational framework of educational and training support:

> "…*they have all gone through courses, they have all gone through training, I am assuming it is good enough that the hospital has awarded them jobs. I have to take it that on trust really…They have gone through a system that obviously works."* Anthony (P7)

Johnny (FS3) stated a similar view of trust to Anthony (P7), in that:

> *" as long as whatever they are doing is within their capabilities and training that's fine...they know what they are doing…"* Johnny (FS3).

The trust described by Anthony (P7) and Johnny (FS3) was positioned at varying organisational levels; from individual trust in one person's competency through to trust in the organisation overall having employed competent staff. Sally (P10) described her feelings as a combination of trust and faith, leading to an acceptance of staff and their roles without question:

> *"No I just take it on face value to me she was a nurse, she was dressed as a nurse she knew what she was doing she was there I wouldn't…. it had never crossed…why would someone take me somewhere where they didn't know what they were doing? That's the faith I have."* Sally (P10).

Some participants expressed trust at a general ward level. Judy (P16) recalled the trust she felt on leaving her terminally ill mother in the hands of others to get some rest, in contrast to a later ward placement where there was no trust:

> *"I mean she was really very, very poorly then and they would say, "You need to go home, you need to get some rest," and I would feel quite happy going and knowing that she was being on that Ward but when she moved, I wasn't."* Judy (P16).

Mary (P11), by contrast, was very specific in her lack of trust in a member of staff who had not demonstrated consideration towards her:

> *"The hospital was great the operation was good everything's been fantastic… Yes, her attitude… didn't trust her."* Mary (P11) .

Despite her loss of trust in this particular individual, Mary (P11) appeared to have a residual faith in the wider organisation articulated as an overall positive review of her experience. Similarly, Jessie (P14) described where a member of staff was not attentive towards her but then clarifying how the resultant loss of trust in that particular individual did not affect her trust in others:

> *"Like I say, the only time, which I've told you and that is totally the truth…"* Jessie (P14).

Sally (P10) experienced a surgical intervention that had resulted in complications. She described the event in detail:

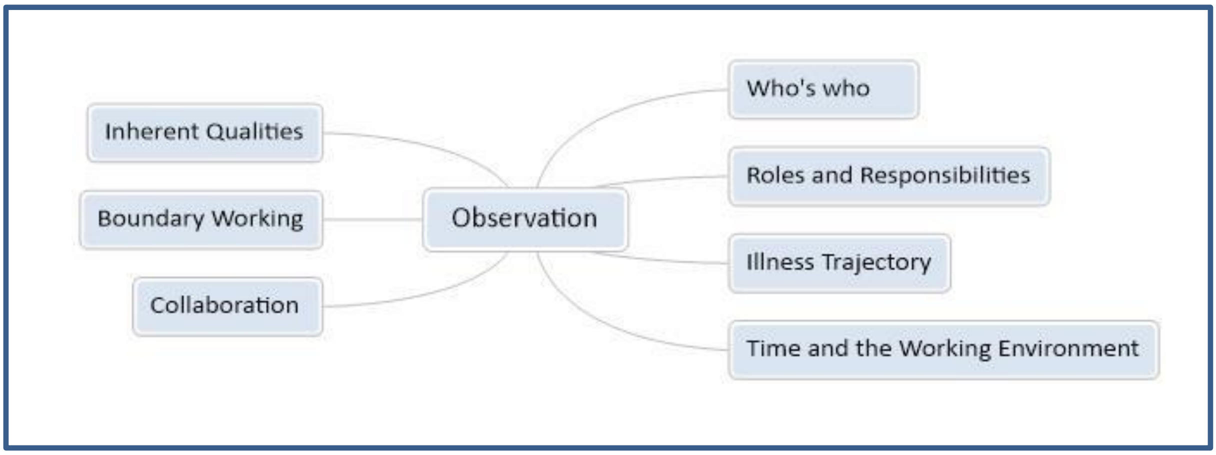
> *"I had a biopsy... and I had a haemorrhage and I did think something went wrong there. I am not that type of person, I wouldn't blame anyone for that, I think it's one of them things that happened, and I do trust what the NHS, I mean I am in their hands, I have to don't I? It wouldn't do me any good to not trust."* Sally (P10).

This unquestioning trust in the staff and organisation was evident from Sally's (P10) narrative, along with an unquestioning trust in the medical staff and in the wider NHS that equated to faith. Sally (P10) went on to explain that her views of the event contrasted with those of her husband:

> "*Yes, I thought I was just unlucky. My husband he thought differently he thought (well he would wouldn't he) oh no, no, they've made mistakes, but no just put it down to bad luck really."* Sally (P10).

Sally (P10) was resigned to the event, whereas her husband was not so accepting. It was Sally (P10), however, who was dependent on the NHS for subsequent care and intervention which may have had a part to play in her acceptance.

5.4 Core category 2: Observation



Mind Map 2: ***Core Category 2. Observation.***

Participants described their observations and how these brought insight to the workings of the clinical area and the impact this knowledge had upon them. They described how they worked out who was who and what roles and responsibilities these various staff undertook. Some were not so concerned about the various roles and responsibilities, being more concerned with the overall care they received. Participants also noted when they saw staff working under pressure at times which additionally impacted upon the staff working to the limits of their roles.

5.4.1 Who’s who

‘Who’s who’ describes how participants worked out who the staff they came into contact with were, compiling knowledge and understanding of each of these roles through a combination of the names of the individual members of staff, their association with tasks and the colour of their uniforms.

When he talked about patients that had been in his care as an RN, Darren (P1) was unconvinced that patients knew who staff were:

> *“They don’t know who the staff nurse is and who the sister is you know…. I mean some patient do ask what is the significance of the uniform? …and maybe from there they are able to pick up what their role actually is.”* Darren (P1).

Some participants used the colour of staff uniforms both as a way of identifying their role and as a colloquialism to collectively describe each role:

> *"The brown coats are the auxiliary."* Molly (P2).

She went on to say that using the name of "brown coats" for the HCA "was awful", however, she had also called the RNs "blue and white stripy" but did not mention that this could be seen as a negative term. I wondered if the reference to the brown coats had connections with 'dirty work' or was associated with shop floor workers, whereas the blue was more indicative of blue collar workers in a more managerial role. Colin (P3) identified the hierarchical significance of the colour blue:

> *"…the top rank with the blue coat on."* Colin (P3).

Anthony (P7) was familiar with these colloquial terms for the uniforms, but was much more concerned about 'the person behind the uniform':

> *"I don't see them as brown shirts or white shirts I see them as people."* (Anthony P7).

This is in contrast to Bill (P4), who used the colour of uniform to identify the role of each member of staff and clearly placed considerable emphasis on the implications of their uniform colour:

> *"I'd need to know what colour uniform they are."* Bill (P4).

Some participants used an unfamiliar uniform colour to identify a staff role outside of what they were used to or expecting, which in Mary's (P2) case resulted in a degree of suspicion:

> *"She was wearing a funny coloured uniform."* Molly (P2).

Colin (P3) described, during his initial inpatient stay a number of years previously, how he had assumed that a member of staff wearing a uniform automatically indicated them as a nurse. He was not aware of any role difference between the RN and the HCA during his stay that made him think otherwise:

> *"I didn't understand what uniforms they were wearing I took them to be fully qualified nurses."* Colin (P3).

John (P17) was not concerned with 'who was who', instead articulating a more generic collective view of the clinical staff and making no differentiation between them:

> *"Oh I just see it as the general staff."* John (P17).

For participants who entered the hospital through the pre-operative admission process, where they come into the hospital on the day of surgery, there was often no time to process 'who's who'. These participants found little or no opportunity to work this out until after the operation, partly because staff in the pre-operative area often wear generic theatre scrubs irrespective of their role. Anthony (P7) described how, as he came round from the anaesthetic on a new ward, he had not concerned himself with staff or uniform:

> *"So the issue of uniforms wasn't interested really."* (Anthony P7).

The system of 'named nurse' was active in some inpatient clinical areas, whereby each patient was allocated a nurse whose name was written above the bed space. It would appear, however, that this allocation and naming process didn't always work as Mary (P11) described how she still wouldn't recognise the person behind the name:

> *"…the next day I found out she was my named nurse but I still don't know who she was."* Mary (P11).

Ali (P20) suggested that a longer length of stay helped him in working out who was who:

> *"I have been in long enough to work it out."* Ali (P20).

Ali (P20) subsequently confirmed his deductions as his health improved, walking to the ward 'who's who' identification board' to place names to faces.

Closely linked to "who's who", participants described how they observed activities and tasks undertaken by the RN and HCA to help them work out identification of roles.

5.4.2 Roles and responsibilities

Some participants identified for themselves how the position of the HCA related to the RN:

> *"A sort of back up team for the nurses err for everybody actually... This frees up the nurse to get on with more important work, I think."* Stanley (P6).

Others suggested that the HCA had more time that the RN:

> *"Yes, the nurses seem to have a lot more to do."* Polly (P15).

Mary (P11) took a different position, regarding the HCA role as assisting the RN by working alongside them:

> *"I know what the nurses do and is the HCA someone that helps with the nurse and works with and helps the nurse?"* Marys (P11).

Participants described their understanding of what they saw as being the various roles and responsibilities for staff members within the organisation. Some saw roles and responsibilities as a point of difference between the RN and HCA that was underpinned by education and training, alluding to limitations of the HCA role:

> *"I just see it as err its err a process of qualification. I think sort of the nurses have done the courses they need to do… and I would imagine the nurses have done the degree course and the HCA haven't."* Stanley (P8).

Darren (P1), as a RN in practice, understood that various roles and duties have developed for both the RN and HCA, where tasks requiring a technical ability may be performed by either an RN or an HCA:

> *"…probably there is some overlap I would have said. There may be some S/N that take bloods maybe in OPD I know some of the Health cares do, depends on what band they are*." Darren (P1).

The difference between RNs and HCAs was, for Freda (P12), more about performance within the scope of each role. Freda (P12) had worked as an auxiliary in a nursing home for a number of years, where her views on this issue may have been shaped by her experience. She saw each role as making a contribution to the patient experience at its own level:

> *"There is not much difference. It's just that the nurses are qualified and the care assistant are qualified in their own way to do the job that they are employed to do. You know and you have got the professionalism from both sides.…it's not that they're cheap nurses…"* Freda (P12).

Observing tasks and duties reinforced the difference in roles and responsibilities for some participants. This observation clarified their understanding in a way that enhanced the demarcation of roles:

> *"Well I always knew there was a difference but just by observation really…The main thing is they [the HCA] are not involved with the medication [pointing to the IV machine]."* Jane (P5)

Anthony (P7) went further than mere observation. He stated that there was a 'known' role boundary wherein the HCA did not address anything to do with medication. Anthony also described a legal dimension that added to his jurisdictional understanding of the HCA role:

> *"There is a difference. They know they can't touch the drugs, the drips the pipes… They have what they can and can't do legally."* Anthony (P7).

This ‘knowing’ was also articulated by others, who also gained clarity around roles and responsibilities with an added dimension of the HCA not wanting to mislead or raise the expectation of the patient with respect to what they could do. This was clearly articulated by Ivan (P6):

> *“They are limited with what they can do …what they do… as far as I can see they do very well…They are not doing anything they shouldn’t do. They are not doing ‘I can’t do that’ or ‘I’m not allowed to do that’. ‘I’ll go and get the nurse for you’ and they duly do.”* Ivan (P6)

Ivan’s (P6) experience contrasted somewhat with Mary (P11), who was concerned when the HCA implied greater knowledge than she felt they should have. Although the HCA did not necessarily perform the duties relating to this knowledge, Mary (P11) was worried that they would forward their interpretation of the situation to someone more senior to act upon this:

> *“…what I don’t like is them saying* ‘oh we will see if we can get you an injection for that’*, or* ‘we’ll see if we can get you medication for that.*’ That’s got nothing to do with them they should say ‘*I shall get a nurse to come and talk to you’*.* Mary (P11).

This illustrates how Mary had worked out the boundaries for care and support from all grades of staff that she was comfortable with. She was unhappy about individuals overstepping the roles and responsibilities as she saw them. Mary (P11) concluded her view on roles with the following:

> *“Yes, yes. Sticking by their roles, let the tea lady serve their tea and let nursing staff do their bit.”* Mary (P11).

Freda (P12) described her perceptions of what an HCA does from the perspective of having been a care worker who had dealt with the clients in an equal relationship. She went on to say that the HCA role is different to the RN and, more specifically, is concerned with the general wellbeing of the patient:

> *"And they're there to look after you and they do it. I think the registered nurse, they come in and they make sure that the medication and all that, whatever, runs smoothly. The role of the health one is more personal to make sure you're okay."* Freda (P12).

Freda (P12) acknowledged there were clearly defined roles but also used her insight into the role of the HCA to identify something more that the HCA offers both the patient and the staff beyond what is in the job description. She suggested the HCA may have almost a sixth sense that tells them something is not right, leading them to raise their concerns to someone who has more knowledge about what that could be:

> *"You've got a nurse who is qualified. She knows her job she what's got to be done whether it's a tube that has to be changed or whatever. But the care assistant who is a little bit experienced over the years of doing it. They will come past and chat away then look and think that doesn't look right and then they will go and get a nurse or a Dr."* Freda (P12).

For Colin (P3), the HCAs he came across had presented a confident understanding and expression of their role. He identified the HCAs as being *'comfortable',* indicating he saw them as working within their capability and implying that this was reassuring to him.

> *"I think that the HCA stand out to me, because in my experience they know what their role is and they are comfortable with their role."* Colin (P3).

This idea of having a 'sense' is something that Catherine (P18) was mindful of when she tried to explain what qualities were necessary for a good HCA:

> *"Well I think you've got to have practical common sense which doesn't sound very Degree-led does it but you need it and you've got to be intelligent to be able to see perhaps which situations you can deal with and which you should pass on to another person and intelligent*

> *enough to understand the readings which might require you to point out something, I don't know if that's their job or not."* Catherine (P18).

The recognition of the limitations of the HCA role and how through experience they adapt and contribute to the patients' wellbeing beyond meeting basic needs was addressed by other participants. They perceived that the HCA was able to do more and some participants would have been happy for the HCA to do more:

> *"… what I am aware of is that they know what the procedure is, they know what the next step is and I feel they are confident enough to do the next step and I would be happy enough for them to do the next step but they just won't do it."* Stanley (P8).

Anthony (P7) concurred in terms of the HCA's abilities but stopped short of mentioning whether he would be happy for the HCA to take things further:

> *"Obviously they are very capable. A lot of them are very, very capable."* Anthony (P7).

The potential for informal extension of activity for the HCA role was recognised by some as a job role issue where, at the margins, lines of responsibility will blur between roles. Ivan (P6) suggested that an increase in responsibility for the HCA may not be what an individual aspires to in their HCA role:

> *"I think they can be given more responsibility should it be deemed. But there again are they a HCA or a nurse then?... Maybe some of them don't want the responsibility."* Ivan (P6).

Ivan (P6) saw the enthusiasm staff had for their job and the tasks that they undertook as giving assurance that they were performing these tasks to the best of their ability, conflating job satisfaction with competent performance:

> *"You know when someone likes doing what they are doing, they are going to do it well. It gives me more confidence."* Ivan (P6)

Anthony (P7) was unequivocal in his belief in the competence of staff, going on to state he was confident that the other participants would feel the same:

> *"Coz they know what they are doing…Has anyone come across as anxious about staff? I don't think you worry about staff?"* Anthony (P7)

5.4.3 Illness trajectory

Illness trajectory describes the phenomenon whereby some participants had little concern for the grade and designation of nursing staff looking after them while they were very unwell but became more aware of staff designation as their health improved. Darren (P1) described what he had observed of this in the patients he had nursed as a RN:

> *"I think a lot of them are quite unwell and most of them don't seem to question what happens… they take what happens to them. Most of them don't sort of … question are you qualified to do this and everything else… maybe while they are in hospital… feel as though they are here to get better, whoever is here to help them get better, they don't seem to mind … The ones who are a bit more maybe more 'well' might notice a bit more about what is going on maybe.*" Darren (P1).

Many of the participants had undergone surgery and it was interesting to hear, as they reflected upon their journey, how a number of them had been concerned by an impending operation or procedure and therefore seemed not to have given thought to their recovery or care afterwards. The operation, together with the person performing the procedure, was an overriding issue for Jane (P5):

> *"… you just know you are coming in for an operation you don't think of it at the time who does what or anything like that apart from the surgeon."* Jane (P5).

Judy (P16) had thought her concerns were no different to any other patient at that stage:

> *“…my main worry was just about the actual operation, whether I was going to come round and those sort of things that obviously go through everybody’s head.”* Judy (P16).

Anthony (P7) concurred with Jane (P5):

> *“Just particularly worried about the operation not thought about coming into the ward… the operation was…. The big thing.”* Anthony (P7).

I asked Anthony (P7), as he looked back over his admission period, whether he had been concerned about who was looking after him when he was not *“compus mentus”* (his words). His reply was emphatic and also touched on issues of trust that were explored earlier on page 116:

> *“**Not** (emphasis) at all... I wasn’t bothered who did what to us coz they were obviously doing the right things coz I have got this far.”* Anthony (P7).

Anthony (P7) described a period of time when he was not himself due to the prescribed pain relief, describing both a loss of days and of his individual self:

> *“A lot of it was a blur. No, I was on morphine so I was err pretty not making much sense to anybody, and they weren’t making a great deal of sense to me, so they were having to look after us.”* Anthony (P7).

I wanted to know how Anthony (P7) felt during this time in terms of relationships with the staff. He described the process of admission prior to his procedure and the implications of not knowing who anyone was:

> *“Well is wasn’t an issue coz I came into a day care centre. I was injected, I was asleep. I woke up here a day later. It was like a whole day had gone. So the issue of uniforms wasn’t interested really. I wanted to see the Dr… The nurses were not of any interest what so ever.”* Anthony (P7).

Anthony's (P7) narrative brought into sharp focus his immediate world of medical intervention and the surgery that drove his primary concern - his life in the hands of the surgeon. He had given no thought as to who was who or who would be looking after him when he was in the immediate recovery phase of the operation. This world he was entering was visceral.

For Stanley (P8), it was not about the level or grade of staff that came when he called, rather it was about the continuity and familiarity that he felt from being cared for by the same people:

> *"Oh yes I knew who was looking after me. I couldn't tell you their names but every time I pressed me buzzer, it was the same one or two people coming back to me."* Stanley (P8)

5.4.4 Time and the working environment

There was no doubt that participants recognised the busy nature of the clinical area, the demands this activity placed upon staff and the ability of staff to navigate their way through such an environment. Participants used their own internal measures, often based on their own experiences, to articulate the level of effort required to work within the day-to-day clinical environment. Matching his own working day against what he observed while in hospital, Colin (P3) identified the effort required by staff in such circumstances to still perform their duties:

> *"They are busy and I know flat out… they were rushed off their feet, they work harder than what we work… but err I've always been appreciative of people that make the effort."* Colin (P3).

Ivan (P6) described both the day-to-day and the extraordinary events that challenge staff and their ability to keep things going seamlessly for the patients, recalling one particular HCA's effort:

> *"…she is brilliant, she sees I've got a drink, she sees I've got clean stuff she changes the bed, nothing is too much trouble at all, at all. I had a messy day yesterday with my wound exploding and with that*

> *happening I was very, very sick it was messy that was. She was on top of it in a flash she was."* Ivan (P6).

Participants recognised that there was some extra quality required of staff in order to manage these situations in a professional manner. Jane (P5) was amazed by the level of patience demonstrated by staff under what she felt were often extreme conditions. Her narrative was animated and she shook her head almost in disbelief at the behaviours demonstrated by staff, which she was unable to relate to her own personal experience:

> *"…sometimes there is people coming in at night time you know and sometimes you think you don't know how they are managing to do this. Especially when they have people wandering up and down the ward not quite with it… There is no shouting or anything like that they just try and keep calm really… I have never seen any panic at all. I just don't know how they do it!"* Jane (P5)

Freda (P12) had a great deal of insight into the working day as she had retired only two years previously from her role as an HCA in a care home. She was acutely aware of the pressure that staff face day-to-day, stating staff were working up to their limits of energy and effort, and identified how this pressure appeared not to directly affect the patient experience. I was left wondering how patients felt when observing staff working up to these extremes. She did further observe, however, that some staff were compromising their own wellbeing in order to deliver the care necessary for the patients:

> *"…the nurses in here are working nonstop and I can see absolutely shattered. But we had one nurse in here this morning who has been here all week she has not been away for her coffee break. You know she is always working through."* Freda (P12).

Availability of time and work pressures were significant factors affecting the delivery of care. Staff were often very busy and participants noted how staff managed their time in those circumstances. Judy (P16) and Colin (P3) both identified how the HCAs divided their time up between patients as the day unfolded. Judy (P16) saw the HCAs as a collective group that tried to bring greater comfort and something more to the patient experience but who were hampered in this respect by the busy state of the ward and other demands:

> *"It was more than that. They were very, quite caring and warm and would chat but they obviously then had to sort of move on to… So it was more than just coming and doing… I think as a whole, they were very kind of caring kind of crowd."* Judy (P16).

> *"Erm, her demeanour was very professional… both of them knew what time could allot to each patient on the ward."* Colin (P3).

In a fast moving clinical area there is an urgency to patient admission and discharge that limits the time available, which in turn may reduce the potential for deep connectedness between staff and patients. Judy (P16) observed the differing levels of patient and HCA relationship that developed during the time she was an in-patient. Her experience was that the HCAs did more than just perform their duties but that those patients who were in for longer had a deeper connection to staff than herself, who was in for a shorter period of time:

> *"I think that's quite hard to describe. I think it was… I mean it was more than just a level of, 'Well we're doing our job,' it was certainly more than that, but I don't think it was really a very deep level of kind of relationship but I think again, that was because it was a short-term… I mean there wasn't any lack of care."* Judy (P16).

A relationship existed between Judy (P16) and the staff but it was not at the depth that further time and frequency of interaction would bring. When asked if she felt that this was due to her shorter length of stay or whether there were time demands on staff, she felt it was due to both:

> *"I think it was probably a combination of the two."* Judy (P16).

Others recognised the wider context for staff working within healthcare, noting that the NHS at this point was under a great deal of media scrutiny as articulated in the literature review. Catherine (P18) and Stanley (P8) both recognised that there may be more demands on staff than are seen day-to-day in the clinical area. Catherine (P18) was informed in this view by the media and by her son, who worked as an RN in acute care:

> *"… if I open my daily paper, I will see something pretty much every day about the National Health Service and how it's going to hell in a handcart, and whenever I come in, everybody's really very good. But I have a feeling, and knowing my son as well, that in the background, they're really hard pressed."* Catherine (P18).

There is a tension here between what she has read and discussed and what she has experienced, which is that staff managed to deliver good care despite all the pressure they are under. This response was similar to Stanley's (P8) perception of the external pressure staff face:

> *"Looking after you, yes, they are dealing with any problems they might have difficulties or concerns they may have around over the security of their job. Or the future of the NHS, they* ***don't*** *show it to the patient at all. They don't show any, or give any indication they are concerned about their own future, they just get on with the job and the care you need."* Stanley (P8).

Stanley (P8) tried to understand why someone would want to work within care, recognising that the NHS was not an easy place to work in and placed demands across all professions:

> *"I think they must have this idea that they want to care for people… the problems that the NHS have got does not reflect itself on the staff on the ward."* Stanley's (P8).

Johnny (FS3) also had experience of staff working under difficult situations, ranging from a busy ward environment to a challenging patient:

> *“the ratio of patients to staff…he did his best you know…he was running around…trying to get everything sorted.”*
>
> *“the staff bent over backwards to accommodate him…honestly he put them under so much pressure…I did not see them flicker…that’s dedication.”* Johnny (FS3)

5.4.5 Inherent qualities

Participants recognised that there were often certain inherent qualities shared by staff working within healthcare. They described these qualities as being necessary for a generic healthcare role and also felt there were other, more elusive, qualities that were more difficult to identify and describe. The participants were aware, however, when these qualities were not present and articulated how the lack of these qualities made them feel.

Idris (P9) felt that the care given to him and his late wife was something he could not put into words - it was beyond mere description. This was in contrast to a recent experience of community care he had observed when visiting a friend, although this latter experience had not diminished or tarnished his perception of what he had experienced with his wife’s care or his own more recent care:

> *“A subtle thing, that is almost indescribable.”*
>
> *“I find it varied… the carers, it’s very mixed…”* Idris (P9)

Catherine (P18) was one of several participants who described the qualities they believed were required of staff to work within healthcare, which were more than just wanting to work in care:

> *“…intelligence to follow the course. So you need intelligence, common sense. I think you need to be physically fit and I think you would have to be in it for the long-term. You would have to want to do it.”* Catherine (P18).

I asked Freda (P12), as a retired auxiliary, what she felt were the qualities necessary for an HCA:

> *"Listening, empathy, patience errm and a very good ear for listening."*
>
> Freda (P12).

We laughed as Freda (P12) acknowledged that she had said 'listening' twice but she argued the case that listening was the most important attribute for the HCA role. A number of participants described certain qualities, such as compassion and common sense, as being either present or absent. This binary state was often considered to be inherent, rather than being a learned or acquired quality. Colin (P3) recognised qualities in the staff that he himself didn't possess and specifically mentioned compassion as being binary, either in its presence or absence:

> *"I wouldn't be able to keep me cool. Not so much losing me cool, I would have something to say…I think some people have got more compassion, that other people, I am not sure they identify and sort of identify how much compassion they have got. I think it's your basic values…it's not people trying to become compassionate. You either are or you aren't."* Colin (P3).

Sally (P10) also described a binary state when articulating whether anyone could work within healthcare:

> *"I think it comes natural with some? Doesn't it? I think some people have got that natural ability to do it?"* Sally (P10).

John (P17) was clear that common sense was necessary for the role even before considering other relevant factors:

> *“A modicum of common sense can’t be learnt, it’s in you and if you haven’t got that, it doesn’t matter what qualifications you’ve got.”* John (P17).

Francis (P13) had experience of the non-professional side of caring via her husband and this reinforced her understanding of the staff as having different qualities to those who do not work within care. They possessed something extraordinary - in her words, a ‘*gift*’ to be able to do what they do - as she recognised she was not in possession of such a gift:

> *“They’re gifted…Yes. I couldn’t do it… in the past seven years my husband has seen to this, the fistula. Now my own brother said, no way could he do it. So there’s a difference you see, one can, one can't… I mean I've got stoma on and I have to use a pot and they take it away to measure it, now I couldn’t do that.*” Francis (P13).

This recognition of elements of the role that are difficult was also articulated by Jane (P5). She was grateful towards the HCAs for the manner in which they dealt with the measurement and disposal of her bodily fluids during her monitoring phase:

> *“Yes it doesn’t worry them even taking your pots. I’ve got a stoma here it’s got to be emptied and my urine’s got to be emptied but they don’t worry about it. You just say ‘I’ve been in there (pointing to the bathroom) will you take it away’ sort of thing…They don’t turn their noses up about having to do anything like that. They are very good.”* Jane (P5).

The naturally occurring presence of inherent qualities was further addressed by Idris (P9), who used his understanding of education to illustrate qualities that he suggested cannot be taught or learned. The inherent qualities, as he perceived them, were related to the nature of many staff working in caring professions. He perceived that these qualities may be taught within healthcare but that the effort to do so would be futile.

> *“the only thing you require to teach special needs is infinite patience and infinite concern with children…you can’t teach that. They either have it or they don’t have it. If they don’t have it then it is useless trying to teach them to be teachers of special needs. They will lose patience and lose interest.”* Idris (P9).

Colin (P3) applied his knowledge and experience of working long days in recognising the effort required for staff to maintain consistency during the totality of their shifts. He also observed how staff managed their time and demands across each shift, expressing his surprise at how staff remained patient throughout each day:

> *“Erm I think you can tell when someone is busy with what they should be doing and they don’t see it as a… they might see it as a chore but another 14-hour shift in I know I am going to be tired…but being able to do all that without losing your patience with people…”* Colin (P3).

Judy’s (P16) husband sat through the interview with her and, towards the end, asked if he was able to contribute. His description of the qualities required for the HCA provided additional insight to Judy’s own observations (P16):

> *“Well, I mean I sort of recognise a lot of what Judy has said about the Care Assistants, and I’ve thought for a long time how good a job they do. And, I’ve thought, when you were talking about qualifications, a lot of them it’s not about educational qualifications, a lot of them it’s about life experience, and I was thinking an awful about when Judy’s Mum was in Hospital a few years ago, and it was those Care Assistants that were the mainstay for the people that looked after the people.”* Judy (P16).

Johnny’s (FS3) comments concurred with the earlier interviews, suggesting that:

> *"You've got to be more caring to take the job in the first place…it draws them to the job…it's a vocation"* Johnny (FS3).

5.4.6 Boundary working and the impact for patients

Boundary working emerged as an issue when participants described the grey areas where staff were working at or beyond the edges or limits of the job role. It was clear that there were a number of contributing factors to instances of boundary working, primarily related to accessibility and availability of staff.

Participants understood that the HCA was more available to them than the RN in terms of their visibility, roles and responsibilities and numbers:

> *"that they were the people who were around"* Judy (P16).

> *"a lot of the sort of day to day contact and care would probably be with them rather than with somebody who was a bit, you know what I mean, higher up the… the nurse."* Catherine (P18).

Participants also noted the ratio of HCAs to RNs in certain departments:

> *"there's only about one, maybe two regular qualified staff on there and all the others are Healthcare people."* Catherine (P18).

Colin (P3) also saw the HCA as more available than the RN and concluded that the HCA was more likely to be asked for assistance or advice due to their nearness and accessibility. He also recognised the difficulties the HCA faced when patients asked for something they were unable to attend to:

> *"It's them that… seem to be more available to ask questions to. I know it must get on their nerves that a lot of people ask them… questions that there are not actually qualified to give the answers too."* Colin (P3).

Colin (P3) was reassured by the manner in which the HCAs recognised their authority limits and reassured him that more senior staff were being engaged. He identified the HCAs as being clear about their role as they contributed to the communication flow from patient to doctor:

> *"… in my experience they have always mentioned what's been said to the right people or reassured… I will mention to Dr such and such when he comes."* Colin (P3).

Stanley (P8) was also aware of the impact on the workforce arising from limits to authority. The limitations of the HCA role coupled with their higher level of accessibility to patients made them vulnerable to the pressure of working beyond their roles and responsibilities:

> *"It's the line of their sort of authority if you like it is as far as they can go. Therefore, they have to go and get the nurses to do that. Even though the nurses are really busy you know."* Stanley (P8).

In situations where the HCA did not have the jurisdiction to act they would need to get a RN, which caused a delay for the patient. Participants were, however, accepting of the delay and understood why some tasks were not within the remit of the HCA:

> *"OK yes there's a delay but I mean she goes and talks to the nurse and the nurse comes."*
>
> "*Sometimes I think well why not. Why can't a nurse do that…it would save so much time. They had been so busy here."* Ivan (P6).

The limitation imposed on particular roles was a cause of frustration for some in situations when none of the nursing staff were able to undertake a technical intervention. Ivan (P6) had to wait a number of hours for a procedure to be escalated higher up the clinical ladder. He questioned why nursing staff would not be able to perform such duties.

The HCA’s availability and accessibility to patients, coupled with their level of experience, makes for a powerful, although not easily defined, contribution to the overall delivery of care. The grey area Freda (P12) referred to is the boundary working that developed over time as the HCA built up implicit knowledge together with the presence of mind to do something about it:

> *“you have defined roles… but at the same time its little things that they pick up on their job without them being conscious of it…(the HCA) recognise things, pick things up with sheer number of years they have been working …they look and turn round and think they will go and ask a nurse.”* Freda (P12).

From his perspective as both a patient and an experienced RN, Darren (P1) was concerned that sometimes certain HCAs undertook tasks and duties outside what he perceived as being their jurisdiction:

> *“…you may get a very experienced HCA and they think they can do more than what they are allowed to do... Someone might be on a drip or something, and they may decide to turn the drip off. They don’t always ask us they just do it. But, generally they are aware of their limitations.”* Darren (P1).

Evidence of boundary working is apparent in the earlier section in this chapter on roles and responsibilities, wherein Mary (P11) alluded to how the staff imply they know more than their jurisdiction. She felt uncomfortable with this blurring of roles, appearing to prefer a clear delineation between the different staff roles:

> *“…people thinking they know too much. It is your person you know you and I know when I need a pain killer, or a trained person could advise me that I need one but an assistant,* ***well*** *an assistant…”* Mary (P11).

One participant expressed his concern that changes in NHS staffing policy may bring about an increased scope for the assistant role. Although he implied this would make things worse, he had no specific issues with those assistants he had met or had cared for him. His perception was therefore different to his experienced reality:

> *"Well obviously I would rather a registered nurse but as we haven't got a fully functioning national health service, those days are way off. They are even talking about having assistant Drs aren't they if you read your papers? So things are going to get a lot worse before they get better. But I have found the assistant nurses or whoever have all been most helpful. You know, No problem."* Idris (P 9).

Machines that delivered IV fluids or medications were in operation for some patients. It was suggested that the HCA does sometimes operate these machines to silence them as the RN was often absent. Participants describe how they watch what the HCA does to silence the alarm and take on the role themselves thus reducing the HCA or RN coming to the bedside:

> *"Yes it often beeps and I do my own, but (laughs). They will come in and do that you know and stick it off going again you know."* Ivan (P 6).

Mary (P11) took a different option and described her concern for the flashing lights on the IV machine and the manner in which her concerns were dismissed by some of the staff:

> *"Some of them made you feel like you were a nuisance if the problem was trivial."* Mary (P11).

Asking for help directly or indirectly as in the case previously described will be further described in the core category of adaptation (section 5.6).

5.4.7 Collaboration

Stanley (P8) described how impressed he was by staff working together and demonstrating equity and power reduction across the nursing team:

> *"I think it is really good, I think it is excellent because it's what it's doing, what it's showing the HCA is that I am a Sister but I am not above doing this job with you… The HCA gets that. The sister will come and do it all that she will do it with her. Either that or the nurse. They work together. It is really good."* Stanley (P8).

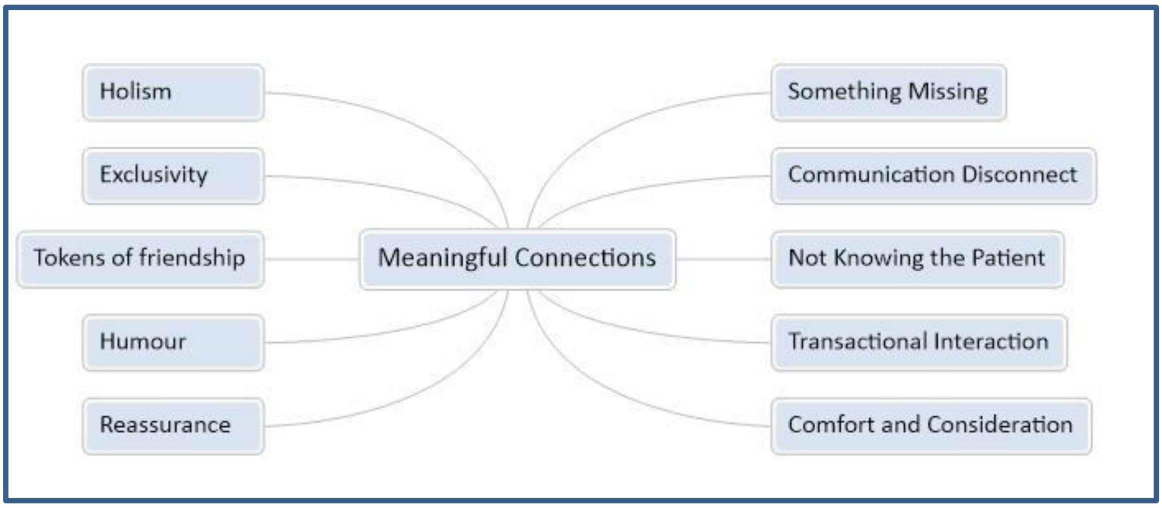
This observation was comforting to Stanley (P8): he was reassured by the team work and perhaps by the sister demonstrating her accessibility to him and to the staff, despite being in a role possibly seen as distant from the patients. Staff still appeared to hold some degree of power over Stanley (P8), however, which was borne out by his suggestion as to what he would say to a friend who was coming into hospital for the first time:

> *"I would reassure them they have nothing to worry about as long as they listen to what the staff tell them and what the staff ask them to do, you know."* Stanley (P8).

Idris (P9) recognised the presence of power but noted that staff were not always able to employ their power in certain challenging situations:

> *"This is where I think the staff in the NHS should be protected especially when the drunks come in. I think they should be given the authority to throw them out… Staff should not be expected to deal with that."* Idris (P9).

5.5 Core category 3: Meaningful Connections



Mind Map 3: ***Core Category 3. Meaningful Connections.***

Meaningful connections were an important aspect of the participants' experience and were apparent through a range of interactions between staff and participants that brought comfort and feelings of consideration to the participants.

5.5.1 Comfort and consideration

Comfort and consideration, as described by a number of participants, is associated with more than the mere response by staff to a request from patients. It suggests that, although immediate feelings of comfort were felt by participants when their specific needs were dealt with, there was an extension of comfort beyond the moment resulting from the forethought of members of staff before the interaction ended.

Ivan (P6) described tasks performed by the HCAs and the way in which, while doing these tasks, the HCAs asked if there was anything else they could do for him. He mentioned one HCA in particular, who he had not previously met, making a point of coming to see him as soon as she had heard about a disturbed night he had experienced. In this first meeting, the great consideration she showed for his situation was of significance to him.:

> *"…can I help you..? Can I do this for you? Can I do that for you? Take my arm…"* Ivan (P6)

> *"Oh yes first thing…about 8.10 the new nurse which I haven't seen before… errm, she said 'I heard you had a rough night. Is there anything you need?'"* (Ivan P6)

Molly (P2) described the HCA bringing her tea and also taking time to ensure both her immediate and on-going physical comfort:

> *"…they would say 'Oh Molly,' as if I had known them years and years. 'Would you like a cup of tea or do you want a cup of coffee or whatever, are you comfortable like that? Do you want this or do you want that? Shall I move your pillows for you?' The nurses didn't bother too much doing that." (Molly shook head and dropped her head down, looking towards the floor).* Molly (P2).

For Molly (P2), these comfort sustaining episodes occurred regularly throughout her stay in an orthopaedic ward. She contrasted the HCAs and the RNs in this respect, getting the impression that the RNs felt they were not there to do these things for her and thus making a clear distinction between the availability of the HCA and RN for such comfort-giving moments.

Interestingly, it was an RN that eventually attended to Molly's (P2) request for a blanket. She described the physical response she felt from the warmth and comfort and how much that meant to her. The RN also met more than her immediate need for a warm blanket and considered the impact of the open window and the open blinds, closing both for her comfort:

> *"He shut the window because it was left open, he drew the blinds… he says 'I will put the light out'... What a difference! I was so warm and cosy and comfortable and yet I had asked not one nurse, had asked two-three nurses."* Molly (P2).

Molly (P2) also contrasted the frequent interventions of the HCA with the more irregular contact with the RN:

> *“… the auxiliaries when they passed would always pop their head in and say, ‘Hello Molly how are you doing? Do you want this or do you want that, or shall I make you a cup of tea?”* Molly (P2).

Jessie (P14) was full of praise for one particular HCA, who made every interaction more meaningful than just attending to a mere task. She was also full of praise for the moments when the HCA checked in with her before Jessie (P14) called or pressed the buzzer:

> *“The same one… I told you that came in, she used to, I don’t know, half past eleven, twelve o’clock at night, she used to come in and make sure I was okay, is there anything I need? A drink or help with the toilet or whatever? And I hadn’t pressed, I hadn’t pressed for her. And then she used to come and take the blood pressure at two o’clock and ask can I help with your pillows and things like that, she was so attentive, she was unreal.”* Jessie (P14).

This anticipation of patients needing comfort on the part of the HCA is clearly illustrated by the narrative of Francis (P13). One particular HCA considered Francis’ (P13) needs even when not on duty, taking some of her own off duty time to collect beauty samples to give to Francis (P13) to cheer her up. It was not just Francis’ (P13) connection to this particular HCA; she felt a connection with all of the staff and illustrated this when recounting her journey to theatre for another long and complex procedure:

> *“… when I was all ready to go the staff came to see me and without a word of a lie there must have been about eight or nine staff in a line ready to give me a kiss and a cuddle before I went downstairs to the theatre.”* Francis (P13).

She was very positive about her experience with staff of all grades and designation, stating she:

> “*loved them all.”* Francis (P13).

In contrast, Molly (P2) was struck how the RNs presented as being distant and aloof. In her view, they were not friendly partly because they conformed to the rules, indicating that perhaps the HCAs adopted a less formalised and proceduralised approach:

> *"… you know they stuck to the rules a bit (hushed secretive tone) there was no, erm, friendliness you know."* Molly (P2).

She told me this in a secretive manner, despite the confidential private nature of our conversation. I wondered if she felt she was sharing something she had not discussed with others where she may have felt disloyal in doing so.

Besides the giving of physical comfort, Jane (P5) and Gary (P19) appreciated spending time chatting with the HCAs. Jane (P5) described these moments as cheering her mood:

> *"They are very considerate and most of them are very, very friendly. Aye, you know if you are feeling a bit low they will have a good chat sort of thing. I think they are all very good especially on this ward."* Jane (P5).

Gary (P19) described the mere conversation with an HCA as bringing him something more than the physical meeting of his needs:

> *"Well it's comforting, isn't it? Aye, I like it, aye."* Gary (P19).

Consideration of the patient as an individual was also seen by participants as important to their overall patient experience. When a member of staff notices that a patient needs something more than attention to their immediate need or request, a value is added to the patient experience that can be important for them in terms of recovery. Colin (P3) described a moment in his care when an HCA took it upon herself to suggest he needed more than the immediate care that staff or family could offer. He was so grateful for the HCA's insight into his distress and his need to talk his difficulties through that he recalled the event with a real emotion that is evident in his narrative:

> *“I sat talking to her for about an hour and a half and I felt absolutely rejuvenated after that it sort of got us back into the game of you know onwards and upwards. And that was through (HCA)…. she identified that I need someone to talk to that wasn’t me mum or me dad and somebody who wasn’t involved in my day to day care and she went and sorted that out...”* Colin (P3).

As HCAs were interacting with the patients on a one to one basis, it seemed they often took the opportunity to see if there was anything else the patient required. The holistic approach the HCA took to the patient was noted and valued by participants. When participants were uncertain about their immediate trajectory as a patient, the HCA made valuable contributions to them getting through this phase. Sally (P10) appreciated the manner in which the HCA presented to her, helping Sally (P10) deal with these uncertainties. She was unsure whether this was due to the HCA being caring but felt that the anxiety and concern was lessened as a result:

> *“Yeah, yeah, she was friendly and I felt that I could talk to her. I think it was caring, she was caring and, but she made us feel at ease because I was in pain and err I didn’t know what was happening and she just made me feel like feel at ease and explained what was going on.”* Sally (P10).

Colin (P3) also used the term *‘feel at ease’*, which suggested he felt the broad contribution of the HCA in the management of these uncertainties:

> *“I’ve certainly found all the HCA that I’ve erm, been involved with have always been urm I’d say above all interested in erm, very professional, very helpful, put you at your ease.”* Colin (P3).

There are a number of points for consideration arising from Colin’s (P3) narrative. He referred to the HCA as being interested in him and having a manner that portrayed assurance in their role, which in turn promoted a sense of peacefulness for Colin. Sally’s (P10) experience was more about the reassurance the HCA provided her, wherein she associated these feelings of reassurance with caring.

5.5.2 Reassurance

Participants often described times when reassurance was sought from, and met by, direct interaction with staff. Participants often associated elements of reassurance with confidence in the system, service or staff.

Stanley (P8) described a circumstance where he spilt his urine bottle and was anxious and concerned that it was his fault. Staff, through their management of the situation, reassured him and brought him comfort, which thus reduced his anxiety:

> *"… a nurse and an HCA came and they were ever so kind they didn't say it was my fault, they said 'oh it happens, don't worry about it'. It was fine, they were just so good. It was really kind experience…It just gave me errm confidence and it gave me more confidence in the staff here. It made me understand just how sort of empathetic they were and how sort of kind."* Stanley (P8).

Through the dialogue between patient and nurse, Stanley (P8) understood that the event was not unusual, he was not an exception and that this had happened before and was all in a day's work for the staff. However difficult, staff appeared able to diffuse patient concerns in situations where dignity may otherwise have been compromised.

Colin (P3) was reassured by his previous experience as an inpatient so much that he was not unnecessarily anxious about any subsequent return to hospital:

> *"…relaxed in between visits thinking I'm going to have to go back there again… but if you come away with good positive memories and experience of it …you're in good hands."* Colin (P3).

Examples of how staff indirectly brought about reassurance for the patient were through the exclusivity shown in care and interaction (see further examples in the section on exclusivity in section 5.5.5). When staff were interested in getting to know participants as individual people rather than bed numbers associated with particular tasks, there was a sense of reassurance provided to participants that there had been some personal investment in them. I wondered if that investment might have contributed to the level of trust that was built up over time for the participants:

> *"It gives me a lot of confidence because they are I know they are taking an interest in me. They are not standing at the bottom the bed just saying ermm, ermm, you know."* Mary (P11).

Freda (P12) also recognised the feelings of exclusivity between patient and staff that led to enhanced wellbeing:

> *"… they make you feel like they are doing, making you safe and secure and they also know what they are doing is for your benefit…"* Freda (P12).

Don (FS1) held similar views:

> *"I knew a few of them [nurses] I knew which ones were going to be there…I felt a bit more at ease after I knew I was going to have the operation."* Don (FS1).

The frequency of Jessie's (P14) medical staff visits and interactions were a great source of comfort for her and she specifically recalled the Surgeon visiting and communicating with her:

> *"… the surgeon, can't sing his praises enough. There were some days where I was really poorly, he must have been at my bed ten times a day and I thought no surgeon does that, and he said I pray for you every day and I just thought that was lovely. That was absolutely… There's not a lot of surgeons would say that."* Jessie's (P14).

Polly (P15) explained that the medical team gave her reassurance through the ‘information giving’ approach they adopted with her:

> *“Well, as I say, I can’t fault the doctors and they explained everything what they did to you and what they’re going to do.”* Polly (P15).

In contrast to the above comments, there was a lack of assurance in situations where there was an absence of staff. Judy (P16) was told she was likely to feel unwell after her procedure, however, as there was no one to remind or comfort her after the procedure, she reflected that it could have been a better, less fearful, experience had this help been forthcoming:

> *“…that made me quite anxious because like when I had the liver embolization, they said, ‘Well you might, some people do feel a bit ill after it but other people are fine and you’ll be home in like the next day or something,’ but I was really felt terrible and I was really sick and... Physically sick as well and just felt lousy and I don't think anybody was there who really helped with that.”* Judy (P16).

5.5.3 Humour

‘Humour’ describes both an appreciation and an expression of humour. This code emerged early in the coding process and remained a consistent theme throughout. Although this is simply a descriptive code, I have not sought to abstract it further as it is firmly rooted within much of the participants’ narratives from across many contexts and it also played a large part in their view of self.

Freda (P12), having listened to a joke that was shared between a nurse and patients in the bay, described how humour can transform a situation. The trading of humorous comments between participants and members of staff is worth consideration as there is a strong theme of reciprocity here, which is an interesting dimension in an otherwise dependent relationship:

> *“I mean we have had a male nurse he comes on the ward ‘I’ve got a joke for you!’ and everyone goes ‘have you?’ he says ‘it’s a clean one’*

> *and we says 'yeah we've heard that one before!' he comes out with a joke as simple as a kid of five year old would you know and the point is for those two seconds you can laugh and then you can tease him for coming out with it. 'Oh I won't bother if that's how you feel about me jokes!' But it makes you smile and lifts you."* Freda (P12).

The use of humour to bring about a shared moment in a collective way was valued by Freda (P12):

> *"…it does it lifts the spirits... and I thought we are all sitting here laughing about it."* Freda (P12).

Molly (P2) described an episode in which she experienced another self, brought about by some medication she had been prescribed that subjected her to an episode of hallucination. The feelings she had during the experience and afterwards were of disorientation and disconnection. She was distressed by this presentation of herself, one with which she was not familiar. When she recalled a particular interaction with an HCA after this event, it was with a genuine sense of relief and increasing animation that she described to me how the humorous aspect of the situation was brought to the fore:

> *"Well, I told one of them and she laughed and she says 'Wore is it you had in your last drink before you go to bed?' …I was saying 'Nothing like that coz I don't drink'. But they was just laughing."* Molly (P2).

I asked Molly (P2) whether she saw humour as important and she described how she herself used it in her previous work as an auxiliary to bring about a sense of connection with patients:

> *"Well, think more so if you are in hospital. When I worked in the hospital I used to go in, a bit of a joke and a bit of a laugh with the patients."* Molly (P2)

Some of my earlier analysis of the narrative made me wonder whether humour was sometimes used by both patients and staff as a token - a gift of friendship – and a way of making connections deeper than the transactional interactions as described in section 5.5.8 of this chapter.

(Is she describing here the use of humour as a way of establishing some sort of relationship? Is humour a token that is shared a commodity to be shared, offered, secretively, club membership, engaged in?) memo dated Nov 2014.

Stanley (P8), like Molly (P2) above, described how humour was initiated by staff to potentially help them navigate difficult issues:

> *"Well, for instance when I was having the bottles at night. One of them in particular I can't remember her name, she would say. 'How many do you want?' I would say '3'. She would say 'they are £1.50 each mind'. And I would say 'I will pay it at the end of the week'. Laughter between us both. Just a little bit to ease the situation."* Stanley (P8).

I considered whether the HCA may also have been using a humorous approach to get Stanley (P8) to start thinking about the time he may need to start getting up and out of bed; a time for increased mobility as preparation for him going home. Rather than addressing this subject head on, perhaps the HCA used this humorous event to set the scene for a later dialogue. The episode was recalled by Stanley (P8) willingly, enthusiastically and in a relaxed way, with an interesting recognition that he could not remember the HCA's name. Connection between the HCA and Stanley (P8) was perhaps more about the content rather than a personal, more intimate moment.

(*Further thought on this narrative led me to think about don't call the HCA until the three are used. An efficient use of the HCA's time or another point of patients getting on with some of their daily living activities with minimal assistance).* Memo Dec 2014.

The narrative between Stanley (P8) and the HCA could be seen as a humorous 'threat'; a way of initiating a conversation that may otherwise be perceived as somewhat dictatorial. Releasing a patient for home leave is a point of trust for both staff and patient; staff may be thinking whether the patient will return in a timely manner ready for the week of treatment or investigations and patients may be wondering whether their bed will be used for someone else. Freda (P12) recalled how the RN used humour to negotiate her responsibility for returning from home leave:

> *"But you come back Monday night, you had better come back Monday night otherwise we will come and get you!"* Freda (P12).

Interestingly, Freda (P12) thought this amusing but did not reciprocate, effectively taking this as a form of humorous instruction, perhaps due to her perspective as a patient requiring the bed on her return.

Using humour through sharing of a 'secretive' dialogue may be evidence that there is a deeper connection between HCA and patient. The act of sharing a secret is illustrated in Stanley's (P8) recollection of an HCA's birthday celebrations:

> *"I mean the HCA and the nurses, they talk to you…, they tell you what they are doing and where they are going. One of them says 'I am in tomorrow but I might be a bit over the top tomorrow coz it's my birthday today. So if I come in tomorrow a bit bleary eyed'..."* Stanley's (P8).

I felt the HCA was telling him an 'exclusive' secret as he shared this narrative with me in hushed tones, honouring her secret and keeping this away from the hierarchy in a joking manner. Exclusivity is discussed later on in the findings chapter and this example illustrates a level of exclusivity between patient and staff.

Freda (P12) herself uses humour to bring a sense of community to the 6-bedded bay and, despite the 'basic' nature of her humour, all but one patient appeared to enjoy it. Freda (P12) suggested that there is a long lasting benefit of bringing humour into a difficult personal situation wherein privacy is limited:

> *“Yes we have a bit of a joke, because Jenny went for an enema this morning and we said ‘tell us when the baby is due?’”*
>
> *“It lifts you up you don’t get so depressed about it. Alright it is not going to cure your illness by any means or cure how you are feeling but it lifts the spirits a little bit.”*
>
> *“Even though the comments last a few moments the effect lasts a little longer.”* Freda (P12).

Freda (P12) used humour as the lens for recalling a number of events, including a discussion of bowel movements, and I was mindful of this being something that would be less likely to happen outside of the clinical environment that participants found themselves in:

> *“Everybody sort of thing I am like everybody else and if you get one who says ‘Oh no’ so you just say ‘well if you want to be isolated’ which is literally what it does to you if you don’t want to join in the fun it isolates you doesn’t matter how hard you try she want to draw in to she’s ill and I understand that. It’s bad, as it isolates her more.”*
>
> *“Yes it … doesn’t matter who you are or where you have come from when you are ill it is a great leveller…and if you are cracking jokes and things it’s nice, you don’t sort of get this blank wall.”* Freda (P12).

The patient who did not want to join in with the humorous episodes was viewed as someone outside of the others’ community. Freda (P12) added an additional perspective, suggesting that humour was a way of bringing a community of individuals together who may not otherwise naturally form a community under different circumstances.

John (P17) was an OPD participant and, while sat with his wife, recalled the time he was given his terminal diagnosis. He used humour to bring a sense of himself and the relationship he had with his wife into the conversation. He turned to her, smiling and laughing as he recalled the conversation between him and his wife when he lay thinking about his diagnosis:

> *“So and this is true, she’ll back me up here, so I’m lying in bed that night staring at the ceiling and she says, ‘You know if you do die within 12 to 18 months,’ she says, ‘I love this house’, we’ve got a big house, lovely garden, she says, ‘I couldn't afford to keep it by myself so if you die I’d have to downsize!’”* John (P17).

This humour remained very much part of him and his being, and he used it to deal with his poor prognosis. Gary (P19) also illustrated how humour was important to him and his personal relationships, describing how his family brought an immediate sense of himself back post operatively:

> *“I was laughing and joking in there with my partner, my Mum and that, you know, straight after the operation.”* Gary (P19).

There also appears to be an additional facet to humour, wherein staff use humour to seek connectedness and ‘get the measure’ of the patient over a period of time. This connection through humour was very important to Ali (P20), as he had been under investigation in hospital for some time, feeling quite unwell but with no definitive diagnosis. This liminal space Ali (P20) occupied was difficult for him. Staff teased him about how long he had been in, in an attempt perhaps to help him manage this liminality saying that:

> *“…he will be drawing his pension soon.”* Ali (P20).

The way staff used humour with Ali (P20) brought about some lightness and relief for his indeterminate length of stay, during which time there has been little improvement in his condition. Humour was discussed as a theme with the participants during the feedback session element of the data collection and they were equally keen to describe the importance of humour for them. Johnny (FS3) experienced dark humour from staff to help him manage a critical situation. He himself was receptive to this level of humour, whereas his wife was sure that she would not be laughing and joking if she had such odds against her:

> *“Even under the anaesthetic, when he was coming round, he was cracking jokes.”* Johnny (FS3).

Interestingly, Johnny’s wife was aware of the contribution that Johnny (FS3) made to the staff and to the atmosphere on the ward:

> *“They’re sad when he goes home because that’s him all the time.”* Johnny (FS3).

Johnny (FS3) added further perspective, suggesting that staff were aware of patients’ humorous natures, working this aspect out on an individual level and incorporating each patient’s context into their interactions:

> *“It never overstepped the mark. It was always an appropriate level of humour.”* Johnny (FS3)

5.5.4 Token of friendship

‘Token of friendship’ describes the activity of staff and participants trading gifts. These gifts were sometimes, but not always, physical objects and may have created a level of closeness and shared moments that added to the connectedness felt by participants.

Molly (P2) was mindful of the workings of the nurse/patient relationship and used her personal chocolate store to access a more intimate relationship with certain staff through her tokens of friendship:

> *“The thing was, with working in a hospital I knew what the, I took a bag of chocolate I, ‘take a bar of chocolate.’ Well we had such a laugh about this chocolate because one of the girls who was really funny used to say ‘eee so and so has been in here 4 times she keeps putting on a hat a wig, eee she has got a load of chocolate down there.’ (Laughter) It was very, very funny.”* Molly (P2).

Staff used tokens to bring about a connectedness that was deeper than dialogue, effectively a physical representation of the moment shared. A present given with meaning resonated with Francis (P13), who had been in and out of hospital over a number of years. A specialist nurse who had known Francis (P13) over the years felt enough of a connection to give her a small token, a trinket guardian angel. The nurse may have wanted to reinforce her connection with Francis (P13), particularly when Francis (P13) was away at theatre for yet another procedure. Through a set of circumstances, the RN also gave a trinket to Francis' husband, an act that held deep meaning for Francis as she was taken away from the ward and from her husband for a lengthy procedure:

> *"…one of the speciality nurses came and she says 'that's for you, you keep that with you all the time'…He's been here every day. So he's got that one. And that's the kind of staff they are."* Francis (P13)

> This deep connection through the giving of tokens was expanded for Francis (P13) when an HCA, who had looked after her a number of years previously, visited to give her some toiletry samples:

> *"There was one of the healthcare workers, she was here when I was here seven years ago, and she came in one day and she said I was in Boots and I went and got some free samples and there were two perfumes and a body lotion. She says they're for you to cheer you up."* Francis (P13).

As Francis (P13) recalled these stories, she was aware of sharing with me something that she herself saw as extraordinary. The length of her stays, and the frequency with which Francis (P13) came into hospital, also brought about a foundation of relationships with staff from which these tokens were meaningful.

I related Francis' (P13) experiences to Gary (P19), who had been an in-patient for no more than 6 days but had also received a token of friendship from one of the HCAs. Gary (P19), an avid football fan, was visibly touched by the effort the HCA went to in order to meet his desire to hear the football one Saturday afternoon:

> *“Because we were on about the football match and that we couldn't get it on the radio and that here and she just says that she’ll bring her dad’s radio in in the morning and brought in a radio for me.”* Gary (P19).

Although length of stay contributed to the depth of connection between HCA and patient, there were other episodes, not involving extended lengths of stay, in which staff did something more than was expected.

Tokens were not necessarily in the form of physical items or gifts; they also arose from conversations or recollections and contributed significantly to the patients’ sense of belonging and connectedness, as described in the following quote from Francis (P13):

> *“…there was a girl from theatre came past my bed one day and she stopped and she said, ‘I know you’. I said ‘do you really?’… I said ‘I’ve got you, you walked alongside the bed when you took me outside one night from critical care’. It came to me who she was. But after seven years I'm so chuffed when they remember who I am!”* Francis (P13).

Acknowledgement by staff of what was important to the participants also acted as a token of friendship. Ali (P20) described how his health was improving following a long period of time without any diagnosis or feelings of hope:

> *“As I am starting to get a little bit better they are excited about my progress. All the staff across the disciplines say ‘looking better!’ I then feel better within myself, this is positive feedback and they care.”* Ali (P20).

This thoughtfulness, and acknowledgement of progress by staff, for Ali (P20), displayed as a token of friendship, gave him the motivation to keep going. Stanley (P8) told of how he felt when there was mutual information sharing:

> *"Yes and they are prepared to give you that little bit of information about themselves. They do ask about you as well you know as a patient what your background is which is nice as well. It shows they have got an interest*." Stanley (P8).

The interaction described by Stanley (P8) was not one way - there was a shared moment – and Stanley (P8) placed value on the carer sharing personal information with him. By way of contrast, a level of professional distance between staff and patient was assumed by Jane's (P5) narrative:

> *"Err. I don't think you sort of delve too far in their lives you know they are sort of happy friendly atmosphere err you wouldn't have a like an intimate sort of relationship with any of them like that apart from asking normal things about how they are in that sort of thing*." Jane's (P5).

Molly (P2) described her earlier contributions to the patient experience when she had been working as an auxiliary, recalling that patients looked forward to her starting a shift. She brought something of herself to these patient relationships, revealing what she had been doing prior to starting her shift. This gift or token of sharing her personal narrative for the benefit of the patients was powerful in that it brought about a connectedness for the patients with both her and the world outside:

> *"Arhh they used to wait for me to come in and if I were late 'Oh here she is!… What've you been doing?'"* Molly (P2)

Issues around lack of staff continuity caused by shift changes and days off may have implications for patients in situations requiring round the clock care provision. A few participants noted staff making the effort to invest some catch-up time with those patients whom they had cared for previously. This could be viewed as a token towards, or acknowledgement of, their previous relationship, creating a sense of connectedness from earlier experiences:

> *"They just always errm, if they've been off for a while they or like they've changed a shift and gone elsewhere they've come back and they try and catch up with what's been going on with you and they take an interest sort of thing."* Jane (P5).

> *"…you build up a sort of relationship with them all… and the disappointing thing was I had been here 2 ½ weeks…and they switched the staff around again… You get new faces, and new nurses, new HCA to get on with. But the old ones would pop back in again you know."* Stanley (P8)

Judy (P16) also recalled the care her mother had experienced and the observations she herself had made while her mother was an in-patient:

> *"And when she'd moved Wards, one of the Care Assistants from the Ward that she'd been in used to come and visit her to see how she was…It makes me feel quite emotional when I think about it."* Judy (P16).

This example of the 'visiting' HCA demonstrates continuity and is potentially of huge value for both patients and relatives when facing a change, where she was herself a token. Equally, it serves to highlight the different dimensions of the care experienced on each ward. Judy (P16) became really emotional at the point of recounting this episode, touched by having witnessed the tenderness and care demonstrated by the staff for someone whom she loved.

The well-being of staff and their outward display of happiness also played a significant part in the patient experience, with staff offering to share their emotional wellbeing as a token of friendship:

> *"Well… Yes, I mean you can sometimes have a laugh with them yes but errm not too much buts it's just nice when they are smiling and happy sort of thing it cheers you up."* Jane (P5)

Smiling and happy staff were approachable and provided the patients with an opportunity to raise their spirits through a mutual response that would be hard to ignore – ‘I smile therefore you smile.’

5.5.5 Exclusivity and inclusivity

‘Exclusivity’ describes the one-to-one attention that participants experienced with staff members. The dimensional aspects of this code ranged from momentary through to extended experiences and were expressed by reference to both particular carers and general experiences.

Mary (P11) described how the staff from all areas of the organisation manage to make even the mundane activities exclusive to her. When asking staff for directions, they took the time to accompany her to a point she recognised without being distracted by other tasks along the way. She felt this attention to her needs was really important and brought her a sense of well-being:

> *“…everybody who has spoken to me has spoken to me as an individual… They were all giving me the attention I needed to get me from place to place. That’s all I needed.”*
>
> *“You are the only one…they are talking to me…yes…Confident in the care that I am getting.”* Mary (P11).

It was clear from Mary’s (P11) narrative that staff in the highly process driven OPD department had taken considerable effort to bring this level of personal attention to the giving of directions. Mary (P11) suggested that the exclusive nature of the attention from the HCAs added to her trustful reliance on the care that she received.

At a micro and macro level, Colin (P3) recognised the exclusive attention he got from an HCA but also acknowledged that this ‘exclusivity’ was extended to how she dealt with other patients:

> *“You know it was just the fact she took the time out and I’ve got no doubt she was doing it with other patients as well.”* Colin (P3).

There were times when participants recognised that the exclusive relationship they experienced may have been clinically led. When Sally (P10) described the one to one care she had received during a previous hospital admission, she recognised the peace of mind that it had brought her:

> *“I think she made me feel like I wasn’t just another patient. You know I was the one person she was looking after and it was her job to do it. Just, I don’t know, that she made me feel at ease and that everything was going to be ok.”*
>
> *“And I knew she was there, but I just took her role personally for me she was there for me.”* Sally (P10).

The exclusive relationship she had with the RN during this acute phase of her recovery was deeply felt by Sally (P10). She trusted this RN completely, in fact so much that the RN’s presence was felt by Sally (P10) as she drifted in and out of consciousness. This provided Sally (P10) with a reassurance that was powerful enough to contribute to her overall experience. It was not clear whether the one to one care as described by Sally (P10) was delivered by an HCA or RN. Whatever her job role, however, the staff member displayed qualities that created a powerful impression on Sally (P10), wherein she perceived exclusivity, centrality, focus and concentration on herself. Sally (P10) felt that she had her own member of staff and that a one-to-one relationship was built up over a period of time from which she benefitted. Gary (P19) also received one to one care during his immediate recovery phase and, as he looked back to that time, described it as a point of reassurance:

> *“One to one care aye. Well it felt well always secure and getting well looked after and safe, you know?”* Gary (P19).

Exclusivity of care, as perceived by the participants, may not always have been based on specific one to one care plans but could also have arisen from the interactions between staff and participants that brought 'meaning in the moment'. To illustrate this, the day to day activity undertaken by the HCAs was recognised by Jane (P5), who identified that although there were demands placed upon the HCAs, they still managed to make Jane (P5) feel like herself, a person in her own right. She also recognised that staff of all grades and roles were behaving in a similar way:

> *"It makes you feel like a person as opposed to a non-entity sort of thing (laughter)……They treat you as an individual when they are coming round."*
>
> *"I think they are on a par with really you know (hands move together illustrating a joining/level between RN and HCA)."* Jane (P5).

Mary (P11) had clear views on how exclusivity should present itself. She was, however, not so sure that all staff managed this aspect of care equally well:

> *"It means treating me at the particular time as if there is no nobody else in the ward. No one of a group, not part of a group. Just see to me and then go on to see to others. Don't put me as we do it as a group." "Yes and they could be seeing to you and talking to the one over there and you know…Upset. I don't do it but I would love to say 'excuse me will you* ***just*** *see to me'".* Mary (P11).

Mary (P11) was in a bay of six and from my observations it appeared that staff sometimes treated the patients in the bay with a collective rather than individual approach, popping their heads around the door to check on everyone at the same time and, by implication, managing the bay collectively. Mary (P11) was hard of hearing and I wondered whether this collective approach by staff led to Mary feeling disconnected, as she found it difficult to hear and therefore understand these episodes. Adopting a collective approach to the bay could be interpreted as a genuine labour saving device, with the HCA sweeping across the bay to check on everyone at points where there was limited time to attend to individuals. There was, conversely, a positive aspect to this collective approach, with Freda (P12) and Gary (P19) both seeing this as a friendly manner that built upon the community aspect of their in-patient experience:

> *"Everyone in here will tell you they are always busy, always doing things but you never feel as if they must rush out and do another job. They make it as if they have got all the time in the world to sit with you."* Freda (P12).

Gary (P19) was also in a bay of six and concurred with Freda (P13) that when the staff addressed the whole bay collectively, it brought a sense of community to the environment:

> *"They'll speak to everyone really, if everyone's up and that, they'll speak to the full, you know? Because this Bay where I am, everyone sits and talks to each other anyway…so when they come in like everyone gets in on the conversation, you know?"* Gary (P19).

For Ali (P20), this collective approach was welcomed as he had been an in-patient for a considerable time. He had arrived in the UK from overseas to work and then became unwell. When his family came to visit, staff extended the exclusivity of the relationship towards them, which made the relatives very much part of the care. This extension of exclusivity was not lost on Ali as he recalled how this made him feel:

> *"They treated my overseas family who were visiting me for a 3-week period as part of the hospital family. If you have been here for a while you are part of the family."* Ali (P20).

The exclusivity of care he had received had been transferred to a collective, inclusive approach for him and his family.

Judy (P16) saw some differences in the relationships between staff and patients but was heartened when she witnessed deep connections, even if she herself was not part of it:

> *“Well I thought it was a good thing and it was nice but I did sometimes feel as if I was kind of outside of that because I wasn’t going to be there long-term and therefore there wasn’t long enough to establish that kind of relationship.”* Judy (P16).

Jessie (P14) had experience of exclusivity, her dependency and length of stay being contributing factors in this respect. She described the exclusive relationship she felt with one of the HCAs but added that they all contributed to her improvement in health:

> *“I literally said ‘I can’t go any further’… and one of them came in, held my hand and said literally, ‘Jessie, you’ve got a fabulous family, there’s only you can do it, but we can all do it together’ and that to me thought that’s the only way we can do it. I can’t do it on my own without the help of the girls, and then I gave me head a shake and I thought, listen, you’ve got to do it.”* Jessie (P14).

Other participants articulated a presumption of reciprocity, wherein the patient also had a responsibility in forging the exclusive relationship. Francis (P13) described how staff made her feel but made the assumption that her behaviour towards them was a contributory factor:

> *“Yes, you feel that you’re a person not just a number, they’re doing something for you.*
>
> *Well, they’re there to care and they do. But my husband and I always say it’s how you treat them as to how they will treat you.”* Francis (P13).

Mary (P11) identified that sometimes, when there was an exclusive interaction, it was more about the professional’s need than the patient’s need:

> *"I find the more senior the staff are the more they treat you as an individual. I think it is because they don't have that much contact with you and they* ***only*** *come to you when they* ***absolutely*** *have to, so they* ***absolutely*** *need it."* Mary (P11).

Freda (P12) wanted more information about her planned procedure and described the sense of partnership she had felt with the RN as they learned about the procedure together on a one-to-one basis. It seemed as if there was a redressing of the power dynamic evident from this narrative as it unfolded:

> *"I thought, eee what's going to happen? And one of the nurses said 'I am not quite sure give us 5 minutes and I'll go and find out'. And she did. She went to find out coz she said 'I have never seen this procedure' so she got me the information so the two of us were sat and went though it which was great, it meant she learnt something and I learnt something…"* Freda (P12).

Judy (P16) later went on to explain that the HCAs were present more often than other members of staff and that connections were made between the HCAs and those patients who had been in for a period of time:

> *"… And that's where I think the Healthcare Assistants, because they were around and if you saw people had been in long-term, they had a much better relationship with them, that was an observation, that wasn't my experience because I wasn't in for long enough to really form a close relationship with them but if you noticed on the Ward, that was the people who they held their closest… Who were doing their day to day care."* Judy (P16).

5.5.6 Holism and feelings of being human

'Holism' describes the approach that staff took in treating the whole person and not just the condition that the patient presented with. This approach linked to how they managed to bring exclusivity into those interactions also. It extended from the physical through to the emotional and social aspects of a person. Participants described how the HCA and other staff made them feel more human through the effort to get to know the patients for who they were and not just for the condition they had.

Colin (P3) was impressed by the knowledge the HCA had of him even before there had been any interaction; the fact that they knew him and his condition gave Colin the feeling that staff were interested in him as a person:

> *"I think you can tell by their demeanour their body language and the questions they ask… they seem to have read the notes and know why I am there… they were the 2 people that got me through the next 2 weeks, and they were interested."* Colin (P3)

Colin (P3) clearly stated that dialogue was only one aspect of this sense of holism, with the behaviour and outward presentation of the individual also telling him whether the staff were interested or not. He was specific in his reference to two particular HCAs, whereas Jessie (P14) identified that all of the staff, regardless of their role or profession, made her feel like a human, giving her hope and opportunity to envisage a time when she would return home:

> *"… like I say, it's like from the bottom to…even the cleaners, the cleaners will come in and they don't do anything personal for you but, 'how are you, Jessie', all this sort of thing, you think there is a bloody light at the end of the tunnel."* Jessie (P14).

Interest in the patient as an individual contributed to Ivan's (P6) sense of well-being:

> *"That makes me feel good that they are that concerned."* Ivan (P6).

There was further depth to Jessie's (P14) perception of how she felt with respect to particular HCAs. She went on to describe how feelings of humanness were addressed by one HCA whose similarity in age and gender to Jessie were factors that helped the connection:

> *"I feel as if they've experienced what I've experienced. You know, like a child, you know, you're not getting one of these kids of 18, 19… because to me it's like a kid getting you ready, isn't it, whereas a 50-year-old, which I am, that is more experience of life."*

> *"Companionship, I think. On a night when I'm feeling a bit low and I sit and…they only have two minutes, that's all I'm talking about… and when you're sad, they make you happy…"* Jessie (P14).

Judy (P16) alluded to the responsibility she felt that the patient has to articulate feelings and emotions, allowing the HCA to understand something more of you than the physical symptoms you present with. She indicated a requirement for patients to open up and tell staff about their feelings:

> *"Yes, I mean you'll mention all your sort of physical symptoms but you're not be prepared to say, 'Look I'm absolutely scared and I'm afraid of this,' or afterwards, 'I'm really feeling absolutely dreadful and I don't know who I should be seeing or whatever'... I think what's missing is, it doesn't have to be a physical feeling, I think your emotional feelings sometimes as well; you need to recognise yourself because I think that'll help you through*." Judy (P16).

Judy (P16) alludes to not all staff are sensitive to this aspect of care. She also alludes to her known self dealing with issues not experienced before and the feelings that result from that.

The lack of being treated as an individual in OPD was apparent for Freda (P12), in direct contrast to Mary (P11) who earlier on in the chapter alluded to the individualised attention she got for general directional instructions in the OPD:

> *"Oh yes, you feel like a number there sometimes (OPD)."* Freda (P12).

The feedback session participants discussed the theme of meaningful connections in general terms, with a consensus arising that staff contributed to their patient experience. It was interesting to note that Georgie (FS2), who had been in and out of hospital since she was 8 years old, suggested it was not specific incidents that she remembered, rather it was the staff who were part of those experiences:

> *"not the bits I remember; the staff I remember. Yes… good ones that I remember for the right reasons."* Georgie (FS2)

5.5.7 Transactional interactions

'Transactional' or 'task driven' interactions were identified by Darren (P1), who was an RN as well as a patient within the organisation. Darren (P1) saw the HCA as someone who performed no more than a series of tasks that included routine observations:

> *"Urrm… well if I needed It I would expect them to give me hand with my personal hygiene, I might need a hand to get my blood pressure done. They would introduce themselves to me…. I, would be orientated to the ward by them, maybe introduce me to staff possibly, and they might help, urm help deliver the meals to me (A long intake of breath and a sigh). I don't know what else they would do, urm they would help serve the drinks urm and that's basically what I would expect anyway."* Darren (P1).

When explanations from staff were lacking for these routine tasks and duties, some participants felt that they may be unnecessary. Bill (P4) described the lack of connection he felt towards staff undertaking these tasks, indicating a sense of resignation towards those involved in his care:

> *"No I just let them get on with it."* Bill (P4)

There was a sense of the HCA just getting the work done through task orientated activity; divorcing themselves from the humanness and connectedness that patients valued. Interestingly, Bill's (P4) perspective of resignation was partly driven by a deference to the doctor, whom he suggested "knows best". As he assumed that the doctor was requesting the frequent observations, Bill (P4) therefore saw the observations as being medically driven and not patient driven. Bill (P4) described the tasks and duties as a list of things done to him; he himself was absent from this, not active in the actions and therefore merely a passive recipient. Anthony (P7) described his relationship with the RNs as functional and transactional, wherein it was less about the RNs getting to know the participant but more about dealing with the task in front of them:

> *"Deal with on a need to basis…"* Anthony (P7).

Ivan (P6) offered a different perspective as he described the HCA activity as transient, coming into his room and doing what they need to do before immediately leaving again:

> *"Well errm I'm not really on first name terms with many of them because they are fleeting... they do a job they are gone, in out fishhh, very speedy, rapid with what they have got to do. And they get on with it."* Ivan (P6).

When Ivan (P6) described the swift interaction he had experienced, coupled with not knowing the names of the staff involved, suggestive of trusting without knowing them. He was still quite dependent on the staff for his daily activities and so one could conclude there would have been a frequency of interactions but that each one may have lacked duration. These frequent, fleeting moments with staff did not allow him a depth of connection, despite Ivan's (P6) acceptance of this.

Adding to this, Anthony (P7) recalled the HCA and the tasks and duties they undertook with him by articulating an additional perspective that if you asked they would do more:

> *"They are dead keen, I mean they come in change your bed, make it nice and polite, they do their job, they go the extra mile if you ask them for something they will go and get whatever it is you want."* Anthony (P7).

Interestingly, in the above narrative Anthony (P7) does not mention care, communication, empathy or any sort of relationship with the staff, instead just listing the task orientated duties that were delivered. The list seemed to be lacking in humanness, although he did also recall the interactions he had with staff immediately after his surgery:

> *"I think it just came. It just came. I was receiving, thank you, thank you. (Looking up towards heaven making arm gestures upwards) that was how it was to be honest."* Anthony (P7).

With Anthony's (P7) totally dependent post-operative state, he simply passively received care. This may have been due to a reduced level of consciousness and, as a consequence, he may have been unable to establish any sort of connection, instead just giving himself up to the carer. He smiled as he told me his acceptance of the transactional nature of the care he received.

Don (FS1) was only an inpatient for a day and suggested that some staff engaged with him and were able to meet his needs for the short time he was an inpatient. He conversely recognised episodes of care where staff were not interested in him:

> *"a couple of nurses took time to …talk to you while they were doing your blood pressure...you could see others are just seeing it as a job, get it done and they were gone."* Don (FS1).

5.5.8 Not knowing the patient

'Getting to know patients' was clearly an important process for the staff in order to facilitate connectedness. The contextual situation played a part in this process, as Judy (P16) described the different relationships she had with OPD and ward staff. She saw a difference between the transactional functions of an HCA in OPD where contact, although pleasant, was often reduced to tasks and the pivotal and observational inpatient HCA role:

> *"Well I mean when you come to the Outpatients Clinic, there's very little [contact]. And that seems to be the only role they fulfil. You know it's very pleasant and not… But in Hospital, I think they play quite a (when I've been in) I think they've played quite a key role because a lot of the sort of day to day contact and care would probably be with them rather than with somebody who was a bit, you know what I mean, higher up the… The Nurse or the..."* Judy (P16).

Judy (P16) also described the effect that length of stay had upon relationships between staff and patients, with a greater connection and level of knowing achieved with respect to those patients who had been in longer and needed more assistance*:*

> *"And that's where I think the Healthcare Assistants, because they were around and if you saw people had been in long-term, they had a much better relationship with them, that was an observation, that wasn't my experience because I wasn't in for long enough to really form a close relationship with them but if you noticed on the Ward, that was the people who they held their closest… Who were doing their day to day care."* Judy (P16).

In contrast, Mary (P11) described how she was called by her name but did not feel the connection to staff, effectively articulating feelings of dehumanisation when she stated that she felt like a bed number as noted on page 147. She saw the opportunity to develop connections and getting to know her as being missed by staff and instead replaced by process and dehumanisation. When she was describing this, there was a sense of the weight of the system bearing down upon the small little moments that meant so much to patients and the resignation of staff to give in to the situation due to day-to-day pressure.

Acceptance of the situation, coupled with a limited willingness on the part of staff to pursue alternative solutions, was evident when Molly (P2) recalled those frequent mealtimes where no alternative meal was offered. When she rejected the offer of a cheese sandwich, she was left feeling neglected and ignored. The ward sister eventually offered her an alternative in a humorous manner and she felt this offering was personal to her and added to her sense of connectedness, in contrast to her earlier feelings of rejection:

> *"'Oh no! I says, not the cheese sandwich!' 'Well would you like some', what were they, she was a bit friendly, well when you told, when the other nurses 'Oh, oh I don't want anything.' 'Oh well are you sure?' That's it, not 'why?' Or, 'can I get you something else?' or you know?"* Molly (P2).

Catherine (P18) described the mindless questions the HCAs and students asked her each time she attended clinic:

> *"Well if they're ploughing through a pre-script, then they're being diverted really from something else they could be doing."* Catherine (P18).

She understood the necessity for these questions but also saw the burden and routine that dominated this activity for both patient and staff. She suggested that there was no thought given to, or consideration of, the person, just a task that needed to be attended to and that required the patient's responses only if they fitted the question being asked. Catherine (P18) questioned what the HCA felt like when performing these duties. Was this about just getting the work done in situations where no clinical judgement was required, effectively task and box ticking?

> *"I thought it was quite bureaucratic. I thought every time I've been in there's been loads and loads of paperwork and I come from a bureaucratic kind of thing and I know what that must feel like and I feel that it's a bit upsetting for them that they've got to plough through all this stuff."* Catherine (P18).

She articulated how frustrating this potentially could be by relating these activities to a bureaucratic system she herself had worked within, suggesting also that she had some empathy with the staff as a result. Such activity can be perceived as mitigating the risk when staff do not know the patient ensuring all bases are covered. Patients therefore may see this as less personal to them as they become part of a process less about the individual more about how the individual fits into the medical task before them.

5.5.9 Communication disconnect

‘Communication disconnect’ describes the action of missed communication, whether in the form of verbal, non- verbal, written or mechanical communication. For example, when patients made a request it was the resulting action of the carer that indicated to the patient whether the receiver of the request had interpreted and acted as per the participant’s request. Often participants meant more than the basic request and it was the interpretation and exploration of these requests by staff that contributed to the patient’s sense of connectedness.

Molly (P2) told of her increasing urinary frequency and her request for a commode, which was duly brought to her room. The request, however, was not completely fulfilled as she still needed her frame to get across the room and use the commode. She therefore had to suggest that the commode could be nearer her bed, making access easier and increasing her independence:

> *“I says to one of the nurses ‘Well could I have commode here?’ By the time I struggle, by the time you put your legs together to get out of bed and whatever ‘Could I have a commode in this room here as I have to struggle out her and over there?’ ‘Oh no problem.’ Well when she brought the commode I was lying in the bed here and the commode was over in that corner.”* Molly (P2).

Her request was answered in a way that appeared to give little consideration as to her limitations when using the commode. Bill (P4) described the frustration he experienced between his anticipation of the timeframes to obtain some treatment prescribed for his announced discharge home and the expectation of staff of an extended timeframe. For Bill (P4), the delay, coupled with the resigned response from the staff, impacted upon his connectedness to the staff, despite him being aware the system was at fault:

> *"This afternoon comes and I don't get the enemas, tea times comes and I don't get the enemas, so I get off me bed and I go to the station and I says err 'what's happened about these enemas?' 'Well we haven't got them yet' and I ended up having to wait until the following day for these enemas so it just another delay in hospital so you feel pretty…"* Bill (P4).

Idris (P9) saw the system as impacting upon his experience but managed to distance himself from any potential fallout with respect to his relationships with staff:

> *"So it is not the Drs that is the problem it is the administration that get fouled up."* Idris (P9)

Mary (P11) also suggested that if a call for help was perceived by the patient as important then the responder should treat it as such and not dismiss it. This disconnect between what patients saw as a concern and its dismissal by staff as not being a concern was not conducive to feelings of connectedness. Freda (P12) was more confident in her call for help or assistance:

> *"Because if you don't ask you don't get to know. There is no good sitting in your bed or sitting in your chair terrified about what might happen to you if you don't ask you don't get the answers."* Freda (P12).

This was indicative of Freda (P12) taking control of her situation, a feature that is discussed within the adaptation category (section 5.6).

5.5.10 Something missing

Sally (P10) recalled a situation in which her Mother's needs had not been met. She was not able to add to this recollection in the interview but simply went on to say that hospital was not a good place for the elderly:

> *"She had care but as an older person I don't think the care is there for the older person, the elderly."* Sally (P10).

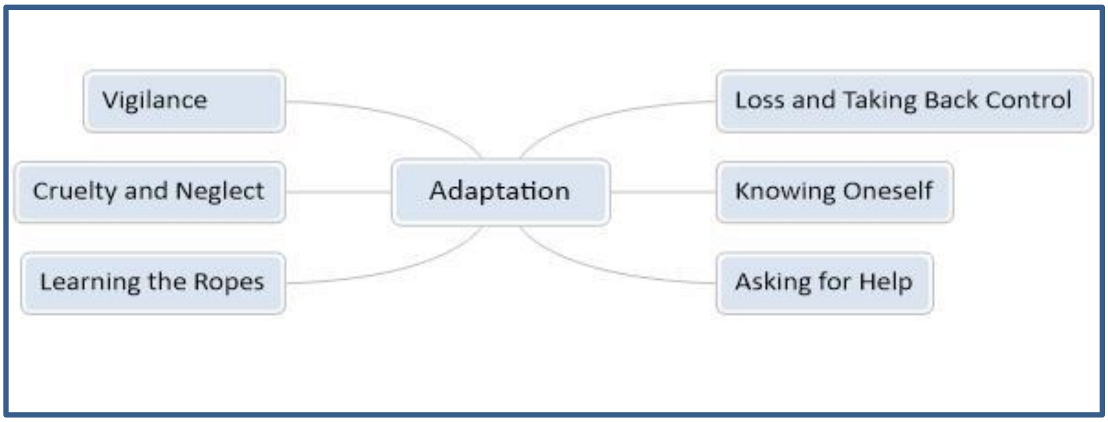
Overall, many participants articulated some examples of substandard care that either they themselves had experienced or else had witnessed with respect to relatives or friends. Despite this, they adapted and adjusted to situations that were less positive or interactive than they expected. A number of strategies were employed by participants to help them adjust, ranging from working around the system to helping meet the needs of relatives requiring additional care and attention or, in the case of Gary (P19), taking direct responsibility and escalating their concerns within the existing system.

Idris (P9) was quite clear on his views with respect to the care delivered by the NHS:

> *"I would say they have nothing to fear. As far as I am concerned they are in very good hands which is why one of the reasons I get quite irritated with politicians where they pick up on mistakes and a lack of care and they talk about that being the NHS to my mind it is not it's the exception rather the rule."* Idris (P9).
>
> *"Yes I think people do pick it up and think there is something wrong with the NHS. And I err I don't see that there is much wrong with it. I think we are very fortunate I regard myself as very fortunate because otherwise I would be dead quite bluntly. My wife she had cancer of the womb and she eventually she died but the treatment was quite perfect."* (Idris P9).

Idris (P9) reasoned that without the NHS providing his care and treatment he would not be here and that, even though there was nothing that could be done for his wife’s condition, she was treated without any complaint. Idris’ (P9) position is interesting in that he described the substandard care his mother had received but ‘forgave’ this episode when considering his own care and treatment and the last memories of the care his wife had received.

5.6 Core category 4: Adaptation



Mind Map 4: ***Core Category 4. Adaptation.***

The core category of “adaptation” details how participants began to understand their new environment, including the techniques that patients used to help them adjust to the new environment they were experiencing. It also incorporates narratives related to how negative personal or observed experiences shaped how they became vigilant as a patient or carer.

5.6.1 Learning the ropes

Participants described various perceptions about their experiences as a new or experienced patient, the adjustments they needed to make for themselves and who was there to help them work it all out.

Darren (P1) worked as a Registered Nurse (RN) in a large unit within the organisation supporting this research, in which patients were treated for a range of acute and complex long term conditions. He described his position as an RN as having informed his own knowledge of ‘who’s who’ and the clinical routine to work out the likely course of events for his own outpatient department (OPD) appointment. He described his social identity as an RN helping him navigate through his other social identity as a patient:

> *"I would probably look around to see who was on duty and what grade of nurses were around. I am used to being in hospital as in like from a working point of view. I like to see who is around really."* (Darren P1)

Other participants described being ready to learn, using observations to aid their knowledge of being a patient:

> *"Well it feels strange, it feels new… Well there is a lot you have to get used to that you don't know anything about. Like pressing the buzzer, where is the buzzer, which buttons do you press for the lights? Things you pick up and learn for yourself you know."* (Stanley P4).

Bill (P4) described this process of learning and adjusting, suggesting that most people should be able to work it out for themselves:

> "*I am sure that if I had asked they would have told me but err. I soon found out… I think most intelligent people can pick up whatever needs to be picked up."* (Bill P4).

Mary (P11) recognised the learning curve she experienced as a new patient but, in contrast to Bill's comment, felt that this was unnecessary. In her view, staff should have supported her adaptation to her new patient role:

> *"So yes you have got to sit and try and work out what you are supposed to do. Well you shouldn't have to do that it is their job to do what you…. You are just the patient…. it is their job."* (Mary P11).

The quotes from Bill and Mary illustrate how patients learn about their new environment is often dependent upon an individual's perspective. With repeated hospital visits there is an element of familiarity that takes over from the initial uncertainty, enabling the patient to form expectations as they learn routines and 'who's who'. Sally (P10) visited the OPD frequently between inpatient admissions and described what she learnt from the routine:

> *“When I come in for me appointment, I err receptionist, the girl on reception is the first person I see, then it’s normally the girl, the lady in brown [HCA], that does the weight, then the Dr, then bloods, that’s the routine I have when I come… it is normally the same lady that does it, that does the weight and the blood pressure.”* Sally (P10).

Her narrative indicates that she gained understanding of patient processes through a combination of the events themselves, the colour of the uniform and ‘who does what’, all elements informed her as a patient. The “lady in brown” that Sally (P10) refers to is the HCA, who also informs clinic attendees if there are delays even though there is an information screen to do this. This human touch is an additional point of contact and provides a valuable source of information for the patient:

> *“Errm normally it’s put on the board…you just have to sit. If you go in that girl would say there is a delay about half an hour errm whatever’s happened a lady took bad or something. Errm that’s it I just have to sit and wait. (Laughter). I don’t mind as long as you are told. You are not sitting waiting and nobody has said anything.”* Sally (P10).

This human contact depends on the availability of staff for patients, who described times when staff were busy and therefore less available. Jane (P5) suggested that patients should be understanding and she adapted to these busy times by preparing herself for anticipated delays in her care:

> *“Yes occasionally… an odd time they might say if they are very, very busy they would say ‘could you wait a minute?’ coz they will be busy with somebody else they will always remember and come back and do what I have asked of them, but it mightn’t be immediately.”* Jane (P5).

Ivan (P6) also understood that there were times when the clinical area was busier, leading to a delay in response, but was not afraid to use the buzzer if he needed assistance. This was in contrast to Sally (P10), who had not used the buzzer despite needing pain relief, although for future inpatient episodes Sally suggested she would be less reluctant to call for help if needed:

> *“I had to go in the October for one operation and then I went back in the November for the second operation. The first one was fine the second was not. To go in again I don’t know. And maybes I wouldn’t be as patient. I would ring the bell and keep ringing it. I have learnt a bit about myself there.”* Sally (P10).

Sally’s (P10) and Jane’s (P5) understanding of waiting for assistance were in contrast to one other. As described above, Sally (P10) was aware she may need to assert her requirements more fully in the future whereas Jane (P5) remained assured that her call for assistance would be answered eventually.

When staff change due to a ward team reorganisation, patients need time to adjust, as indicated by Stanley (P8) who told of his frustration and disappointment at a team change having built up a connection with the initial team. This was mitigated by the effort of HCAs from the new team:

> *“You sort of build up a confidence and rapport with the first group, but as soon as one of the new group came in who had not been in before she just introduced themselves straight away.* ‘I am Penny I will be looking after you today I am so and so … I will be looking after you with Penny today. If there is anything you want just give us a buzz.’ *So you start build it up from the first minute.”* Stanley (P8).

Stanley (P8) reflected later that although he felt disappointed the old familiar staff were only working nearby:

> *“Yes it was fine. It felt a little bit awh disappointed that they had gone.”* Stanley (P8).

Stanley’s (P8) immediate world was contained within the confines of a 6 bedded bay. As his health improved his world expanded as he pieced together the workings of a system he was part of but had little control over, leading to recognition and understanding that the old staff were nearby. The powerful force of change was felt sharply by him as he looked back with a nostalgic view to his earlier connections before adjusting to the new staff and their way of working:

> *"… it didn't take long to build up. A day maybe day and a half to build up the same confidence when you realise that although you haven't seen them they are all out there together anyway."* Stanley (P8).

Don (FS1) concurred and suggested that familiarity with the staff helped him adapt to patient hood:

> "*The same nurses were there…I knew how to be a patient…I knew what to expect. Everything was explained to us."* Don (FS1).

It was not only the immediate clinical area for which patients needed to 'learn the ropes' and they also spoke about the need to understand how the wider healthcare organisation and systems worked. Idris (P9) described his daughter's persistence as she took charge of a situation and navigated through. Idris (P9) recognised that someone less tenacious would find difficulty in this:

> *"Anyhow my daughter…said 'in that case I want you to get on the phone* ***now*** *to the [hospital] and tell them'. 'Oh I'll see to that'. 'No she says you'll not see to it. I want you to get on the phone…* ***now*** *while I am here… and* ***I insist****...'. And err so he did."* Idris (P9).

Idris' (P9) daughter worked out what was required in order to ensure that the doctor performed his duty in a timely manner and she supervised the process from start to finish, which was the only reassurance she was prepared to accept.

5.6.2 Cruelty and neglect

As participants recalled past events, some described episodes of cruelty and neglect. This code is closely aligned to vigilance and the vigilant behaviours some participants adopted in their adaptation of such episodes. The code of cruelty and neglect therefore helps to contextualise these behaviours setting the stage for the subsequent code of vigilance that follows in section 5.6.3.

Molly (P2) told of a time when she herself was an auxiliary and witnessed the cruel actions of two auxiliaries who left a tray of food on a sleeping woman's fluid laden body. She suggested that the actions of these two were a one-off, although it appeared that their actions at the time were tolerated by other staff. When John (P17) recalled witnessing two nurses being *rough* with an elderly patient whilst visiting his mother, he immediately felt anger but did not raise the issue for fear of reprisal on his mother:

> *"If I give them two a go for, they might take it out on my Mother."* John (P17).

John (P17) reflected later in his interview that the nurses in question must have just been having a bad day:

> *"I think these two Nurses; I just think they had a bad day."* John (P17)

Idris (P9) recalled an earlier situation where his mother was ignored by staff:

> *"they sat and gossiped when they should have been caring…"* Idris (P9).

Idris (P9) recalled this situation late on in the interview, despite having been provided with numerous opportunities to bring poor experiences to the fore. Although this episode was in a different organisation that has since closed, he recalled several episodes of poor care and neglect. It was really interesting to note, however, that this had not shaped his own experiences or expectations:

> *"Very satisfied, that we have such good… I can only concur. Couldn't have wished for better treatment than I have had."* Idris (P9).

Idris (P9) made clear that he recognised mistakes and errors could be made but that he himself had not experienced them as a patient:

> *"I would say they have nothing to fear. As far as I am concerned they are in very good hands which is why one of the reasons I get quite irritated with politicians where they pick up on mistakes and a lack of care and they talk about that being the NHS to my mind it is not it's the exception rather the rule."* Idris (P9).

Gary (P19) described having witnessed, on a number of occasions, a fellow patient's buzzer being switched off and the nurse walking away having made no attempt to find out what this patient required. He was shocked and upset by what he had witnessed and felt a sense of protection towards his fellow patient, who he described as being elderly. Acting through a sense of responsibility for those not able to voice for themselves, Gary (P19) called the senior nurse team to articulate his own concerns and raised the issue of staff ignoring the other patient's requests or calls for help. There was resolution following this, with the staff concerned being moved elsewhere and the care and attention for him and his fellow patient improving as a result.

5.6.3 Vigilance

Vigilance is a code describing the position that participants took when they lacked assurance for themselves or others. For some this vigilant state raised their awareness of what was going on around them, leading them to question and lose confidence in staff.

Sally (P10) described how she monitored staff when they were looking after her mother:

> *"… it's my Mam and I want to make sure she gets what she should be getting."* Sally (P10).

Catherine (P18) also described her perception of the need to be vigilant for elderly or more vulnerable patients:

> *“Well I’d just be looking to see if they’ve got drinks and that they can drink, that they’re not frightened or just stuff like that.”* Catherine (P18).

When someone experiences something negative for themselves, there is a heightened sense of vigilance that can suspend trust and reliance on others. This is illustrated by Mary (P11), who described taking a sip of water immediately post operatively when she was confused and drowsy from the anaesthetic. She tasted a fizzy solution and was alarmed and, on raising her concern with the RN, was told abruptly that it was pain relief left for her to take during the night. She was warier with that particular member of staff afterwards and cautious about who left what on her bedside table, taking care of her own safety as she saw it. This reduced her reliance on others and distanced her from staff, with Mary remaining cautious and concerned and with a heightened sense of vigilance for the remainder of her stay. The RN’s response had affected her; although Mary did not question the RN’s competency, the way the RN had spoken to her did cause concern:

> *“she knew what she was doing…Well, I didn’t care for her after that. I was more careful. I was more awake after that, look after meself after that.”* Mary (P11)

Competency without courtesy, as Mary saw it, had changed how she felt. She alluded to a state of vigilance for the remainder of her stay and shared her advice for others coming into hospital where she stated:

> *“I think my advice to anyone going into hospital would be always try if you can somebody on the outside your family or your friend always giving an eye to you, so that if the staff aren’t doing what you want, patients won’t shout up as they are too not well and not wanting to be a nuisance, so I’d say have someone on the outside who can speak up for you. I think everybody needs that.”* Mary (P11).

Gary (P19) described how he became more vigilant when he noted things weren’t right about his care and treatment. Once he was armed with the evidence he then challenged the staff member concerned. He was not satisfied with the response and therefore “took it further”, raising his concerns through an internal complaints system. This worked well and the issue was resolved to his satisfaction:

> *“I feel alright, you know? it’s all changed now because I mentioned something, I think someone off another ward… mentioned something and since then it’s all changed.”* Gary (P19).

This episode did, however, leave him with a heightened state of vigilance in which he started to compare his treatment to others who had the same operation. As an example, he challenged the medical team about his different medication to that of a fellow patient with the result that his medication was changed and he gained a degree of reassurance. Gary (P19) was watchful of his and others’ care and treatment. Neither resigned nor accepting of what he was told, Gary challenged and navigated his way around the internal complaints system.

There was a different situation for Sally (P10), whose vigilance for her mother’s care took the form of comparison against the care Sally herself had received as a patient. She described how much pain she had experienced after a particular procedure and how she had required some analgesia that was never administered to her. She described, with resignation, the lack of attention to management of her increasing pain:

> *“…I just waited and waited in agony.”* Sally (P10).

Sally described how she had felt powerless but not wanted to be a nuisance by buzzing, in case buzzing reminded staff of her previous request. Unlike Gary, Sally (P10) did nothing about this at the time.

A number of participants recalled negative incidents from a time when they were visiting a relative or friend and how they adapted to this situation themselves rather than seeking resolution with staff within the clinical area.

These episodes led to vigilance for later experiences of healthcare for themselves or others.

Idris (P9) recalled a time visiting his mother when he felt sure she was not getting the nutrition she needed to sustain herself. Rather than addressing the issue with the clinical area, he and the family adapted to the substandard care his mother received by getting a family rota together to ensure that her dietary needs were met.

5.6.4 Asking for help

Participants described ‘asking for help’ as they navigated their way through their new environment. Mary (P11) suggested patients were frightened of making a nuisance and that this sometimes led to neglect by staff when patients needed help or assistance. In advancing this view, Mary spoke not only about her own experiences but about those of other patients:

> *“Yes frightened, yes a lot are frightened coz a lot of them think if I make a nuisance I won’t be looked after. A lot of people feel that.”* Mary (P11) .

“Frightened” is a strong description of how Mary thought others would feel but her concern was not isolated. Darren (P1) was less forceful in his language but, all the same, alluded to patients appearing compliant and accepting of their situation:

> *“Erm … (sigh) I think most of them don’t want to question you know, don’t want to cause any trouble.”* (Darren P1).

Jessie (P14) told of how she manages her dependency in terms of asking for help:

> *“I only bother them if I have to.”* Jessie (P14)

For some participants, there was also a concern around becoming the “unpopular patient”:

> *“I don’t want people to think I am being annoying. Keep pressing the bell all the time, stopping them from doing what they should be doing all the time and spending time with me.”* Sally (P10).

Sally (P10) was concerned as to how she was viewed by the staff. Sally was interviewed in OPD so it was unclear as to whether she spent time in a side room or a bay which may provide some insight into the understanding patients have around the use of the bell. Sally’s narrative about needing to exercise caution in “asking for help” or “pressing the bell” was, however, in total contrast to what she would say to a friend who was going to be admitted.

> *“Oh yeah, yeah don’t put up with anything!”* Sally (P10)

There are distinctions for Sally about what she would be prepared to put up with for herself in contrast to her advice for others facing the same situation. Staff have power and Mary (P11) described how some staff made her feel if she rang the buzzer for reasons they considered unnecessary:

> *“Awful! Awful and you don’t want to ring again. And then someone else will come in and say ’ooh this is out you should have give us a shout!’”* Mary (P11).

This lack of consistency as to how staff respond to patients seeking help can leave some patients with a state of anxiety, which was illustrated by Mary (P11):

> *“So yes you have got to sit and try and work out what you are supposed to do. Well you shouldn’t have to do that it is their job to do what you… You are just the patient... it is their job.”* Mary (P11).

Jessie (P14) had been an inpatient for some time in a side room of the ward and she had sought a balance between calling for assistance and taking steps towards independence:

> *“I’ve got my dignity and I press a button and I try to do as much as I can, and when they come, they’ll say,* ‘oh, that’s what we’re here for, don’t worry about it.*’”* Jessie (P14).

Mary (P11) was also adamant that there needs to be some control taken by oneself and where this is not possible the family need to ensure that they offer support. The advice Mary would give to a new patient adds nuance to what Sally (P10) had said:

> *“…they’ll [the staff] look after them [the relative] I know they will but YOU make sure you look after them you make sure you get right behind them [the relative]… Don’t let them [the staff] do it all.”* Sally (P10).

The effort required in asking for help at times when participants felt unwell was illustrated by Jessie (P14). She experienced an episode of what she saw as substandard care, during which an HCA was impatient with her and her needs. She felt so unwell at the time that she felt resigned to the situation, describing an inertia and inability to tackle the issue at that time. At the time of her interview, with an element of strength and hindsight, she felt able to deal with the situation were it to happen again:

> *“I couldn’t be bothered, I said something the next day… say, I press my buzzer tonight and she was on, I would definitely say something to whoever was in charge. Because I wouldn’t put myself through that again.”* Jessie (P14).

Rather than troubling the RN, Judy (P16) worked out that by asking the HCA for help she could observe how her request was managed and thereby ascertain the various levels of staff responsibility:

> *“It was good to have an intermediary so you could sort of say to them and if you’ve pressed your button that’s who came if you needed immediate… So then you would find whether it was sort of something*

> *that really needed to be dealt with by a Nurse or whether it was something that was just sort of…"* Judy (P16).

Judy used the HCA to filter her concerns for fear of being a nuisance to the RN. Similarly, Mary (P11) worked out what she wanted and then decided who she would ask. The language chosen by Mary (P11) suggests she saw the RN as too important to bring a drink to her, which provides a point of consideration, when understanding how patients position their own needs, in terms of skills required to meet those needs:

> *"...the higher the nurses are the more important. If I don't feel too important because I want a drink or whatever the trainees or anything I am fine with anything like that."* (Mary P11).

Johnny (FS3) had a similar strategy in asking for help, suggesting if it was not an urgent situation he would wait until he saw a member of staff:

> *"if they're passing you can just say if you get a minute… its not vital…"* Johnny (FS3).

This was in contrast to Don (FS1), whose experience was one of immediacy:

> *"I did ask for help after my operation. They were straight there. They knew straight away what was wrong."* Don (FS1).

Don (FS1) also recognised that some patients were reluctant to call for assistance:

> *"they said the nurses are too busy…I don't want to stop them from doing something so they suffered in silence."* Don (FS1).

5.6.5 Knowing oneself and adapting to another self

'Knowing oneself' describes how participants understood or articulated their values and beliefs within a number of different situations. Participants articulated a variety of forms of self-knowledge and described a range of ways in which 'knowing themselves' helped them to navigate their way through their stay, to deal with hierarchical teams and to position themselves as patients or carers. Participants also described how their ‘known self’ was sometimes lost due to the effects of medication and anaesthetic interventions.

Knowing oneself was illustrated by Sally (P10), who explained that as a patient she felt unable to negotiate with those in a senior position, for example the consultants. She instead accepted their words and interventions, only reflecting later on questions she wanted to ask as she viewed direct questions at the time as confrontational deferential to his power. In contrast, Sally (P10) described how she navigated through the system when her mother was in hospital, in which circumstances she felt more able to confront even senior staff in support of her mother:

> *“Well…in respect of the consultant’s position… and I am just not that type of person. I am not confrontational.”*

> *“Me mum was in hospital and probably because it’s me mum isn’t it? And maybe I might feel differently if any of my kids were in hospital an’ I felt things weren’t going quite right I’d maybes say something, but when it comes to me I wouldn’t.”* Sally (P10).

For some patients their sense of self was very important as they tried to hang onto what was valued by them even through periods of great adversity. Jessie (P14) valued her dignity as she considered the potential for loss of bladder control. Even though an HCA had tried to reassure her that, while “accidents can happen” they were capable of dealing with them, this was not enough for Jessie (P14). The sense of shame from loss of bladder control was such a strong element of who she was that Jessie used all the strength she had to get to and from the bathroom to avoid an accident:

> *“I’d die if I weed myself, I’d absolutely die and they put you at ease to say, well, you know, if you do, you do, we’ll get on with it, and it’s all right for them saying that, but it’s me that’s the other side…she just said, ‘Jessie, it’s no embarrassment if you ever did’, but it is to me, I*

> *am what I am, I can't change who I am…It's my dignity. It's not yours, it's mine."* Jessie (P14).

'Adapting to another self' emerged as a further code in my analysis describing the dislocation participants felt in reflecting back to a time when they had been affected by their illness or condition, under medication or recovering from an anaesthetic. From the analysis process, I saw 'another self' as a continuation of 'knowing oneself' and therefore I brought these two focussed codes together within this section of the analysis. Recall of participant journeys throughout the immediate recovery phase or under the influence of medication or anaesthetic was often blurred but a number of narratives described below help us to understand the feelings of dislocation variously described and how the staff contribute to these experiences.

Molly (P2) had retired a number of years earlier, having previously worked as an auxiliary within the organisation. She described the medication she had been prescribed as affecting her capacity to communicate or make sense of what was happening to her. It was only after the event that she identified it was pain killers which had taken her into an altered state of mind:

> *"They were the most horrendous things I have ever, ever, ever had. I was hallucinating, I was seeing things that wasn't there. And at one point, at one point, I lost me lips (laughter)"*

> *"I'm thinking eeh what's been happening? And it was definitely these tablets."* Molly (P2).

Ivan (P6) associated his medication with a sense of not being himself. He used "they" to describe the staff who prescribed and administered the morphine that brought about his altered state:

> *"…they gave me some morphine liquid morphine. That just put me over the top."*

> *"A blur, that's the scary thing I feeling around yourself, think what I've got tubes in here and there catheters. What's that you know, what's happening?"* (Ivan P6).

Gary (P19) also described a situation in which he experienced complete and utter dislocation, with no recollection of which members of staff were present at the time. He suggested that the timing of his arrival to the ward from theatre at the point of shift changeover contributed to this dislocation, sense of confusion and disorientation:

> *"I didn't even know what was going on around us, I didn't know anything I said, I didn't where I was or… I come up onto the Ward on like on the night when they were changing shift…Aye, like I say, I didn't really know what was … much of what was going on.*" (Gary P19).

Molly (P2), Ivan (P6) and Gary (P19) all saw their dislocation as an isolating experience, within which they were left wondering what had happened and what was likely to happen. In contrast to this, however, other participants illustrated how staff had supported participants through their dislocation. Stanley (P8) provided a humorous perspective on his transient confusion. Through the description he provided, I identified that there was a strong connection between him and the HCA, with humour evidencing that some moments were shared and created a 'bridge' between the known self and the altered self:

> *".. the staff and we have laughed about it, this is what he's done, he's gone on trips through the wall!! Somebody else would come in, one of the HCAs and say 'eee your bed went through the wall again last night'!"* (Stanley P8).

Jessie (P14) described a night when she was prescribed medication to help her pain and sleeplessness and where, despite transient moments of altered state, the constant reassurance from the HCA kept her grounded within reality:

> *“I had loads and loads of pain relief, and although I knew what I was saying, I knew I was talking pure rubbish but Betty* [the HCA] *was there that night and she reassured me ten times…’*It’s obviously the medication they’ve given you to sleep’, *and she was in and out, God bless her... She just used to pop back just to make sure I was okay…She brought us down to earth every time, you know?”* (Jessie P14).

Jessie (P14) clearly recalled her experience with fear. The contribution from the HCA, however, was significant and helped Jessie (P14) come through. The words Betty used were reassuring and made sense to Jessie (P14); the frequent contact with Betty brought about feelings of journeying through the event together and enabled Jessie (P14) to relinquish control to Betty.

Sally (P10) recalled one staff member in particular during her immediate recovery phase and described her recollections with tenderness. The continuity with this particular member of staff was a comfort when Sally was ‘not herself’:

> *“I can only really remember coming here and one nurse in particular and she was in white errm because I was a bit out of it as I was on morphine at the time. I just remember her role and what she did. Coz she took us one to one coz I had that one to one thing with her for a while”.* Sally (P10).

This incident had taken place four years previously and Sally (P10) was unsure whether the “nurse” was an RN or an HCA, though she assumed the nurse was an RN. Whatever her job role, however, this “nurse” displayed qualities that had created a big impression on Sally’s (P10) experience with care staff. The ‘one to one’ care she received during this time provided Sally (P10) with a sense of exclusivity, centrality, focus and concentration. Sally (P10) felt that the “nurse” was her dedicated carer, with a relationship built up over the period of time that she was not able to care for herself:

> *"I didn't know what was happening with me. From what I can remember, as I was a bit out of it with the morphine, errm, so a lot of it was a bit hazy. But I remember her coz she was with me for a good few days after wards. I mean like washing and err turning, making I was getting what I was getting, making sure I was OK."* Sally (P10)

Sally (P10) had experienced this connection even though she had been unable to reciprocate; the care was received and not asked for. Issues of trust and reciprocity will also be explored later on in the chapter:

> *"Coz I was out of it. Even though I knew she was there you know her presence and that. I was sort of a bit high (laugher)."* Sally (P10).

In contrast to the connectedness Sally (P10) experienced, Mary (P11) identified a staff member who did not contribute to connectedness and displayed behaviours unconducive to a connected relationship:

> *"…she was bad tempered that one that night and it was uncalled for. I was in bed under anaesthetic and couldn't help meself and I got no help from her at all except a squirm and it wasn't nice. But that was the only one."* Mary (P11).

I found it interesting to note that Mary (P11) alluded to isolating this incident from the rest of her inpatient experiences with staff. She did however, allude to less connectedness with staff through her observation of feeling part of the hospitalisation process and not an individual self:

> *"You are a bed number erm, they will call you Mary, your name is on the board err but you are a bed number. You are treated according to your bed that you are in. That bed is there for a reason and you are in it for a reason…"* Mary (P11).

Elements of this narrative describe how as part of a system there is a loss of control.

5.6.6 Loss and taking back control

‘Loss’ and ‘taking back control’ were initially two separate focussed codes. I found, however, that these two focussed codes were related within the narratives of many participants and were therefore best presented alongside each other.

Ivan (P6) described ‘loss of control’ when there was a significant delay in the administration of his pain relief. Ivan (P6) understood that he was dependent on staff for his pain relief due to the need for intravenous (IV) access. His cannula had been removed, however, and he had resigned himself to having to wait for a member of staff to re-site the cannula:

> *“Yeah, oh yeah. It is yeah. Coz I was in pain in serious agony actually. And there was nothing I could do about it.”* Ivan (P6).

This loss of control led to him feeling angry that the doctors did not have the foresight to keep the IV access in for another couple of days, something that would have been able to ‘see him over’ the worst of his post-operative pain:

> *“…I was thinking why did they take it out if I wasn’t ready? The doctors are experienced in this larkyarky. They should have been aware…”* Ivan (P6).

The sense of resignation articulated by Ivan (P6) contrasted with the control exercised by Bill (P4). When there appeared to be a delay in treatment that had been prescribed earlier, Bill took control as best he could, trying to understand the reason for the delay and work out implications for his care as evidenced in his quote in communication disconnect (page 172). Sally (P10), by comparison, would only take control if she was feeling unwell. If there was nothing to concern herself about, Sally (P10) felt she would not challenge or ask:

> *“If I felt ill yes and I wasn’t getting what I wanted…I would think so yeah. I would think it depends, I would think so I am quite laid back I*

> *am walking around here and I am fine, if I was feeling ill it may be different.”* Sally (P10).

Gary (19) described relinquishing control of his complex condition to the staff:

> *“No, they’re the experts, not me.”* Gary (P19).

Similarly, Ivan (P6) gave up control of his pain relief to the staff, trusting the system to work in bringing him timely pain relief:

> *“They know when I am due.”* Ivan (P6).

The physical challenges faced by Jessie (P14) were immense as she had been critically ill for some time. Jessie (P14) described the control of her care being taken over without consideration for what she wanted. She described how she took that control away from the medical staff who were keen to continue taking blood for monitoring purposes and for her to continue to receive IV feeds, despite her arms being sore, swollen and painful: Jessie (P14) had a level of connectedness with the HCAs that was missing from those in more senior positions; professionals who, in her eyes, medicalised her needs in isolation from her as an individual. The relationship between Jessie (P14) and the HCAs appeared such that she was able to express her frustration with them directed at those that were not listening to her as a person:

> *“There was one time, honestly I was so poorly and I said give me 24 hours, nothing, I couldn’t be doing with anymore scans and anything and feeds and…’no, no, we can’t stop that’. ‘I’m telling you I can’t… You need to leave us alone for 24 hours’. I was really upset then because I didn’t have the feed and I thought, no, my arms they kept putting needles on, both my arms went massive, and I thought you’re not doing that anymore neither. I thought there’s a time to stand up and say enough pain is enough pain.”* Jessie (P14).

> *"And I wasn't taking it in, but I did want to know what was happening, and I felt as if I could ask the healthcare assistants much more than I can the higher ups…and at one time I said again, 'nobody's listening to what I want. Nobody's listening'."* Jessie (P14)

I asked her how the HCAs reacted to her decision for 24 hours off IV medications and blood tests:

> *"They don't have any input in that. They never say anything."* Jessie (P14).

Jessie (P14) took some control back, requesting to be left alone for 24 hours. She went onto explain that the HCAs listened in a way that other staff had not without passing judgement.

There were other participants for whom taking control developed more covertly. By working out 'what was going on', these participants developed a process of self-management that sat outside policy and protocol. Molly (P2) explained that she had identified her hallucinations as being due to the medication staff had given her. She had feigned compliance with medical treatment while taking her own path towards control and recovery:

> *"Oh it was definitely the tablets. And I stopped them and started to empty them into my bag."* Molly (P2).

Molly (P2) had worked out that the prescribed painkillers were not needed as the pain had been "cut out" by the surgeon undertaking her hip replacement. Rather than continually refusing the medication, she had accepted and then secretly disposed of it, instead taking her own medication when needed. She had lost trust in the staff around her medication and would take only her own pain relief, taking control back from the staff for her pain relief needs:

> *"…well I am not going to take anymore. If I need painkillers I will take my own my own…"* Molly (P2).

The covert approach Molly (P2) took to her medication was not an isolated example. Two other participants found out how to silence bleeping IV machines and shared this fact secretively with me, which suggested that they knew this action was beyond their remit as a patient:

> *"Yes it often beeps and I do my own, but… (laughs)."* Ivan (P6).

Stanley (P8) concurred:

> *"Oh, I though right, Ok I can do that, so I didn't say that to her but thought I can do that. I would pressing it…"* Stanley (P8).

Gary (P19) also talked of how it feels to manage the activity of getting better through one's own drive and determination:

> *"You know, well I realise that I've got to do this myself, really, you know, down to me to do it.*
>
> *Well alright once you get your head around it and realise what you've got to do, you know?*
>
> *You know, just want to get myself better and get out of here really! You know?"* Gary (P19).

Wherever there was a tension described between participants and clinical staff regarding the direction of their care and treatment, there were both emotional and physical elements to the tension. Freda (P12) had previously worked as an auxiliary within a nursing home and she took the view that, no matter who was available, she would ask about what was happening to ensure she remained in control of events that involved her. Freda's (P12) experience illustrates the tension between power and control, whereby the medical team has the knowledge to which the patient needs access. Freda (P12) regarded asking questions as the only way to access such information and she made no distinction between different disciplines, or grades, of staff in terms of who she asked:

> *"… listen to what is being said to you ask questions continually ask. …The doctor or the nurse may come to you and say we are going to cut that off. Would you accept that? I wouldn't. I would have to ask and I think if you don't ask the question you'll get no answers. It doesn't matter whether it's a care assistant nurse or a doctor ask questions."* Freda (P12).

In contrast, Colin (P3) described how he had direct dialogue with a doctor who was not engaging him in his own care and decisions treating him with little courtesy and lack of consideration for Colin as an individual. By taking control and asking for a change of medical practitioner he was rewarded with more considerate care for his complex needs:

> *"I thought this man is extremely rude and on top of that he's not interested… I says 'that's it I'm off' and he says 'I'm not finished with you yet' and he still hadn't looked up at us he just sat at his desk. I says 'well I'm finished with you …you've asked us questions the answers have been on average 3-4 words per sentence and you've chopped us off with a wave of the hand'… I made a formal request to come here and things couldn't have been any better."* Colin (P3)

Gary (P19) took control by contacting a helpful member of staff and his narrative inferred a shift in control: from the RN ignoring his complaint to him accessing a route to escalate his concern:

> *"Angry really, you know… I told them what I thought, you know, because I wasn't happy with it…and I'd tell them about it and they seemed to have went on their break, you know, and never told anyone about it. So I actually phoned the [hospital] and the Assistant Nurse come down, you know?"* Gary (P19).

Not all participants felt so empowered and Sally (P10) described how she was unable to question the consultants' differing opinions during her OPD consultation:

> *“The only thing I do question…one consultant might say one thing and I might go 2 months later and another will say something totally different. That does get to me a little that side of it. I take it on face value what they say. I take it and I say “alright fine” really what I should be saying is “hang on I was here a couple of months ago and he didn’t say that”. But I don’t. I say “right fine” and come away (laughter). And then when I am sitting on the bus I think why didn’t I just say “well why did you say that?”* Sally (P10).

Taking control and navigating within a system that is complicated required resilience on the part of the participants and some were reluctant or had difficulty in taking control. Idris (P9) was unable to take control but was full of admiration for his daughter, who worked through the system and obtained the outcome she needed her for peace of mind as illustrated in the quote learning the ropes (page 179):

> *“Anyhow my daughter…said ‘in that case I want you to get on the phone* ***now*** *to the [hospital] and tell them’. ‘Oh I’ll see to that’. ‘No she says you’ll not see to it. I want you to get on the phone…* ***now*** *while I am here… and* ***I insist****...’. And err so he did.”* Idris (P9).

Gary (P19), by contrast to Idris (P9), described how he took direct control during a series of episodes where he felt things weren’t right:

> *“There’s just one or two that I don't really like really just for the way they went on in the first few days but like I say, it’s all changed now because I mentioned something, I think someone off another ward, another bay further up mentioned something and since then it’s all changed.”* Gary (P19).

5.7 Chapter summary

As the participant enters secondary care either as an outpatient or inpatient they do so with a degree of **expectation,** informed by their own previous experiences, knowledge, understandings and perceptions. Participants adapted and modified these expectations as they journeyed through their patienthood experience. **Adaptation** is central to their experience and is informed by their **observations** and the **connections (meaningful)** they make with staff. The position of adaptation as central to the expectation, observation and meaningful connections has elevated this core category to a core process which is illustrated in the theoretical model (diagram 8) on page 203.

The HCA played a significant role in each of the core categories and core process and thus shaped the overall participants patienthood experience.

Chapter 6: Discussion

Chapter 6 Discussion

6.1 Introduction

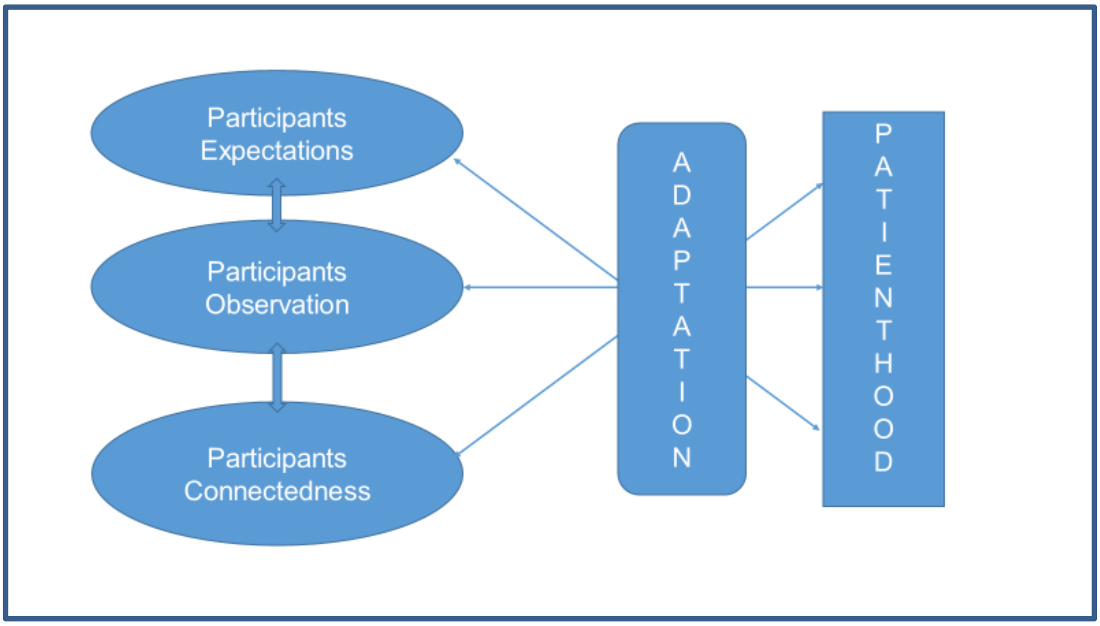
This chapter synthesises and discusses the findings covered in the previous chapter (5) for each of the four core categories. I start the chapter by introducing a model that conceptualises the core categories from the findings (chapter 5). I have positioned the model early on in this discussion and will refer to it throughout as I take the reader through each of the core categories that make up this model. Literature and theoretical perspectives from a variety of sources will be used to help explain and further synthesise the findings.

Diagram 8 depicts a model illustrating the conceptual elements contributing to patients transitioning from the known self to patienthood in a journey that shapes the patient experience. The model proposes that within each of the four elements, the HCA offers a unique contribution to this transition, both from being the provider of much of the bedside care and from being the member of staff that the patient understands is most available to them (Keeney et al 2005; Hancock and Campbell 2006; Kessler et al, 2010).

I acknowledge that this model as shown in the diagram is static and therefore does not represent the dynamic nature of the interplay between each of the elements that would exist in the lived social world. Patienthood is also not an end point for patients and again the sequential process of writing does not necessarily represent the fluidity and dynamism of this concept. The reader is therefore reminded that as patienthood is a shifting and changing concept, subject to the ebb and flow of a lived dynamic social world, the model and the writing that supports it cannot fully reflect the complexity and inter-relationships of the lived experience. In addition, it is worth noting that the HCA does not work in isolation, instead forming part of a team in a complex environment. This added complexity is not ignored and is addressed throughout this chapter, ensuring depth and richness is brought into this discussion.

6.2 Transitioning to patienthood; a theoretical model

Diagram 8: Model depicting the relationship between the four elements contributing to the patient experience through the process of adaptation.



The four core categories are depicted in this model, are as follows:

- Participants' **expectations** as they enter the healthcare environment,
- Participants' **observations** that inform them of 'who's who' in this new social world
- These two elements add to participants' feelings of **connectedness** with the HCA through the interactions they have with them.
- These first three core categories are shaped by **adaptation** (a fourth core category) as a process through which the patient develops a sense of patienthood. Adaptation will therefore be referred to from this point as a core process to signify the position adaptation plays in patienthood.

As part of this discussion, I will seek to illustrate the way in which the HCA plays a significant part in participants' adaptation to patienthood within each of the above categories. A number of theoretical perspectives have been drawn upon, each one underpinned by different sociological and philosophical epistemological perspectives. The rationale for such an approach is to add depth and understanding to the multiple perspectives narrated by the participants in this study and is congruent with a constructivist grounded theory (Charmaz, 2014).

In summary the following section outlines the theoretical perspectives applied:

- Symbolic Interactionist theorists, in particular the work of Goffman, will bring a theoretical understanding to concepts of self, identity and roles and how these concepts inform both the understanding of how participants managed themselves in a new social world and the motivations for the stories they told.
- Structural Functionalists, particularly the work of Talcott Parson’s sick role, will help illuminate the context of the contemporary patient experience within secondary care.
- Post-modernism and the work of Foucault, a post-structuralist, will explore the connections that participants described between themselves and the HCA and the influence that ‘power/knowledge’ has on trust and agency.
- General nursing academic literature will help to explore care and humour as two focussed codes, with an emphasis upon the patients’ perspective.

The sequential presentation of codes in this chapter (chapter 6) do not relate completely to the previous chapter (chapter 5). This illustrates the further conceptual development of these codes through theoretical sensitivity comparing data with the literature as further links and relationships are explored.

6.3 Core category 1: Expectations

6.3.1 The positive narrative

As participants transitioned to patienthood, they brought with them certain expectations that were informed, in part, by previous experience, knowledge and understanding. Before exploring this core category further, it is important to note that the overwhelming initial response in the interviews was a positive one, in that participant expectations had generally been met. This positivity, along with the resultant trust that it engendered, was expressed across the whole spectrum, from individual carers to the organisation as a whole and the wider NHS. As the interviews progressed, although participants went on to describe incidents and interactions that were less than positive and could therefore have negatively influenced their experience, they tended to separate these incidents from their overall experience by ‘burying’ them within a positive narrative or providing excuses for the staff involved in these incidents. There may therefore be a need to believe, rationalising these incidents otherwise they would lose faith, overwhelmed by feelings of vulnerability.

There are methodological explanations as to how and why these positive statements may dominate the narrative, which have already been explored within chapter 3 methodology (section 4.4.1). In addition, the location of the interviews may also have had a part to play and this has been reflected upon within appendix 11. The positive response is further explored in the following section through the work of Festinger (1957), Kvåle et al (2015) and Gergen and Gergen (1983).

6.3.2 Cognitive dissonance

Leon Festinger’s (1957) work on Cognitive Dissonance (CD) comes from the social psychology discipline and helps us to understand how and why participants managed some of their negative experiences when faced with further episodes of inpatient or outpatient exposure. CD (Festinger, 1957) arises when individuals experience something that is inconsistent with their beliefs and values bringing them towards a state of psychological disquiet which may be a position some participants find difficult to manage.

It may be suggested that individuals make a significant personal investment in many aspects of healthcare provision, dependent upon staff and the system to deliver care and treatment. When they experience episodes of care that are less than positive their belief system is challenged. Festinger (1957) recognises this personal investment and suggests that there is a greater level of dissonance when the individual has a significant investment in their view as opposed to their experience. Additionally, individuals seek to return to a state of consistency between their expectations and their reality by avoiding situations that will increase dissonance, clearly a situation that is difficult for the patient dependent upon staff for their care and treatment. Festinger (1957) also suggests that individuals wanting to return to a state of consistency will change behaviour, and or change their belief and or through the acquisition of information that reduces the dissonance the latter known as confirmation bias.

Changing their belief to “accommodate” or explain away poor or substandard experience was also evident. One participant who witnessed a number of years previously two members of staff treating another patient with little respect or dignity suggested this was just a bad day for the staff isolating the incident away from the belief he held that his mother’s care was of a high standard.

Those individuals that have heavily invested in a particular view or understanding will go to significant lengths to justify their position. There are therefore implications for healthcare providers in understanding the negative experience masked or buried within a positive narrative.

There are also implications for the researcher seeking to elicit views, beliefs and understandings from the participant’s perspective. We must also be mindful as uncovering the investment of a positive view against a negative experience has significant ethical, and safety implications that need appropriate, timely response and management. In doing so it may therefore be worth consideration for how participants construct their narrative.

Gergen and Gergen (1983, p263) describe “nested narratives” - a story within a story - that may provide additional understanding of why participants narrated an incident or episode of care that was in contrast to their overall narrative of positive experience. They describe the “nested narrative” as a broad concept deriving from an individual’s cultural or historical context, in which the individual presents a consistent narrative despite specific contrasting experiences. The concept therefore could be used to explore a tension or dissonance when participants described a less than positive experience ‘nested’ within an overall positive experience. Gergen and Gergen (1983) describe that the experience of dissonance may also depend on the duration of, and exposure to, the overall experience; those with less exposure or duration may be freer to act on contrasting experiences, therefore not bound or constricted by history and exposure. This may add further insight into the contemporary patient experience, for which the impact of reduced length of stay and increased use of day case surgery may reduce the duration and potential exposure to positive experience and thus bring into sharper focus any contrasting negative experiences.

Kvåle et al’s (2015) work offers additional insight into how participants realign their negative experiences through a positive narrative. All of the participants in Kvåle et al’s (2015) study were seriously ill, facing life changing events and dependent on the staff for much of their daily activity. Kvåle et al (2015) observed that participants presented their views of staff in a favourable manner, which they described as a “positive interchange” (Kvåle et al, 2015 p 153). With a reflexive approach framed within Goffman’s work (1969) the authors went on to explain that as participants portrayed staff in a favourable light, they potentially were indirectly rewarding staff to whom the positive narrative was directed and could therefore gain from this through receipt of timely and appropriate care and in so doing they additionally presented themselves as “good” patients satisfied with the care they were receiving.

The non-confidential aspect of some of the interviews in my study may have contributed to this ‘positive interchange’ through the participants’ narrated investment in the staff. The ‘positive interchange’ was still apparent, however, when participants were interviewed in a confidential space. It could therefore be concluded that the ‘positive interchange’ and narrated investment in staff was felt more deeply by the participants as they perhaps considered their potential future dependency on staff which may also have confirmed for them their role as a “good” patient.

It could be posited therefore that the work of Kvåle et al (2015) and Gergen and Gergen (1983) adds to understanding of how participants absorb negative experiences within an overall positive narrative. This will have implications for how care staff, managers and researchers seek to gain a more insightful view of the patient experience. There also needs to be consideration for how the good patient role that may be adopted by some could dominate their beliefs and subsequent behaviours. This has the potential to hide a reality that may otherwise have provided opportunity for service improvement.

The epistemological perspective of constructionism does not, however, recognise one single truthful reality or an objective truth (Crotty, 1998; Blaikie 2007). As previously noted social constructionism is used to refer to the influence the social world has on the individual’s perception, meaning making and understandings (Gergen, 2009). As such, the positive narrative that has been presented by the participants represents the meaning and sense made of their world as they have experienced it. It should therefore not be assumed that this view is any less valid than any other meaning or interpretation. What these concluding thoughts offer is how these multiple realities have meaning for both individuals and service providers. The use of single questions for patient experience measurement (NHS England 2013b) is therefore likely to elicit a positive response without capturing some of the hidden negative narrative, with further methodological implications for the researcher.

6.3.3 Nostalgia

Nostalgia played a part for some participants, with previous experience firstly shaping their expectations of patienthood and secondly acting as a point of reference or frame with which to understand the present. Howard (2012) suggested that nostalgia is defined by a past experience that is more positive than the current one (Davis, 1979; Hutcheon, 2000), in which it is not possible to recreate or recover the past.

One participant's recollection of a "golden age" led to him articulating disappointment when the reality of contemporary patienthood did not match the perceived past. Notwithstanding this nostalgic view of past experience, the participant gave a very positive account of his current patienthood experience and of the experiences of those close to him. He could find no fault with his overall current experience, despite referring to a time past that he saw as better. Howard (2012) suggested that selective memory may also have a part to play in idealising the past, which may help us to understand why this golden age was recalled from the participant's perspective. In the context of nostalgia, selective memory involves selecting only positive past experiences that are then projected on to, and contrasted with, current and future experiences. This may partly explain the disconnect between past perception and current experience that was described by the participant.

Another participant articulated that her current connections with staff were not as strong as her past connections had been when she had worked as an auxiliary a number of years previously. She too looked back and described feelings of disappointment when those connections most particularly with the RN were not as she had expected for her present. This sense of disappointment was informed by her work as an auxillary as she transposed the relationships she had with the RN and other staff onto what her expectations were for her patient experience. Additionally, it could be suggested that her working relationship with patients in her care was going to be reciprocal; what she felt for the patients in her care would be as she understood in their response to her when she entered patienthood. It was however the HCA who provided continuity for her, building a depth of relationship that compensated for her lack of connectedness with the RN, at the same time moderating her expectations.

As participants recalled more current episodes, they often looked back fondly on earlier moments when the HCAs had gone above and beyond their role. These moments were recalled by some with an immediacy and a strength of description as to how those episodes made them feel. For others, these recalled memories were more transient; often prompted by something in the interview that drew them to that particular episode.

Being cognisant of the existence and impact of nostalgia provides the HCA with an opportunity to assist the patient in re-positioning their past experiences within the context of their current experience if appropriate to do so. It also provides an insight into the way in which seeds of future nostalgic recollections can be sown through positive patient experiences in the present.

6.3.4 Trust and Faith

Many participants told of their ongoing trust and faith in various combinations of: the NHS, the organisation, the clinical area or ward and the care staff. Trust, as a concept, was narrated by the participants directly as they reflected on their feelings and experiences, which were described from a variety of patienthood and contextual positions. These findings concur with Hagerty and Patusky (2003), who suggested that trust is contextual, situational, perspectival and multi-dimensional. As such, trust is linked to many of the sections within this discussion and will be signposted where relevant.

As participants used the words ‘trust’ and ‘faith’ directly, the commonly accepted definitions are worth noting as they are often used interchangeably but have different meanings. The Oxford English Dictionary (2016) states:

> Trust; *a firm belief, a confident expectation.*
> Faith; *complete trust in a person or thing, a promise, loyalty or sincerity, a religious belief.*

Trust describes a certainty in the face of contingent outcomes; an absolute confidence that was articulated by many participants. Trust as a word is common in everyday language and is often used with varying degrees of intensity, as described by Giddens (1990). The participants used the word ‘trust’ as related to an experience or an interaction: something tangible that they could relate to. Giddens (1990) supports this, adding that, in modernity, trust needs a different understanding. A shift from trust based in custom and tradition but one related to a greater extent to risk as there are more uncertainties in the globalised modern world.

Faith, by way of contrast, was of a higher order and therefore less tangible. It invoked a feeling or sense that was held, or alluded to, by participants. For some, faith had an almost spiritual dimension, representing a validation of what the NHS had achieved for them and their health. The existence of faith, either in an individual or in a system, leads to trust in the face of uncertain or contingent outcomes. In turn, trust provides individuals with confidence that certain desired outcomes will be achieved. Faith is therefore a pre-requisite for a trustful state (Giddens, 1990).

The domains of trust, as identified by Hall et al (2001) and Ozawa and Sripad (2013) are: communication, honesty, competence and confidence. The inter-relational aspect between patient and care providers is of paramount importance and influences patient satisfaction (Safran et al 1998; Platonova et al 2004; Thom et al, 2004), symptom improvement (Thom et al, 2004) and access to medical care (Russell, 2005). Relatives of end of life patients also suggest trust is an essential element in their loved ones’ care (Heyland et al, 2006). Dinç and Gastmans’ (2013) literature review identified that trust, whilst an essential element in the dynamic of the nurse patient relationship, is fragile and susceptible to influences that can variously break or repair it. Trust may be shaped by previous experience of healthcare and is also related to nurse competence and caring qualities (Dinç and Gastmans, 2013).

The concept of trust therefore appears to be complex, situational and bound up with the relationship between the individuals concerned, as identified by

Frederiksen (2012). The following sections on trust and mistrust illustrate these themes in more depth.

6.3.5 Trusting in the system

For some, expressions of trust related to the overall system of healthcare delivery and therefore represented a higher order of trust that was effectively ‘faith’ based, a reference that was used by one particular participant as she spoke about her enduring “faith” in the NHS and the organisation where she had received her treatment and care. Participants described trust as an accepted part of their patienthood and had either no reason to question their level of trust or had given the concept little thought. This level of trust may be in part explained by the relationship between interpersonal trust between doctor and patient and trust at an organisational level (van der Schee et al, 2007; Ozawa and Sripad, 2013; Fuglsang and Jagd, 2015).

Simmel (1950 p 318) proposes that trust is a confidence between what is known and what is not.

> *“a hypothesis certain enough to serve as a basis for practical conduct.”*

Giddens (1990, p33) explains that trusting in another comes about from an understanding of the ‘probity’ of the other, in other words that they will ‘do the right thing’ based on moral and ethical behaviours. He also suggested that trust is closely aligned with having confidence and reliance of a person or system, where full and transparent information is not available.

Simmel (1950, p318) sees faith as a higher order, mystical and unaccountable phenomenon that lies beyond the more tangible trust-based confidence. This ties back to the findings, in which participants generally expressed faith in the NHS or organisation, rather than using faith with respect to staff at an individual or collective level. There is a further impact on participants’ faith in the organisation and wider NHS arising from the relationship between staff and patients. Giddens (1990, p88) describes trust as arising from “facework” commitments between individuals as a result of direct interactions. He goes on to explain that “facework” activity can contribute to “faceless commitment”, in which there is faith in the workings of what is a largely unknown system. This therefore helps to understand how face to face interactions can engender in patients a greater sense of trust and faith in the wider organisation. It may also help us understand the non-questioning, trusting relationship that many participants had with the organisation and the NHS.

The expressed faith that participants described in the organisation and NHS is further explained by Fuglsang and Jagd (2015). They state that in situations where organisations or institutions are regulated and are relatively stable (which arguably describes the NHS), trust is enabled and may influence both inter-personal relationships and the relationship individuals have with the wider organisation. This was evident from some participants' narratives, in which they described the trust they felt across all their encounters and experiences. In those situations, where they had no reason to doubt their trust, it transcended all dimensions of healthcare at a macro, meso and micro level.

This expressed trust across all dimensions of healthcare contrasted with the wider contemporaneous NHS narrative and context. At the time of the participant interviews, the NHS was the subject of negative media coverage related to failing services (BBC, 2015) and stressed NHS workers (Guardian, 2015). This wider context for the participants' patienthood could potentially have impacted on the trust they expressed in the NHS and in the staff delivering their care. Within this doctoral study, however, despite the negative national backdrop, participants expressed trust that had been informed by their local experiences, which contrasted with the media reports.

This difference between media narrative and participant experience could also in part be illuminated by Simmel (1950), who suggested that trust is connected with one's knowledge of the 'other'. Our knowledge of the 'other' may not be enough to inform expectations and so, not knowing how an 'other' will perform, we assess the probable outcomes based on what we are familiar with. It could therefore be posited that the participants' positive familiar experiences engendered trust in the wider context of health provision and that, despite the negative media coverage, their trust base was not destabilised. It is therefore worth noting that participants' own experience appeared to transcend the anticipated experience informed by the media.

Möllering (2001, p 412) additionally describes trust as the “mental leap” that is taken from a position of the known, interpreted and understood across to what is expected but is not known. This concept may help to illuminate the views of those participants who felt there was no alternative other than to have trust in staff with whom they had little knowledge or experience, basing this trust on their known past experiences.

6.3.6 Trust and immediacy

Many of the participants described situations where they knew little about the HCA caring for them, had not met them before or were subjected to new relationships due to teams swapping over following a period of consolidation with previous staff. The ability of individuals to bring immediate levels of trust into a relationship is of significant importance within healthcare today, especially with a fast paced clinical area and reduced length of stay. Some HCAs were able to quickly engender trust in their interactions with the participants, as evidenced by the participants' narratives.

Hagerty and Patusky (2003) challenged the traditional linear view of establishing foundational trust before the nurse patient relationship (NPR) can flourish, leading to mutual goal achievement. They suggest that this linear model is limiting in contemporary healthcare, where short immediate relationships need to function to negotiate care and personal goals where there has been little or no opportunity to lay the foundations of trust. They instead reconceptualise trust within a theory of human relatedness (THR), which in turn reduces the emphasis on trust and time but re-emphasises the immediacy of the interaction and what is important to both patient and carer. Consideration needs to be given, therefore, as to how the immediate relationship between HCA and patient can be further enhanced. This is particularly the case within settings such as OPD, where traditional models of care may need to be revisited if the NPR is to be enhanced.

The impact of trust in a longer term relationship, for example with patients who experience an extended length of stay, can, however, be interpreted through a traditional linear sequential progression. This scenario, together with the concept and potentiality of the dyadic relationship of HCA and patient, will be explored more fully in meaningful connections (section 6.5).

6.3.7 Trusting in the uniform

Further context for the trust implicit within one to one situations between staff and patient can be gained from the work of Joseph and Alex (1972) on uniforms. Despite the early date for this work Timmons and East (2011) note that it is of significance today as there is little research on uniform within healthcare as a central issue (Timmons and East 2011; Hatfield et al 2013; Jenkins 2014).

Joseph and Alex (1972) explore the role of uniform on interactions between the wearer and non- wearer. The observer of the uniformed wearer has some expectation of the performance of the wearer in their capacity as a member of the denoted group and will also have some knowledge of the duties undertaken and interact accordingly.

For the participants who were dependent on one to one care, vulnerable and reliant on others in meeting their needs, the uniform offered a point of identification and reassurance. Joseph and Alex (1972) see the uniform as a point of separation between the wearer and non-wearer. The participants took on the role of the non- uniform wearer and therefore were constantly reminded of the difference between them as patients and the uniformed staff as the uniformed staff behaviour is anticipated and understood within the frame of reference of the uniform. Joseph and Alex (1972) do not necessarily see the difference and separation as detrimental to interactions and relationships so long as the difference is not exploited by the wearer. The consequence of such exploitation is suggested by Rafaeli et al’s (2008) study citing Milgram’s (1963) experiment an unfailing compliance to the authoritative uniformed wearer.

6.3.8 Mistrust

Some participants expressed mistrust, mainly directed at individuals involved with their immediate experience and rarely transcending to staff in general or the wider context of the NHS. This mistrust sometimes manifested in a heighted state of vigilance either for themselves or for other patients whom they cared for. In consequence, vigilance is referenced throughout this chapter but as a separate concept it is explored more fully in adaptation (section 6.6 and 6.6.4).

Availability and accessibility of staff is an important dimension of interpersonal relationships. One participant told of leaving her mother in the care of a ward where there was a high level of staff availability, where the HCAs were visible and built strong, caring relationships with the patients and the relatives. The level of mistrust this participant felt when leaving her mother on a subsequent ward where there was less availability and accessibility to staff left her with a heightened state of vigilance. This left her expectant of substandard care and therefore managing and supervising her mother's care herself to avert any issues before they happened. Frederiksen (2012, p737) posits that proximity may influence and shape our belief and understanding of trust. He suggests that in relationships based on low proximity (less availability and accessibility), the individual may expect or suspect a level of mistrust. This contrasts with high proximity relationships that are likely to be based upon "confident dependence", which may help breach the mental leap as described by Möllering (2001).

This 'confident dependence' articulated by Frederiksen (2012) cannot, however, explain the immediate belief and trust in staff who provided the one to one care that participants described as they woke from their anaesthetic. Unable to look after or care for themselves during this stage in their patient journey, the one to one relationship with care staff that would normally facilitate higher levels of trust had not yet been established or had the time to develop. The participants often had no knowledge of their carers before they woke from the anaesthetic, given that they often entered the ward for the first time following their procedure. The immediate trust described by participants, in these circumstances, is best explained by trust in the organisation and

NHS, as described by Giddens (1990) “faceless commitment”, and the trust in regulated organisations as described by Fuglsang and Jagd (2015). The mental leap (Möllering, 2001) taken by the individual and proximity (Frederiksen, 2012) of staff reinforce trust as the one to one relationship continues and develops.

The issue of proximity being related to higher levels of trust can be further illustrated by the situation when one participant experienced a life threatening complication. She felt there was nothing she could do other than to continue to trust the staff and their skills, whereas her husband was less trusting across the entire spectrum from the direct care staff to the NHS as a whole. The participant clearly had a number of high proximity relationships that may have partly mitigated any mistrust, whereas her husband, whose experience would have been of lower proximity, did not have that brake on the level of mistrust. Interestingly, the same participant did not express an equivalent level of trust in her mother’s care, which may indicate that her lower proximity to staff in respect to her mother’s situation effectively mirrored her husband’s lack of proximity and consequent viewpoint on trust with respect to her care.

This participant narrative illustrates that there is often a difference between what one is prepared to accept and tolerate for oneself and what one is prepared to accept on behalf of another. This further validates the idea that trust is a relative concept that varies in strength depending on the proximity of the relationship between carer and patient or family member.

Another consideration in situations such as the one described above is the tension between adopting a compliant conventional patient role in which the patient doesn’t want to be seen as a nuisance versus a role where the patient is perceived as being more demanding of staff time and resource. This issue is considered later on in the chapter when addressing asking for help (section 6.6.5).

“Misplaced trust” was not alluded or referred to by participants but does provide an additional dimension when considering trust. Andreassen et al (2006, p240) suggest that the state of imbalance resulting from unconditional trust should not be allowed to develop. There are obvious patient safety and ethical implications that could arise from such an imbalance. Andreassen et al (2006, p240) explore the relationship between clinician and patient suggesting the potential for misplaced trust will be reduced where the interaction between clinician and patient is positioned as a partnership. The relationship between HCA and patient may be viewed as located within the concept of partnership as described in the section reciprocity and mutuality (section 6.5.4). It could therefore be posited that trust between HCA and patient is not subject to the concept of misplaced trust so long as the HCA patient relationship is one where there is recognition of the reciprocity and mutuality between them.

There are points when patients trust the HCA will transfer information they have imparted to them appropriately. Limited or reduced control of transference of information was identified by Spilsbury and Meyer (2004, 2005) as a potential area of concern in their study, due to a tension that may exist between RN and HCA. Participants in my study did ask the HCAs for information outside of their jurisdictional role. Although this implies that participants did not have cause for concern about the safe and timely transference of information, the literature suggests that problems can occur (Spilsbury and Meyer, 2004, 2005). The HCA and RN relationship, and the tensions that can result in reduced transference of information, is therefore necessary to understand to ensure patient safety and positive experience.

The concepts of trust, mistrust and misplaced trust infiltrate and permeate many aspects of patienthood and the patient experience. As a concept, trust is complex and is neither static nor stable. It is also subject to macro, meso and micro influences, all of which have the potential to shape and inform patients' expectations of future healthcare experiences. Employers and managers involved in recruitment, training and development of staff need to consider how trust can be enhanced within the immediate and longer term nurse-patient relationship whilst acknowledging and mitigating the potential for mistrust and misplaced trust. Any strategies employed should involve the HCA, as their contribution to participants' feelings of trust within the immediate and dyadic relationship is very significant. The trust engendered within these direct relationships should also have a positive cascade effect for the organisation as a whole that will ultimately enhance reputation and the overall patient experience.

6.3.9 Summary

Due to the high level of availability and accessibility of the HCA to the patient (Hancock and Campbell, 2006; Kessler et al, 2010; Cavendish, 2013), it is proposed that the HCA is in a unique position to support the patient as they enter this new social world, managing expectations through an enhanced understanding of the patient perspective.

In seeking to gain greater understanding of the patient perspective, there needs to be an awareness of the positive narrative that may hide experiences that are less so and may otherwise be missed. This includes organisational survey techniques that seek to measure the patient experience, and research inquiry that aims to gain depth of insight.

The engendered trust placed within the NHS, the organisation and the staff is an area of research that if explored from the patient HCA dyad would provide opportunity to see how misplaced trust and mistrust impacts upon patient safety.

Recognition of the impact the HCA has on building a trusting immediate relationship in contemporary healthcare is essential and illustrates the importance of this relationship. Not attending to the impactfulness of this relationship in terms of recruitment, education and training of the HCA suggests a missed opportunity for understanding and improving the patient journey to patienthood and their patient experience.

6.4 Core category 2: Observation

6.4.1 Role identification

The participants interviewed for this study were all at various points in their individual patient journeys and articulated differing levels of comprehension and interest with respect to ‘who does what’. Kessler et al (2010) suggest that it is important for the patient to be able to distinguish between the HCAs and other members of staff, emphasising the importance of explaining these differing roles to the patient so they know who to ask for what.

Those who were concerned to identify roles and responsibilities used various techniques to work out ‘who was who’. One approach was by association of uniform with task, which suggests a symbolic representation through the use of uniforms to assist participants in working out what to expect in terms of behaviour and professional status. A number of participants used staff names to differentiate roles, which suggests that the relationship component of the interaction was of importance to them in identifying ‘who was who’. This latter point has been of concern to the work of Kate Granger and the “My name is...” campaign (drkategranger, 2013) endorsed by Jane Cummings and the 6Cs initiative (NHS England, 2013a).

Another technique of identification relied on observing tasks performed by staff, for example the administration of medication that was only undertaken by RNs. By contrast, some participants appeared unconcerned as to ‘who was who’, instead trusting that the system took care to ensure the right staff with the right qualifications and experience were supporting them. Others perceived no difference between RNs and HCAs, seeing the care staff as a homogenous grouping.

Uniform was worn by all nursing and HCA staff and therefore offered an immediate point of potential recognition for participants. Some participants, however, were unsure as to who the HCAs were, raising questions about the usefulness of uniform as a means of identification. Uniforms offer practical solutions within healthcare, assisting with issues of infection control and ergonomics (RCN, 2013). The observer of the uniformed wearer notes professional identity and gains reassurance of that identity, as suggested by Joseph and Alex (1972), as the uniform provides a visual legitimacy to the group membership. A similar position was taken by Goffman (1969, p34) in his understanding of how uniform forms part of the “personal front”, the “appearance” of the “social status” presented to the observer, and thus what behaviour is associated with, and expected from, the individual in that uniform. These broad observations around uniform do not, however, consider the complexities and subtleties that arise from the wide range of types and colours within healthcare today (Jenkins, 2014) an issue which Clavelle et al (2013) noted was not of concern to the patients in their study. Joseph and Alex (1972) do, however, suggest that with the proliferation of uniforms there is the potential for confusion, with a more recent study confirming such difficulties (Kessler et al, 2010).

‘Stratified homogeneity’, as described by Rafaeli and Pratt (1993), is the difference in colour of uniforms within the professional group that provides a visual representation of the group’s implicit hierarchy. Within the UK, there is no central policy on uniforms within the hospital setting (Timmons and East, 2011), but the colour shading within many organisations is blue for nurses, the darker blue often denoting the more senior RNs. Within the context of this study the HCA wore brown, which clearly does not sit within the palette of blue, and one particular participant referred to the HCA as the ‘brown coat’, indicating that patients themselves perceive the colour difference. The fact that some hospitals use brown for HCAs may imply that the healthcare system sees the HCA as not being part of the nursing family and therefore requiring a colour reference that differentiates them from the professional group. Joseph and Alex (1972) suggest that pride in wearing the uniform relates to the prestige accorded to that uniform. Although they form part of the hierarchical structure of the ‘uniform wearing’ professional, the contrasting uniform colour of HCAs may act as a reminder that their status is at the lowest rank and therefore not recognised as being positioned within the professional group of nursing. One organisation in Kessler et al (2010) study recognised that there were benefits for the HCA in bringing them into the nursing family changing their uniform colour from purple to blue. Organisations may therefore wish to consider that the stratification demarcation resulting from the use of a different colour of uniform for HCAs may not support their acceptance by the patient, or indeed the HCA themselves, within the caring workforce. The demarcation may also impact on the nature of the relationship between patient and HCA, potentially acting as a barrier to patients requesting help from the HCA on what they consider to be issues for professional staff, such as medication and symptom management.

Hertz (2007) additionally suggests that the symbolism of a uniform may be interpreted differently by individuals, which she explains in terms of Santino’s (1998) work studying the different perceptions of the African American Pullman porter as narrated by them. For the passengers, the uniform was a reminder of their superior economic status and the deferential position of the porter. To peers of the African American porter, however, the uniform was perceived as a step up from the working class clothing worn by farm labourers. The HCA may therefore perceive the lack of uniform homogeneity as a reminder that they are often not recognised at a national or local level their contribution to the professional group. The nature of the uniform has not yet been determined for the new “Nursing Associate” (NHS HEE, 2016) role, which sits above the HCA in the care staff hierarchy. It will therefore be interesting to see what colour is adopted and whether the colour sits within the palette of blue to imply location with the professional group or is not, positioning it within the assistant role stratum.

Recognition of staff and their roles through the observation of tasks and task performance may be supported by Goffman (1969). His work offers insights into role and performance by addressing how individuals bring about and portray their outward appearance, their socialised self, in their day to day activities. He does this through the dramaturgical metaphor of theatre, which suggests individuals are akin to actors on a stage, and uses dramaturgical terms to position the performers, the audience and the various roles. Goffman (1969) identified that the performer and audience roles are interchangeable, affective and interdependent. When applying his work to the complex interactions between patients and staff, this suggests that staff and patients take on either actor or audience role. Much of the literature that references Goffman’s (1969) work however takes the position of role performance for staff (Holmes 1992; Hildebrand et al 2009; Lewin and Reeves, 2011; de Vries-Erich et al, 2016) and not the patient and therefore my approach may provide a different perspective and added insight into the patient role.

Successful performance or presentation of the performer (the self) is achieved through impression management, employing verbal and non-verbal (body language) approaches to present the self to the audience and thus produce a performance. The setting and dramatization of staff at work therefore helps us understand how patients may perceive the HCA and RN activity. It also provides us with an understanding that our performance, when being observed by patients, may impact on their perceptions of our role and responsibilities.

Although medical and surgical duties for the nursing staff within contemporary healthcare are different to the circumstances prevailing in Goffman's (1969) work, the concept of participants identifying staff designations, roles and responsibilities through observation of tasks performed may still have relevance today. Goffman (1969, p41) noted a difference between the very visual and "purposeful" activities of the surgical nurse as compared to the less visually obvious activities of the medical nurse. He suggested that patients recognise and acknowledge the obvious visual activities (for example, the surgical nurse managing orthopaedic frames, dressings and infusions) whereas they don't necessarily identify the more subtle work undertaken by staff (for example, the medical nurse observing patient breathing and other outward signs as an indicator of health while he/she communicates with the patient). The setting of the performance is further enhanced by the machines and technical equipment located or brought to the patient's bedside for example the IV machines that serve as an additional means of identifying the roles through the staff engagement with these machines. There may be an opportunity therefore to help patients identify the variety of roles through their visual and observable tasks and activities rather than reliance upon uniform and or name.

Role identification is complex and depends upon many factors which include the patients' capacity and capability to retain information at the start of their patienthood and build a coherent sequential picture of who does what despite activity not always being so clear.

6.4.2 Role boundaries

For those participants with an interest in ‘who does what’, there is a related concern around where one role ends and another begins, which can be conceptualised as boundary working.

Using the earlier example of IV machines, some participants noted in hushed tones that HCAs were responding to, and silencing, machines that alarmed. Although not expressly mentioning a concern, the tone used by participants in relaying this information suggested that they had an awareness that this activity was outside their role responsibilities.

Another example of boundary working is when a number of participants described asking the HCA, in the absence of the RN, for interpretation of information initially communicated by doctors during ward rounds. In most situations, the HCA declined to answer such queries and instead requested assistance from the RN. The output from this study therefore indicates that the boundary of responsibility in this context was adhered to. This is in direct contrast to the work of Spilsbury and Meyer (2004, 2005), who suggested that the bedside work of the HCA, and the information gathered therefrom, is not necessarily transferred to the RN due to limited opportunity and lack of suitable mechanisms. Spilsbury and Meyer (2005) add that transference of information may be consciously withheld by the HCA in situations where there are tensions between RN and HCA, which suggests the HCA may be attempting to hold onto the power they have gained through access to this knowledge (further explored section 6.5.10). The work of Ceci (2004) adds to this perspective, wherein she described a situation in which there was a failure to recognise and acknowledge the nursing concerns that were raised when a number of child deaths occurred during or after heart surgery in a Canadian Hospital in 1994. A similar situation was noted in the Francis Report (The Mid Staffordshire Public Inquiry, (MSPI, 2013)) resulting in ‘freedom to speak up’ policy (NHS Improvement, 2016a) addressing how staff can now raise their concerns of risk, malpractice and wrongdoing without fear of reprisal. The lack of acknowledgement for the RN in Ceci’s (2004) work was partly explained by the nurse’s subordinate position in relation to the medical and anaesthetic staff, which indicated that a truth can be ignored or lost when it is perceived by someone further up the hierarchy as not worthy of listening to. This gives rise to a concern whereby the HCA has information that can be missed or ignored by those in a position to assimilate and act on that information, with a resultant impact upon patient safety and experience. Organisations therefore need to consider the traditional, hierarchical structure of workforce in situations where hierarchical power is greater than the individual voice, making it more difficult to transfer information where necessary.

The participants implied that the immediacy of the moment was lost in those situations where the HCA had to ask for assistance from the RN or was unable to answer the participant's request. Although patients accepted there was a difference between the roles and capabilities of RNs and HCAs, there was a potential disconnect arising from this situation. As the participants generally did not have such an immediate and nuanced connection with the RNs as they had with the HCAs, there could have been a missed opportunity for a deeper level of connection that could otherwise have been established. Notwithstanding this potential problem, there is an opportunity in this circumstance for the RN to build meaningful and trusting relationship based upon the THR (theory of human relatedness) as posited by Hegerty and Patusky (2003)

One particular participant was concerned when an HCA suggested a solution to their request that the participant perceived as being beyond the HCA's jurisdiction. This raises the question as to what the HCA was permitted to discuss with the participant and whether any of the knowledge and information being drawn upon sat outside the HCA's jurisdiction. Ceci's (2004, p1884) work looked at power, knowledge and acknowledgement of truth through a Foucauldian lens and suggested that we will not be seen “to know” unless our knowing is confirmed by the listener. In this particular case, the participant did not validate the HCA's claim of ‘knowing’, which gives rise to further questions as to whether this lack of validation might impact on the HCA's future behaviour in such situations. This particular situation which left the participant in a heightened state of vigilance (addressed further in section

6.6.4 resilience); uncertain and concerned as to who was legitimised to do what for her.

Other participants saw potential for the HCA to take on more duties and tasks, particularly in situations where the HCA was working in extreme conditions and at the boundary of their jurisdiction. The participants who commented on this did so from the perspective of seeing only the restrictive nature of such boundaries, which some suggested was a wasted opportunity for role development. The participants, however, would not have taken into account the need for controlled development of roles and the resultant implications for patient safety.

This may however provide an opportunity to think differently about how service delivery could be developed to meet the needs of the patient, rather than the restrictive nature of organisational and professional boundaries.

6.4.3 Summary

The HCA role at present remains an unregulated, unregistered practitioner, who at present sits outside the professional boundary of nursing (DH, 2013b). As such, the role differs from that of the RN (RCN 2004) despite carrying out much of the bedside care (Hancock and Campbell, 2006; RCN, 2007a; Kessler et al, 2010; Cavendish, 2013). The identification of such a role from the patients' perspective is not without difficulties and appears to be addressed by uniform in many organisations. The symbolic representation of uniform in general as an identification of professional staff does not appear to be problematic it is the number and diversity of uniforms that is difficult for patients to navigate. Using a number of other strategies to work out who is who patients build up a knowledge base of who is who and who does what, which may be worth considering in helping patients orientate to this new social world, dependent upon role clarity and understanding of boundary working that may add to confusion.

6.5 Core category 3: Meaningful connections

Participants described their relationships with staff, including HCAs, as being at varying levels of connectedness and intensity, ranging from a distant transactional relationship based on meeting immediate needs through to situations where there was a level of connection likened to the ‘love’ more usually associated with one’s family members.

There were a number of factors that contributed to the relationship between staff and participant. Time was a factor that participants referenced from two main perspectives. There was firstly the time staff spent on individual relationships, which ranged from the ‘fleeting’ amount of time spent in meeting the participants’ immediate care needs to spending as much time as possible with the participant. Secondly, time was described by reference to the duration of participants’ patienthood, whether for inpatient or outpatient settings. The factor of trust, discussed earlier in the expectation section, also played a part in the connection participants felt with staff. The factors of humour and tokens of friendship were deployed as strategies at times by both HCA and participant to bring about greater connection within the dyadic relationship. In addition, there were environmental factors that influenced the relationship, which included the workload and consequent availability of staff within a bay of six as compared to an individual side room.

The comfort and consideration contributed by the HCA in meeting the participants’ care needs had both a physical and an emotional dimension. Some participants described a physical response to interactions and others alluded to interactions where their emotional needs were met through acts of reassurance and presence and through appreciation and anticipation of their needs. Participants described the care they received in terms of the way staff undertook tasks and duties, in which interactions were often punctuated with moments of connectedness. These, often transformational, interactions illustrated how the HCA brought more than the performance of mere tasks to the participants’ experience, in contrast to episodes where tasks were conducted in a manner for which the participants alluded to a resultant disconnect.

6.5.1 Transformational interactions.

For many participants the HCA was seen as being skilled in bringing about combined episodes of task and connection and in initiating further connections with them as they went about their day-to-day work.

Participants also described interactions in which there was exclusivity ‘in the moment’ between them and staff which contributed to their sense of holism and humanness. This exclusivity also provided a reminder to them of their dependencies that required the sole attention of the carer and acted to provide confirmation and validation both of their role as a patient and of their patienthood a concept later explored in the adaptation (section 6.6).

An additional aspect to this one to one exclusivity, which was experienced by some participants, was the inclusion of members of the participant’s immediate family in an extended exclusive narrative shared between them all. Participants who described this aspect had all been patients for a significant period of time and they all welcomed the fact that their care extended to incorporate the care and consideration for their immediate family.

These one to one moments were very important to participants and contributed to the patient-HCA dyad. The “nurse- patient” dyad is often researched from the perspective of RN and patient (Shattell 2004; Tejero 2011; Evans, 2016) without mention or recognition of the HCA. Shattell (2004) noted that much of the literature focussed on the perspective of the RN, which may therefore act as a limitation on the transferability of findings to the HCA-patient dyad, particularly from the patient perspective. Tejero (2011, p994) posits that the dyadic interaction between patient and nurse is about more than just the moment; it suggests a connecting relational link where the elements of the interaction work cumulatively to greater effect than they would as individual elements. This results in an integrated interaction, in which there is synergy and bonding that helps to bring about an optimal outcome for patients. Some of the literature points to the technical competency of the RN as a factor that contributes to the strength of the nurse-patient dyad (Curley, 2007). Tejero’s (2011) quantitative study explored the mediating impact of the nurse-patient dyadic relationship in terms of patient satisfaction. She concluded that patient satisfaction was enhanced when the RN imparted knowledge around medication and health that increased patients’ compliance with treatment and improved health. It is, however, more difficult to identify how the HCA could contribute with respect to dissemination of knowledge due to jurisdictional limitations of the role. This suggests that further research into the concept, impact and potentiality of the HCA-patient dyad may be necessary, particularly from the perspective of the patient adding to greater depth of understanding of the patients’ dyadic relationships.

Participants recognised that staff worked hard, often under difficult circumstances, and were aware of the demands placed upon staff when working under extremes. They also alluded to the qualities necessary to carry out responsibilities effectively and were sometimes in awe at the capacity and capability of the staff to deliver high standards of care in such circumstances remaining patient and not losing their professionalism.

This ability of staff to perform under difficult circumstances is in part explained by the theories around the emotional labour of nursing and how practitioners ensure the patient is met with care and compassion (Smith 1992, 2012; Huynh et al, 2008).

Nurses drew upon both deep and surface emotions (Hochschild, 2003; Smith 1992, 2012) to manage both themselves and the situations they found themselves in throughout their working day (Smith and Lorentzon, 2005). Emotional labour was first described by Hochschild’s (2003) description of flight attendants, in which she suggested that effort is required to manage the negative emotions and feelings into socially accepted and organisational behaviours.

Surface emotions are those emotions that are kept in check in order to demonstrate the ‘public’ persona of professionalism, which requires effort or ‘labour’ whenever the professional is interacting with the patient. The ‘public’ persona of the HCA was recognised by participants and described by them as being caring, capable and considerate; not seen as ‘labouring’ (Smith, 2012), but as the qualities inherent within an individual or comments made more generally to all HCAs. This inherent characteristic of emotional labour has been previously suggested by others (Hunter 2001; Foster and Hawkins 2005, Gray, 2009,) where they add that it has the potential to contribute to the therapeutic relationship. The personal value felt by participants of such observations was alluded to however, at an organisational level there is the risk that this value is not recognised (Smith and Gray, 2000; McCreight, 2005; Hunter and Smith, 2007) or is seen as a reward in itself (Hochschild, 2003). Smith (2012) posits that the advancing technological roles and medicalisation of the RN has seen the HCA more involved in emotional work where there are implications for care delivered by the HCA if emotional labour is not managed and supported. Additionally, Kessler et al (2010) suggest that much research has been conducted from the RN perspective in particular emotional labour that has largely ignored the HCA.

For meaningful connections and care to be maintained by staff there needs to be recognition of the deep emotional labour required. However, the delivery of deep emotional labour needs an understanding of oneself, a liking of oneself and an ability to reflect and continually develop (Stein-Parbury, 2009). The HCA who has limited access to further education and training may well not have been exposed to such practice and may also lack the necessary skills to undertake such activity

Neglecting management of the effort required to deliver care may result in staff burnout (Sawbridge and Hewison, 2011) that may potentially result in poor care delivery. Staff therefore need support, supervision (Sawbridge and Hewison, 2011), education (Finch, 2008; Huynh et al, 2008; Griffin, 2012) and strong clinical leadership (Sawbridge and Hewison, 2011; Smith, 2012) to help manage the emotional effort in care delivery. This framework must include and make provision for the HCA who does not always have access to education, training and supervision as part of a workforce susceptible to such consequences.

6.5.2 Transactional interactions

Some participants described situations in which the interactions with staff were more transactional, which left some feeling disappointed and alluding to a disconnect between them and the staff. A number of inpatient participants described the HCA undertaking technical interventions in a transactional way without further engagement from the HCA and, as a result, participants recalled a sense of disconnect and missed opportunity.

Some participants recognised there was something missing in these interactions with staff; a sense or feeling that they found difficult to define. Bone (2009) described how practitioners resorted to the delivery of less emotionally demanding care and labelled this as "*care deficit",* whereby the patients' experience was potentially less rewarding. Bone's (2009) concept of 'care deficit' may also relate to Halldorsdottir's (1991) Type 3 bio-passive state, in which interactions are based upon apathy and detachment. This links back to the participants' views of certain tasks and duties being carried out in a detached manner, leaving the patient being 'looked after' but not 'cared for'. These transactional interactions appeared to be dependent on a number of aspects linked to the care context, including length of stay and opportunities to interact. NHS England (2013a) have addressed this in part with the local action plan linked to the 6Cs initiative stating carers need to make every contact count. Research conducted by Mottram (2008) within two day-surgery units concluded that there was, however, a disconnect between what the patient valued and what the nurse perceived to be therapeutic in a fast paced environment. Transactional superficial interactions, not necessarily recognised for their value for patients by staff, were reassuring to participants, as was the mere presence of the nurse. There are implications for how staff in such environments develop a therapeutic relationship despite time pressures and recognition of what the patient values.

The HCA could be helped to recognise the potential for meaningful engagement with the patient at the bedside. Through the transactional activity of directly monitoring patients' vital signs, an opportunity exists to build a therapeutic relationship. Role development and training needs to emphasise that every interaction counts for the benefit of the patient and for the development of meaningful connections.

A number of participants described a disconnect with staff more generally, which can be further explored by reference to Goffman's (1969, p28) work on opposing performances. He described the activity and interpretation of opposing performances, which may be used to understand how participants describe the difference between transactional and transformational interactions. Goffman (1969) suggested two opposing positions of the performer; firstly, where there is self-belief in the performance (attributed as 'sincere') and secondly where there is not (described as 'cynical'). Although these positions are not at the extremes of a continuum, the performer is still able to move between the two positions: from a perspective of disbelief toward belief as the performance becomes part of the known self. Mottram's (2008) work indicated that the situation may be more complex than indicated by our understanding derived from Goffman (1969). Mottram's (2008) study portrayed a disconnect between the value that the RN perceived from an interaction and the patient's realised value of that interaction: the RN was 'convinced' of the value of their performance but doubted that the patient would perceive this value. However we choose to interpret this disconnect, episodes of transactional interaction that might be viewed as insincere or 'cynical' from the participant's perspective can, with self-belief on the part of the performer, be shifted towards sincerity and thus become a valuable contribution to the patient experience.

A further insight is provided by Goffman (1969), in which he describes a desired consistency between manner and appearance. The appearance of the uniformed professional combined with a manner that is inconsistent with that appearance may bring about feelings of incongruence for the observer. This in turn indicates an interaction that is unstable and lacking in certainty and trust, which is unhelpful for both patienthood and the patient experience.

A cynical performance, however, may not necessarily be delivered solely from the staff as Goffman (1969, p29) suggests the patients may offer a cynical performance, as might occur when a mental health patient exaggerates symptoms in order to meet the expectations of a student nurse. His example may offer insight into behaviours exhibited by patients in situations where relationships are based on expectation rather than on meaningful connection. This latter point may be best illustrated by those participants who articulated their concern at being perceived as difficult or demanding and giving a less favourable perception than a well behaved compliant patient. This aspect is explored more fully in the section 6.6.5 that addresses the concept of asking for help.

By way of contrast, the inclusivity described in the previous section was not always viewed so positively in situations where staff ‘collectively’ included the whole bay in conversations and monitoring of need. This collective, inclusive approach was possibly used by staff to bring a sense of belonging for participants where they occupied a bed in one of the many six-bedded bays. The corridor was studied in a large teaching hospital in Australia where it was noted that the corridor was a liminal, marginal space where decisions were held with a degree of temporality (Iedema et al, 2005). It could therefore be posited that the space located at the entrance to the bay is one such liminal space where activity is present but decisions are suspended.

Staff therefore may have used this collective approach to assess individual needs at a distance, particularly during times when there were workload pressures. Whatever the rationale for this collective approach to inclusivity from staff, some participants voiced discontent. Goffman (1969) suggests that disappointment is felt in situations where there is a lack of exclusivity within the dyadic relationship. Feelings of disappointment may arise as a result of all patients in a bay perceiving they are being treated in the same way, sharing the same ‘intimacies’ and thus impacting upon each patient’s sense of themselves as an individual; effectively not being worthy of an exclusive relationship, impacting upon patients’ sense of holism and humanness. The HCA therefore needs to be mindful of a collective approach being one of the factors that may hinder the development of a dyadic relationship.

6.5.3 Mechanised interactions

The patient is aware of the IV fluid machines and the restrictions they bring as often the site of administration is hand or arm limiting their function, a reminder of what they no longer can do without help. The machines are necessarily sensitive to restrictions, blockages and air, bleeping with alarm for patients unfamiliar to these sounds. There are studies in intensive care units that illustrate the effects noise levels may have on patients leading to sleep disturbance (Little et al, 2012; Elliot et al, 2013; Chahraoui et al, 2015), irritation and stress in turn affecting patient experience (Chahraoui et al, 2015) and outcomes (WHO, 2009) within intensive care. Florence Nightingale (1806, p485) noted

> “Unnecessary noise, then, is the most cruel absence of care…”

There is a difference between in patient in intensive care and those I interviewed where the latter had capacity and capability to intervene themselves to the source of such disturbance directly and indirectly. There were times that participants managed the alarm system embedded within each machine themselves by silencing the alarm once they recognised a pattern of action from those with the jurisdiction to do so (the RN). The alarm alerts staff to interruptions to the flow of fluid which some participants covertly switched off or silenced. In a previous era, before the mechanisation of IV fluid treatment, the RN would have been at the bedside administering the medications or staying close to the bedside carrying out other duties with one eye on the rate and flow of the fluid suggestive of indiscreet surveillance (Foucault, 1991). Machines may contribute to safety but have reduced the human contact and interaction from the equation that has potentially rendered the patient “responsible” for management of the alarm system. The patient silencing the alarms is in part contributing to this reduction of interaction but additionally may have implications for safety if they are not aware of what alarm they silence.

An alternative explanation may be that participants saw the alarming machine as a nuisance for staff repeatedly returning to the participant’s bedside. Not wanting to be associated with the demands this mechanical nuisance placed upon staff the participant took it upon themselves to silence the alarm. Others by way of contrast called for assistance sometimes responded to by the HCA. When one participant was dismissed as worrying too much over the alarms she was left with an array of feelings that was suggestive of a power imbalance later explored with Foucault's (1980) work on power and knowledge (section 6.5.10).

The concept of mechanised treatment has brought about a different dimension to the associated interactions, where staff may otherwise not have been present, an interaction dictated by the alarming machine and not the patient themselves. How staff respond in such circumstances is a point of consideration for organisations seeking to understand more fully the patient experience. In addition, patients silencing alarms is a consideration for the safety of such activity. Further exploration into this may help to understand more fully the patient motivations for such activity. In so doing this understanding may lead to policy and procedures that recognise and address safety initiatives for the future.

6.5.4 Reciprocity and Mutuality

Reciprocity and mutuality capture elements of the HCA and participant relationship that enhanced participants' relational experiences. Participants told of connectedness to the HCAs, who sat and chatted with them when they could. Gaining knowledge about the HCA that was beyond the immediate therapeutic interactions rebalanced the relationship and created a connection for the participant outside of this new social world. This effect has been identified by some researchers, who noted that for the development of a therapeutic relationship between nurse and patient there needs to be reciprocity with mutual sharing of information (May 1991; Morse 1991) described as the threads of commonality by Hagerty et al (1993).

Reciprocal behaviours are informed by the social rules, whereby individuals return a favour in kind through mutual exchange of benefits, a social norm that is universal but not necessarily performed with equity (Gouldner, 1960). He adds that such behaviours are not necessarily available to those who are incapacitated. Pound (2011) concurs, suggesting that within health and social care reciprocity may be difficult for some patients, resulting in a more imbalanced relationship that will in turn impact on self- efficacy, control and patient choice. She further suggests that, through skilful and creative communication on the part of the professional, this imbalance can be addressed.

There were times when there was evidence of a lack of reciprocity between HCA and participant which led to feelings of indebtedness to staff. Tokens of friendship and humour, may also have gone some way to addressing this indebtedness. As an example, tokens of friendship (e.g. chocolates) were occasionally exchanged between participants and staff, sometimes from participant to staff and at other times from staff to participant. The former of these assisted in participants' feelings of reciprocity, as they gave something back to the staff. The latter added to the depth of connection that participants felt towards staff, leaving lasting memories that were recalled nostalgically. It may also be suggested that feelings of indebtedness were linked to the performance of a good patient, compliant and uncomplaining (explored more fully in asking for help, section 6.6.5)

Reciprocal behaviours and moments of mutuality were important to participants and provided some way of explaining the different relationship the participants experienced with the HCA as compared to the RN. The latter sometimes being a relationship of distance in both physical and perhaps relational sense. The imbalance of such a relationship was described by one participant as a connection made only when the RN needed something from her with no opportunity to bring mutuality or reciprocity.

It may therefore be suggested that within the healthcare setting, interactions between patient and HCA have the potential to benefit from mutuality, and reciprocity adding to the notion of a balanced connection that in turn may impact upon patients' self- efficacy.

6.5.5 Care

Participants described care from two main perspectives, firstly the caring nature of the individual staff and secondly the care that they themselves experienced or that they observed others receiving. Care was therefore seen both as an individual behaviour and as a process. The delivery of care also engendered feelings of comfort for the participants. They particularly appreciated situations in which the care they received went further than their initial request through staff anticipating or considering a further unexpressed need. These interactions contributed to participants' sense of personhood and uniqueness as individuals, ultimately enhancing their transition to patienthood.

The literature on care is helpful in understanding both the physical and emotional responses that participants described in situations where there was comfort and consideration for them as individuals. The definition of 'care', however, remains elusive to both researcher and practitioner (Swanson, 1991; Bailey, 2009; Watson, 2009; Papastavrou et al, 2010). Participants in this study knew when they were in receipt of a positive experience of care and, conversely, when they or others were not. They did, however, find it difficult to identify individual components that constituted care or to articulate what these meant to them other than "feeling cared for".

Care is central to nursing in both practice and theory (Leininger, 1978: Watson,1990, 2005, 2009; Brewer and Watson, 2015), a consideration that has been more recently reemphasised within the 6Cs initiative (NHS England 2013a). Care, along with compassion, competence, courage, communication and commitment, is viewed as a valuable component of the patient experience (DH, 2012a; Smith, 2012).

Bailey (2009) explored a number of theoretical frameworks of care and caring that have developed from various ontological and epistemological positions. Bailey's (2009) study highlighted the diversity of these positions but did identify common themes such as the centrality of the patient and the importance of holism in care. A number of participants articulated how important it was to them to be treated as an individual, which serves to reinforce the need for patient centrality and holistic care.

Some theorists refer to '*the nurse'* within their works from a position of registration or licence (Gaut, 1986; Watson & Smith, 2002) but with other studies *'the nurse'* was not determinable as HCA or RN (Finch, 2008). This raises a number of questions as to how caring theories, measurement tools for care and caring and the nursing literature might relate to the HCA as a significant contributor to care of patients, or is there an assumption that care transcends all of nursing from the registrant to the assistant. To explore this complexity further, the patients' perspective is therefore helpful.

Papastavrou et al's (2010) systematic review of 23 quantitative studies that measured care and caring from the patient and RN perspective revealed a lack of congruence between the patient and the RN on aspects of care. Many of the studies emphasised that patients valued the RN's technical skills, along with the competence to carry out these skills. In contrast, the RNs themselves ranked the giving of psychological support and "comfort" as their first priority. Goffman's (1969) work concurred with these findings, suggesting that the visible tasks observed by patients were valued more highly by them than the non-technical skills and tasks, as discussed in performance in section 6.4.1 in this study. These findings suggest that there may be a disconnect between what the patient values as components of care and what the RN perceives as being of value. This area is therefore worthy of further inquiry, partly to ensure that patients' experiences and expectations are aligned but also to ensure that the patient/HCA care relationship is explored.

Finch (2008, p27) explored the caring behaviours of RNs within a dyadic relationship between nurse and patient using grounded theory. The caring behaviours demonstrated by the nurses that patients viewed as impacting positively on their wellbeing were as follows; *"Responding to the patients' needs", "doing the little things", "following through"* and *"taking care of the patients' needs"*. Smith (2012) has recognised the importance of "little things" to patients in her work. Recent work by Dr Kate Granger (NHS Confederation, 2014), who was both a healthcare professional and a long term patient, concurred as to the importance of the "little things" that help to make human connections. She additionally suggested that the "little things" bring balance to her perception of what is an often unbalanced relationship between patient and carer. A balanced relationship depends upon reciprocity addressed earlier (section 6.5.4) and power which will be explored later on in this chapter (section 6.5.7). Smith (2012) does however question the term “little” when such activity makes a significant contribution to patients’ sense of wellbeing. She suggests when positioned against the high tech interventions, they may appear insignificant and undervalued. The high profile work of the late Dr Kate Granger (NHS Federation, 2014) has the potential to reposition such little things within the wider context of clinical care.

Participants described feeling ‘cared for’ in a variety of situations and from a number of different circumstances. In some situations, they were vulnerable and unable to manage their own needs and in other situations they were more independent, although still able to recognise feelings of being cared for. This sense of feeling cared for was identified by the patients in Finch’s (2008) study as having positive effects on comfort, appetite and physical strength. The rationale for these positive effects can be explained by Watson’s (2005) work. She asserted that the patient who perceives they are receiving good care will be in receipt of a cascade effect of healing biochemical markers; decreased cortisol, increased oxytocin and increased IgA; which in turn will have a positive impact on the patient’s illness progression. In a review of psychoneuroimmunology (PSI) research, Halldorsdottir (2007; 2008) concurred, identifying that the immune response is positively impacted by a strong nurse- patient relationship. These findings (Watson, 2005; Halldorsdottir, 2007; 2008; Finch, 2008;) support the observation made in this study that participants noted both a physical and emotional dimension to the interactions they had with HCAs and the other staff.

Within this doctoral study, participants described examples of both positive and substandard care, either that they had received or that they had observed others receiving. It is important to therefore understand what effects both positive and substandard care can have on patients.

Halldorsdottir’s (1991) study placed five types of nurse-patient relationship into a ‘bio-nature’ continuum of outcomes ranging from caring to non-caring and also identified what each outcome related to in terms of feelings of being with another. The significance of Halldorsdottir's (1991) work was recognised by Watson (2005) where the professional carer has the potential to be destructive to the patient leading to physical, emotional and spiritual violation.

Box 3: Halldorsdottir's (1991, p38-39) continuum of nurse patient relationships

Type 1: Biocidic - life destroying (toxic, leading to anger, decreased well-being)

Type 2: Biostatic -life restraining (cold or treated as a nuisance)

Type 3: Biopassive- life neutral, (apathetic or detached)

Type 4: Bioactive- life sustaining (classic nurse-patient relationship as kind, concerned and benevolent)

Type 5: Biogenic –life giving (mutuality and interconnectedness, giving and receiving in the moment)

Halldorsdottir's (1991) work on the effects of caring and non- caring interactions shed light on the views articulated by participants. Swanson's (1999) meta- analysis of 130 empirical studies adds to this work suggesting that non caring outcomes for patients may result in fear, loss of control and helplessness where there may be a physiological result of decreased healing. For staff who undertake such non-caring activity they too are fearful, but hardened and potentially oblivious to their performance.

Some described a fear of being perceived as a nuisance that they possibly understood may result in being treated as such; a life restraining state (Halldorsdottir, 1991) that has implications for both their physical and emotional wellbeing. Negative and substandard care experiences have been described in the expectation section as being nested or buried within a positive narrative. There was one participant however who did describe feelings of anger towards staff he saw as not caring for a fellow patient a feeling which is evident within Halldorsdottir's (1991) Type 1 Biocidic state.

This anger did compel him to do something about this accessing the internal complaints system to rectify this situation. As already articulated many did not and became resigned to negative situations or else excused them.

Others, mainly long-term inpatients, recognised that they were in receipt of something special; a life-giving moment as described Type 5 Biogenic (Halldorsdottir, 1991). With an extended length of stay, these participants perhaps unsurprisingly articulated a much stronger sense of connectedness with staff than others. Positive experiences were narrated with a lightness of voice, often a smile and a degree of enthusiasm, indicating that these episodes were valuable to the participants and contributed to their patienthood, experience and wellbeing.

Associated with these positive experiences, participants described feelings and perceived relationships being brought into this new social world that would more usually be associated with their own family. One participant, who had been an inpatient for an eight-month period, evidenced this blurring of lines as she described feelings of “love” and “family” towards the nursing staff in general. Charmaz (1999) suggested that those with chronic illness may lose a sense of their inner and outer boundaries. For this particular participant, staff had performed their duties with such care and consideration that her feelings towards the staff appeared to transcend beyond mere appreciation towards love. Sacks (1984) suggested that those who are chronically ill see their world shrink; as their world shrinks, their frame of reference also shrinks. This ‘shrinkage’ appeared to have a physical, relational and geographical aspect for this participant, as her physical world was reduced not only in geographical terms but also in terms of those who visited. It can therefore be concluded that care staff became more important as these external frames of reference either shrink or potentially disappear for the longer term patient. Understanding more deeply how these patients’ length of stay is improved by relationships and connections with staff is therefore worthy of further research.

6.5.6 Humour

Participants described humour and humorous events as being important to them. Humour represented a part of their social identity that was effectively transferred from their other known world into the new world of patienthood, still very much part of their selves.

Humour and laughter are important aspects in the interactions of everyday life (Dean and Gregory, 2004; McCreaddie and Payne 2011; Haydon and van der Riet 2014) that has both psychological and physiological benefits, related to high self-esteem and overall psychological wellbeing (Martin et al, 2003). There are physiological benefits to laughter (Berk and Tan, 1996) that include lower serum cortisol and raised T-cells, both of which have the potential to positively impact upon raised stress levels. Additionally, increased release of endorphins such as dopamine may reduce depression, which is also likely to impact positively upon patients' wellbeing (Berk and Tan, 2006). The physiological and psychological benefits of humour and laughter for patients are therefore evident, particularly in situations where health and wellbeing are otherwise compromised.

Participants also saw humour as a conduit for making or cementing connections, both for themselves and for the HCA. The use of humour by HCAs contributed to participants' feelings of humanness and provided a connection back to their previous known selves; their patienthood effectively suspended as their known self was heightened. McCreaddie and Payne (2011) explored spontaneous, observed humour and employed multiple methods that included observation, interviews with patient focus groups and patients' interactions with clinical nurse specialists (CNS). They found that patients associated humour with a sense of self and suggested that humour was used by patients to help develop meaningful relationships.

There was also evidence (within this doctoral study) of how staff used humour to both diffuse and manage sensitive situations, previously noted by McCreaddie and Payne (2011), and to relieve tension, previously noted by Dean and Major (2008).

Lack of congruence between patients and staff with respect to the expectations and experiences of humour was noted by McCreaddie and Payne (2011), wherein the CNS may ‘miss’ the subtleties of patient driven humour and thus compromise their response. The same concern was identified earlier by Adamle et al (2008) and Dean and Major (2008). McCreaddie and Payne (2011) suggest the ‘miss’ may constitute a conscious strategy on the part of the CNS not to engage with such humour, which otherwise may be seen as a risk to ‘professional’ behaviour. This interpretation may also be related to some of the transactional behaviours noted by some participants that may have been impacted through a lack of engagement with humour. The humorous episodes that were described by participants, however, involved only HCAs, not RNs. Conclusions are difficult to draw from this as the research focus was on the patients’ relationship with the HCA, not the RN. One participant did allude to how she found it easier to connect with the HCAs than the RNs, describing how important these humorous connecting moments were to her.

Sumner (1990) suggested that older nurses may be more inclined to ‘take the risk’ of engaging in humour with patients, suggesting that experience may be a factor supporting the initiation and management of humorous interactions. If humour is perceived as a ‘risk’ to professional behaviours, it may be suggested that the HCA has opportunity to exploit the use of humour more readily than the RN due to their hierarchical position. Not everyone is conversant or comfortable with humour at all levels, however, and therefore general assumptions should not be made about the importance of humour in constructing meaningful connections.

It has further been suggested that humour plays a significant role in how patients establish their identity as individuals and within groups (McCreaddie and Payne, 2011). One particular participant placed significant value upon humour as a way of bringing the six-bedded bay together and ensuring everyone provided support to each other through the days. Pryor (2010) suggested that interactive humour between patients helps to build trust, friendship and peer support, which in turn will support those patients who are new to the healthcare environment. The participant went on to explain, however, that when a fellow patient did not engage with the humour, it led to tension between the patients within the bay and exclusion of the patient from subsequent episodes of humour.

Haydon and van der Riet (2014) noted that humour was more common in multiple bays, albeit their research was conducted with staff rather than patients. It is, however, difficult to draw conclusions or inferences from these findings as it is perhaps inevitable that larger groupings of patients (as would be found in six-bedded bays, for example) would experience greater numbers of social interactions, in which humour would play a part. It is interesting to note, however, that those participants who narrated many of the humorous stories were located within multiple-bedded bays.

The use of humour in the healthcare setting can therefore be seen partly as a way of generating feelings of reciprocity, together with reassurance that the investment made will be realised through good care. Humour can also be employed to reframe and reason through past events, bringing to them a greater sense of perspective and, in so doing, helping to manage future health episodes.

All of the studies referenced in this section researched humour from the perspective of the CNS, RN or patient and therefore did not specifically address the HCA. As discussed previously, there is a clear difference between the role positioning of the RN and the HCA in terms of hierarchy, access and availability for the patient, all of which are factors that may shape how humour is managed between HCA and patient.

6.5.7 The concept of power

The positioning of the HCA within the care staff hierarchy, and with respect to the role and experience of the patient, can be further explored through how power was perceived by the participants, both directly and more subtly. Within hierarchical environments, such as healthcare, there is a perspective that power relates to, or derives from, authority; it is exerted to bring about control over another; as articulated by Weber ‘s perspective of power that within healthcare can be seen as both ‘authoritarian’ and ‘legitimate’ as articulated in his work on bureaucracies (Weber, 1966)

Foucault (1980, p96), however, saw power as both positive and productive; he asserted that power can be understood as “capillary” in that it functions not from the perspective of possession of power or submission to power.

Power is considered from three perspectives in the discussion that now follows: the observation of patients by staff, the systems and processes that frame some of the activities and interpretation of the relationship between HCA and patient. Foucault’s (1991) work on disciplinary power is used throughout the discussion to provide insights, and Goffman’s (1969) work on roles and performance adds a further perspective when considering the potential effect of surveillance on the ‘backstage’ of the participants.

6.5.8 Power; observation and surveillance

Many participants were located in six-bedded bays, where doors opened out onto busy corridors used by staff who split their time between bays, single rooms and other ward areas. Within each bay, a thin curtain separated each patient. Patients were observed, sometimes covertly and at other times more overtly, from a window that ran alongside the bay into the main corridor of the ward.

I noted that as staff went about their work, they would often turn to look into the bay, either through the corridor window or through the doors into the bay. At times they caught the eye of individual patients and at other times they appeared to visually scan across all occupants of the bay. This corridor observation by staff was equally visible to all patients within the bay.

The observation[5] of patients by the staff in this context could be interpreted through Foucault’s (1991) work on the exercise of disciplinary power, in which he distinguished between indiscreet (overt) and discreet (covert) surveillance. Disciplinary power, as described by Foucault (1991, p177),

---

[5] *Observation: I have used “observation” to describe the direct activities performed by staff. Surveillance is used in context of the theoretical perspective of Foucault.*

“functions permanently and largely in silence”, it permeates and is self-sustaining. For disciplinary power to work, however, individuals need to be aware of its presence, which for this study required the observation of participants by staff to be visible to the participants themselves. The fact that this was the case may therefore have acted as a reminder to the participants’ of their patienthood status and containment within the healthcare system.

In Foucault’s (1991) work, the prisoners were incarcerated and unable to leave the confines of prison. Although the contemporary patient within secondary care is not incarcerated (with the exception of those detained under the MCA), for many their health status renders them unable to leave or remove themselves from the clinical area. This leaves them dependent upon staff and reliant on staff surveillance to ensure that their needs are met. As they are therefore ‘prisoners’ of sorts within the confines of the healthcare system, parallels can be drawn between Foucault’s (1991) work and the context of contemporary healthcare.

A behaviour noted from the participants’ narratives and direct observation was an approach the HCA (and other staff members) employed in ‘checking’ the wellbeing of patients collectively within the six-bedded bays. Staff did this by addressing the bay as a whole from the entrance: neither stepping in completely nor addressing each patient individually. Staff were therefore engaged in an overt or indiscreet form of surveillance, wherein participants were aware of the presence of staff whilst recognising that this presence was not specifically for them as individuals. Participants did not describe what these activities meant to them directly. They did however note times when they saw staff were busy dealing with others. These participant observations were met with different perspectives, some not wanting to interrupt activity they perceived as more important than their immediate need, to feeling a degree of comfort knowing care was being administered to those who needed it. These perspectives may be in part explained by Foucault’s (1991) work on docile bodies and Forbat et al’s (2008) suggestion of perceived comfort.

Foucault (1991, p135) argued that once subjects are aware of the gaze, they turn themselves into ‘docile subjects’ or ‘docile bodies’ that are compliant with the medical treatment. The ‘docile bodies’ may therefore not want to make nuisances of themselves in asking for help, particularly from the perspective of having a collective audience. Forbat et al (2008), by way of contrast, suggest that the medical gaze can be comforting if it is perceived by patients as monitoring their wellbeing and considering the things they are worried about, although the latter point would be difficult to achieve if only utilising a collective surveillance technique. It is therefore important to consider how observant the HCA is in noting the responses from patients within a collective surveillance check, as they will need to draw on heightened observational skills to gather individual meaning from this collective approach.

Observation of individual participants by staff was performed partly from the bedside; a direct and overt form of observation in which nursing and medical staff performed clinical observations, activities and monitoring of vital signs. One participant refused a continuation of medical surveillance in the form of repeated blood tests as the taking of blood samples had caused her physical pain, temporary deformity of her arms and considerable distress. Although it was in the participant’s power to take such a decision, she was left with an unnerving perception of tension between her and the medical staff that gradually undermined her sense of empowerment. The participant saw the situation as a battle between ‘them’ (the medical staff) and her. This battle, and the resultant perceived tension, could be interpreted through Foucault’s (1991) work as the disciplinary power of the medical system and the patients’ right for agency being brought into conflict. The participant’s interpretation of the situation may be explained by hierarchical patient-doctor roles, in which the patient feels it is not appropriate to question the medical instruction.

The HCA did not get involved in the decision making process with this participant but instead provided a listening ear once the participant had made her decision. The neutrality of the HCA was significant to the participant, who perhaps, as a result, felt her relationship with the HCA was not within this tension and therefore provided her with a welcome release. HCAs may therefore fulfil a valuable role as support for patients during such hierarchical challenges.

Another type of observation within a healthcare setting is the ‘directed care round’, also known as ‘intentional rounding’ or ‘comfort round’ (Harm Free Care, 2016). These ‘rounds’, which are performed by staff, are used to check individual patients’ comfort and requirements throughout the day and thus may address some of the limitations of collective surveillance techniques discussed earlier. The routine involved in these care rounds, and the consequent visibility of staff at certain times of the day, may provide reassurance to patients, as suggested by Forbat et al (2008).

Conversely, the HCA may be performing tasks and duties that the patient perceives as unnecessary but complies with due to the orders emanating from further up the nursing or medical hierarchy. This was articulated by one other participant who, although believing that the observations carried out by the HCA every four hours were unnecessary, was resigned to the process because the observations had been requested by the doctor and the medical staff “knew best”.

The capillary nature of power is compared by Foucault (1980, p98) to a netlike group of threads, wherein the individual situated in that network is not a target of the effects of power but instead is both agent and vehicle of power:

> *“Individuals are the vehicles of power and not its point of application.”*

A Foucauldian perspective therefore challenges the hierarchical perception of the HCA limited in their power. Through their acts of discreet, indiscreet collective and individual surveillance they are very much part of the vehicular network of power within healthcare. The implied medical dominance is difficult to resist when considering the examples of requested blood tests and observations for both patients and HCA and thus a Foucauldian perspective is somewhat limited in understanding how agency and structure are shaped in these circumstances.

Based on the observations discussed in this section, it is clear that the HCA undertakes a variety of forms of both discreet and indiscreet, near and far, observation, surveillance and monitoring of the patient. These observations may lead to the HCA identifying areas of concern with respect to the patients' health and wellbeing. A number of participants were aware of the jurisdictional limitations of the HCA in these situations, which implied that participants believed the HCA would report or escalate their concerns. In many cases the escalation point would be the RN. A number of participants described being generally less well connected with the RNs and therefore it can be argued that, through both indiscreet and discreet forms of hierarchical observation (Foucault, 1991), surveillance of patients by the RN often occurs through the eyes of the HCA. This perspective adds to what is already known around appropriate delegation of duties from RN to HCA, the competence of the HCA to undertake these duties and the resulting accountability (RCN, 2006). The triadic relationship between patient, HCA and RN is therefore of further consideration in its entirety to understand more fully the consequences of delegatory activity and the direct and indirect surveillance for all.

With respect to power through surveillance in general, it is also worth considering Goffman's (1969) work on role performance and, in particular, the nature of front and back stage regions. The successful performance of roles requires the actor to utilise two regions; a front, or public, region where there is social interaction and a back, or private, region where the actor (patient) is away from the public gaze (surveillance), can relax and be themselves to prepare for their next front region interaction (Goffman, 1969 p109).

If we acknowledge Foucault's view of surveillance and docile bodies within the context of secondary care as valid, the issue then arises as to where and when patients and staff have time or space for the backstage and what the implications are when this is not possible.

The patient environment often consists of a number of beds per bay, with lots of activity and little privacy, that mean retreat to the back stage may be somewhat limited. Although Goffman (1969, p115) does not specifically state the backstage activity as needing a geographical location away from the audience (merely stating a partition is sufficient), he describes the ‘worker’s’ position as requiring physical access to a space away from the public gaze. Within this study, the geographical layout of the clinical area provided a number of spaces for staff to retreat to in comparison to the patient, who was somewhat restricted. Staff were also able to return home each day (the ultimate back region from the public gaze) and could take breaks during the working day, although some work environments may be more challenging in this respect. Lewin and Reeves (2011) note that staff have other ‘back stage’ areas, for example the nurses station, where they may be able to relax their front region performance from time to time.

In considering the patient and their performance, therefore, it is necessary to identify where and, indeed, whether patients are able to retreat to the backstage: It is difficult, for example, to retreat backstage when a patient is physically unable to leave their bed or bed space. We should not assume that the bed space is necessarily a suitable location for their back stage activity. As a result of this inability to retreat into a backstage environment, patients may find themselves exhausted and in a state of heightened anxiety by having to put on a front stage performance throughout their patienthood. Alternatively, if they find the space to retreat backstage but that space happens to be still visible to the audience, they may inadvertently find themselves in a vulnerable and exposed position. It can be argued that neither of these situations lend themselves to rest and recovery for patients.

Provision for back stage space should therefore not only be considered for the workforce but also for those in receipt of care and assistance from others. Policy around visiting times (BBC, 2011d), protected meal times (DH, 2010) and ‘intentional rounding’ (Harm Free Care, 2016) adds to the complexity and difficulty of patients accessing some quiet retreating space, which has implications for HCAs and other care staff who are looking to support patients’ performance needs and to develop positive dyadic connections.

6.5.9 Power; systems and processes

Power was alluded to by some participants in their descriptions of the organisational and institutional systems that they felt were dehumanising but that they also felt powerless to change. For example, when staff referred to participants as bed numbers rather than as individuals, participants implied that their individual selves were lost and subsumed within the systems and processes of healthcare. Another example was the paperwork one HCA was expected to fill out as part of the admission process, which one participant saw as unnecessary and overly bureaucratic and generalising. Many participants experienced a sense of resignation when confronted with the sheer weight and volume of systems and processes, often coupled with an underlying sense of loss of self and frustration.

The identification of staff via a system of role specific uniforms has already been discussed (section 6.4.1) as a way in which participants worked out staff roles and responsibilities. As part of this identification process, the relationship between hierarchy and power was inferred by participants when they associated roles with the different coloured uniform. The use of staff uniforms therefore acted as an additional reminder for participants of the organisational and professional systems of hierarchy, as posited by Hertz (2007) when she traced the use of uniform as a symbol of status within the hierarchical authoritarian world of the military. It is interesting to note, however, that one participant was comforted when he saw hierarchical power abandoned by staff. The team working observed by this participant provided him with evidence that more senior staff were prepared to ‘muck in’ and undertake less demanding tasks, supporting each other when necessary.

The sometimes overwhelming presence of the systems and processes of healthcare can therefore be mitigated by the actions and interactions of staff in bringing human elements into this procedural world. The HCA and patient interactions are often performed with a backdrop of system and process, it could be argued that these interactions form a framework where the interactions are bound by roles, performances that could be limiting and restricting. There is however real potential for staff to resist the dominance of systemic power in some of the little things they do to recognise the patient's personal self and identity as they go about their work.

6.5.10 Power, knowledge and relationships

Participants described a tension between themselves and certain members of professional staff, wherein they took decisions related to their care that were contrary to the views of those professionals. This brought several of these participants into combative situations with staff, whereas others became more secretive as they managed these tensions by taking back control covertly. Yet others, by way of contrast, did not enter into combative or covert behaviours at all, instead resigning themselves to the belief that the professional knows best.

The issues of agency and power illustrated by these episodes related primarily to the medical staff, the RNs and the general organisation. There was, however, little or no mention of similar overt or covert conflicts arising with HCAs. This may suggest a reluctance on the part of the participants to impact negatively on their relationship with the HCAs, given their importance in meeting the immediate needs of the participants. It may also indicate that hierarchy and power have a part to play in how participants adapt and who they co-opt into their new social world to assist them in adapting to patienthood.

The power relinquished by patients to professionals is well documented in Parson's (1991) work, in which the patient is seen as a passive recipient of care that is provided by a knowledgeable other, in what could be described as a paternalistic situation. More contemporary researchers have recognised the difficulty in shifting from paternalism towards client engagement (Petriwskyj et al, 2014) and shared decision making (Heggland and Hauslen, 2013). The notion of paternalism is in direct conflict with policy around the centrality of the patient with respect to decision making (DH, 2012b) The idea of there being a 'more knowledgeable other' is also questionable in today's society, as the patient now has easy access to large amounts of health information from the internet. Forbat et al (2008) posited that, as a consequence of the availability of information regarding their conditions, patients have more scope for counter-surveillance by applying their new-found knowledge to inform and challenge their own, and others', beliefs.

A question remains, however, as to the potential for this new-found knowledge to be exercised within the professional-patient relationship more generally. To do so requires a repositioning of the traditional view of the knowledgeable other or knowledgeable professional. The concept of the informed patient can be interpreted through a Foucauldian perspective (Foucault, 1980), wherein power and knowledge are seen as not being fixed. This therefore requires practitioners to understand the effect that the availability of knowledge has on both their own practice and on their patients. Practitioners may also need to assist patients in repositioning themselves within this power construct, as opposed to passively accepting the primacy of the knowledgeable other.

The realignment of knowledge and power was illustrated when one participant stated how she and the RN had learnt something new about her procedure together through information that the RN had sourced from the internet. The participant described a sense of exclusivity from the shared moment, feeling 'special' and exceptional because the 'knowledgeable' nurse had not known something about her procedure. The resulting conversation and shared learning between RN and participant brought about a rebalance of power and knowledge to the relationship. This knowing and sharing of information therefore potentially produces a relationship that is less about traditional hierarchy but more about the individual within that particular situation. This situation serves to illustrate how, more generally, the HCA can support patients in their repositioning within a changed power and knowledge construct.

Participants asking for information outside of the HCA's jurisdiction (first described in the section on mistrust 6.3.8) will be explored further in the following section through the work of Foucault. In some situations, the participant asked for assistance from the HCA to act as a conduit for their requests when they were unsure who to ask. This may have arisen due to the high level of accessibility of the HCA for the participant and requires consideration along with the added dimension of the power that accrues from being a conduit.

Foucault (1980) suggests that power, truth and knowledge are important to consider together, as they influence and support each other and are thus inextricably woven. Power, according to Foucault (1991, p176-177), is not solely the preserve of those with a legitimate authority within an organisation but arises across a network where:

> *'its functioning is that of a network of relations from top to bottom… and laterally; this network 'holds' the whole together and traverses it in its entirety...'*

Therefore, from a Foucauldian perspective, the HCA has legitimate power that is forever shifting and therefore needs to be contextually situated. By reference to the example of participants using the HCA as a conduit to others, the HCA holds that information in the moment, deciding where this information should go to and using their contextual knowledge of the situation to inform them accordingly. Although participants would expect the HCA to pass on the information they have been provided with, the work of Spilsbury and Meyer (2005) when exploring role boundaries (page 224) suggested that information was sometimes withheld due to hierarchical, relational tensions. The Foucauldian perspective of knowledge and power as being capillary and network based, as opposed to strictly hierarchical, may help bring greater understanding of this aspect of the HCA-patient relationship. Shaller (2007) acknowledges the importance or free flowing accessible information for improved patient-centered care which in turn has the potential to improve the patient experience. By acknowledging the power that is held by the HCA in this communicative activity, there is the potential to identify how communication flow could be improved, notwithstanding the jurisdictional restrictions that exist within roles and responsibilities. I would therefore suggest that repositioning of conduit activity between patient and HCA within a non-hierarchical perspective could enhance the flow of information and knowledge improve patient centered care and the patient experience.

6.5.11 Summary

Throughout this section on meaningful connections, it could be concluded that the HCA is in a particularly strong position to make connections with patients through getting to know their individual selves. For this to be fully realised, there needs to be an appreciation of the unique relationship and interactions held within the HCA-patient dyad. There is opportunity for every interaction to have some meaning for the patient. Staff should be aware that working under extreme conditions may result in transactional activity and a consequent missed opportunity to connect with their patients as individuals.

It is important to understand and acknowledge the patients’ perspective on these issues to fully appreciate the elements of connection that have meaning to them. These include the physical and emotional dimensions of care and caring, the physiological and psychological benefits of humour and the importance of relationships in which there is reciprocity and mutuality.

Achieving this appreciation of the patients’ understanding may require a different perspectival view that recognises the power the HCA has in their relationships with patients: a view that that traditional perspectives may leave buried or difficult to access. By accessing and addressing this perspectival view, there is potential for the patient experience to be enhanced.

6.6 Core process 4: Adaptation to patienthood, developing the model

6.6.1 Adaptation

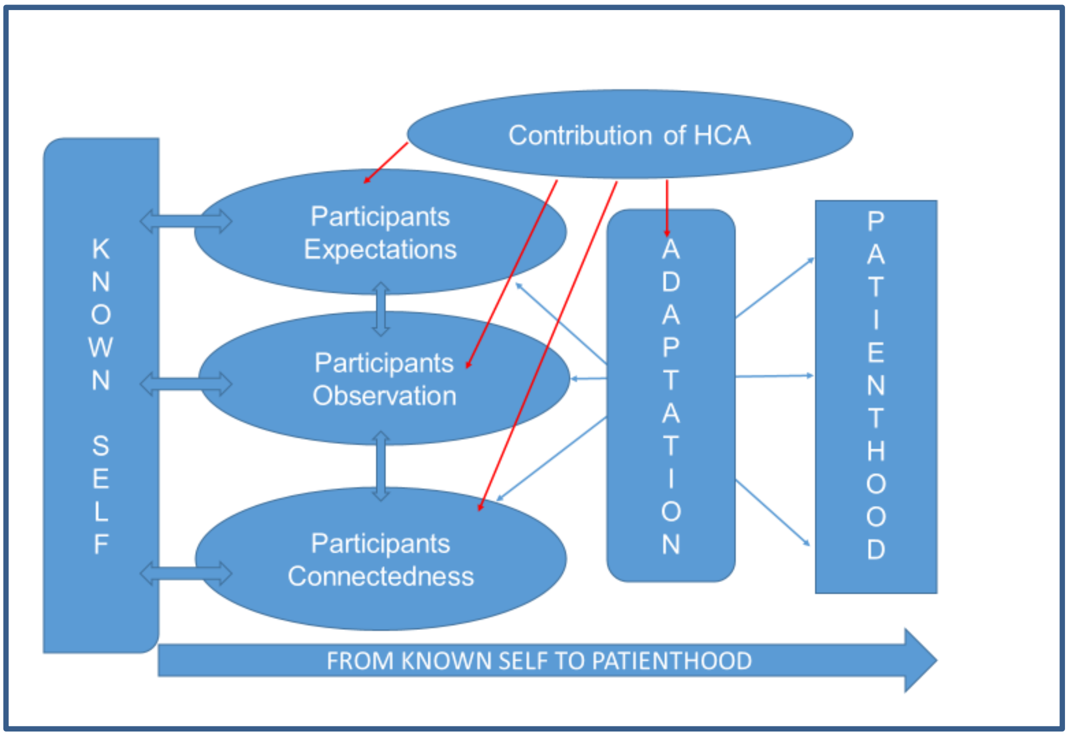
The concept of adaptation is described as an action or process (OED, 2016) whereby an individual adapts to a new environment, a physical space previously unknown to them or a new social situation that may be determined by cultural norms and expectations (Fulcher and Scott, 2007). It may be suggested that adaptation to a new environment is underpinned by an unconscious biological need for survival (Burgoon et al, 2007) that drives certain responses and behaviours. There are however tensions between biologists and sociologists in respect of behaviour as learnt or biologically determined (Fulcher and Scott, 2007). Taking a sociological perspective, adaptation is shaped and influenced by social structures of gender, ethnicity and class and additionally the social structures of organisations such as a hospital setting (Fulcher and Scott, 2007). Goffman's (1969) work has contributed to the concept of adaptation. He suggests how individuals may promote themselves in a favourable light (section 6.3.2), which may be recognised as adapting to a social situation as well as how participants adapted to the presence of a uniformed other (section 6.4.1, p 221). Additionally, Foucault's (1991) work suggests individuals may adapt and modify their behaviours through the covert and overt surveillance they are subjected to.

The core process (core process 4) of adaptation illustrates how participants adjusted their known self, learning new behaviours that were incorporated into their social identity as part of the world of patienthood. Participants described learning about this new social world through their own efforts and with the assistance of the HCA. Whenever participants observed something they were uncertain about, or that was of concern to them, it appeared that this resulted in a heightened state of vigilance. For some, this affected their relationships with other members of staff and how they saw themselves as patients. For others, negative experiences made them vigilant not only for themselves but also for friends and relatives who might become patients in the future. As they described this heightened state of vigilance, which was tiring and not necessarily conducive to rest and recuperation, there were references made to the relationships and interactions that had contributed to this state.

Adaptation also describes a mechanism through which prior expectations were modified: as participants observed and made sense of what they saw, they used this information to adapt to the new social world and to the role of patienthood. Connections with staff were also made through this process of adaptation as they learnt about their role as a patient.

The diagrammatical representation below (diagram 9) shows how these elements sit together, interact and are shaped by the HCA.

Diagram 9: The known self, transitioning toward patienthood through the facilitating and mechanistic process of adaptation.



Adaptation occurred when participants adjusted their known personal self to incorporate a new social identity, the need for which was driven by their current health and wellbeing status. Under this change there were times when the participants had little or no control of their known or adapting self and were therefore almost wholly reliant and dependent upon staff for their care needs. They still, however, needed to incorporate behaviours that were part of this new social world of patienthood. Adapting to a new environment entailed learning about the embedded social processes and norms, which were already known by staff and therefore acted as a point of difference between staff and participants potentially a reinforcement of Parsons (1991) work on the knowledgeable other addressed in the previous section of power, knowledge and relationships.

Participants described moments in which the HCA was there to assist in the adaptation process, supporting some participants towards actualisation and being there for them as they made difficult decisions. Participants also alluded to the healthcare organisation and systems that they perceived were more powerful than them, almost overwhelming their individual selves. They implied the feeling of the organisation being an impenetrable wall that they were powerless to resist or shift. For some this may have felt unnerving whereas others may have derived comfort from the solid, reliable nature of the systems. Participants trust in the system was addressed in part in the section 6.3.5 and Giddens (1990) work on faceless commitment page 217.

Participants occupied a healthcare social world where their ill health, condition or presentation was ‘worthy’ of treatment, investigation or monitoring. This legitimisation of their healthcare needs positioned them as patients, wherein acceptance of patienthood roles and responsibilities and adherence to rules was required of them as they navigated through the complexities of healthcare (Parsons, 1991). Friends, family, work and the pre-patienthood social fabric of participants was still very much part of them but became temporarily suspended; left behind for a period of time, which ranged from a few hours in outpatients to many days spent as an inpatient.

For some participants, there was an immediacy to their admission due to an unplanned and sudden emergency, whereas for others there was a more considered and planned approach that provided time for the participant to adjust in advance to the potentiality of patienthood. The context of patienthood was therefore different for each participant, depending partly on circumstances, contexts and timescales.

Additional insight from Parsons (1991) and Goffman (1969; 1986) each from differing sociological perspectives (Parsons being a functionalist and Goffman a symbolic interactionalist), is discussed below to support further understanding of the role of the patient and patienthood.

6.6.2 Patienthood, person centred care and personal identity

Participants’ personal identities played a part in their patienthood experience. They drew upon prior knowledge and experience from their known work and social world to help navigate the complexities of the new social world of patienthood, matching and cross referencing their current situation with what was known from their other social world. These moments of recollection were important to participants, as they used this narrative to tell me more about “who” they were. This suggests that the interpretation of their patient identity through the lens of their known social world was used to hold onto their known selves through the transition to patienthood. Goffman (1969) concurs with this observation and suggests that the individual does not just take the new situated role and leave his other selves behind but instead holds on to aspects of their other selves.

Holistic care that purports to consider the whole person through person centred care may well need to appreciate more fully the individual selves that are the elemental components of patienthood. ‘Knowing the patient’ is central to nursing practice to ensure patients’ needs are met (Bolster and Manias 2010; Suhonen et al 2010) and establishing a caring relationship (Gallant et al 2002; Macdonald 2008). There are however barriers for staff in getting to know the patient, with the RN claiming time is a contributing factor (Macdonald, 2008) and advancing technology coupled with the increase in short stay also contributing to this difficulty (Bundgaard et al, 2011). Staff therefore may need to adapt to their work environment to ensure holism and person centred care remains a fundamental aspect of care.

Failure on the part of healthcare staff to recognise the motivations behind, and display of, patienthood performance has the potential to undermine the process of transition, lengthening the liminal space and impacting negatively upon the patient experience. It is therefore incumbent on the carer including the HCA to gain deeper understanding of the individual their adjusting and adapting self for whom they are caring to support their transition to patienthood.

It may be suggested, however, that the HCA is in a unique position to adopt practices of person centred care as they are the member of staff most available to the patient (Keeney et al 2005; Hancock and Campbell 2006; Kessler et al, 2010). The dyadic relationship between patient and HCA is built upon frequency of interaction coupled with opportunity to get to know the patient as a person; their likes and dislikes, preferences, fears and concerns. This dyad has potentiality for empowerment and actualisation for the patient as they make decisions based on their known individual selves rather than their passive patient selves.

6.6.3 Patienthood in context

Participants occupied a variety of contextual positions during their patienthood. For some the transition between their known and patienthood selves was smooth, undertaken with a degree of unconscious control. When participants' known self was temporarily interrupted due to medication and anaesthetic interventions, some described being in a lonely place, in which there was little human contact and a perceived loss of control. Participants inferred that the loss of control gradually reduced as they recovered and started to take back some control of their known and patienthood selves. Throughout this process, some participants alluded to a liminality: a suspension of what was known and an attempt to make sense of the new. This liminal space was punctuated with episodes of interaction by staff, of which the HCA was most visible. This provided continuity, something to hold onto and thus a sense of reassurance. The liminality occupied by these participants provides an additional context for their articulated behaviours and understandings that allows insight into some of the influences upon their patienthood journey.

Goffman's (1986) work on frame analysis is helpful in understanding how we act the way we do in social situations. He stated that the social framework provides the individual with points of reference, consisting of social 'standards' that guide the individual in their ongoing actions. The way individuals behave depends upon their interpretation of frames of reference and is thus subjective. There are any number of frameworks that individuals may refer to within any situation. An individual's use of these frames is, however, subject to their engagement with, and aims of the individual in, any given situation, which illustrates that individuals do have agency over, or control of, their actions. The agency of the individual is, in itself, susceptible to change from the influence and engagement of others who may offer encouragement or threats. “Guided doings” (Goffman, 1986 p22) is the term used to describe such influence of others. The guided doings are therefore shaped by the ‘social appraisal’ being exercised by these others, in which value is assigned, in terms of social expectations, to the behaviours and actions of individuals. This explanation helps to illuminate the cognitive dissonance that some participants displayed in their narratives between belief and action. The participant who would not ask for help herself, but would suggest to future patients “not to put up with anything”, is an example of this disconnect. She was acting as a compliant patient, fearful of what the ‘social appraisal’ of her request for help may be in terms of being labelled as a difficult or demanding patient.

The known selves of patients are in a state of constant flux as they transition to patienthood. There are a number of influences, ranging from illness to medication and anaesthesia, that bring about this shifting state of their known selves. The space occupied whilst under these influences may be both liminal and temporal. The presence of the HCA at the bedside provides a constancy that supports the transition through this liminal space and mitigates the temporality, although continuity and consistency is not always achieved due to shift and work patterns. There must be consideration as to how the workforce maintains consistency and continuity as far as possible to ensure patients adapt to their new social world through the contribution of a stable workforce.

6.6.4 Resilience

Participants described learning about their new environment through their own efforts and with the assistance of the HCA. Whenever participants observed something they were uncertain about, or that was of concern to them, it appeared that this engendered a heightened state of vigilance. For some, negative experiences made them vigilant not only for themselves but also for friends and relatives who might become patients in the future. As participants described this heightened state of vigilance, they inferred that it left them feeling tired and stressed and was therefore not necessarily conducive to rest and recuperation.

From a sociological perspective, Pearlin (1989) suggested that a ‘stressful state’ cannot be viewed in isolation if it is to be fully understood. He posited that it is necessary to recognise the context within which the stressful state arises, which includes the social world and the relationships that exist within that world. Pearlin’s (1989) work analysed the role restructuring, and consequent stressors, that individuals faced when caring for a loved one who had become dependent, for example on visiting a family member when the family member had themselves become a patient. Some told of adapting their own life to fit in with the needs of their loved ones when those needs were not being met within the healthcare setting. This compensatory action was often recalled from a position where they felt there was no alternative but to meet their family member’s needs themselves. Pearlin (1989) suggests that this role restructuring can also bring about a state of vigilance. It could, however, be suggested that a vigilant response may also arise for patients when under stressors related to their own healthcare. Participants in this study who were under stress often became hyper-observant, attempting to manage their own needs in situations where they had the capacity and capability to do so, or seeking the assistance of others. These circumstances of hyper-observation and hyper-vigilance may go some way to explain the ‘frightened’ state of mind that was described by one particular participant.

It is therefore incumbent upon the entire care team to recognise such stressors, and the resultant vigilant behaviour that manifests itself, with a degree of inquiry into the causes rather than just acceptance. Additionally, if we accept that a heightened state of vigilance is related to stressors within the participant’s experience and social world, the psychological and biological impact on health and wellbeing in such circumstances needs to be recognised.

Other participants, however, did not describe a heightened sense of vigilance, instead approaching negative experiences with a degree of separation or temporality. These participants may have therefore employed a coping strategy, drawing upon their own resilience, whereas those describing heightened vigilance may not have had such resources to draw upon.

It is worth exploring how the construct of resilience and adversity impact upon the patient experience. Adversity, as defined in Hildon et al’s (2008) study, is located around the limitation of personal circumstances and opportunity brought about by restriction or loss in one’s physical, mental or social wellbeing. Admission to hospital following a diagnosis brings about such loss and limitation through disruption and curtailment of one’s day to day activity and thus is classed as an adverse event.

Alpers et al’s (2012) study interviewed six past ICU patients to elicit what factors contributed to a sense of inner strength, which as a concept is closely related to resilience. Relationships were identified as a key contributor, for which benefits ranged from the immediateness of their family to the professional relationships where they felt they were treated as an individual. Alpers et al (2012) also identified that the physical manifestation of recovery and being on the recovery trajectory were both important factors that supported inner strength. This latter point was illustrated in the deep meaningful connection between a highly dependent participant and an HCA at a point when the participant felt unable to go on. The encouragement offered by the HCA to this participant was during a time when there was little or no improvement in her health. The participant remembered these times the HCA spent with her as ‘life giving’ moments, implying that the meaningful relationship she described had the potential to contribute to her inner strength.

The existence, and anticipation, of routine can be associated with experiences of adversity and subsequent expressions of resilience. When the routine of the clinical area was well understood and anticipated by participants, they expressed feelings of comfort and reassurance. When, however, routine was disrupted (for a range of reasons), some participants coped with this disruption better than others. Hildon et al (2008) recruited participants from the Boyd-Orr cohort, (University of Bristol, no date) (age range 70-80 years) and, although they did not directly explore resilience within a healthcare setting, some parallels can be drawn from their work. They discussed the possibility that strict routine may offer a type of insulating factor for participants, bringing structure to their days that in turn provided a framework for social interaction. When this routine was disrupted, however, some participants experienced adversity. They concluded that within a healthcare setting, adversity coupled with an unstable routine may increase patient vulnerability. This vulnerability may also impact upon the heightened state of vigilance and hyper-observancy noted in the previous section which are all deleterious to patienthood.

Patients face adversity by the very nature of their patienthood but how they cope with and manage this adversity is related to their ability to harness inner strength or resilience, which itself is affected by environment, routine and relationships. The meaningful connections that can be established between HCA and patient therefore have great significance in increasing resilience and inner strength, which has the potential to enhance the experience of patients and their ability to manage their future health and interventions.

6.6.5 Asking for help

Participants described varying degrees of willingness in asking for help, with some being unconcerned about asking for help from any member of staff. Others, however, were fearful of being thought of as a nuisance but did not expand on what the perceived consequences of being labelled a nuisance would mean for them; merely referring to not wanting to be a nuisance. Some participants were aware of times when the clinical area was busy and thus supported staff by self-managing their requests for assistance and waiting for what they perceived to be a quieter time.

The subjugation of care needs in preference of presenting an agreeable persona may in part be explained and understood from the sociological perspective of labelling theories. Psychological theories of attachment may also help illuminate this phenomenon, however, it is beyond the scope of this study to critically analyse the psychological literature.

In understanding participants' fear of being perceived as a nuisance, labelling theory, in particular the work of Felicity Stockwell (1972), provides some insight. Stockwell (1972) studied the popular and unpopular patient from the perspective of the RN and proposed that nurses label patients as ‘popular’ or ‘unpopular’ based on criteria that may have been difficult, if not impossible, for the RNs to influence or redefine (social class, diagnosis). The binary notion of the concepts ‘good’ and ‘bad’, ‘popular’ and ‘unpopular’ may suggest the patient being ‘liked’ or ‘disliked’. In situations where there is little recourse to redefine oneself if labelled unfavourably, this has the effect of creating divisions between, and subjugating, individual patients. Stockwell’s (1972) study firmly placed the responsibility for, and outcomes from, labelling the patient within the nurse’s or professional’s domain. Those involved in patient care therefore need to consider the implications of projecting their views onto another, which may or may not have consequences both in terms of behaviour towards the patient and the behaviour of the patient themselves.

The labelling concept that emanates from labelling theory suggests those with power are able to construct a reality that has the potential to disadvantage those with less power. This disadvantaging of others has the potential to manifest itself as substandard care, although later works describe nurses’ awareness of these labels and the effort required to manage them so as not to subject the patient to inequity of care and treatment (Johnson and Webb, 1995).

Johnson and Webb (1995) suggest that, rather than categorising the patient in a binary manner, labels are more pluralistic and complex. They are subject to multiple interpretations at any one time and patients themselves may have a ‘patient career trajectory’ in terms of their popularity. The concept of patient career trajectory suggests that labelling does somehow influence and shape the behaviours of patients as they interact with staff. There has been little research exploring this from the patient perspective, which may indicate the difficulties in both design and ethical approval of such a study. Some insight is offered by Johnson and Webb’s (1995) ethnographic observation of nurse patient interactions in one inpatient ward, but the study only asked staff for their thoughts, which left the patients’ voices effectively silenced. The conclusions that can be drawn for this study are therefore rather more from the professional’s perspective, providing insight into how staff managed negative feelings towards some participants but lacking in depth of insight into the participants’ own perspectives. Questions therefore remain as to how the managed negative feelings of staff impact upon patients and what impact unmanaged negative feelings have for both staff and patient.

Some patients, fearful of being labelled a nuisance, may behave in ways that conflict with their true feelings or experiences. The participant who did not ask for pain relief overnight perceived her potential request for pain relief as being a demand that sat outside of her perceived compliant patient role.

If we accept that the social world of healthcare has established norms of behaviour, it follows that those with power have the capacity to unfavourably label those with less power. Conversely, they also have it within their power to consider how to redress the behaviours associated with this negative labelling.

Participants variously described “asking for help” or “pressing the bell”, two phrases that could be interpreted in quite distinct ways. Use of the phrase “asking for help” may have alluded to the fact there was someone available to hear the request and respond to help. By way of contrast, use of the phrase “pressing the bell” may suggest there was no one immediately available, which places a different context on the patient experience. It may be, for example, that pressing the bell reinforces the ‘absent carer’, indicating that staff are busy with things other than the patient.

The HCAs often told participants not to fear ‘pressing the bell’ for assistance, which made a connection with the participants through the distance that existed in the working day. Participants were still reluctant to ‘press the bell’, however, whereas the alternative perspective of ‘asking for help’ may have helped overcome their reluctance.

The process of intentional rounding (Harm Free Care, 2016) and the presence of staff add to their visibility and perceived availability within the clinical area, which has a consequent positive impact on the patient experience. This availability of staff to attend to needs in a timely way that avoids the patient having to recourse to the call bell is of significant value to patients, particularly if they are already fearful or reluctant to press the bell.

6.7 Summary

The output from this study indicates that the HCA is clearly assisting the patient through their patienthood and overall patient experience. The connections that patients form with the HCA make a significant contribution towards the patients' adaptation of their known self to patienthood. As patients adjust to this new social world, their known self is transitioning: a liminal state that may be present for a short intensive period of time or for longer, depending on circumstances. For those patients monitored and cared for within an OPD setting, their patienthood is somewhat disconnected and has no clear start and finish. This results in their known self being intermittently punctuated and interrupted as a result of visits to and from the clinical environment. The role of the HCA within OPD is therefore somewhat different to that of the HCA in the inpatient setting. This study, however, shows that there may be opportunity for development of the HCA role in both inpatient and OPD areas. This, in turn, could enhance how the HCAs understand and interact with patients in this setting, providing further support for patients in their journey of adaptation to patienthood.

Chapter 7 Conclusion

Chapter 7 Conclusion

7.1 Introduction

My research has explored the patients' perceptions and understandings of the role of the HCA. Within the literature review, I set out the context of the patient within secondary care and I reviewed the role of the HCA.

The methodological selection of grounded theory is an appropriate approach when little is known about a subject (Birks and Mills, 2011). Charmaz (2006, 2014) constructivist grounded theory acknowledges the co-construction between participant and researcher something I believed to be important in how the participants' narratives would be represented. In addition, constructivist grounded theory as a methodology was an approach that helped to capture multiple perspectives in an area where there had been little research, an approach that brought about depth as well as breadth.

The findings from the data analysis process were presented independently of the academic literature. This important decision helped to ensure that the participants' voices came through, acting as a point of demarcation between my first stage literature review and my subsequent return to theory and literature within the context of the discussion.

The discussion chapter drew upon a wide range of sociological and nursing literature, which supported the analysis and illuminated the findings taking them to another level of abstraction but also illustrated my development as a researcher. I have reflected in more detail later on in this chapter to further illustrate my academic development (section 7.5.3).

This conclusion chapter addresses the initial aim, objectives and question and whether these have been met. I then look at this research in light of existing knowledge that addresses issues around identification of staff, patient responsibility, seeking assistance, vigilance and resilience and relationships. Reframing issues addressed within the discussion chapter using an altered focus has enabled me to make suggestions for further research and to identify implications for policy, practice and education, all of which are summarised at the end of this chapter.

7.2 Recapitulation of purpose and findings

The aim of this study was to explore the role of the HCA from the patient perspective. I have achieved the overall aim of this research through the careful consideration and application of methodology, methods and data analysis. In line with inductive studies, the initial title developed and changed, led by the participants' stories.

The final title for the study is as follows:

> "Adaptation to patienthood: a grounded theory study on the contributions of Healthcare Assistants towards the patient experience."

The final objectives for this study are as follows:

1. To investigate and describe what the patient conceptualises as the role of the HCA.
2. To develop an understanding of what influenced these concepts.
3. To gain an understanding of the interactions between HCA and patient.
4. To explore the meanings of these interactions for patients.

I acknowledge that these objectives are broad and the rationale for this was to ensure that the participants had the opportunity to narrate what was important to them, whilst ensuring that the research remained within the overall frame of inquiry. A brief summary of achievement for these objectives follows.

7.2.1 Objectives 1 and 2

The conceptualisation of the HCA role did not lead to a consensus across all participants. Whilst some knew or had worked out who the HCA was, others were either unsure or unconcerned. Participants who were motivated to find out used a variety of techniques to work out who was who. These included the association of tasks with roles, one such task being the administration of medication.

Some saw the HCA role as providing assistance to the RN. It was often noted that the RN was less available to participants but conversely was perceived as undertaking more ‘important’ tasks than the HCA, something that has been observed previously (Kessler et al, 2010). The perception of more important tasks implies participants in this study and those in Kessler et al’s (2010) see the bedside care they are in receipt of as less important than the duties performed by the RN.

Future research may help to understand this more fully and in so doing there is opportunity to reposition direct patient care as having equal importance to ‘other’ tasks. There may be positive benefits for such repositioning whereby the patient who is reluctant to ask for help or assistance may be more inclined to value their needs against what is perceived as more important.

Participants’ expectations, which were often shaped by previous experience within healthcare, helped to inform some of these understandings. Some of these prior experiences had been negative and yet despite this, participants reported a largely positive overall narrative. Participants appeared to distance themselves from these negative experiences, burying them within a positive narrative that evidenced an ‘investment’ in their immediate and future relationships with the HCA and with staff more generally. Future research into patients’ perspective on care and elements of their experience need to consider appropriate methodologies and methods that capture the negative narrative which in turn will inform policy and practice for a greater patient experience.

These findings suggest that the HCA is in a unique position, to orientate the patients with respect to ‘who does what’ as they transition into the world of patienthood.

7.2.2 Objectives 3 and 4

The descriptions that participants gave of their interactions with the HCAs appeared to range between highly transactional and highly transformational. Transactional, task-driven interactions provided the participants with little meaning and therefore represented a missed opportunity for the HCA to get to know them as individuals. The transformational interactions, by way of contrast, were greatly appreciated by participants and provided moments of connection that had a lasting positive impact upon their patienthood.

Trust as a concept contributed to the relationships participants developed with the HCA often through an experience; a tangible something they could relate to. The ability of the HCA to put some participants at their ease alluded to an immediacy of a therapeutic relationship as described by (Hagerty and Patusky, 2003). However, others built up their relationships over time as they based these on sequential interactions that developed trust. Proximity, as described by Frederiksen (2012) of the HCA had the potential to bring about an immediacy in the relationship that was of benefit to some participants who described dependency and reliance on the HCA.

The mechanisation of some nursing tasks has brought the patient closer to the HCA through an increased number of interactions they are engaged in. They deliver much of the bedside care and they monitor patients’ vital signs, all opportunities for the HCA to add transformational activity to what is sometimes less individualised and more transactional.

Transformational interactions were described as moments when there was exclusivity between the HCA and participant, attention for them as an individual. Reciprocal and mutual behaviours also contributed to participants’ appreciation of transformational interactions as they described the importance of humour and tokens of friendship that added to a sense their known self within the context of patienthood. Collective interactions were carried out at times when it was noted there was a loss of exclusivity, not an opportunity for participants to raise concerns but assisted the HCA in their observation of participants, a behaviour that is described by Foucault (1991) as indiscreet surveillance.

As the findings and subsequent discussion suggest, the contribution of the HCA to patienthood can be transformative for the patient experience and may be significantly under-presented and under-researched within the existing literature. This is part of the original contribution of this doctoral study.

7.3 Implications

This section of the conclusion draws on the discussion chapter which illustrated the relationship of this study to the pre-existing literature and thus will present new knowledge and insights. It also addresses the implications for further research, policy, education and practice. A summary of suggestions and recommendations for each of these areas is located at the end of this chapter (section 7.4).

7.3.1 Identification

The accepted doctrine within healthcare of the importance of uniform as an identifier of roles and responsibilities suggests patients and staff are equally concerned about the differentiation of roles. The findings of this study, however, indicate that some participants were unconcerned with identifying roles, instead viewing the care staff as a single, homogenous group. For those participants wanting to identify roles, doing so through uniform can be challenging (Kessler et al, 2010). Participants often constructed role knowledge through association with tasks undertaken by the HCA, which implies they did not rely on uniform as a role identifier. The introduction of the new Nurse Associate (NuA) role (NHS HEE, 2016) will add an additional layer of uniform that may be colour coded to sit within or outside of the ‘registered nurse’ family. The choice of colour therefore needs careful consideration, both for the symbolic message it has the potential to send in terms of reinforcing hierarchy and for the positioning of the role within the nursing family.

7.3.2 Patient responsibility

The fact that patients are often provided with an explanation of roles and uniforms at the point of admission implies that the information is required in order that patients can conduct themselves accordingly; in effect, forming part of their ‘responsibility’ as a patient. The notion of responsibility is taken up by Parsons (1991) who suggests the ‘sick’ person is exempted for responsibility of his presenting state but needs to take responsibility to get out of the sick state. This latter position of responsibility for patients in getting themselves well combined with responsibility to know who is who and perform their patient responsibility accordingly appears to place emphasis on the patient getting and holding onto this knowledge to support their patient experience.

It is, however, questionable as to whether this knowledge supports the patient experience or should even be necessary to make the healthcare system work. This approach is particularly questionable in situations where the patient journey is fast paced and changing; a situation that allows for little time or resource for the patient to adjust and adapt to a new social world. I therefore question the notion of patient responsibility and suggest that further research is required to gain depth of understanding about the interplay between uniform as a role identifier, the implicit knowledge of roles and the responsibility that this brings to the patient and the benefits of such knowledge. The patient journey differs across healthcare disciplines (e.g. day case surgery as compared to management of long stay patient) and it is further suggested that research into the responsibilities of patienthood are therefore contextualised for the individual patient journey within each discipline.

At an organisational level there needs to be consideration for patient responsibility that is embedded within the patient journey. This would need to be with an appreciation of the variation across disciplines that would make a blanket approach difficult and inappropriate. Education and training to support the HCA (as well as the whole workforce) in appreciation of the contextualised patient experience and the inherent patient responsibility that is embedded within each patient journey would help to develop greater understanding of and thus an improved patient experience.

7.3.3 Seeking assistance and implications

This study brings insight into how and why patients seek help and assistance from the HCA as the carer that is most available to them and as a conduit for their requests for help and assistance. Some of the help and assistance requested may fall outside the HCA’s role jurisdiction, which illustrates the relational dimension and mutual dependence between patient, HCA and RN. The patients’ perspective of this inter-relationship and dependency requires further research that has the potential to add depth to what may be an important patient safety issue. Patient safety remains a key agenda item for the NHS (NHS Improvement, 2016b) following The Mid Staffordshire Public Inquiry (MSPI, 2013) and Keogh Review (NHS, 2013) where the implications for the HCA role included continuing debate around registration (Cavendish, 2013; MSPI, 2013; RCN 2007b; NMC 2006; UNISON, 2013) and commencing a care certificate for the HCA role (NHS Employers, 2015) emphasising safe and compassionate care.

There may also be an opportunity to explore the development of the HCA role beyond traditional roles and responsibilities to understand what this might contribute to the patient journey and experience. A note of caution is that the driver for such an initiative should be patient outcomes and not the fiscal demands for delivery of healthcare.

A Foucauldian lens may help refocus and reframe practices of observation and surveillance that have the potential to impact upon the HCA/Patient relationship. At the same time, applying this lens to the hierarchical relationship and flow of communication between RN and HCA may add understanding to the narrative around patient safety. This proposed future research may underpin policy development that further recognises the jurisdictional limitations of the HCA and the impact this may have upon their work, which could help to ensure patient safety is not compromised.

The process of interpreting and re-framing the patients’ narratives around their experiences and observations provides opportunities for service development, role development and service provision that go beyond a merely hierarchical and jurisdictional view of staff within healthcare. This would open up the debate for rethinking the patient journey in terms of their needs, rather than the needs of staff and professions. This refocus may also help bring greater insight as to why some patients are reluctant to ask for help or assistance.

If the HCA’s position is viewed through a hierarchical lens, it runs the risk of their voice and perspective being drowned out by the professional narrative that has more direct access to policy makers and senior management (Waring and Bishop, 2010; Martin et al, 2015;). Additionally, opportunities to capture the patients’ voice will be lost if research does not seek to gain a greater understanding of the unique narrative between patient and HCA. It is therefore proposed that, for the voices of both patient and HCA to be heard, the relationship should be explored from the perspective of both participants within this dyad having agency and power that is actualised and not merely referenced. Education and development for HCAs that helps in understanding roles and performance, and the impact this has upon relationships with patients, would add value to the patient experience.

7.3.4 Vigilance and resilience

The relationship between trust, mistrust and vigilance was identified in this study with observations made around the potential for the HCA contributing to resilience for some participants as they faced adversity.

For some participants a heightened state of vigilance was as a result of observing or experiencing something that caused them concern. They then took on the responsibility of managing themselves through these episodes where they could. For some occupying a liminal state there was no such management as they then had to trust in the individual, somewhat mitigated by their trust and faith in the NHS and organisation as a whole. The relationship between organisational trust that transcends towards the individual was noted by Giddens (1990) “faceless commitment” and the trust in regulated organisations as described by Fuglsang and Jagd (2015).

Personal resilience was inferred by some participants as they described how they managed adversity. The contribution the HCA made was both subtle and obvious where the literature notes professional relationships contribute to inner strength in adverse situations Alpers et al (2012) and where routine may also contribute (Hildon et al, 2008). This latter point may be further supported by the comfort alluded to in Forbat et al's (2008) understanding that surveillance (Foucault, 1991) in the form of the routine observation of the patient through the directed care rounds may provide reassurance to patients. These rounds do however need to be meaningful if they are to reach the full potential of increased connection for the patient and the possibility of increasing patients inner strength.

7.3.5 Patients relationships with staff

Patients commence their patienthood journeys with expectations informed by their own past experiences or by the media and the NHS's place within the general public's awareness. With respect to this study, it was anticipated that such exposure would influence some of the participants' expected relationships with staff. The narratives suggested that personal experiences appeared to shape their expectations rather more than media reports. Consideration should be given to undertaking critical analysis of the discourse pertaining to this subject area in order to fully illuminate the effect of the media narrative on patient expectations.

Humour and care were additional concepts that led to significant findings within the research, offering a unique insight into the meaning of these concepts for patients in terms of their relationship and interactions with HCAs.

The use of humour was valued by participants as part of their known selves. They identified interactions where there were humorous moments between them and the HCA. The interactions initiated by the HCA may have possibly been employed by them knowingly or unknowingly to reframe events, disguising messages that may have otherwise been difficult for them to impart. What my study has illustrated is there was a significant contribution made by the HCA in humorous interactions. What may be concluded was the value of and contribution to the patients known self in these humorous interactions with the HCA. Further research into the use of humour between patient and HCA within a dyadic relationship would illuminate an important dimension of care as articulated by the participants in this study and help to provide guidance for staff who may be concerned about the professional implications where humour may not have been employed as part of their professional role.

The care and consideration the HCA showed the participants was also valued and ranged from short interactive moments meeting the immediate needs of participants to the investment of a great deal of time for those participants who were in hospital for longer. The transformative interactions went beyond care and compassion as detailed in the 6Cs (NHS England 2013a) as there was real consideration for the participants as individuals. These considerate transformational moments sometimes transcended into the HCAs' own private space as they brought tokens from the outside world to those unable to access them for themselves. The 6Cs (NHS England 2013a) does not include consideration in the strategy which I would suggest is an important element of care, arguably related to care and compassion but more specific in the relationship to the care and compassion for the individual. This omission adds to the complexity of the nurse-patient interaction that initiatives like the 6Cs will not necessarily address (Baillie, 2015). Further work on how consideration for the individual patient can be brought into healthcare where there is emphasis upon reduced length of stay and improved day case surgery where opportunity for consideration for the individual may be compromised.

The findings were in part supported by the nursing and sociological literature. There was little or no reference within the literature, however, to the unique relationship between HCA and patient as much of the literature only referenced the RN. This observation suggests that further research is needed to address each of these concepts, (that include humour, care, resilience, trust) which should not only be from the perspective of the dyadic HCA-patient relationship but should also incorporate relationships between the HCA and the RN. Such research would be expected to add to the existing breadth and depth of knowledge of the patient experience. Including both HCA and RN within future research would ensure that it captures these significant relationships that constitute much of the patient experience. As such, policy direction will avoid a skewed, non-inclusive understanding.

The contribution of the HCA to patienthood is an area of healthcare that has had little attention from the nursing research community. More specifically, there remains a paucity of research on the patient experience with the HCA, in terms of relationships and connections, and how these past experiences may set expectations for their future healthcare needs. This doctoral thesis helps begin to fill that void, adding original work to the existing body of literature.

7.4 Summary of suggestions

In summary suggestions for research, practice, education and policy are outlined as follows:

7.4.1 Research

Further research into the reluctance of some patients to ask for help is suggested. There is recognition that such research may require a creative ethical approval approach and organisations may have reservations about such study from a reputation issue. The ethical approval process for patient participation is complex (Lincoln 2005 p166) and often seen as difficult to achieve within a specific period of study. Lincoln (2005 p167) also notes there is a wave of conservatism within ethical review boards that may see some qualitative methodological approaches questioned as to their support of evidence based research. The challenge for the researcher is how to navigate such difficulties in order to reach and capture the patient narrative. The consequences of not gaining a deeper understanding of ‘asking for help’ for example from the patients’ perspective leaves a rather one-sided perception making policy and practice improvement problematic. Additionally, research that seeks to understand this type of behaviour may be best served with a multi-disciplinary approach which addresses the psychological aspect as well as the sociological.

The relationship and interactions between HCA and patient influences and shapes the patient experience. There needs to be a greater appreciation of the triadic relationship between RN, HCA and patients to ensure a more holistic and systematic understanding of the interplay and interactions within this group that will impact upon practice.

A Foucauldian lens for research that explores the restrictions and limitations of roles and responsibilities for the HCA (and indeed others) may provide an opportunity to redesign some roles that meet patients’ requirements as opposed to jurisdictional limitations of roles and responsibilities.

Studies that seek to explore the patients’ perceptions and experiences must make consideration for the methodological approach that will address the articulated positive narrative that potentially buries the negative. Patient interviews are complex and the ethical approval process adds to this complexity. This study sought responses from participants that were over the age of 18 and had capacity. There is clearly a need to explore further the patient perceptions of the HCA that is inclusive of all patients to gain a full and complete understanding however challenging ethical approval of such a study may be.

7.4.2 Practice

There are implications for practice from research that explores issues such as asking for help, boundary working, the triadic relationship between RN, HCA and patient and role redesign, all of which have the potential to enhance the patient experience.

The dyadic relationship between HCA and patient, however, is little understood or recognised, in as much as the narrative is often missed or not captured. This missed opportunity prevents the narrative reaching the board from the ward and, as such, silences the significance of the contribution made by the HCA to the patient experience. Through realigning and adjusting communication routes, this missing narrative could be captured, bringing a more holistic view of the patient experience to board level and contributing to the organisational decisions made.

Incorporating the HCA within the nursing family is not without controversy. The introduction of the HCA role was perceived as a ‘loss’ to the RN role and ‘devaluing basic care’ (Spilsbury and Meyer, 2005), with the HCA role also contributing to the discourse on skill mix (Lankshear et al, 2005; Kane et al 2007; Shuldham et al 2009; Ball et al 2013; Schreuders et al, 2014; Griffiths et al 2015; Twigg et al, 2015). These issues have the potential to bring tensions into the workplace, wherein difference, difficulties and separation are not conducive to holistic to team working. It may be suggested that, where opportunity permits, the uniform colour may visually contribute to the inclusion of the HCA role within the nursing family if stratified within the RN uniform colour.

There are patient safety issues around boundary working, wherein clarity around roles and responsibilities needs to be embedded within both policy and practice. There also needs to be greater recognition of boundary working contributing to role shift, which then becomes accepted practice over time if left unchallenged. Organisations that understand this phenomenon may also see these areas as potential opportunities for role development. If boundary working is to be seen as an opportunity, there needs to be greater transparency around such activity resulting in controlled role development, which will reduce the risk for patient safety.

7.4.3 Education

The HCA is an immediate and constant contact for patients and often provides the first point of contact for many patients entering healthcare. The HCA’s demeanour, manner and appearance in which these expectations are anticipated, understood and managed will offer patients an immediate point of reference that will shape their ongoing experience within healthcare. A point of consideration for employers seeking to improve the patient experience may be to further invest in the HCA workforce which often sits outside of workforce development training.

Initial and ongoing education and training to support the HCA is essential. There is an opportunity to use less traditional methods of training and education that have the potential to assist the HCA in recognising the subtleties of patient behaviours. These methods include simulation and forum theatre that may support more interactive learning.

7.4.4 Policy

It could be argued that ignoring or not acknowledging the HCA within policy development results in a large part of the patient experience not being considered. It remains incumbent on all policy makers, therefore, to include the HCA and make specific provision for this large workforce if the holistic care and treatment of patients is to be properly considered.

Patients’ centrality in healthcare is a principle that requires policy makers to recognise the data from which policy is generated. The reduction of patients’ views through the use of quantitative survey and binary questions will not necessarily capture the breadth of views and perceptions provided by richer narrative data. There needs to be recognition that all forms of inquiry offer certain insights into the patients’ perceptions, understandings and views and policy therefore needs to be based upon the most appropriate data that informs such areas.

Uniform policy at a local and national level that addresses the HCA and the new Nurse Associate role as part of the nursing family would contribute to the visual representation of the nursing workforce at every level. This approach would not only benefit the patient in working out who is who but would also support the inclusion of HCAs themselves within the holistic provision of nursing care.

Boundary working has the potential to contribute to role development, however, policy needs to address the potential impact and implications of such in terms of patient safety and delegatory responsibility.

7.5 Limitations and lessons learnt

The limitations of using grounded theory have been discussed within the methodology chapter and thus this section will detail limitations that relate to the process as a whole and will also include data collection and data analysis.

As an early career researcher each stage was a new experience where reflection and reflexivity provided the necessary impetus to seek personal and professional improvement as the journey proceeded. This personal and professional improvement was assisted through supervision and attending regular grounded theory interest group meetings that provided peer challenges that were valuable for the early career researcher and also provided opportunity to reciprocate for those earlier on in their research journey as my research journey progressed.

The scope, time and design limitations of this doctoral study meant the research focus was the patient within secondary care and not the HCA or other healthcare professionals or from a context of social care. This decision allowed for a greater depth and analysis of the patient data that otherwise would not have been given. It is of consideration that future research in this area would benefit from a dual approach to seek further understanding of the dynamic between patient and HCA across many settings.

When writing up this study there were areas noted that could have been explored further in the interviews that may have added breadth to the area under study. A pragmatic view was taken at the time and considered with reference to the interview guide, aims and objectives of the study. Pursuing a greater breadth would not have altered the thesis but potentially provide an opportunity for further research.

The methodological approach of this research was not designed to meet issues relating to transferability of the findings, however I have attempted to bring depth and rich description through contextualising the findings. This approach was taken with understanding the reader may see areas of practice they too recognise and thus provide opportunity to prompt further thought and inquiry.

The demographic of the participants is representative of a predominantly white population. Despite numerous attempts to recruit greater number of participants from diverse ethnicities this did not happen. This limitation therefore does impact on the potential of wider narratives that could have informed more widely.

7.5.1 Problems arising during the research

The redesign of the feedback session was one such problematical issue which is detailed in appendix 12a.

The use of reflective journaling, and reflexive practice were essential skills in managing problems and issues which in turn ensured this research journey was completed within the timescale set.

7.5.2 Responses from presenting this work.

Presentation of this work at a number of conferences has provided me with a critical audience that has enabled me to reappraise and rethink in ways that otherwise would have been absent from this academic trajectory.

The RCN conference in April 2015 provided me with further thoughts around how I continue to apply Clarke’s (2005) work generally in my reflexive practice and more specifically during data collection and analysis. There was a wide and varied debate about the value of such recordings in cartographic form. This presentation was well received with suggestion that the novice researcher would find such an approach helpful in recording their thoughts and developments in their doctoral studies. I anticipate taking forward the concept of capturing these episodes with cartographic representation in my own academic career and sharing with others through further development of a grounded theory interest group and whilst mentoring and supervising other students.

The RCN conference in April 2016 provided me with additional perspective on the contemporary patient within secondary care. One member of the audience a nurse researcher herself said:

> “*you really don’t know what it’s like (to be a patient) unless you have been there*.”

This gave me a moment of reflection as I had not been a patient myself but had most recently provided nursing care in a professional capacity and more personally for a close family member. This comment provided me with further momentum and determination to continue to represent the patients voice to the best of my ability in this research.

Both conferences and my poster presentations at International Qualitative Methods research conference in May 2015 allowed me the perspective of positioning my research within a national and international network. Seeing where there were gaps and areas for additional work.

7.5.3 Autobiographical reflections.

In this section I will offer my reflections on my personal research journey from the start. Illustrating this throughout will be “live” memos that help to show how and what I reflected upon.

It is pertinent at this point to note within the reflexivity section I note the subtle difference between reflection and reflexivity and within chapter 4 section 4.7 describe the cartographic mechanics of reflexivity.

A three-year full time PhD was not going to be without significant challenges. I wondered how I would manage full time study and commit to academia without the loss of some of my clinical and managerial skills. I felt that these skills were held solely within practice. This loss was a concern and I identified a tension within me that recognised there was going to be a point where I felt vulnerable. This vulnerability was about me acknowledging there was much to learn and I was for once not the expert, vulnerable for where a further career in academia would lead to and would this PhD equip me in that journey. There was also vulnerability as my clinical career had become very much part of my social identity as I left that behind.

To manage this loss, I engaged with wider academic activity, setting up a Grounded Theory interest group, teaching on the undergraduate nurse education programme and working on the nurse bank as a relief registered nurse as and when I could. In addition, as already detailed I attended and presented at conferences, applied and was successful in achieving the RCN early career researcher post. I was also nominated and shortlisted for the Student Nursing Times Post Graduate Learner of the year award 2016. As I now reflect upon this variety of activities and achievements I am mindful of the academic growth that has now enriched my potential future career becoming part of me as I am reaching the end of my three years.

I started this journey late summer 2013 having read Aitchison and Mowbray (2013) and Carter et al (2013) sent to me by my MSc supervisor who was instrumental in getting me to even consider undertaking a PhD. These authors suggested that once a period of study starts there are changes in relationships outside of the academic community that occur. I recognise the change in myself, my beliefs, my perceptions and my criticality and I reflect. I reflect frequently on how best to manage this change as I am now emerging as someone quite different in the eyes of those around me. I have since re-read and concur with much of what was suggested by the authors and have embraced this transformational development never once wanting to squeeze myself back to where I was.

I am incredibly lucky to have an immediate supportive family that have laughed, cried and giggled with me over these last 3 years. There are others however for which this has been difficult and I acknowledge this and try to manage these difficulties as best I can for those who I love and care for.

References

Abbott, A. (1988) *The system of professions: an essay on the division of expert labour*. Chicago: University of Chicago Press

Adamle, K.N. Ludwick, R. Zeller, R. Winchell, J. (2008) Oncology nurses' response to patient-initiated humour. *Cancer Nursing.* 31(6) E1-E9.

Aitchison, C. Mowbray, S. (2013) Doctoral women. Managing emotions, managing doctoral studies. *Teaching in Higher Education.*

Alcon and Topping (2009) Registered nurse' attitudes towards the role of the healthcare assistant. *Nursing Standard*. 23(42) p39-45

Allied Health Solutions (no date) Pre-nursing degree care experience evaluation
Available at:
https://hee.nhs.uk/sites/default/files/documents/Pre-nursing%20degree%20evalutaion.pdf
Accessed on 22.8.16

Allen, D. (2004) Ethnomethodological Insights into Insider-Outsider Relationships in Nursing. *Nursing Inquiry.* 11(1) p14-24

Allen, D. (2001) *The changing shape of nursing practice*. London: Routledge.

Allsop, J. Mulchay, L. (1995) Dealing with clinical complaints. *Quality in Healthcare.* 4. p135-143

Alpers, L.M. Helseth, S. Bergbom, I. (2012) Experiences of inner strength in critically ill patients- A hermeneutical approach. *Intensive and Critical Care Nursing.* 28 p150-158

Alvesson, M. (2002) *Postmodernism and social research*. Buckingham: Open University Press.

Alvesson, M. Sköldberg, K (2009) *Reflexive methodology. New vistas for qualitative research*. (2nd edn). Los Angeles: Sage.

Anderson, L. (1997) The introduction of generic workers into the ward team: an exploratory study. *Journal of Nursing Management.* 5. p69-75.

Andreassen, H.K. Trondsen, M. Kummervold, R.E. Gammon, D. Hjortdahl, P. (2006) Patient who use e-mediated communication with their doctor: new constructions of trust in the patient doctor relationship. *Qualitative Health Research*. 16(2) p238-248

Andrews, T. (2012) What is social constructionism? *Grounded Theory Review. An international Journal.* 1(11)
Available at: http://groundedtheoryreview.com/2012/06/01/what-is-social-constructionism/
Accessed 10.8.16

Atkinson, P. Silverman, D. (1997) Kundera's Immortality: The interview society and the invention of self. *Qualitative Inquiry*. 3(3) p304-325.

Bach, S. Kessler, I (2012) *The modernisation of public services and employee relations*. London: Palgrave Macmillan.

Bach, S. Kessler, I. Heron, P (2012) Nursing a grievance? The role of Healthcare Assistants in a modernized National Health Service. *Gender Work and Organisation.* 19 (2) p205-223

BADS (2011). Day case and short stay surgery.
Available at:
https://www.aagbi.org/sites/default/files/Day%20Case%20for%20web.pdf
Accessed 1.4.16

Bailey, D.N. (2009) Caring defined: A comparison analysis. *International Journal for Human Caring.*13(1)

Baillie, L. (2015) Perspectives: We need to talk about the 6Cs: perspectives on a recent debate. *Journal of Research in Nursing*. 20(4) p331-336

Ball, J.E. Murrells, T. Rafferty, A. M. Morrow, E. Griffiths, P. (2013) 'Care left undone' during nursing shifts: associations with workload and perceived quality of care. BMJ Quality and Safety.
Available at: http://qualitysafety.bmj.com/content/early/2013/07/08/bmjqs-2012-001767.full
Accessed 30.3.16

BBC News (2007) Hospital Bugs "scandalous".
Available at:
http://news.bbc.co.uk/1/hi/health/7037657.stm
Accessed 20.10.15

BBC News (2010) Hospital left patients sobbing and humiliated
Available at:
http://news.bbc.co.uk/1/hi/health/8531441.stm
Accessed 20.10.15

BBC News (2011a) NHS 'failing to treat elderly with care and respect
Available at :
http://www.bbc.co.uk/news/health-12464831
Accessed 20.10.15

BBC (2011b) RCN wants longer visiting hours.
Available at: http://www.bbc.co.uk/news/health-15052636
Accessed 12.5.16

BBC News (2011c) Regulator raises elderly care concerns
Available at:
http://www.bbc.co.uk/news/health-13545780
Accessed 20.10.15

BBC News (2011d) Stafford Hospital gave no cause for concern
Available at:
http://www.bbc.co.uk/news/uk-england-stoke-staffordshire-15078033
Accessed 1.4.16

BBC News (2012) Winterbourne view abuse shocks nation.
Available at: http://www.bbc.co.uk/news/uk-england-bristol-20084254
Accessed 22.10.15

BBC News (2013a) Hiding mistakes should be a criminal offence
Available at:
http://www.bbc.co.uk/news/health-21341766
Accessed 20.10.15

BBC (2013b) Francis Inquiry into Stafford Hospital cost government £6m.
Available at:
http://www.bbc.co.uk/news/uk-politics-23355195
Accessed 20.10.15

BBC News (2013c) Will the Keogh Review make hospitals safer?
Available at: http://www.bbc.co.uk/news/health-23342503
Accessed 22.10.15

BBC News (2013d) *Stafford Hospital Report: as it happened*
Available at:
http://www.bbc.co.uk/news/uk-21350572
Accessed 20.10.15

BBC News (2013e) Hospitals in England told to publish staffing levels
Available at:
http://www.bbc.co.uk/news/health-24994016
Accessed 21.10.15

BBC News (2014) Care home abuse. Staff sacked or suspended over poor care.
Available at:
http://www.bbc.co.uk/news/uk-27217218
Accessed 20.10.15

BBC (2015) NHS England to tackle failing services.
Available at:
http://www.bbc.co.uk/news/health-32991129
Accessed 23.5.16

Beauchamp, T.L. Childress, J.F (2009) *Principles of biomedical ethics* (6th edn) Oxford: Oxford University Press.

Berk, L. Tan, S (1996) The laughter-immune connection: New discoveries. *Humour and Health Journal.* 5(5) p1-5

Berk, L.S. Tan, S.A (2006) Beta-endorphin and HGH increase are associated with both the anticipation and experience of mirthful laughter. *The FASEB Journal.* 20 (sup A382)

Berwick (2013) Berwick review into patient safety.
Available at: https://www.gov.uk/government/publications/berwick-review-into-patient-safety
Accessed 19.8.16

Bevan, G. Hood, C. (2006) What's measured is what matters: targets and gaming in the English public health care system. *Public Administration*. 84(3).

Birks, M. Mills, J. (2011) *Grounded theory a practical perspective*. London: Sage.

Blaikie, N (2007) *Approaches to social enquiry* (2nd edn). Cambridge: Polity Press

Bloor, M (1997) 'Techniques of validation in qualitative research: a critical commentary'. 'in' Miller, G. Dingwall, R. (ed) *Context and method in qualitative research*. London: Sage. pp(37-50)

Blumer, H. (1969) *Symbolic interactionism perspective and method*: California: Prentice Hall

Bolam, B. Gleeson, K. Murphy, S (2003). "Lay person" or "health expert" Exploring theoretical and practical aspects of reflexivity in qualitative health research. *Forum: Qualitative Social Research*. 4(2) p1-9

Bolster, D. Manias, E. (2010) Person centered interactions between nurses and patients during medication activities in an acute hospital setting: qualitative observation study. *International Journal of Nursing Studies.* 47(2) p154-165

Bonner, A. Tolhurst, G (2002) Insider-outsider perspectives of participant observation. *Nurse Researcher* 9(4) p7-19

Bone, D. (2009) 'Epidurals not emotions: The care deficit in US maternity care' 'in' Hunter, B. Deery, R. (ed) *Emotions in midwifery and reproduction*. Basingstoke: Palgrave Macmillan pp(56-70)

Booth, A. Papaioannou, D. Sutton, A (2012) *Systematic approaches for a successful literature review*. London: Sage.

Bowman, S., Bray, K., Leaver, G. and Pilcher, T. (2003) Health care assistants' role, function and development: results of a national survey, *Nursing in Critical Care,* 8(4)

Brewer, B. Watson, J. (2015) Evaluation of authentic human caring professionals. *Journal of Nursing Administration*. 45(12) p622-627

Bryant, A. Charmaz, K. (2007) 'Grounded theory in historical perspective: An epistemical account.' 'in' Bryant, A. Charmaz, K. (ed). *The sage handbook of grounded theory*. London: Sage. pp(31-57)

Bryman, A. (2012) *Social research methods*. (4th edn). Oxford: Oxford University Press

Bulmer, M (1979) Concepts in the analysis of qualitative data. *The Sociological Review.* 27(4) p651- 677

Bundgaard, K. Nielsen, K.B. Del, A.R, C. Sørensen, E.E. (2011) What to know and how to get to know? A fieldwork study outlining the understanding of knowing the patient in facilities for short-term stay. *Journal of Advanced Nursing.* 68(10) p2280-2288.

Butler-Williams, C. James, J. Cox, H. Hunt, J (2010) The hidden contribution of the health care assistant: a survey-based exploration of support to their role in caring for the acutely ill patient in the general ward setting. *Journal of Nursing Management.* 18 p789-795

CACHE (no date)
Available at: http://www.cache.org.uk/Pages/Home.aspx
Accessed on 9.6.16

Carlson, J. A (2010) Avoiding traps in member checking. *The Qualitative Report.* Vol 15 (5)

Carter, S. Blumenstein, M. Cook, C, (2013) Different for women? The challenges of doctoral studies. *Teaching in Higher Education*. 18(4) p339-351.

Cavendish Review (2013) An Independent review into Healthcare Assistant and Support Workers in the NHS and Social Care Setting
Available at:
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/236212/Cavendish_Review.pdf
Accessed 20.10.15

Ceci, C. (2004) Nursing, knowledge and power: A case analysis. *Social Science and Medicine.* 59. p1879-1889.

Chahraoui, K. Laurent, A. Bioy, A. Quenot, J.P. (2012) Clinical potpourri psychological experience of patients 3 months after a stay in the intensive care unit: a descriptive qualitative study. *Journal of Critical Care.* 3(3) p509-605.

Chang, A.M. Lam, L. Lam, L.W. (1998) Nursing activities following the introduction of healthcare assistants. *Journal of Nursing Management.* 6. p155-163.

Charmaz, K. (1999) From the “Sick Role” to stories of self: Understanding the self in illness. ‘in’ Contrada, R. Ashmore, R. D. *Self, social identity and physical health. Interdisciplinary explorations.* New York: Rutgers Series on self and Social Identity (Vol 2).

Charmaz, K. (2006) *Constructing Grounded Theory. A Practical Guide through Qualitative Research*. London: Sage.

Charmaz, K. (2014) *Constructing grounded theory*. (2nd edn). Los Angeles: Sage.

Charmaz, K. (2000) Grounded Theory objectivist and constructivist method. ‘in’ Denzin, N. Lincoln, Y. (eds) Handbook of qualitative research Thousand Oaks: Sage. pp(509-535)

Clarke, A. (2005) *Situational analysis. Grounded theory after the postmodern turn*. Thousand Oaks CA: Sage.

Clavelle, J.T. Goodwin, M. Tivis, L.J. (2013) Nursing professional attire probing patient preferences to inform implementation. *Journal of Nursing Administration*. 43(3) p172-177

Clwyd and Hart (2013) A Review of the NHS Hospitals Complaints System Putting Patients Back in the Picture.
Available at: https://www.gov.uk/government/publications/nhs-hospitals-complaints-system-review
Accessed 22.10.15

Corbin, J. Strauss, A. (1990) Grounded theory research: Procedures, canons and evaluative criteria. *Qualitative Sociology* 13(1)

Corbin, J. Strauss, A. (2008) *Basics of qualitative research.* (4th edn). Thousand Oaks: Sage.

Coughlin, C. (2012) An ethnographic study of main events during hospitalisation: perceptions of nurses and patients. *Journal of Clinical Nursing.* 22. p 2327-2337.

Coulter, A. (2002) After Bristol: putting patients at the centre. *British Medical Journal*. 324. p648-651.

Coulter, A. Fitzpatrick, R. Cornwall, J. (2009) *The point of care. Measures of patients’ experience in hospital: purpose, methods and uses*. London: The King’s Fund.

Cowan, J. Anthony, S. (2008) “Problems with complaint handling: expectations and outcomes”. Clinical Governance: *An international Journal of Health Governance.* Vol 13(2) p164-168.

CQC (2011) National report on dignity and nutrition review published. Available at: http://www.cqc.org.uk/content/national-report-dignity-and-nutrition-review-published
Accessed 10.8.16

CQC (2014) Complaints matter.
http://www.cqc.org.uk/sites/default/files/20141208_complaints_matter_report.pdf
Accessed 1.4.16

Creswell, J (2012) *Qualitative Inquiry and research design: choosing among five approaches*. Los Angeles: Sage.

Crook, S. (2001)' Social theory and the post modern.' 'in' Ritzer, G. Smart, B. (edn) *Handbook of sociological theory*. Sage: Los Angeles. pp(308-324)

Crotty, M (1998*) The foundations of social research. Meaning and perspective in the research process.* London: Sage.

Cure the NHS (2016) Campaigning for better NHS care.
Available at: http://www.curethenhs.co.uk/
Accessed 19.8.16

Curry, R (2006) Vision to reality: using patients' voices to develop and improve services. *British Journal of Community Nursing.* 11. p438-445

Curley, M. A. Q. (2007) *Synergy: the unique relationship between nurses and patients*. Sigma Theta Tau International, Indianapolis. p1-290.

Data Protection Act (1998)
Available at:
http://www.legislation.gov.uk/ukpga/1998/29/contents
Accessed 20.10.15

Davis, F. (1979) *Yearning for yesterday*. New York: Free Press

DBS Disclosure and Barring Service (2013)
Available at:
https://www.gov.uk/government/organisations/disclosure-and-barring-service/about
Accessed 3.12.13

Dean, R. A. K. Major, J. E. (2008) From critical care to comfort care: the sustaining value of humour. *Journal of Clinical Nursing.*

Denzin, N.K. Lincoln, Y.S. (2005a) Paradigms and perspectives in contention. 'in' Denzin, N.K. Lincoln, Y.S. (3rd edn) *The sage handbook of qualitative research.* Sage: Thousand Oaks CA. pp(183-190)

Denzin, N.K. Lincoln, Y.S. (2005b) The discipline and practice of qualitative research. ‘in’ Denzin, N.K. Lincoln, Y.S. (3rd edn) *The sage handbook of qualitative research.* Sage: Thousand Oaks CA. pp(1-33)

Department of Health (2000a) *A Health Service for all the Talents: Developing the NHS Workforce*.
Available at:
http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4007967
Accessed 22.10.15

Department of Health (2000b) *The NHS Plan: A Plan for Investment: A Plan for Reform.* Her Majesty’s Stationary Office.

Department of Health (2004) Agenda for Change Final Agreement
Available at:
http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4095943
Accessed 22.10.15

Department of Health, (2005) Research Governance Framework for Health and Social Care.
Available at:
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/139565/dh_4122427.pdf
Accessed 20.10.15

Department of Health (2008) High Quality Care for all. NHS next stage review final report. The Stationary Office.

Department of Health (2010) Better Hospital food programme
Available at:
http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Managingyourorganisation/Workforce/Leadership/Healthcareenvironment/DH_4116450
Accessed 12.5.16

Department of Health (2012a) Compassion in practice.
Available at:
https://www.england.nhs.uk/wp-content/uploads/2012/12/compassion-in-practice.pdf
Accessed 17.5.16

Department of Health (2012b) No decision about me without me.
Available at:
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216980/Liberating-the-NHS-No-decision-about-me-without-me-Government-response.pdf
Accessed 13.7.16

Department of Health (2013a) Patients first and Foremost. The Initial Government Response to the Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry.
Available at :
https://www.gov.uk/government/publications/government-initial-response-to-the-mid-staffs-report
Accessed on 20.10.15

Department of Health (2013b) Transforming care: A national response to Winterbourne Hospital: Department of Health Review and Response.
Available at: https://www.gov.uk/government/publications/winterbourne-view-hospital-department-of-health-review-and-response
Accessed 20.10.15

Dewar, B. Macleod Clark, J. (1992) The role of the paid non-professional nursing helper: a review of the literature. *Journal of Advanced Nursing.* 17 p113-120

Dey, I. (1999) *Grounding Grounded Theory*. San Diego: Academic Press.

Dey, I. (2007) 'Grounding Categories.' 'in' Bryant, A. Charmaz, K. (ed). *The sage handbook of grounded theory*. London: Sage. pp 167-190)

Dinç, L. Gastmans, C. (2013) Trust in nurse-patient relationships: a literature review. *Nursing Ethics.* 20(5) p501-516

Dodge, M. Kitchen, R. Perkins, C. (2011) *The map reader. Theories of mapping practice and cartographic representation*. (ed). Oxford: Wiley Blackwell.

Douglas, C.H. Douglas, M.R. (2003) Patient-friendly hospital environment: exploring the patients' perspective. *Health Expectations.* 7. p61-73

Dowling, M (2006) Approaches to reflexivity in qualitative research. *Nurse Researcher.*13(3)

Drkategranger (2013) Dr Kate Granger blogg. #mynameis...
https://drkategranger.wordpress.com/2013/09/04/hellomynameis
Accessed 19.7.16

Durkheim, E. (1933) *The Division of Labor in Society*. London: Collier-Macmillan.

Easton, K.L. McComish, J.F. Greenburg, R. (2000) Avoiding pitfalls in qualitative data collection and transcription. *Qualitative Health Research*. 10. p703-707

Elliot, R. McKinley, S. Cistulli, P. Fien, M (2013) Characterisation of sleep in intensive care unit using 24 hour polysomnography: an observational study. *Critical Care* 17(2)

Engel, G.L. (1977) The need for a new medical model: a challenge for biomedicine. *Science*. Vol 196 (vol 4286).

Engel, G.L. (1980) The clinical application of the biopsychosocial model. *The American Journal of Psychiatry*. 13. p535-544

Epstein, R.M. Street, R. L (2011) The values and value of patient-centred care. *Annals of Family Medicine* 9(2) p 100-103

Etherington, K. (2004) *Becoming a reflexive researcher using ourselves in research*. London: Jessica Kingsley Publishers.

European Working Time Directive (1998) (93/104/EC)
Available at:
http://eur-lex.europa.eu/search.html?qid=1445008171445&text=EWTD&scope=EURLEX&type=quick&lang=en
Accessed on 16.10.15

Evans, E.C. (2016) Exploring the nuances of nurse-patient interaction through concept analysis: Impact on patient satisfaction. *Nursing Science Quarterly*. 29(1) p62-70

Festinger, L (1962) The Theory of Cognitive Dissonance. Stanford: Stanford University Press

Finch, L.P. (2008) Development of a substantive theory of nurse caring. *International Journal for Human Caring.* 12(1) p25-32.

Finlay, L. (2002) “Outing” the researcher. The provenance, process and practice of reflexivity. *Qualitative Health Research.* 12(4).

Firth, R. (1967) Review of Sans Everything. *Heath Education Journal.* 26 (159)

Fontana, A. Frey J.H. (2005) The Interview From Neutral Stance to Political Involvement ‘in’ Denzin, N.K. Lincoln, Y.S. (3rd edn) *The sage handbook of qualitative research*, Thousand Oaks CA: Sage. pp(695-728)

Forbat, L. Henderson, J. (2005) Theoretical and practical reflections on sharing transcripts with participants. *Qualitative Health Research.* 15.

Forbat, L. Maguire, R. McCann, L. Illingworth, N. Kearney, N. (2008) The use of technology in cancer care: applying Foucault's ideas to explore the changing dynamics of power in healthcare. *Journal of Advanced Nursing.* 65(2) p306-315

Foster, T. Hawkins, J. (2005) The therapeutic relationship; dead or merely impede by technology? *British Journal of Nursing.* 14(13) p698-702

Foucault, M (1980) *Power/Knowledge: selected interviews and other writings 1972-1977*. (Gordon, C.,edn), Pantheon: New York

Foucault, M (1991) *Discipline and punish: The birth of the prison*. Penguin: London.

Frederiksen, M. (2012) Dimensions of trust: An empirical revisit to Simmel's formal sociology of intersubjective trust. *Current Sociology.* 60(6) p733-750

Fuglsang, L. Jagd, S (2015) Making sense of institutional trust in organizations: Bridging institutional context and trust. *Organization* 22(1) p23-39

Fung, C.H. Lim, Y, W. Mattke, S. Damberg, C. Shekelle, P. (2008) Systematic review: the evidence that publishing patient care performance data improves quality of care. *Annals of Internal Medicine.* 148(2) p111-123

Gallant, M.H. Beaulieu, M.C. Carnevale F.A. (2002) Partnership: an analysis of the concept within the nurse-client relationship. *Journal of Advanced Nursing.* 40(2) p149-157

Ganga, D. Scott, S (2006) Cultural "insider" and issues of positionality in qualitative migration research: Moving "across" and moving "along" researcher-participant divides.
Forum: Qualitative Social research
Available at: http://www.qualitative-research.net/index.php/fqs/article/view/134/289
Accessed 2.9.16

Gaut, D.A. (1986) Evaluating caring competencies in nursing practice. *Topics in Clinical Nursing.* 8. p77-83.

Gergen, K. J. (2009) *An invitation to social construction*. (2nd edn). Los Angeles: Sage.

Gergen, K.J. Gergen M.M. (1983) 'Narratives of the Self'. 'in' Sarbin, T.R. Scheibe, K.E. *Studies in social identity.* New York: Praegar. pp(254-273)

Gergen, K.J. Gergen M.M (2004) Social construction: Entering the dialogue. Ohio: Taos Institute.

Gibbs, G. (2008) *Analysing qualitative data*. London: Sage

Giddens, A. (1990) *The consequences of modernity*. Cambridge: Polity press.

Giordano, L.A. Elliott, M.N. Goldstein, E. Lehrman, W.G. Spencer, P.A. (2010) Development Implementation and Public Reporting of the HCAHPS Survey. *Medical Care Research Review.*

Glaser, B. Strauss, A.L. (1967) *The discovery of grounded theory; Strategies for qualitative research.* Chicago: Aldine.

Glaser, B. (1978) *Theoretical sensitivity: Advances in methodology of grounded theory.* Mill Valley: Sociological Press.

Glaser, B (1992*) Basics of grounded theory analysis*. Mill Valley, California: Sociological Press.

Glaser, B. (1998) *Doing grounded theory: Issues and discussion*. Mill Valley, California: Sociology Press.

Glaser, B. (2002) Constructivist Grounded Theory?
Qualitative Social Research [Online Journal].
Available at: http://www.qualitative-research.net/index.php/fqs/article/view/825/1793
Accessed 29.2.15

Glaser, B. (2005) *The Grounded theory perspective III: Description's remodelling of grounded theory methodology.* Mill Valley: Sociology Press.

Goffman, E (1969) *The presentation of self in everyday life*. London: Penguin.

Goffman, E. (1986) *Frame Analysis: An Essay of Organisation and Experience*. Boston, MA: North Eastern Press.

Gouldner, A (1960) The norm of reciprocity: a preliminary statement. *American Sociological Review*. 25. p161-178

Gov. UK (2011) Speech: 15 November 2011. Andrew Lansley. NHS employer.
Available at: https://www.gov.uk/government/speeches/speech-15-november-2011-andrew-lansley-nhs-employers
Accessed 10.8.16

Gov.UK (2014) Department of Health NHS Outcomes Framework (2014-2015)
Available at:
https://www.gov.uk/government/publications/nhs-outcomes-framework-2015-to-2016
Accessed 4.3.16

Gov. UK, (2015) Nursing associate role offers new route into nursing
Available at: https://www.gov.uk/government/news/nursing-associate-role-offers-new-route-into-nursing
Accessed 10.8.16

Graue, M.E. Walsh, D.J. (1998) *Studying children in context: Theories, methods and ethics.* Thousand Oaks CA: Sage.

Gray, B. (2009) The emotional labour of nursing-defining and managing emotions in nursing work. *Nurse Education Today.* 29(2) p168-175.

Green, J. Duran, M.A. Hutchings, A. Black, N. (2011) 'Modernization as a professionalising strategy: the case of critical care in England.' *Sociology of Health and Illness*. 33. p819-836

Griffin, R. (2012) Better care through better training-evaluation of an HCA development programme, *British Journal of Health Care Assistants,* 6(1)

Griffiths, P. Ball, J. Murrells, T. Jones, S. Rafferty, A.M (2015) Registered nurse, healthcare support worker, medical staffing levels and mortality in English Hospital Trusts: a cross-sectional study. BMJ
Available at: http://bmjopen.bmj.com/content/6/2/e008751.full.pdf+html
Accessed 19.8.16

Griffiths, P. Robinson, S. (2010) Moving forward with healthcare support worker regulation. A scoping review: evidence, questions, risks and options. National Nursing Research Unit. King's College London
Available at: http://www.nmc-uk.org/Documents/ResearchPapers/NNRUreportMovingForwardWithHealthcareSupportWorkforceRegulation2010July2010.pdf
Accessed 4.2.14

Grundy, A. Pollon, D. McGinn, M. (2003) The participant as transcriptionist: Methodological advantages of a collaborative and inclusive research practice. *International Journal of Qualitative Methods.* 2(2)

Guardian (2013) Francis Report
Available at:
http://www.theguardian.com/healthcare-network/2013/sep/18/francis-report-care-quality-nhs
Accessed 2.2.16

Guardian (2015) NHS staff most stressed public sector workers.
Available at:
http://www.theguardian.com/healthcare-network/2015/jun/12/nhs-staff-most-stressed-public-sector-workers-survey-finds
Accessed 23.5.16

Hagerty, B.M. Lynch-Sauer, J. Patusky, K.L Bouwsema, M (1993) An emerging theory of human relatedness. *Journal of Nursing Scholarship*. 25. p291-296

Hagerty, B.M. Patusky, K.L. (2003) Reconceptualising the nurse-patient relationship. *Journal of Nursing Scholarship*. 35(2) p145-150

Hall, M.A. Dugan, E. Zheng, B. Mishra, A.K. (2001) Trust in physicians and medical institutions. What is it, can it be measured and does it matter. *Millbank Quarterly.* 79. p613-639

Halldorsdottir, S. (1991) 'Five basic modes of being with another.' 'in' Gaut, D. and Leininger (eds) *Caring: The compassionate healer* New York: National League for Nursing Press. pp(37-49)

Halldorsdottir, S. (2007) A psychoneuroimmunolgical view of healing potential of human caring in the face of human suffering. *International Journal for Human Caring.* 11(2) p32-39

Halldorsdottir, S. (2008) The dynamics of the nurse-patient relationship: introduction of a synthesized theory from the patient's perspective. *Scandinavian Journal of Caring Science.* 22. p643-652

Hammersley, M. (1992). What's Wrong with Ethnography? Routledge, London.

Hancock, H. Campbell, S. (2006) Developing the role of the healthcare assistant. *Nursing Standard.* 20(49).

Harm Free Care (2016) Intentional Rounding.
Available at:
http://harmfreecare.org/a-z/intentional-rounding/
Accessed 20.4.16

Hatfield, L, A. Pearce, M. Guidance, M. Cassidy, C. Samoyan, J. Polomano, R.C. (2013) The professional appearance of registered nurses an integrative review of peer-refereed studies. *Journal of Nursing Administration.* 43(3) p108-112

Haydon, G. van der Riet, P. (2014) A narrative inquiry: How do nurses respond to patients' use of humour? *Contemporary Nurse*. 46(2) p197-295.

Healthcare Commission (2007) Investigation into outbreaks of Clostridium Difficile at Maidstone and Tunbridge Wells. London. Healthcare Commission

Health and Social Care Act (2012)
Available at:
http://www.legislation.gov.uk/ukpga/2012/7/pdfs/ukpga_20120007_en.pdf
Accessed 1.4.16

Health Education England (2015) Raising the Bar – Shape of Caring: A Review of the Future Education and Training of Registered Nurses and Care Assistants. Leeds: HEE/NMC. Chair Lord Willis
Available at:
www.hee.nhs.uk/sites/default/files/ documents/2348-Shape-of-caring-review-FINAL.pdf
Accessed 24.8.16.

Health Foundation (2016a) NHS Reorganisation White Paper 1972
Available at:
http://navigator.health.org.uk/content/national-health-service-reorganisation-white-paper-1972
Accessed 9.6.16

Health Foundation (2016b) The Nurses Registration Act 1919
Available at: http://navigator.health.org.uk/content/nurses-registration-act-1919
Accessed 2.9.16

Health Service Ombudsman. (2011) Care and compassion 2011. a report to the Health Service Ombudsman on ten investigations into NHS care for older people.
Available at:
http://www.ombudsman.org.uk/__data/assets/pdf_file/0016/7216/Care-and-Compassion-PHSO-0114web.pdf
Accessed 22.8.16

Healthwatch (2016)
Available at: http://www.healthwatch.co.uk/
Accessed 1.4.16

Heggland, L.H. Hauslen, K. (2013) Patient participation in decision making and information flow in surgical treatment. *Journal of Clinical Nursing* (230) p1430-1444

Hertz. C. (2007) The Uniform: As material, as symbol, as negotiated object. Midwestern Folklore. 32(1,2) p43-56

Heyland, D.K. Dodek, P. Rocker, G. Groll, D. Gafni, A. Picnora, D. Shortt, S. Tranmer, J. Lazar, N. Kutsogianmis, J. Lam, M. (2006) Canadian Researchers End of Life network. (CARENET). What matters most in end of life care: perceptions of seriously ill patients and their family members. *CMAJ.* 174. p627-633

Hildebrand, J.M. Spafford, M.M. Schryer, C.F. (2009) Attending to audiences: comparing optometry student talk *with* and *about* patients. *Adv in Health Science Education.* 14. p777-789

Hildon, Z. Smith, G. Netuveli, G. Blane, D. (2008) Understanding adversity and resilience at older ages. *Sociology of Health and Illness.* 30(5) p726-740

Hill R.J (2004) Fugitive and codified knowledge: implications for communities struggling to control the meaning of local environmental hazards. *International Journal of Lifelong Education*. 23 (3) p221-242.

Hochschild, A.R. (2003) *The Managed Heart. Commercialization of Human Feeling. (20th Anniversary edition).* University of California Press: Berkley.

Hogan, J. Playle, J.F. (2000) The utilisation of healthcare assistants in intensive care. *British Journal of Nursing* 9 (2) p794-801.

Holloway I and Wheeler S (2010) *Qualitative Research in Nursing and Healthcare*. West Sussex, UK: Wiley-Blackwell Publishing.

Holmes, C. A. (1992) The drama of nursing. *Journal of Advanced Nursing* 17. p941-950

Holton, J.A. (2007) ‘The coding process and its challenges.’ ‘in’ Bryant, A. Charmaz, K. ed *The sage handbook of qualitative research.* London: Sage. pp(267-289)

House of Commons, (2011). Health Committee. Seventh report: Annual accountability hearing with the Nursing and Midwifery Council.
Available at:
http://www.publications.parliament.uk/pa/cm201012/cmselect/cmhealth/1428/142802.htm
Accessed 26.10.15

House of Commons (2012) Health Committee. Annual accountability hearing: appendix 2 Nursing and Midwifery Councils Response.
Available at:
http://www.publications.parliament.uk/pa/cm201012/cmselect/cmhealth/1699/169907.htm
Accessed 26.10.15

Howard, S.A. (2012) Nostalgia. *Analysis* 72(4) p 641-650

HSCIS (2016) 2015 data
Available at:
http://www.hscic.gov.uk/searchcatalogue?productid=20263&topics=2%2fWorkforce%2fStaff+numbers%2fAll+NHS+staff&sort=Relevance&size=10&page=1#top
Accessed 30.3.16

Hsieh, S. (2010) The use of patient complaints to drive quality improvement: an explanatory study in Taiwan. *Health Service Management Research*. 23. p5-11.

HSJ (2014) Investigation: Many HCAs start work on wards without any formal training.
Available at:
http://www.nursingtimes.net/lack-of-hca-training-branded-shocking-and-worrying/5067716.article
Accessed 20.10.15

Hughes, E.C. (1984) *The Sociological Eye.* New Brunswick: Transaction Books.

Hunter, B. (2001) Emotion work in midwifery: a review of current knowledge. *Journal of Advanced Nursing.* 34(4) p 436-444

Hunter, B. and Smith, P. (2007) Emotional labour: just another buzzword? *International Journal of Nursing Studies.* 44(6) p859-861

Hutcheon, L. (2000) Irony, nostalgia, and the postmodern. 'in' *Methods for the study of literature as cultural memory.* (ed) Vervliet, R. Amsterdam: Rodopi. p189-207

Huynh, T., Alderson, M. and Thompson, M. (2008) Emotional labour underlying caring: an evolutionary concept analysis, *Journal of Advanced Nursing,* 64(2)

ICN. International Council of Nurses (2007) Nursing sensitive outcome measures. Geneva: ICN.

Iedema, R. Long, D. Carroll, K. Stenglin, M. Braithwaite, J. (2005) Corridor Work: How Liminal Space becomes a Resource for Handling Complexities of Multi-disciplinary Health Care.
Available at;
http://search.informit.com.au/documentSummary;dn=305691933675194;res=IELBUS> EISBN: 192116638X.
Accessed 21.7.16.

Ingold, T. (2000) *The perception of the environment: Essay in livelihood, dwelling and skill*. London: Routledge.

Institute of Medicine (2001) Crossing the quality chasm: a new health system for the 21st Century.
Available at:
http://www.nationalacademies.org/hmd/~/media/Files/Report%20Files/2001/Crossing-the-Quality-Chasm/Quality%20Chasm%202001%20%20report%20brief.pdf
Accessed on 13.7.16

IRAS (2013) International Research Approval System
Available at: https://www.myresearchproject.org.uk/
(Accessed on 26.11.13)

Iwantgreatcare (2014) The trusted site for healthcare reviews
Available at: https://www.iwantgreatcare.org/
Accessed 19.8.16

James. J. Butler-Williams, C. Hunt, J. Cox, H. (2010) Vital signs for vital people: an exploratory study into the role of the Healthcare Assistant in recognising, recording and responding to the acutely ill patient in the general ward setting. *Journal of Nursing Management.* 18. p548-555

Jenkins, T.M. (2014) Clothing norms as markers of status in a hospital setting: A Bourdieusian analysis. *Health* 18(5) p526-541

Johnson, M. Webb, C. (1995) Rediscovering unpopular patients: the concept of social judgement. *Journal of Advanced Nursing.* 21. p466-475

Jonsson, P.M. and Øvretveit, J. (2008) Patient claims and complaints data for improving patient safety. *International Journal of Healthcare Quality Assurance.* 21(1) p60-74

Joseph, N. Alex, N. (1972) The uniform: a sociological perspective. *American Journal of Sociology.* 77(4) p719-730

Kane, R.L. Shamliyan, T.A. Mueller, C. Duval, S. Wilt, T.J. (2007) The association of registered nurse staffing levels and patient outcomes: systematic review and meta-analysis. *Medical Care*. 45(12) p1195-1204

Keeney, S. Hasson, F. McKenna, H. Gillen, P. (2005) Nurses', midwives' and patients' perception of trained healthcare assistants. *Journal of Advanced Nursing.* 50 (4) p345-355

Kelly M (2010) The role of theory in qualitative health research. Family Practice 27. p 285–290.

Kessler, I. Heron, P. Dopson, S. (2012) *The modernisation of the nursing workforce*. Oxford: Oxford University Press

Kessler, I. Heron, F. Dopson, S. Magee, H. and Swain, D. (2010) Nature and consequences of support workers in a hospital setting. Final report, NIHR Service delivery and Organisation Programme.
Available at: http://www.netscc.ac.uk/hsdr/files/project/SDO_FR_08-1619-155_V01.pdf
Accessed 20.10.15

King's Fund (2015a) Public Satisfaction with the NHS
Available at:
http://www.kingsfund.org.uk/projects/public-satisfaction-nhs/bsa-survey-2015
Accessed 4.3.16

King's Fund (2015b) The number of Hospital beds
Available at:
http://www.kingsfund.org.uk/projects/nhs-in-a-nutshell/hospital-beds
Accessed 13.7.16

King's Fund (2016a) Deficits in the NHS 2016
Available at:
http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/Deficits_in_the_NHS_Kings_Fund_July_2016_1.pdf
Accessed 24.8.16

King's Fund (2016b) The NHS budget and how it has changed.
Available at:
http://www.kingsfund.org.uk/projects/nhs-in-a-nutshell/nhs-budget
Accessed 13.7.16

Kirby, S (2007) The contextual researcher: celebrating 'experiential alertness' in grounded theory in prison research. *Nurse researcher* .14(2) p51-65

Klein, R (2010) *The New politics of the NHS*. 6th edn London: Prentice-Hall.

Koelsch L.E. (2013) Reconceptualising the Member Check Interview. *International Journal of Qualitative Methods.*

Kvale, S (1996) *Interviews: An introduction to qualitative research interviewing.* Thousand Oaks CA: Sage.

Kvåle, K. Synnes, O. Jacobsen, F.F. (2015) Reflexivity on an empirical study about cancer patients' perceptions of good caring in light of Goffman's theory. *International Journal of qualitative Methods*. 14(1) p146-158

Lankshear, A.J. Sheldon, T.A. Maynard, A (2005) Nurse staffing and healthcare outcomes. A systematic review of the international research evidence. *Advances in Nursing Science.* 28(2) p163-174

Layder, D (1998) *Sociological Practice: Linking Theory and Social Research*. London: Sage.

Leininger, M (1978) The phenomenon of caring. *Nursing Research Report.* 12. p2-14

Lempert, L.B. (2007) 'Asking questions of the data: Memo writing in the grounded theory tradition.' 'in' Bryant, A. Charmaz, K. (ed). *The sage handbook of qualitative research.* London: Sage. pp(245-264).

Lewin, S. Reeves, S. (2011) Enacting 'team and 'teamwork': Using Goffman's theory of impression management to illuminate interprofessional practice on hospital wards. *Social Science and Medicine.* 72. p1595-1602

Lincoln, Y.S. (2005) 'Institutional review boards and methodological conservatism. The challenge to and from phenomenological paradigms.' 'in' Denzin, N.K. Lincoln, Y.S. (eds) T*he sage handbook of qualitative research*. 3rd ed Thousand Oaks CA: Sage. pp(165-215)

Lincoln, Y. S. Guba, E (1985) *Naturalistic inquiry.* Beverly Hills CA: Sage.

Lipscomb M (2008) Mixed method nursing studies: A critical realist critique. *Nursing Philosophy* 9. p32–45.

Little, A. Ethier, C. Ayas, N. Thanachayanont, T. Jiang, D. Mehta, S. (2012) A patient survey of sleep quality in the intensive care unit. Minerva Anestesiol. 78(4) P406-414

Lombarts, MJ. Rupp, I. Vallejo, P. Sunol, R. Klazinga, N.S. (2009) Application of quality improvement strategies in 389 European hospital: results of the MARQuIS project. *Quality and Safety in Healthcare.* 18. p128-137

Macdonald. M. (2008) technology and its effect on knowing the patient. *Clinical Nurse Specialist*. 22(3) p149-155

Machi, L.A. McEvoy, B.T. (2012) The Literature review. Six steps to success. (2nd edn) Thousand Oaks CA: Corwin.

Martin, M.P. McKee, L. Dixon-Woods, M. (2015) Beyond metrics? Utilizing 'Soft intelligence' for healthcare quality and safety. *Social Science and Medicine.* p19-26.

Martin, R. A. Puhlik-Davies.P. Larsen, G. Gray, J. War, K. (2003) Individual differences in uses of humour and their relation to psychological well-being: development of humour styles questionnaire. *Journal of Research in Personality.* 37. p48-75

May, C. (1991) Affectives neutrality and involvement in nurse-patient relationships: perceptions of appropriate behaviour among nurses in acute medical and surgical wards. *Journal of Advanced Nursing*. 16 p552-558

MCA Mental Capacity Act (2005)
Available at:
http://www.legislation.gov.uk/ukpga/2005/9/contents
Accessed 20.10.15

McCann, T. Clarke, E (2003a) Grounded theory in nursing research: Part 2- Critique. *Nurse Researcher.* 11(2)

McCann, T. Clarke, E (2003b) Grounded theory in nursing research: Part 3- Application. *Nurse Researcher.* 11(2)

McCreaddie, M. Payne, S. (2011) Humour in health-care interactions: a risk worth taking. *Health Expectations.* 17. p332-344.

McCreight, B. (2005) Perinatal grief and emotional labour: a study of nurses' experiences in gynae wards. *International Journal of Nursing Studies*. 42(2) p439-448

Mcilfatrick, S. Sullivan, K. McKenna, H. (2006) Nursing the clinic vs. nursing the patient: nurses experience of day hospital chemotherapy services. *Journal of Clinical Nursing*. 15(9) p1170-1178

McKenna, H.P. Hasson, F. Keeney, S. (2004) Patient safety and quality of care: the role of the healthcare assistant. *Journal of Nursing Management.*

Mead, G. H. (1967*) Mind, self and society*. Chicago: University of Chicago Press.

MIDIRS (2001) Support workers in maternity care. MIDRIS Midwifery Digest 11 (3) p405-406

The Mid Staffordshire Foundation Trust Public Inquiry (2010) Independent Inquiry into care provided by Mid Staffordshire NHS Foundation Trust from January 2005-March 2009 Part 1. London: Stationary Office (Chair: R Francis) Available at:
http://webarchive.nationalarchives.gov.uk/20130107105354/http:/www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113018
Accessed on 7.6.15

The Mid Staffordshire Foundation Trust Public Inquiry (2013) Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry: executive summary. London: Stationary Office (Chair: R Francis) Available at: www.midstaffspublicinquiry.com/sites/default/files/report/Executive%20summary.pdf
Accessed on 6.1.17

Milgram, S. (1963) Behavioural study of obedience. Journal of Abnormal Social Psychology. 67. p371-378

Milliken, P.J. Schreiber, R. (2012) Examining the nexus between grounded theory and symbolic interactionism. *International Journal of Qualitative Methods.* p684-696

Mills J. Bonner A. & Francis K. (2006) The Development of Constructivist Grounded Theory. *International Journal of Qualitative Methods.* 5(1) p25-35.

Mockford, C. Staniszewska, S. Griffiths, F. Herron-Marx, S (2012) The impact of patient and public involvement on UK NHS healthcare: a systematic review. *International Journal for Quality in Health Care.* 24(1) p28-38.

Möllering, G (2001) The nature of trust: From Georg Simmel to a theory of expectation, interpretation and suspension. *Sociology* 35(2) p403-420

Moore, J. (2009) An exploration of lecturer as facilitator within context of problem-based learning. *Nurse Education Today*. 29(2) p150-156

Morse, J. (1991) Negotiating commitment and involvement in the nurse-patient relationship. *Journal of Advanced Nursing.* 16. p455-468

Morse, J.M. (2001) ‘Situating grounded theory within qualitative inquiry.’ ‘in’ Schreiber, R.S. Stern, P.N.(ed). *Using grounded theory in nursing*. New York: Springer. p1-16.

Mottram, A (2008) Therapeutic relationships in day surgery: a grounded theory study. *Journal of Clinical Nursing*. 18. p2830-2837

National Voices (2016)
Available at: http://www.nationalvoices.org.uk/
Accessed 19.8.16

NHS (2013) Review into the quality of care and treatment provided by 14 hospital trusts: overview report. Professor Sir Bruce Keogh KBE
Available at: http://www.nhs.uk/NHSEngland/bruce-keogh-review/Pages/published-reports.aspx
Accessed 20.10.15

NHS (2014a) Five year forward view
Available at: https://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf
Accessed 2.9.16

NHS (2014b) *Surveys*
Available at:
http://www.nhssurveys.org/survey/1592
Accessed 27.10.15

NHS Careers (no date) *Healthcare Assistants/ Auxillary Nurses*. Available at:
http://www.nhscareers.nhs.uk/details/Default.aspx?Id=485
Accessed 1.4.16

NHS Choices (2014) Your health your choices
Available at: http://www.nhs.uk/pages/home.aspx
Accessed 19.8.16

NHS Confederation (2016) Key statistics on the NHS
Available at: http://www.nhsconfed.org/resources/key-statistics-on-the-nhs
Accessed 12.12.16

NHS Confederation (2014)
Available at:
http://www.nhsconfed.org/news/2014/06/see-me-not-just-my-disease-says-dr-kate-granger
Accessed 20.7.16

NHS Employers (2015) Care certificate
Available at:
http://www.nhsemployers.org/your-workforce/plan/education-and-training/care-certificate
Accessed 1.8.16

NHS England (2013a) Compassion in practice-our culture of compassionate care.
Available at:
http://www.england.nhs.uk/nursingvision/
Accessed 4.3.16

NHS England (2013b) Friends and Family Test
Available at:
http://www.england.nhs.uk/statistics/statistical-work-areas/friends-and-family-test/
Accessed 4.4.16

NHS Health Education England (no date) Pre-nursing experience pilot. The journey so far.
Available at:
https://hee.nhs.uk/sites/default/files/documents/Interactive%20pre-nursing%20experience%20pilot%20booklet.pdf
Accessed 22.8.16

NHS Health Education England (2014) New “Care Certificates” pilots underway in England.
Available at:
http://hee.nhs.uk/2014/04/28/new-care-certificate-pilots-underway-in-england/
Accessed 20.10.15

NHS Health Education England (2016) Building capacity to care and capability to treat. A new team member for health and social care in England. Available at:
https://hee.nhs.uk/sites/default/files/documents/Response%20to%20Nursing%20Associate%20consultation%2026%20May%202016.pdf
Accessed 1.6.16

NHS Improvement (2016a) Freedom to speak up: raising concerns (whistleblowing) policy for the NHS.
Available at:
https://improvement.nhs.uk/uploads/documents/whistleblowing_policy_30march.pdf
Accessed 30.8.16

NHS Improvement (2016b) Who we are.
Available at:
https://improvement.nhs.uk/about-us/who-we-are/
Accessed 1.8.16

NHS Institute for innovation and improvement (2008a) Day surgery. Treat day surgery as the norm.
Available at:
http://www.institute.nhs.uk/quality_and_service_improvement_tools/quality_and_service_improvement_tools/day_surgery_-_treat_day_surgery_as_the_norm.html
Accessed 10.5.16

NHS Institute for innovation and improvement (2008b) Enhanced recovery programme
Available at:
http://www.institute.nhs.uk/quality_and_service_improvement_tools/quality_and_service_improvement_tools/enhanced_recovery_programme.html
Accessed 10.5.16

NHS Scotland (2010a) A Guide to Healthcare Support Worker Education and Role Development.
Available at: http://www.nes.scot.nhs.uk/education-and-training/by-theme-initiative/workforce-development/healthcare-support-worker-(hcsw).aspx
Accessed 20.10.15

NHS Scotland (2010b) Induction Standards
Available at: http://www.hcswtoolkit.nes.scot.nhs.uk/hcsw-standards-and-codes/induction-standards/
Accessed 20.10.15

NICE (2012) Patient experience in adult NHS services
https://www.nice.org.uk/guidance/qs15
Accessed 4.3.16

NICE (2016) NICE releases safe staffing evidence review
Available at: https://www.nice.org.uk/news/feature/nice-releases-safe-staffing-evidence-reviews
Accessed 16.8.16

Nightingale, F (1860) *Notes on nursing, what it is and what it is not*. Appleton, D and Company: New York.

NMC (2006) The regulation of health care support workers: A scoping paper. London.

NMC (2016) Safe staffing guidelines
Available at: https://www.nmc.org.uk/about-us/policy/position-statements/safe-staffing-guidelines/
Accessed 19.8.16

NMDS National Minimum Data Set (2013)
Available at:
https://www.nmds-sc-online.org.uk/
Accessed 27.11.13

NREC National Research Ethics Committee (2011). *Explaining research.*
Available at:
http://www.nres.npsa.nhs.uk/
Accessed 5.11.13

Northumbria University (2011) Research ethics and governance handbook point 8.
Available at: www.northumbria.ac.uk
Accessed 7.10.13

Nuffield Trust (2012) The history of NHS reform
Available at:
http://nhstimeline.nuffieldtrust.org.uk/?gclid=CjwKEAjwsMu5BRD7t57R1P2HwBgSJABrtj-RgmoGA0BpNu-ROBZB3op40feD47OMVV8sM_o-HGe91BoCwfHw_wcB
Accessed 10.5.16

Nuffield Trust (2016) Average number of overnight beds available and occupied in England.
Available at; http://www.nuffieldtrust.org.uk/data-and-charts/overnight-hospital-beds-england
Accessed 10.5.16

Nursing Times (2011) Regulation of HCA not a top priority for the NHS.
Available at:
https://www.nursingtimes.net/regulation-of-hca-not-a-top-priority-for-the-nhs/5035772.article
Accessed 19.10.15

Ochs, E (1979) 'Transcription as theory'. 'in' Ochs. E. Schieffelin (ed) *Developmental pragmatics.* London: Academic Press. pp(9943-72)

Ormandy, P. Long, A.F. Hulme, C.T. Johnson, M (2004) The role of the senior health care worker in critical care. *British association of Critical Care Nurses, Nursing in Critical Care*. 9(4)

den Outer, B. Handley, K. Price. (2013) Situational analysis and mapping for use in education research: a reflexive methodology? *Studies in Higher Education.* 38(10) p1504-1521.

Oxford English Dictionary (2016)
Available at: https://en.oxforddictionaries.com/
Accessed on 20.9.16

Ozawa, S. Sripad, P. (2013) How do you measure trust in the healthcare system? A systematic review of the literature. *Social Science and Medicine*. 91. p10-14

Papastavrou, E. Efstathiou. Charalambous, A. (2010) Nurses' and patients' perception of caring behaviours: qualitative systematic review of comparative studies. *Journal of Advanced Nursing.*

Pappas, S (2008) The cost of nurse-sensitive adverse events. *Journal of Nursing Administration.* 38. p230-236

Parsons (1991) *The Social System*. London: Routledge.

Patient Experience (2013) Criticism of the Friends and Family Test
Available at:
http://www.patientexperience.co.uk/friends-and-family-test/criticism-friends-and-family-test/
Accessed 4.3.16

Patient Opinion (2014) Every voice matters.
Available at: https://www.patientopinion.org.uk/
Accessed 19.8.16

Payne, S. Hawker, S. Kerr, C. Seamark, D. Jerrett, N. Roberts, H. Smith, H. (2007) Healthcare workers' skills: Perceived competence and experiences of end-of-life care in community hospitals. *Progress in Palliative Care.* 15(3) p118-125

Pearcey, P (2000) Role perceptions of auxillary nurses: an exploratory study. *Nursing Times Research*. 5(1) p55-63

Pearcey, P (2008) Shifting role in nursing- does role extension require role abdication? Journal of Clinical Nursing. 17. p1320-1326

Pearlin, L. I. (1989) The sociological study of stress. *Journal of Health and Social Behaviour*. 30(3) p241-256

Petriwskyj, A. Gibson, A. Webby, G. (2014) Participation and power in care: exploring the "client" in client engagement. *Journal of Aging Studies*. 31. p119-131.

Picker Institute (2016) Picker Institute Europe
Available at: http://www.pickereurope.org/
Accessed 22.8.16

Platonova, E.A. Kennedy, K.N. Shewchuk, R.M. (2008) Understanding patient satisfaction, trust and loyalty to primary care physicians. *Medical Care Research and Review*. 65. p696-712

Polit, D.F Beck, C.T (2008) *Generating and assessing evidence for nursing practice* (8th edn). Philadelphia: Lippincott Williams and Wilkins.

Pound, C (2011) Reciprocity, resources and relationships. New discourses in healthcare, personal and social relationships *Journal of Speech-Language Pathology.* 13(3) p197-206

Pryor, J (2010) Nurses create a rehabilitative milieu. *Rehabilitation Nursing.* 35(3) p123-128.

Rafaeli, A. Pratt, M.G. (1993) Tailored meanings: on the meaning and impact of organisational dress. *The Academy of Management Review*. 1 p p32-56

Rafaeli, A. Sagy, Y. Derfler-Rozin, R. (2008) Logos and compliance: A strong case of mindless trust. *Organisation Science*. 19(6) p845-859

Ramalho, R. Adams, P. haggard, P. Hoare, K. (2015) Literature review and constructivist grounded theory methodology. *Forum Qualitative Social Research* 16(3)

Ritchie, J. Zwi, A.B. Blignault, I. Bunde-Birouste, A. Silove, D. (2009) Insider-outsider positions in health-development research: reflections for practice. *Developments in Practice.* 19(1) p106-112

Robb, B (1967) *Sans Everything. A case to answer*. London: Nelson.

Royal College of Nursing (2004) The Future Nurse: The RCN vision. Available at:
http://www.rcn.org.uk/__data/assets/pdf_file/0008/78614/002302.pdf
Accessed 5.3.14

Royal College of Nursing (2006) Supervision, accountability and delegation of activities to support workers. A guide for registered practitioners and support workers.
Available at: https://www.rcslt.org/docs/free-pub/Supervision_accountability_and_delegation_of_activities_to_support_workers
Accessed 25.7.16

Royal College of Nursing (2007a) Ensuring a Fit for Purpose Future Nursing Workforce*.* Available at:
http://www.rcn.org.uk/__data/assets/pdf_file/0003/313581/13.07_Ensuring_a_Fit_for_Purpose_Future_Nursing_Workforce.pdf
Accessed 20.10.15

Royal College of Nursing (2007b) The Regulation of Healthcare Support Workers: Policy briefing 11/2007
Available at:
http://www.rcn.org.uk/__data/assets/pdf_file/0003/287715/11-2007_the_regulation_of_health_care_support_workers.pdf
Accessed 19.10.15

Royal College of Nursing (2010a) Assistant Practitioner Scoping Project
Available at:
https://www2.rcn.org.uk/__data/assets/pdf_file/0003/379155/003880.pdf
Accessed 24.8.16

Royal College of Nursing (2010b) Guidance on safe staffing levels in the UK.
Available at:
https://www2.rcn.org.uk/__data/assets/pdf_file/0005/353237/003860.pdf
Accessed 19.8.16

Royal College of Nursing (2013) Wipe it out. One chance to get it right. Guidance on uniforms and workwear.
Available at:
https://www2.rcn.org.uk/__data/assets/pdf_file/0010/78652/002724.pdf
Accessed 15.6.16

Russell, S. (2005) Treatment seeking behaviour in urban Sri Lanka: trusting the state, trusting private providers. *Social Science and Medicine*. 61 p1396-1407

Sacks, O. (1984) *A leg to stand on*. New York: Summit Books

Safe Staffing Alliance (2016) Demanding safe staffing levels to ensure quality nursing care.
Available at: http://www.safestaffing.org.uk/
Accessed 19.8.16

Safren, D.B. Kosinski, M. Tarlov, A.R. Rogers, W.H. Taira, D.A. Liberman, N. (1998) The primary care assessment survey; tests of data quality and measurement performance. *Medical Care* 36 p728-739.

Saldaña, J. (2013) *The coding manual for qualitative researchers*. (2nd edn). Los Angeles: Sage.

Sandelowski, M (2002) Re-embodying qualitative inquiry. *Qualitative Health Research*. 12. p104-115

Santino. J. (1998) *Miles of smiles, years of struggle: stories of black pullman porters.* Urbana: University of Illinois.

Sawbridge, Y. Hewison, A. (2011) *Time to care? Responding to concerns about poor nursing care.* Policy Paper 12. Health Services Management Centre.

van der Schee, E, Braun, B. Calnan, M. Schnee, M. Groenewegen, P.P. (2007) Public trust in health care: a comparison of Germany, The Netherlands and England and Wales. *Health Policy.* p56-67

Schreiber, R.S (2001) The 'how to' of grounded theory: Avoiding the pitfalls. 'in' Schreiber, R.S. Stern, P.N. ed. *Using grounded theory in nursing*. New York: Springer. p55-84.

Schreuders, L.W. Bremner, A.P. Geelhoed, E. Finn, J (2014) The relationship between nurse staffing and inpatient complications. *Journal of Advanced Nursing.*

Schwandt, T. A. (2003). 'Three epistemological stances for qualitative inquiry: Interpretavism, hermeneutics and social constructionism.' 'in' Denzin, N. and Lincoln, Y (eds.), *The Landscape of Qualitative Research: Theories and issues*. Thousand Oaks, CA: Sage. pp(292-331)

Scottish Government (2009) Healthcare Support Workers in Scotland: Evaluation of a National Pilot of Standards and Listing in Three NHS Boards.
Available at:
http://www.scotland.gov.uk/Publications/2009/06/01144730/32
Accessed 25.11.12

Seale, C (1999) *The quality of qualitative research*. London: Sage.

Seale, C. (2004) 'Validity, Reliability and the Quality of Research.' 'in' Seale, C. (ed). *Researching Society and Culture* (2nd edn) London: Sage. pp(72-83).

Shaller, D (2007) Patient-centered care: What does it take?
Available at:
http://www.commonwealthfund.org/usr_doc/Shaller_patient-centeredcarewhatdoesittake_1067.pdf?section=4039
Accessed 12.8.16

Shattell, M (2004) Nurse-patient interaction: a review of the literature. *Issues in Clinical Nursing.* 13. p714-722.

Shuldham, C. Parkin, C. Firouzi, A. Roughton, M. Lau-Walker, M. (2009) The relationship between nurse staffing and patient outcomes: A case study. *International Journal of Nursing Studies*. 46

Silverman, D (1993) *Interpreting qualitative data: Methods for analysing talk, text and interaction.* London: Sage.

Silverman, D (2000) *Doing qualitative research: A practical handbook* London: Sage.

Simmel, G (1950) The sociology of Georg Simmel. Transl., ed and intr. by K.H. Wolff. New York: Free Press.

Skills for Health (2015) Assistant practitioners in the NHS in England
Available at:
http://www.skillsforhealth.org.uk/index.php?option=com_mtree&task=att_download&link_id=175&cf_id=24
Accessed 1.4.16

Smith, J.K. Hodkinson, P. (2005) 'Relativism, criteria and politics.' 'in' Denzin, N.K. Lincoln, Y.S. (eds) *The sage handbook of qualitative research*, (3rd edn) Sage: Thousand Oaks CA. pp (915-932)

Smith, K. Biley, F. (1997) Understanding grounded theory. Principles and evaluation. *Nurse Researcher*. 4(3) p17-30.

Smith, P (1995) On the unintended consequences of publishing performance data in the public sector. *International Journal of Public Administration.* 18(2-3)

Smith, P. (2012) *The Emotional Labour of Nursing Revisited. Can Nurses Still Care.* (2nd edn). Basingstoke: Palgrave Macmillan.

Smith, P. Gray, B. (2000) *The emotional labour of nursing: how student and qualified nurses learn to care, report on nurse education, nursing practice and emotional labour in the contemporary NHS.* London: South Bank University

Smith, P. and Lorentzon, M. (2005) Is emotional labour ethical? *Nursing Ethics,* 12(6)

Spichiger, E. (2009) Being in hospital: An interpretive phenomenological study of terminally ill cancer patients' experiences. *European Journal of Oncology Nursing.* 13. p16-21

Spilsbury, K. Meyer, J. (2004) Use, misuse, and non-use of healthcare assistants: understanding the work of the healthcare assistants in a hospital setting. *Journal of Nursing Management.* 12. p411-418

Spilsbury, K. Meyer, J. (2005) Making claims on nursing work: exploring the work of healthcare assistants and implications for registered nurses' roles. *Journal of Research in Nursing.*10 (65).

Stanford University (2015) Relativism
Available at:
http://plato.stanford.edu/entries/relativism/
Accessed 2.9.16

Stein-Parbury, J. (2009). *Patient and Person.* (4th edn). Australia: Churchill Livingstone.

Stern, P. N. (2007) 'On solid ground: essential properties for growing grounded theory.' 'in' Bryant, A. Charmaz, K. (ed). *The sage handbook of grounded theory*. London: Sage. pp(114-126).

Stockwell, F (1972) The Unpopular Patient.
Available at:
https://www2.rcn.org.uk/__data/assets/pdf_file/0005/235508/series_1_number_2.pdf
Accessed 12.8.16

Stokes, J. Warden, A. (2004) The changing role of the healthcare assistant. *Nursing Standard* 18(51) p33-37

Stone, G.C. (1979) ‘Health and the health system: A historical overview and conceptual framework.’ ‘in’ George, S. Cohen, C.F. Adler, N.E. (ed) *Health Psychology-A handbook*.) San Francisco: Josey- Bass. pp(1-17)

Strauss, A. (1987) *Qualitative analysis for social scientists*. Cambridge, UK: Cambridge University Press

Strauss, A. Corbin, J. (1990) *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park: Sage.

Strauss, A. Corbin, J. (1998) *Basics of qualitative research: Techniques, procedures for developing grounded theory* (2nd edn). Thousand Oaks CA: Sage.

Strauss, A. Corbin, J (2008) *Basics of qualitative research: Grounded theory procedures and techniques*. (3rd edn) Newbury Park: Sage.

Suhonen, R. Gustafsson, M.L. Katajisto, J. Valimaki, M. Leino-Kilpi, H (2010) Nurses’ perception of individualized care. *Journal of Advanced Nursing* 66(5) p1035-1046

Sumners, A.D. (1990) Professional nurses’ attitudes towards humour. *Journal of Advanced Nursing.* 15. p196-200.

Swanson, K.M. (1991) Empirical development of a middle-range theory of caring. *Nursing Research.* 40(3). p161-166.

Swanson, K.M (1999) ‘What is known about caring in nursing science: A literary meta-analysis.’ ‘in’ Hinshaw, A.S. Freeman, S. Shaver, J (ed) *Handbook of clinical nursing research.* Thousand Oaks CA: Sage. pp(31-60)

Tejero, L.M. (2011) The mediating role of the nurse-patient dyad bonding in bridging about patient satisfaction. *Journal of Advanced Nursing*. 68(5) p994-1002.

Thom, D.H. Hall, M.A. Pawlson, L.G. (2004) Measuring patients’ trust in physicians when assessing quality of care. *Health Affairs.* 23 (4) p124-132

Thornberg, R. (2012) Informed grounded theory. *Scandinavian Journal of Educational Research*. 55(1)

Timmons, S. East, L. (2011) Uniforms, status and professional boundaries in hospital. *Sociology of Health and Illness*. 33(7) p1035-1049

Tsianakas, V. Maben, J. Wiseman, T. Robert, G. Richardson, A. Madden, P Griffin, M. Davies, E.A. (2012a) Using patient experiences to identify priorities for quality improvement in breast cancer care: Patient narratives or both? *BMC Health Service Research*. 12. 271

Tsianakas, V. Robert, G. Maben, J. Richardson, A. Dale, C. Wiseman, T. (2012b) Implementing patient centred cancer care: using experience-based co-design to improve patient experience in breast and lung cancer services. *Support Care Cancer.* 20. p2639-2647

Twigg, D.E. Gelder, L. Myers, H. (2015) The impact of understaffed shifts on nurse-sensitive outcomes. *Journal of Advanced Nursing.*

UKCC (1986) *Project 2000: A New Preparation for Practice.* London, United Kingdom Central Council for Nursing, Midwifery and Health Visiting

UNISON (2013) The NHS post-Francis. A UNISON report. Available at:https://www.unison.org.uk/.../Policies**Francis**-UNISONs-response-November-2013-FV. Accessed 1.8.16

UNISON (2015) Red alert Unsafe staffing levels rising
Available at:
https://www.unison.org.uk/content/uploads/2015/04/TowebRed-Alert-Unsafe-Staffing-Levels-Rising1.pdf
Accessed 19.8.16

UNISON (2016) UNISON says new nursing associate role is no solution to the nursing shortage.
Available at:
https://www.unison.org.uk/news/press-release/2016/01/unison-says-new-nursing-role-is-no-solution-to-the-nursing-shortage/
Accessed 22.8.16

University of Bristol (no date) Boyd-Orr Cohort
Available at:
http://www.bris.ac.uk/social-community-medicine/people/project/1408
Accessed 30-6-16

Waldie (2010) Healthcare assistant role development: a literature review. *Journal of Advanced Perioperative Care.* 4(2) 61

Walker, D. Myrick, F. (2006) Grounded Theory: an exploration of process and procedure. *Qualitative Health Research.*16(4)

Walshe, K. Higgins, J (2002) The use and impact of inquiries in the NHS. BMJ 325(7369) p895-900

Wanless, D. (2002) Securing Our Future Health Taking a Long Term View.
Available at:
http://si.easp.es/derechosciudadania/wp-content/uploads/2009/10/4.informe-wanless.pdf
Accessed 27.11.13

Waring, J. J Bishop, S (2010) “Water cooler” learning: Knowledge sharing at the clinical “backstage” and its contribution to patient safety", Journal of Health Organization and Management, Vol. 24 (4) p325 – 342

Watson, J. (1990) Caring knowledge and informed moral passion. *Advances in Nurses Science.* 13. p15-24

Watson, J (2005) *Caring science as sacred science.* Philadelphia: Davies and Co.

Watson, J. (2009) Assessing *and measuring caring in nursing and health sciences.* (2nd edn). New York: Springer Publishing.

Watson, J. Smith, M.C. (2002) Caring science and the science of unitary human beings: a trans theoretical discourse for nursing knowledge development. *Journal of Advanced Nursing.* 37(5) p452-461

Webb, B (2000) Enrolled nurse conversion: A review of the literature. *Journal of Nursing Management 2000*. 8. p 115-120

Weber, M (1966) The Theory of Social and Economic Organization. New York: Free Press.

Welford C, Murphy K and Casey D (2011) Demystifying nursing research terminology: Part 1. Nurse Researcher 18. p38–43.

WHO (2009) Night noise guidelines for Europe.
Available at:
http://www.euro.who.int/__data/assets/pdf_file/0017/43316/E92845.pdf
Accessed 6.9.16

Wilkinson, I (2001) *Anxiety in a risk society: health, risk and society*. New York: Routledge

Willmott, H. (1992) Postmodernism and Excellence: the De-differentiation of Economy and Culture. *Journal of Organisational Change Management.* 5(3) p58-68.

Woolgar, S. & Ashmore, M. (1988). ‘The Next Step: an Introduction to the Reflexive Project.’ ‘in’ Woolgar, S (ed), *Knowledge and reflexivity: New frontiers in the sociology of knowledge*. London: Sage. p(1-11)

Yanow, D. (2004) Translating local knowledge at organisational peripheries. *British Journal of Management.* 15. p9-25

Appendices

Appendix 1

My underlying assumptions

Underlying assumptions	**Where is the evidence?**
The HCA delivers much of the bedside care as a result in a shift from RN to HCA	literature and professional experience
There are issues around role clarity between the HCA and the RN	literature and professional experience
The HCA is not regulated or registered yet makes up the largest proportion of care staff	literature and professional experience
The HCA is making decisions around care delivery	literature and professional experience
Formal training and minimum standards have been recommended by the government post Francis	literature

Appendix 2

An excerpt from my reflective diary, illustrating thoughts and decisions made.

Reflective notes

Date 12.5.14

Having done some reading I have noted this:

Hughes (1984) focusses on the internal dynamics of the division of labour exploring connections. He claims that it is impossible to describe the work of an individual without reference to that of others with whom they work. In addition, the work they **think** they do and **what** they do.

This perspective has had influence on my understanding of the methodological approach of situational analysis (SA). The research will address the patients' perspective within a largely complex situation. Although the research is NOT looking at the HCAs' perspective and the work they do and the work they think they do there are complexities around the patients' understandings of the role may well come to light with this approach and consideration.

14.5.14. *Attended a lecture by xxxx who spoke about the tensions between paid work and unpaid work. What was interesting was her willingness to state her influences in her research with her interest in "second wave feminism". This got me thinking about standpoint approaches.*

With reference to the HCA I considered what she said on social mobility and career advancement as concepts embedded in Western Society. The HCA is paid a low wage with little chance of promotion or progression within the designation of HCA. Organisations may well offer training and advancement through education but will not always recognise this through pay and career development.

The decline in manufacturing in the North East has seen a raise in service sector jobs. Women in North East were working where? Woman's work? Would some of these HCAs have been employed elsewhere prior to the manufacturing decline?

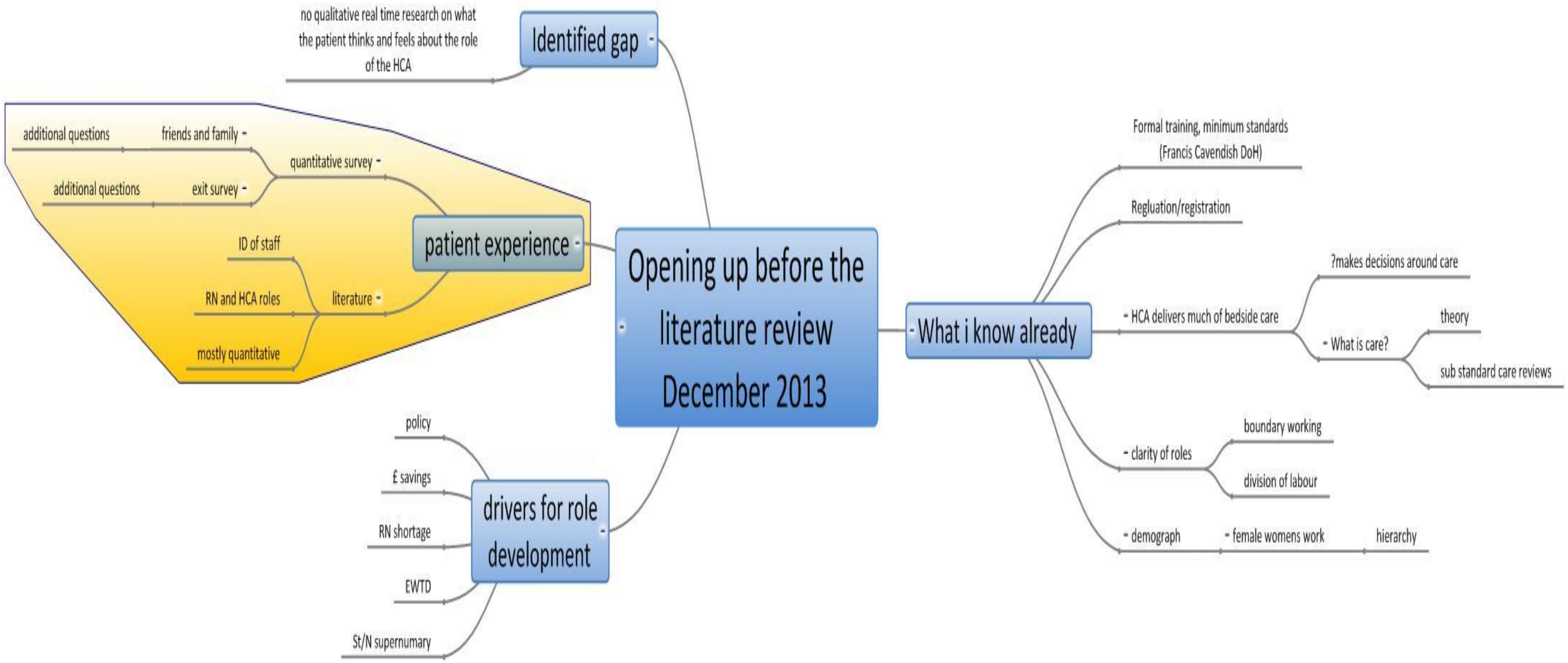
14.5.14 Attended a PGR seminar led by a post- doctoral student who presented GT and SA. This was a really informative session and I was comforted to recognise much of what he was saying. One thing that was key that I need to review is the conceptual framework. Alison and Pauline have alluded to the importance of congruence and although I don't want to "shut down" any potential lenses I may be viewing this research process through I do need to start thinking more now in terms of this.

Thoughts therefore on Conceptual framework are:

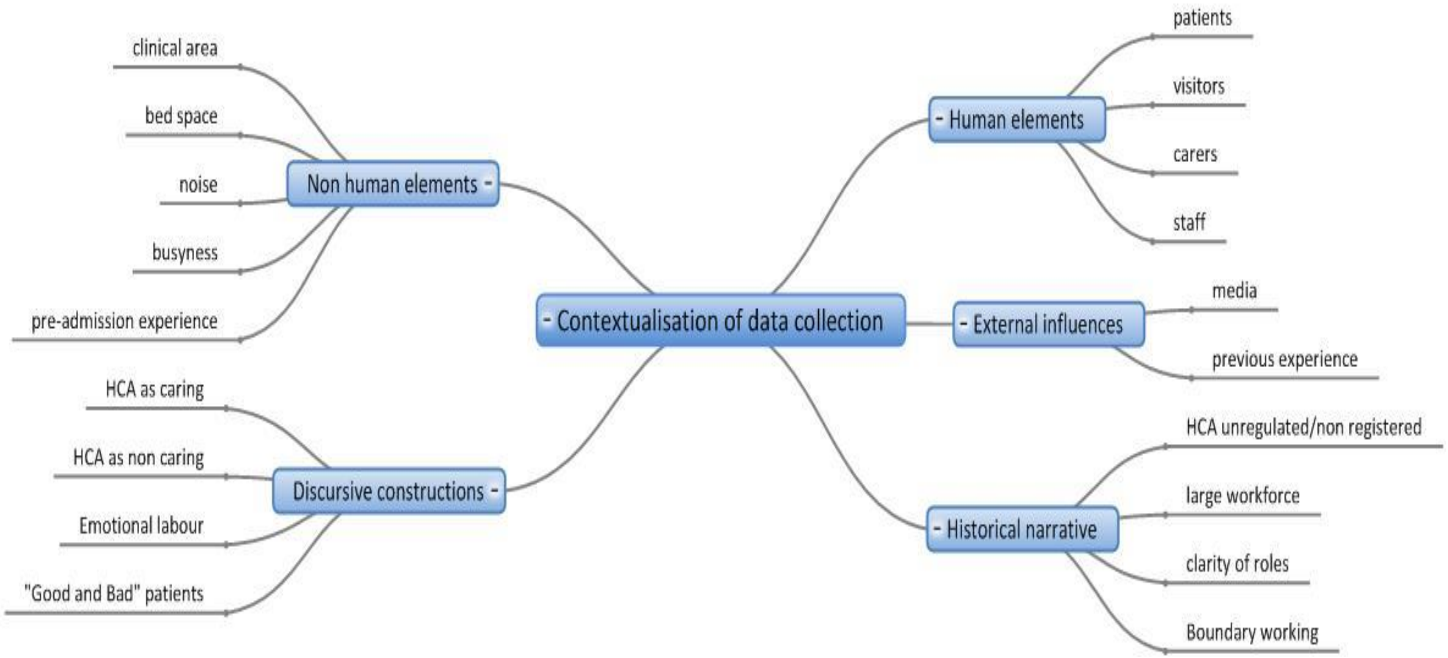
Grounded Theory as a process, underpinned by Symbolic Interactionism as a way of seeing things. The context is important for looking at the (medical ward compared to OPD) then SA will need to be a framework I gather data from. The data therefore comes from the situation with a sensitivity to this that awareness will bring.

Appendix 3.1-3.4

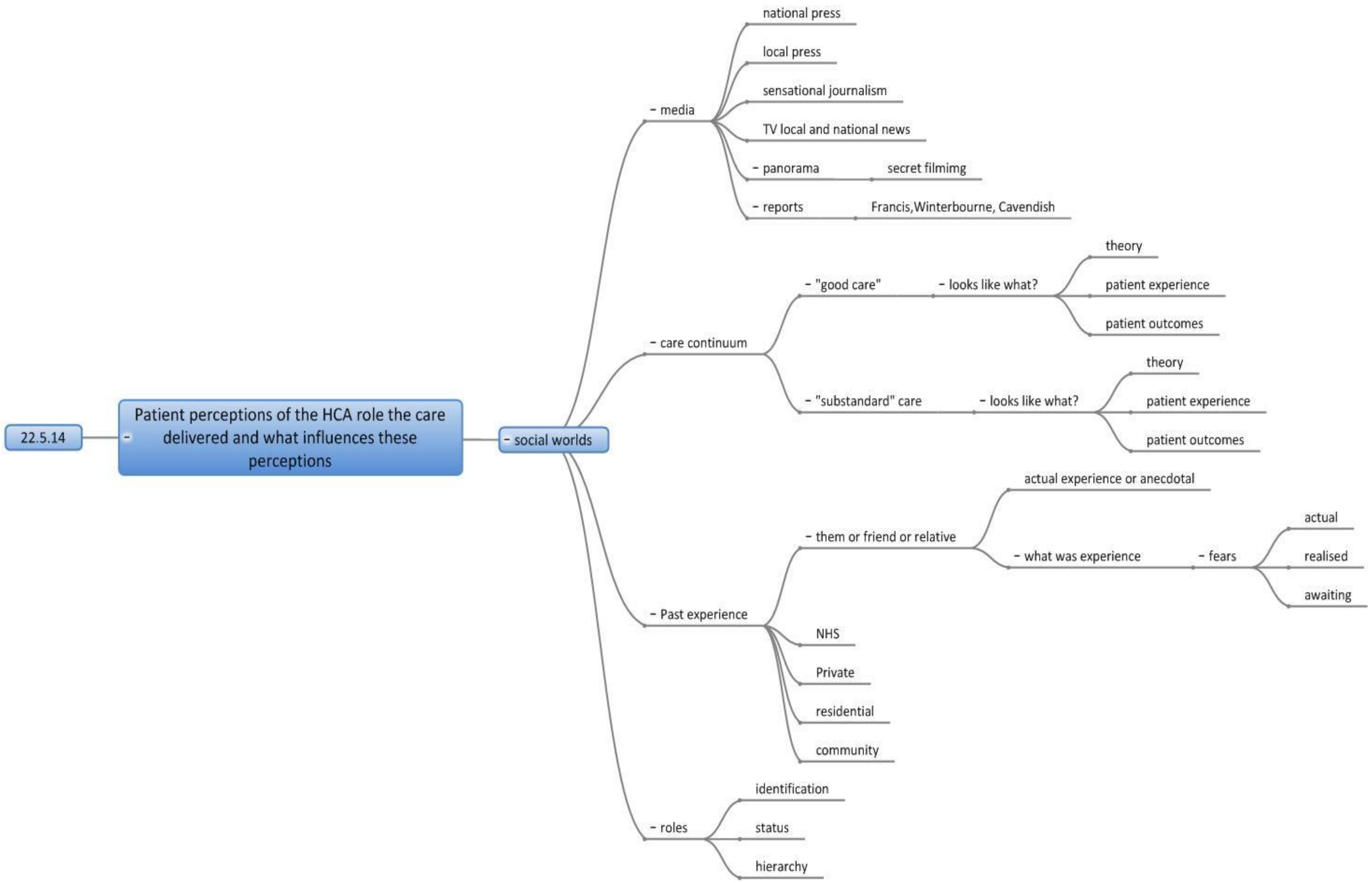
Maps and Mapping exercises



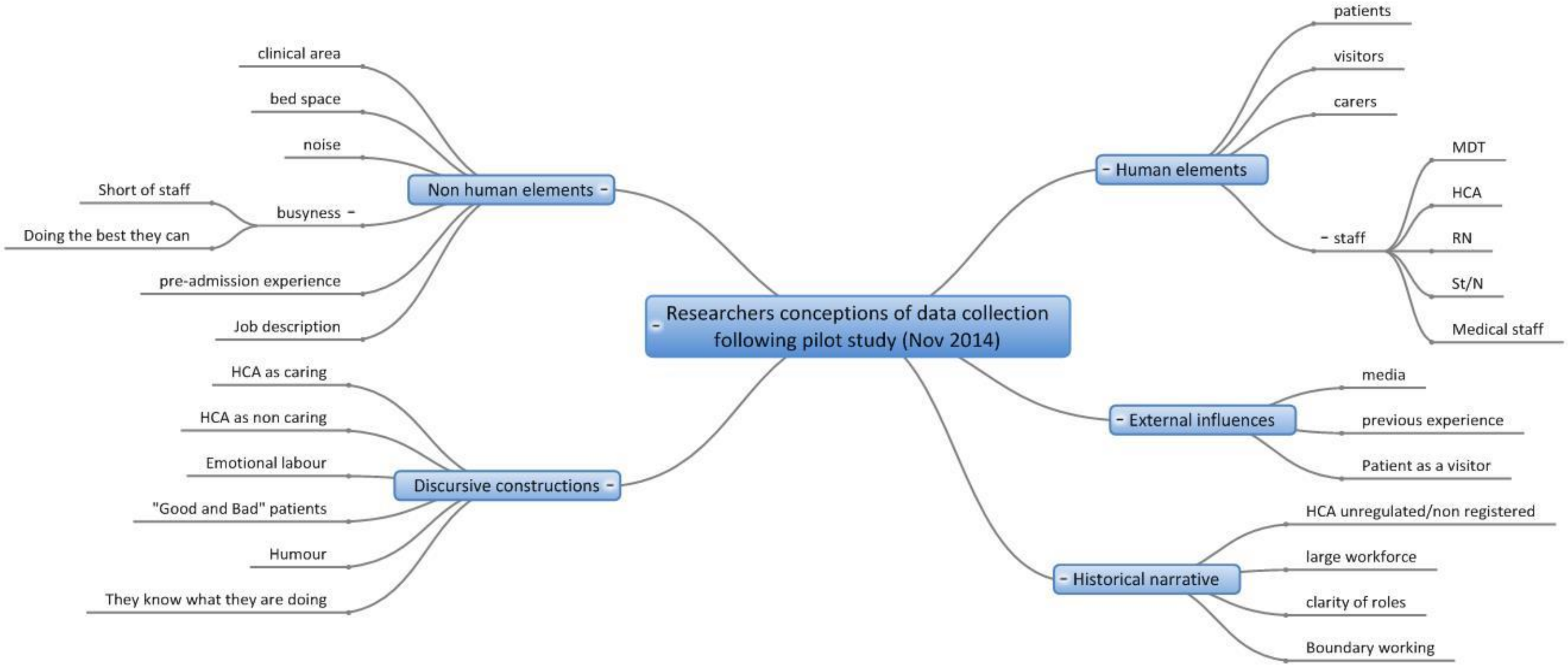
3.1 Opening up what I already knew before the literature review.



3.2 Contextualising the data collection



3.3 Thinking about what I know before data collection



3.4 Rethinking what I know post pilot interviews

Appendix 4

Critical reading and writing

Title: **Date reviewed**:

<u>Why am I reading this?</u>

<u>What are the authors trying to do in writing this?</u>

<u>What are the authors saying that is relevant to what I want to find out?</u>

<u>How convincing is what the authors are saying?</u>

<u>In conclusion what use can I make of this?</u>

Appendix 5

5.1- 5.3 Letter of explanation, Information sheet, consent.

5.1 letter of explanation

[redacted]

northumbria
UNIVERSITY NEWCASTLE

Sarah Morey RGN, BA (Hons), MSc
PhD Research Student
Northumbria University
Coach Lane
Newcastle Upon Tyne
NE7 7XA
Tel No 0191 2326002

Dear Patients, carers, visitors and staff. (Version 1.3)

General information about some research activity in the clinical area.

"What perceptions do patients hold of the Health Care Assistant role and the care delivered and what influences these perceptions?"

The aim of this research study is to explore patients' perceptions of the HCA role within an NHS Foundation Trust. You are either a patient, a carer, a visitor or a member of staff where this research will be conducted.

This information sheet is designed to inform you why the research is being done and what it would involve for you should you be interested in taking part.

The research is being conducted by Sarah Morey who is a registered nurse and a full time research student at Northumbria University. This research study will form part of her PhD study.

In 3-6 days' time Sarah Morey will commence her research within this clinical area. The research activity consists of interviews with patients that have agreed to participate. No staff will be interviewed as part of this research.

For patients who would like to take part an information sheet is available which details the research and what you will be agreeing to do if you agree to take part. Please read this carefully.

Thank you for taking the time to read this letter.

Yours faithfully,

SMorey

Sarah Morey RGN, BA (Hons), MSc

5.2 Information sheet

northumbria
UNIVERSITY NEWCASTLE

Sarah Morey RGN, BA (Hons), MSc
PhD Research Student
Northumbria University
Coach Lane
Newcastle Upon Tyne
NE7 7XA
Tel No 0191 2326002

Research Study Information Sheet
Patient Interview (Version 1.3)

"What perceptions do patients hold of the Health Care Assistant role and the care delivered and what influences these perceptions?"

What is the purpose of the study?
The aim of this project is to explore the perception patients hold of the Health Care Assistant (HCA) role.

Why have I been asked to take part in this study?
You have been asked to take part in this study because you are a patient within a clinical area taking part in this research project.

Do I have to take part in the study?
No, it is up to you to decide if you wish to take part. Sarah Morey, the researcher, will meet with you to discuss the study in more detail. You will also have an opportunity ask any questions you may have.

If you agree to take part then Sarah will ask you to sign a consent form to confirm this. You are free to withdraw from the study at anytime, without giving a reason. Withdrawal will not affect the care you receive in any way and your decision to withdraw will not be shared with anyone.

What am I being asked to do?
If you decide to take part in this study you will be asked to participate in an individual interview with Sarah. This will take approximately 45 to 60 minutes of your time. The interview will be recorded to accurately document your responses.

Are there any disadvantages to taking part?
You may also experience the potential inconvenience of having to take part in an Interview which may last for up to 60 minutes. There also may be the possibility you may find discussing aspects of your care upsetting. The researcher will listen carefully to your comments and offer support where appropriate. There may also be the possibility you inform the researcher about an incident that may require further support where the nurse in charge will need to be informed so that appropriate support for yourself can be put in place and where the incident can be investigated further.

What are the benefits of taking part?
There are not direct benefits to taking part in this study.

CONFIDENTIALITY

Collecting the data
The data for this study will be collected using a Digital Dictaphone Recorder during the interview. Once the interview has ended the recording will be transcribed and a written record of the discussions will be created. The data will be anonymised so that you cannot be identified. All personnel involved in the project are bound by the NHS Confidentiality Policy and the Data Protection Act.

Storage of the interview tapes, transcripts and other papers
The digital recordings will be erased once they have been transcribed. The paper-based transcriptions will be kept in a locked cupboard at Northumbria University until the research is completed. This cupboard is accessed only by the researcher. These documents are link-anonymised and are marked by your unique study identifier.

The only individual who will have access to the digital recordings and paper documents is Sarah, the researcher.

Any information which is produced as part of the project will not bear your name.

What will happen to the results of the research study?
The results will form part of a report which will be completed by 2016. This report will not be made available to study participants. The results will be published in education and health care journals and within a PhD dissertation. You will not be identified in any publication although your words may be published exactly as you said them during the interview.

Who is funding this study?
Sarah Morey is supported and sponsored by Northumbria University through its programme of PhD studentships.

Who has reviewed this study?

The proposed research has been reviewed by an NHS Research Ethics Committee (INSERT NAME) and the Research & Development team within [redacted]

Where can I find further information about the research?

In the first instance please contact:
Mrs Sarah Morey – Principal Investigator xxxxxx

If you are unhappy about this study please contact:
Dr Alison Steven- PhD Supervisor xxxxx

General Information about research can be obtained from PALS [redacted]

If I take part can I withdraw from the study at a later date?

You can withdraw from the study at any time. Simply inform Sarah during the interview that you would like to withdraw.

When you indicate your intention to withdraw from this study Sarah will ask for your permission to keep and use the information that you have already given. If you do not give your permission for this then all of your study data will be destroyed.

Complaints

If you have concerns about any aspect of this study please speak to either Sarah Morey, or her PhD Supervisor (details below) and we will do our best to address these. You may wish to make a complaint directly through a member of the care team [redacted] and the clinical area you are in. This process will be supported by the researcher to ensure the appropriate member of staff is made aware of your complaint
Alternatively you may wish to speak with a member of the PALs team for free and confidential advise.

Researcher	Sarah Morey Northumbria University Telephone xxxxx e-mail sarah.morey@northumbria.ac.uk
PhD Supervisor	Dr Alison Steven Northumbria University Telephone xxxxx e-mail Alison.steven@northumbria.ac.uk
PALS	Telephone xxxxx

Information disclosure

Sarah Morey is a Registered Nurse and is governed by the Nursing and Midwifery Council (NMC), he will inform you at the initial meeting of the NMC code (2008), and also the NMC raising and escalating concerns guidance (2010)

Research Team

Principal Investigator Sarah Morey Northumbria University
Telephone xxxxx
e-mail sarah.morey@northumbria.ac.uk

PhD Supervisor Dr Alison Steven Northumbria University
Telephone xxxxx
e-mail Alison.steven@northumbria.ac.uk

5.3 Consent for interview and workshop

Sarah Morey RGN, BA (Hons), MSc
PhD Research Student
Northumbria University
Coach Lane
Newcastle Upon Tyne
NE7 7XA
Tel No 0191 2326002

CONSENT FORM (Version 1.3)

Patient interview

"What perceptions do patients hold of the HCA role and the care delivered and what influences these perceptions?"

Please initial the box

YES

1, I confirm that I have read and understand the information sheet dated ………… (Version 1.1) ☐

2, I have had the opportunity to consider the information, ask questions about the study, and these have been answered to my satisfaction ☐

3, I am willing to be interviewed ☐

4, I am happy for my comments to be recorded and my words used in the research ☐

5, I am happy for my comments to be audio recorded and my words used in the research ☐

6, I understand that my participation is voluntary; I can withdraw at any time without giving reason if I change my mind and this will not affect me in any way ☐

7, I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐

8, I understand my name and details will be kept confidential, and will not appear in any printed documents ☐

9, I know that because of the study sample that I could be identified ☐

and that the researcher will attempt to maintain anonymity
when writing reports

10, I agree to take part in the above study ☐

I ………………………………… [name of participant] understand the information presented to me by

……………………………[name of researcher] and agree to take part in the research

Signature ……………………………… [Participant] **Date ……………….**

Signature ……………………………… [Researcher] **Date ………………..**

[redacted]

northumbria
UNIVERSITY NEWCASTLE

Sarah Morey RGN, BA (Hons), MSc
PhD Research Student
Northumbria University
Coach Lane
Newcastle Upon Tyne
NE7 7XA
Tel No 0191 2326002

CONSENT FORM (Version 1.3)

Past Patient Workshop

“What perceptions do patients hold of the HCA role and the care delivered and what influences these perceptions?”

Please initial the box

YES

1, I confirm that I have read and understand the information
sheet dated ………… (Version 1.3) ☐

2, I have had the opportunity to consider the information, ask questions
about the study, and these have been answered to my satisfaction ☐

3, I am willing to be interviewed and participate in the workshop ☐

4, I am happy for my comments to be recorded and
my words used in the research ☐

5, I am happy for my comments to be audio recorded and
my words used in the research ☐

6, I understand that my participation is voluntary; I can withdraw at any time
without giving reason if I change my mind and this will not affect me in any way ☐

7, I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐

☐

8, I understand my name and details will be kept confidential, and will not appear in any printed documents

9, I know that because of the study sample that I could be identified and that the researcher will attempt to maintain anonymity when writing reports ☐

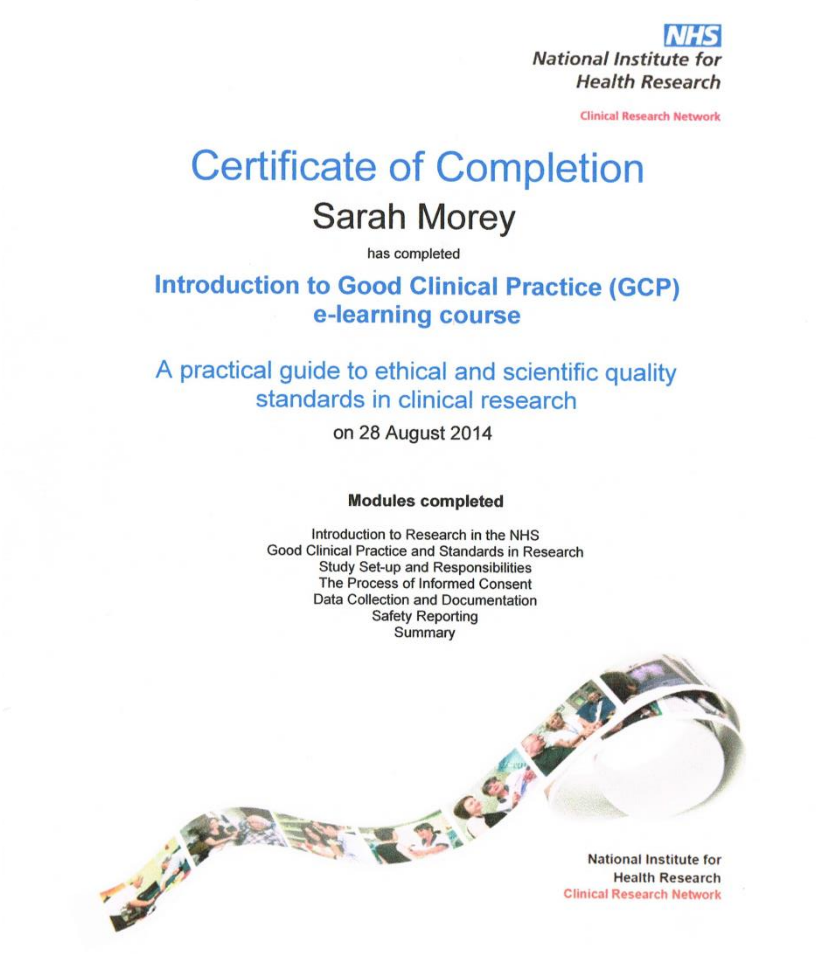
10, I agree to take part in the above study ☐

I …………………………………. [name of participant] understand the information presented to me by ……………………………[name of researcher] and agree to take part in the research

Signature ………………………………. [Participant] **Date ………………**

Signature ………………………………. [Researcher] **Date ………………..**

5.4 Good Clinical Practice Certificate of Completion



NHS
National Institute for
Health Research
Clinical Research Network

Certificate of Completion

Sarah Morey

has completed

**Introduction to Good Clinical Practice (GCP)
e-learning course**

A practical guide to ethical and scientific quality
standards in clinical research

on 28 August 2014

Modules completed

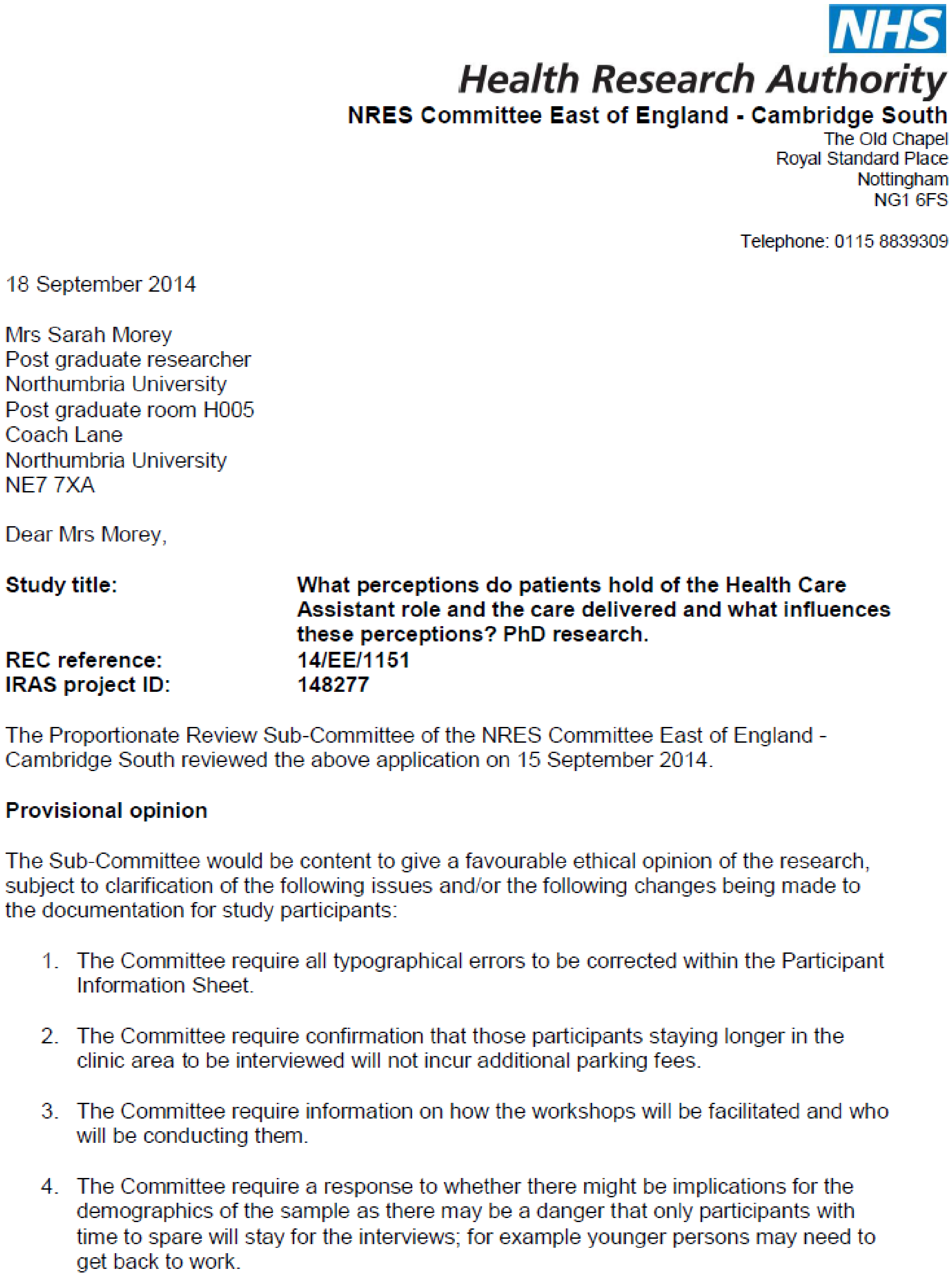
Introduction to Research in the NHS
Good Clinical Practice and Standards in Research
Study Set-up and Responsibilities
The Process of Informed Consent
Data Collection and Documentation
Safety Reporting
Summary

National Institute for
Health Research
Clinical Research Network

5.5 Additional Ethics documentation

University Ethical approval was reached in May 2014

IRAS REC approval was reached 7th October 2014



NHS
Health Research Authority
NRES Committee East of England - Cambridge South
The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Telephone: 0115 8839309

18 September 2014

Mrs Sarah Morey
Post graduate researcher
Northumbria University
Post graduate room H005
Coach Lane
Northumbria University
NE7 7XA

Dear Mrs Morey,

Study title:	**What perceptions do patients hold of the Health Care Assistant role and the care delivered and what influences these perceptions? PhD research.**
REC reference:	**14/EE/1151**
IRAS project ID:	**148277**

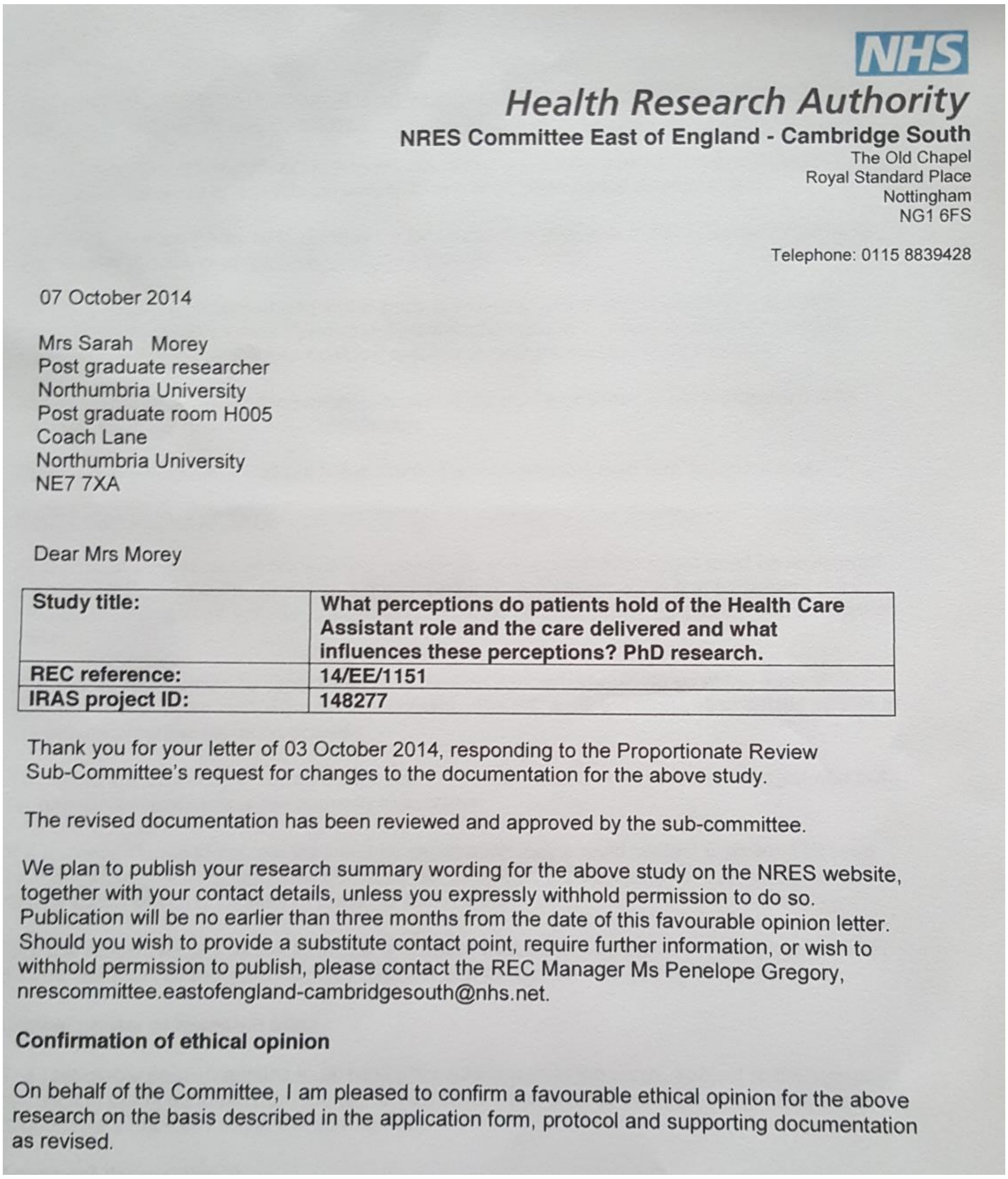
The Proportionate Review Sub-Committee of the NRES Committee East of England - Cambridge South reviewed the above application on 15 September 2014.

Provisional opinion

The Sub-Committee would be content to give a favourable ethical opinion of the research, subject to clarification of the following issues and/or the following changes being made to the documentation for study participants:

1. The Committee require all typographical errors to be corrected within the Participant Information Sheet.
2. The Committee require confirmation that those participants staying longer in the clinic area to be interviewed will not incur additional parking fees.
3. The Committee require information on how the workshops will be facilitated and who will be conducting them.
4. The Committee require a response to whether there might be implications for the demographics of the sample as there may be a danger that only participants with time to spare will stay for the interviews; for example younger persons may need to get back to work.

Initial NRES Approval



NHS
Health Research Authority
NRES Committee East of England - Cambridge South
The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Telephone: 0115 8839428

07 October 2014

Mrs Sarah Morey
Post graduate researcher
Northumbria University
Post graduate room H005
Coach Lane
Northumbria University
NE7 7XA

Dear Mrs Morey

Study title:	**What perceptions do patients hold of the Health Care Assistant role and the care delivered and what influences these perceptions? PhD research.**
REC reference:	**14/EE/1151**
IRAS project ID:	**148277**

Thank you for your letter of 03 October 2014, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the REC Manager Ms Penelope Gregory, nrescommittee.eastofengland-cambridgesouth@nhs.net.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Final NRES Approval

Appendix 5.5- 4.7 Interview guides Phases 1-3

Phase 1

Initial Grounded Theory Interview Schedule for Patients.

This document provides an outline of the types of questions the researcher seeks to undertake.

The methodology of grounded theory is such that interview followed by analysis will inform the subsequent interviews and so on until data saturation is reached.

It is therefore important to note that the interview questions are only a guide as to style, approach and content.

Semi-structured interview with patients

Date of interview_______________

Clinical area___________________

Within study file there will be a participant list that details name and age of the patient along with study identifier. This sheet will remain within the study file at all times.

Provide an Introduction

Thank you for agreeing to this interview

Ensure participant is happy to be interviewed and have this recorded

Ensure participant is happy with the information sheet they were provided with, have read it, and have had all questions answered prior to this interview

Ensure participant has read and signed the consent form, and is still happy to take part in the interview

Inform the participant of the reason for the interview

To gain an understanding of their own personal perceptions of the role of the HCA and the care delivered.

Ground rules

This interview space is to be a safe environment where all information, views and opinions are to be treated as confidential, and should not be discussed outside this room.

The researcher is working with the Nurse in charge of Out Patients to secure a consultation room to ensure confidentiality at all times for all patient interviews.

All information will be recorded then anonymised during the transcription phase

I may have to ask you for clarity of certain information if needed

Please do not name other members of staff or patients or refer to them by name

Please just try and relax; this is an interview surrounding your own views and understandings.

I am a registered Nurse, and so I am governed by the NMC Code, and raising and escalating concerns, if there is any information that I feel in my professional opinion that needs to be addressed or escalated I will refer to the NMC raising and escalating framework, (copy to be provided to the participant)

Initial Open- ended Questions

1. Can you tell me about your recent interaction with the HCA?
2. Could you tell me what was going on before you asked for help?
3. Could you tell me what was going on before the HCA came over to you?
4. How were you feeling?
5. What was it about the care you received that made you feel better/worse?
6. What is your awareness of the different nursing and care roles on the ward?

Intermediate Questions

1. Can you tell me about a time when a HCA cared for you?
2. What was good about that episode?
3. If you look back during your time on the ward can you recall any other events that stand out?
4. Can you tell me what makes a good HCA?
5. What do you think are the most important qualities for the HCA?

Ending Questions

1. Tell me about what views you had about the HCA role before you came into hospital?
2. What are your views now?
3. What advice would you give a friend who was being looked after by the HCA?
4. Is there anything else you would like to tell me?

End of interview

Have you anything more you would like to add to this interview.

Thank you for your time

Appendix 5.6

Phase 2 Post Pilot Questions for Patient Interview

What is your understanding about the different nursing and healthcare roles on the ward/OPD?

If there is understanding and the patient know what the HCA role is then move to left hand column. If there is little or no insight into the role difference between RN and HCA then move to the right hand column:

Can you tell me about a recent interaction between you and a HCA on the ward/in clinic?	Can you tell me what you understand about the nurse? Grades, uniform, roles and responsibilities?
Can you tell me what was going on before the HCA came over to you/asked for help?	Can you tell me about a time when one of the nurses came to assist you? Can researcher Identify whether it is a HCA or RN from description of activity/uniform or straight immediate Identification of staff member?
How were you feeling?	How were you feeling?
What was it about the care that made you feel better/worse? Explore	What was it about the care that made you feel better/worse? Explore
What were your expectations before you came into hospital about the staff that would care for you?	What were your expectations before you came into hospital about the nurses that would care for you?
What experiences have you had that make you think/feel that?	What experiences have you had that make you think/feel that?
If you look back can you recall any interactions or events between you	If you look back can you recall any interactions or events between you

and the HCA that you think are important?	and the nurse that you think are important? Can the researcher identify if the nurse is HCA or a RN?
What are your thoughts now about the HCA role?	What are your thoughts now about the nurses' role? Is the grade, experience, qualification of the nurse/HCA important to you?
What advice would you give a friend who was being looked after by a HCA for the first time in hospital/clinic?	What advice would you give a friend who was being looked after by a HCA for the first time in hospital/clinic?

Appendix 5.7

Phase 3 semi structured interview guide.

Reputation of Hospital/ ward/ clinical area? Has this influenced experience?

Is there a dependency on staff bringing the outside world into the clinical area through communication?

What does HCA bring to your relationship?

Are staff interested? In their job? In you as a patient?

What do they know about you?

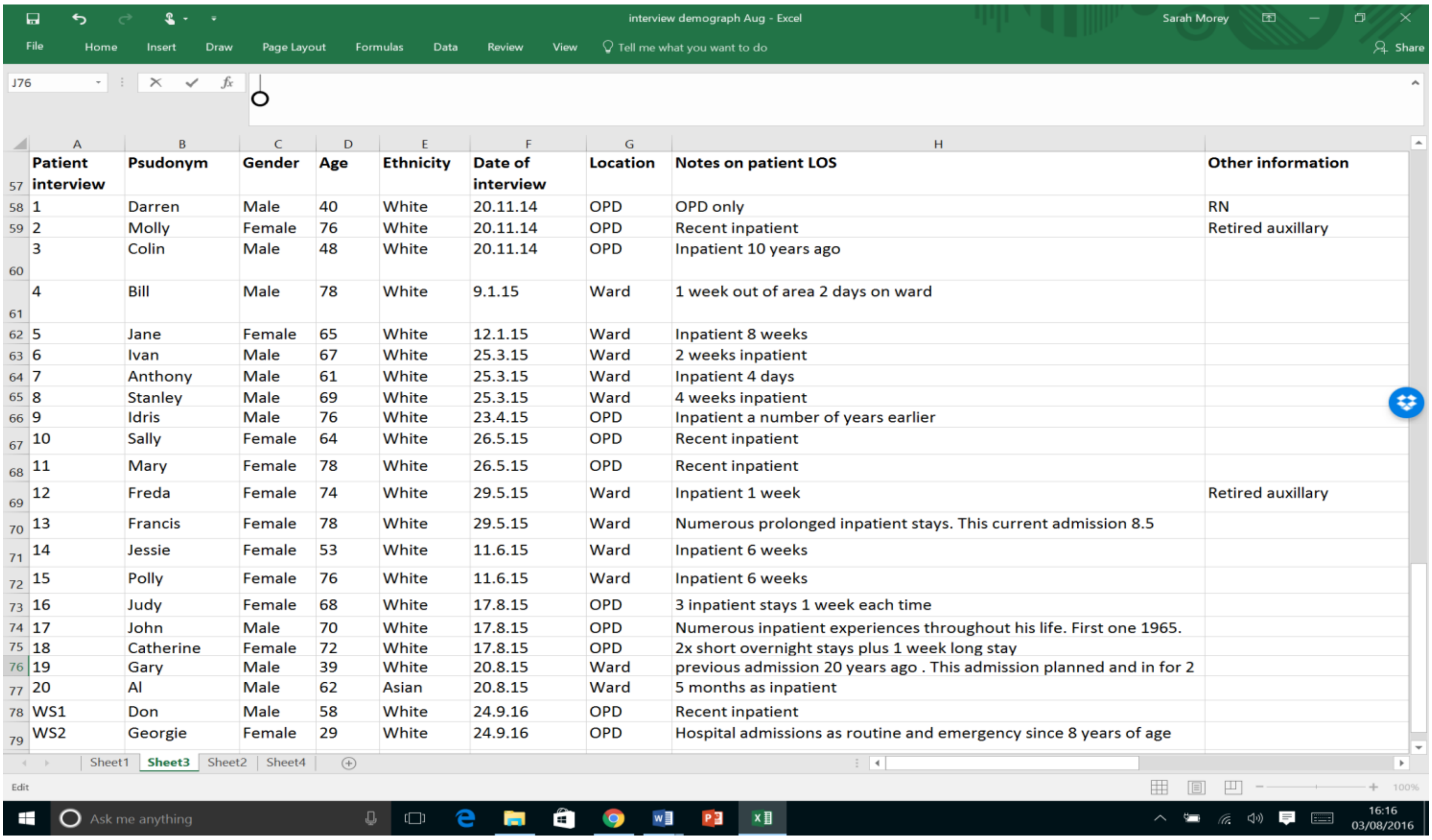
Do staff know you? What makes you think that they do?

Is there an equity between you and the staff at a human level?

How does that impact on you as a patient?

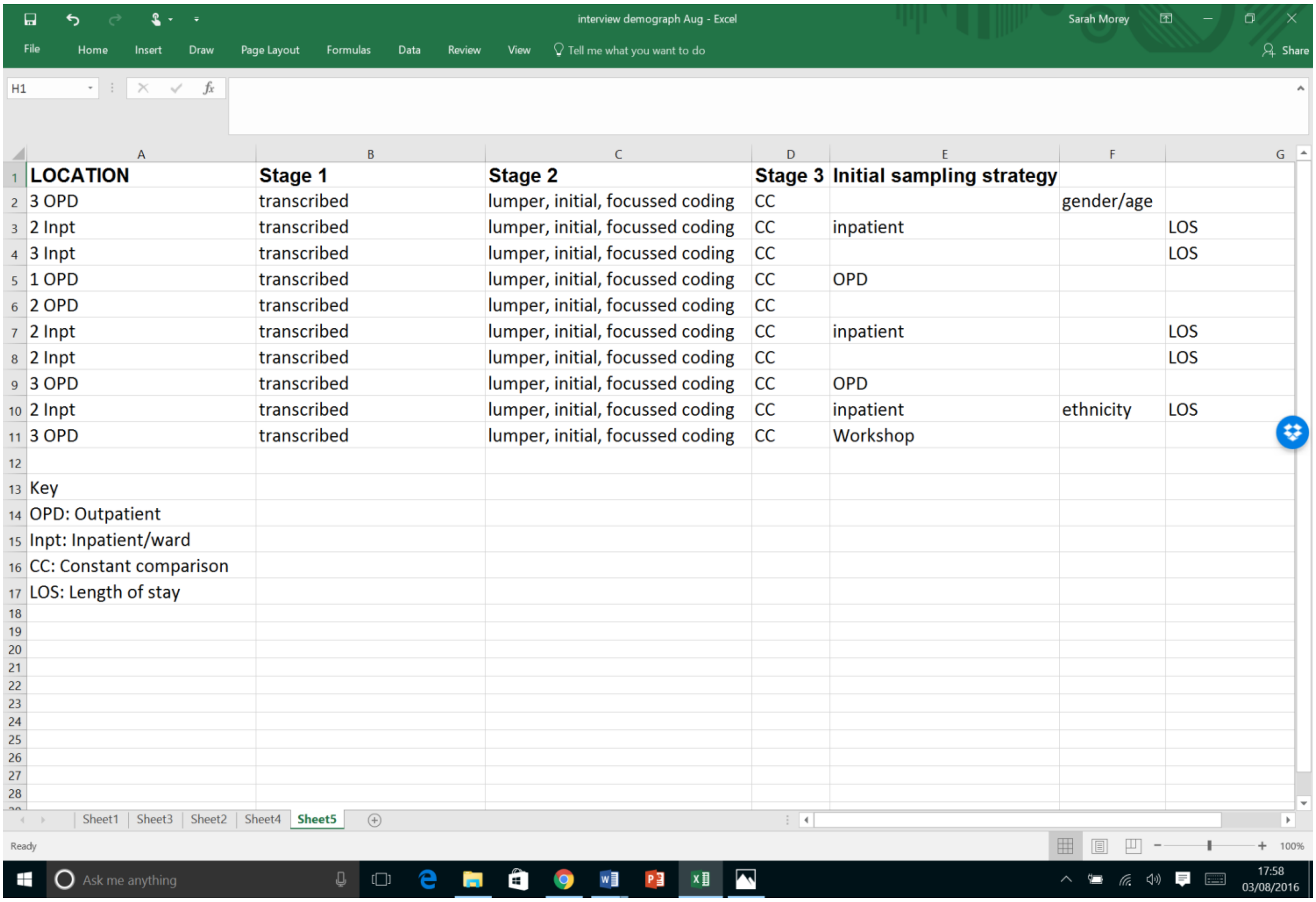
Where is the RN? What is the RN doing? What is important work? Why?
On the ball staff? How do you know that? What tells you they know what they are doing?
Not nice things? How do you feel?

Appendix 6 Demographic details



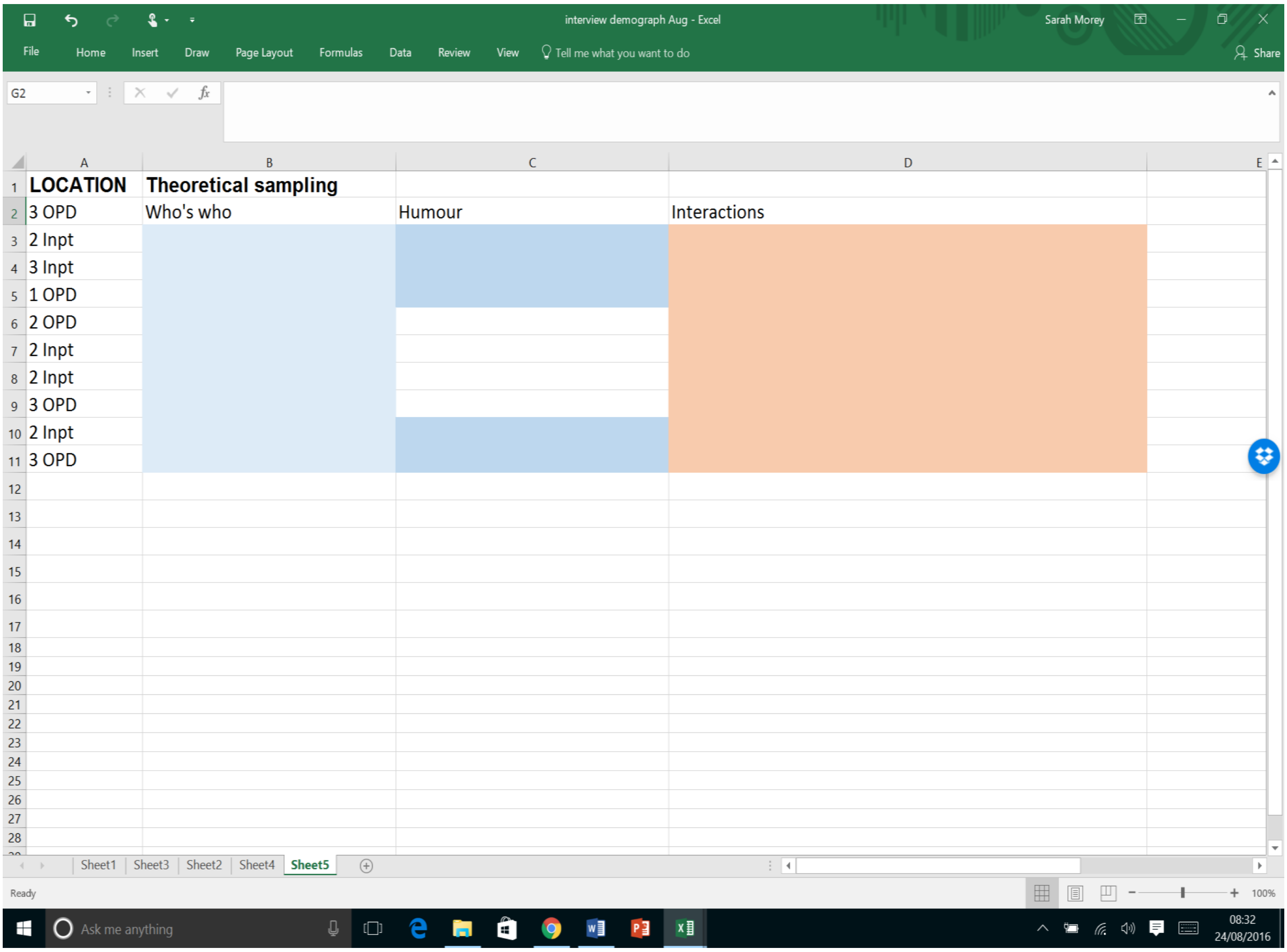
Patient interview	Psudonym	Gender	Age	Ethnicity	Date of interview	Location	Notes on patient LOS	Other information
1	Darren	Male	40	White	20.11.14	OPD	OPD only	RN
2	Molly	Female	76	White	20.11.14	OPD	Recent inpatient	Retired auxillary
3	Colin	Male	48	White	20.11.14	OPD	Inpatient 10 years ago	
4	Bill	Male	78	White	9.1.15	Ward	1 week out of area 2 days on ward	
5	Jane	Female	65	White	12.1.15	Ward	Inpatient 8 weeks	
6	Ivan	Male	67	White	25.3.15	Ward	2 weeks inpatient	
7	Anthony	Male	61	White	25.3.15	Ward	Inpatient 4 days	
8	Stanley	Male	69	White	25.3.15	Ward	4 weeks inpatient	
9	Idris	Male	76	White	23.4.15	OPD	Inpatient a number of years earlier	
10	Sally	Female	64	White	26.5.15	OPD	Recent inpatient	
11	Mary	Female	78	White	26.5.15	OPD	Recent inpatient	
12	Freda	Female	74	White	29.5.15	Ward	Inpatient 1 week	Retired auxillary
13	Francis	Female	78	White	29.5.15	Ward	Numerous prolonged inpatient stays. This current admission 8.5	
14	Jessie	Female	53	White	11.6.15	Ward	Inpatient 6 weeks	
15	Polly	Female	76	White	11.6.15	Ward	Inpatient 6 weeks	
16	Judy	Female	68	White	17.8.15	OPD	3 inpatient stays 1 week each time	
17	John	Male	70	White	17.8.15	OPD	Numerous inpatient experiences throughout his life. First one 1965.	
18	Catherine	Female	72	White	17.8.15	OPD	2x short overnight stays plus 1 week long stay	
19	Gary	Male	39	White	20.8.15	Ward	previous admission 20 years ago . This admission planned and in for 2	
20	Al	Male	62	Asian	20.8.15	Ward	5 months as inpatient	
WS1	Don	Male	58	White	24.9.16	OPD	Recent inpatient	
WS2	Georgie	Female	29	White	24.9.16	OPD	Hospital admissions as routine and emergency since 8 years of age	

Appendix 7.1-7.2 Sampling



	A	B	C	D	E	F	G
1	**LOCATION**	**Stage 1**	**Stage 2**	**Stage 3**	**Initial sampling strategy**		
2	3 OPD	transcribed	lumper, initial, focussed coding	CC		gender/age	
3	2 Inpt	transcribed	lumper, initial, focussed coding	CC	inpatient		LOS
4	3 Inpt	transcribed	lumper, initial, focussed coding	CC			LOS
5	1 OPD	transcribed	lumper, initial, focussed coding	CC	OPD		
6	2 OPD	transcribed	lumper, initial, focussed coding	CC			
7	2 Inpt	transcribed	lumper, initial, focussed coding	CC	inpatient		LOS
8	2 Inpt	transcribed	lumper, initial, focussed coding	CC			LOS
9	3 OPD	transcribed	lumper, initial, focussed coding	CC	OPD		
10	2 Inpt	transcribed	lumper, initial, focussed coding	CC	inpatient	ethnicity	LOS
11	3 OPD	transcribed	lumper, initial, focussed coding	CC	Workshop		
12							
13	Key						
14	OPD: Outpatient						
15	Inpt: Inpatient/ward						
16	CC: Constant comparison						
17	LOS: Length of stay						

7.1 Initial sampling



LOCATION	Theoretical sampling		
3 OPD	Who's who	Humour	Interactions
2 Inpt	🟦	🟦	🟧
3 Inpt	🟦	🟦	🟧
1 OPD	🟦	🟦	🟧
2 OPD	🟦		🟧
2 Inpt	🟦		🟧
2 Inpt	🟦		🟧
3 OPD	🟦		🟧
2 Inpt	🟦	🟦	🟧
3 OPD	🟦	🟦	🟧

7.2 Theoretical sampling illustrating some of the emerging codes relating to participants.

Appendix 8

Memos and notes on observation

Observational notes 20.11.14. (Thursday 10.30)

Micro level.

The main OPD area was busy as patient and relatives filled coffee shops, and rest areas.

Main desk area for the xxxx clinic held that day had clerks and staff nurses around it. Bales of brown notes sat behind desk area. I was taken to Clinic Sister who asked me what I needed and then took me around to the haematology clinic which was quieter. The running of the clinic was quiet, controlled and efficient. There was no excessive noise or disturbance. Area was clean and tidy. There were no obvious interruptions to the flow of activity

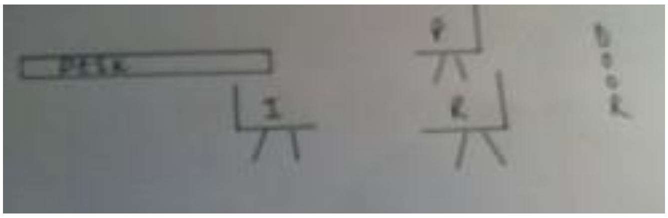
The clinic comprised of 1X Consultant. 1X Specialist/Consultant Nurse. These staff members were working within their own rooms so I did not get to meet them. The ‘running’ of the clinic was managed by 2X HCA. One HCA in particular took charge of the situation asking me if I needed a room and what I would require from them.

I was shown into a clinic room where I sat at a desk with my notes and voice recorder.

I then returned to the HCA to ask if there were ‘suitable patients’ for interview sitting within the waiting area. 2 patients were identified and I went out to this area to see if I could ask them if they were willing to consider participating. This approach continued for the 3 initial interviews that took place that day.

- Interview 1 alone
- Interview 2 with husband
- Interview 3 alone and willing to wait as I was late with the second interview.

Position of interviewer and interviewee



I: Interviewer
P: Participant
R: Relative

I did not observe any display/notice illustrating a uniform who's who.

Meso level.

When I asked for a JD for the HCA staff in OPD I was told it is the generic JD for all the HCAs in the depart.

Macro level.

The winter pressure for A&E were regularly hitting the media where there were a number of report at a local and national level.

Observational notes 21.3.15 Ward xxx

Macro level

A&E winter pressures, targets and delays are tailing off or certainly there is little in the news about this. The election in May dominates the news and papers with little on NHS at present.

Care certificate talked about and launched.

Meso level

Spoke to Ward Sister briefly. She told me the JD is a generic one for the Trust. She has mostly band 2 with a number of band 3's which are a historical inheritance.

Micro level

Similar layout to ward xxx. Bays of 6 and some cubicles. Cubicles were further down the ward area beyond the nurse's station which was located half way down on left. I arrived about 11.40 on Wednesday morning. The ward was quiet, with most patients in or around their own bed space. Staff were either at the nurse's station or else were in the bays preparing for lunch. It was interesting to note on my pre visit earlier the HCA stated I was most welcome to come back but that it would not be possible during protected meal times. This was an interesting observation as no one else had stated there was an issue during mealtime visiting to the ward.

Ward xxx is a mixed sex ward with a speciality of liver disease. Patients are therefore in for some time and some have undergone some quite invasive surgery.

- Interview 6 male in cubicle
- Interview 7 male in bed 1 of a bay of 6
- Interview 8 male in bed 4 of a bay of 6.

It was very, very quiet during interview 6 in the cubicle, there was very little noise or activity outside the door. This was during mealtimes but as he was not eating or drinking (NBM) and away from the rest of the ward area the HCA did not stop me interviewing him. Interview 7 and 8 were after lunch in separate bays but both had a degree of activity with interview 8 having a little more as the observations were being done.

Although on listening to the recordings, there is noise and activity picked up it never felt a busy ward. There were staff around but they did not come in to any area unless there was work to do, a task to undertake or some message to convey.

No notice boards or staff ID info noted. Ward Sister when I left ward was in the office with the door open and we had a brief chat before I thanked her and left.

Observational notes OPD xxx 3 interviews August 2015

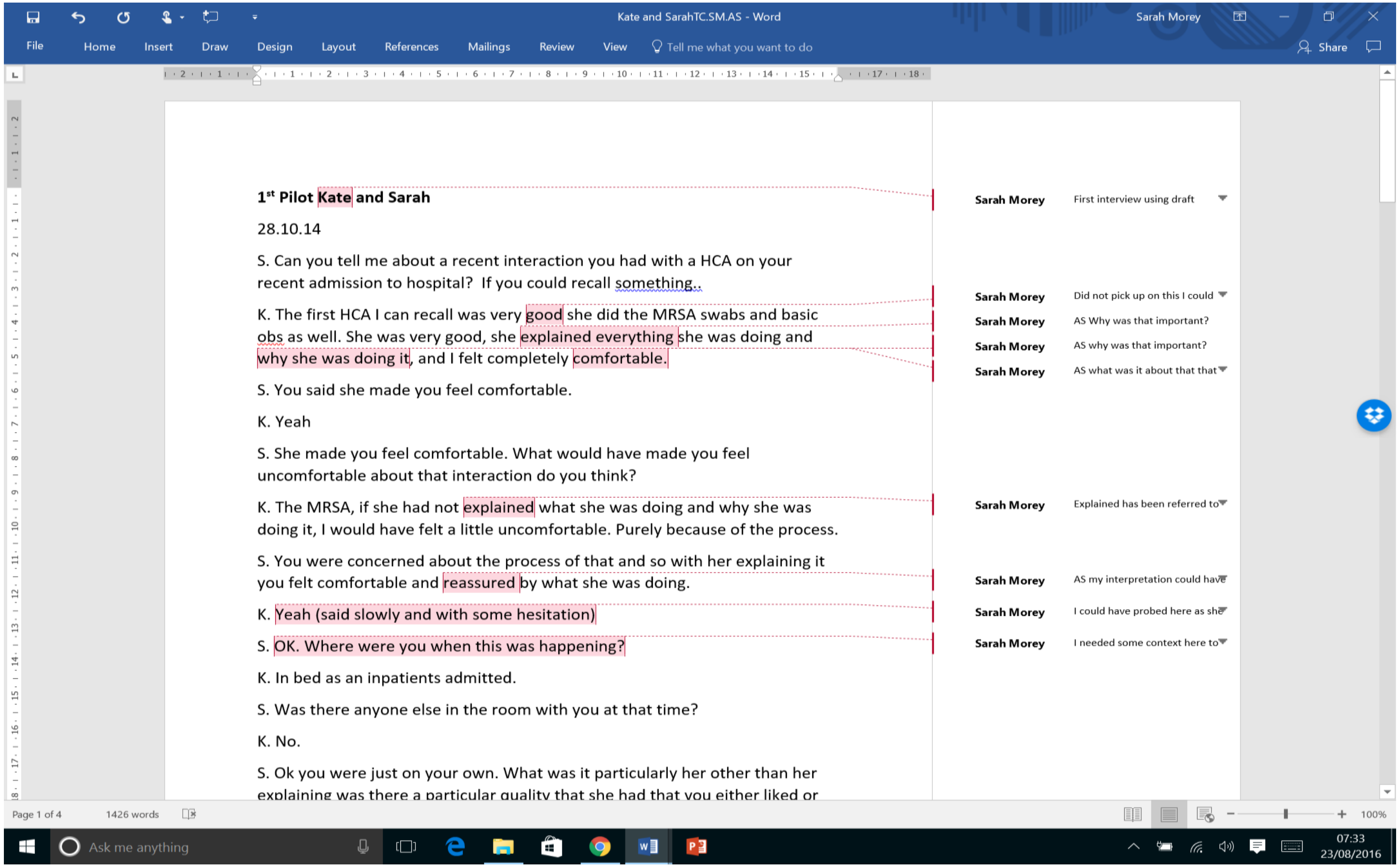
The clinic was really quiet. I was allocated room 8 where I had not interviewed before but it was much like all other clinic rooms.

Staff were really friendly and happy to help. I tried to start up a general conversation which was not easy but once I understood the HCA’s interest in her new job at the new xxxx clinic site we chatted about new roles and new buildings for a while until there were some patients I could approach to ask.

A well-dressed lady in her early 60’s was sat with her husband and although quite quiet she agreed to be interviewed after her appointment. Another gentleman was approached but he was not keen. I was anxious to get someone else on board as patients were looking few and far between. A junior staff nurse asked a gentleman who agreed and I then went to discuss with him what the interview was about.

Following on from these 2 interviews I then approached another clinic where they were running late. I managed to speak to the last patient, she was happy to be interviewed to pass the time.

Appendix 9 Improving my interview technique 1st and 2nd Pilot interview



1st Pilot Kate and Sarah

28.10.14

S. Can you tell me about a recent interaction you had with a HCA on your recent admission to hospital? If you could recall something..

K. The first HCA I can recall was very good she did the MRSA swabs and basic obs as well. She was very good, she explained everything she was doing and why she was doing it, and I felt completely comfortable.

S. You said she made you feel comfortable.

K. Yeah

S. She made you feel comfortable. What would have made you feel uncomfortable about that interaction do you think?

K. The MRSA, if she had not explained what she was doing and why she was doing it, I would have felt a little uncomfortable. Purely because of the process.

S. You were concerned about the process of that and so with her explaining it you felt comfortable and reassured by what she was doing.

K. Yeah (said slowly and with some hesitation)

S. OK. Where were you when this was happening?

K. In bed as an inpatients admitted.

S. Was there anyone else in the room with you at that time?

K. No.

S. Ok you were just on your own. What was it particularly her other than her explaining was there a particular quality that she had that you either liked or

Sarah Morey First interview using draft

Sarah Morey Did not pick up on this I could

Sarah Morey AS Why was that important?

Sarah Morey AS why was that important?

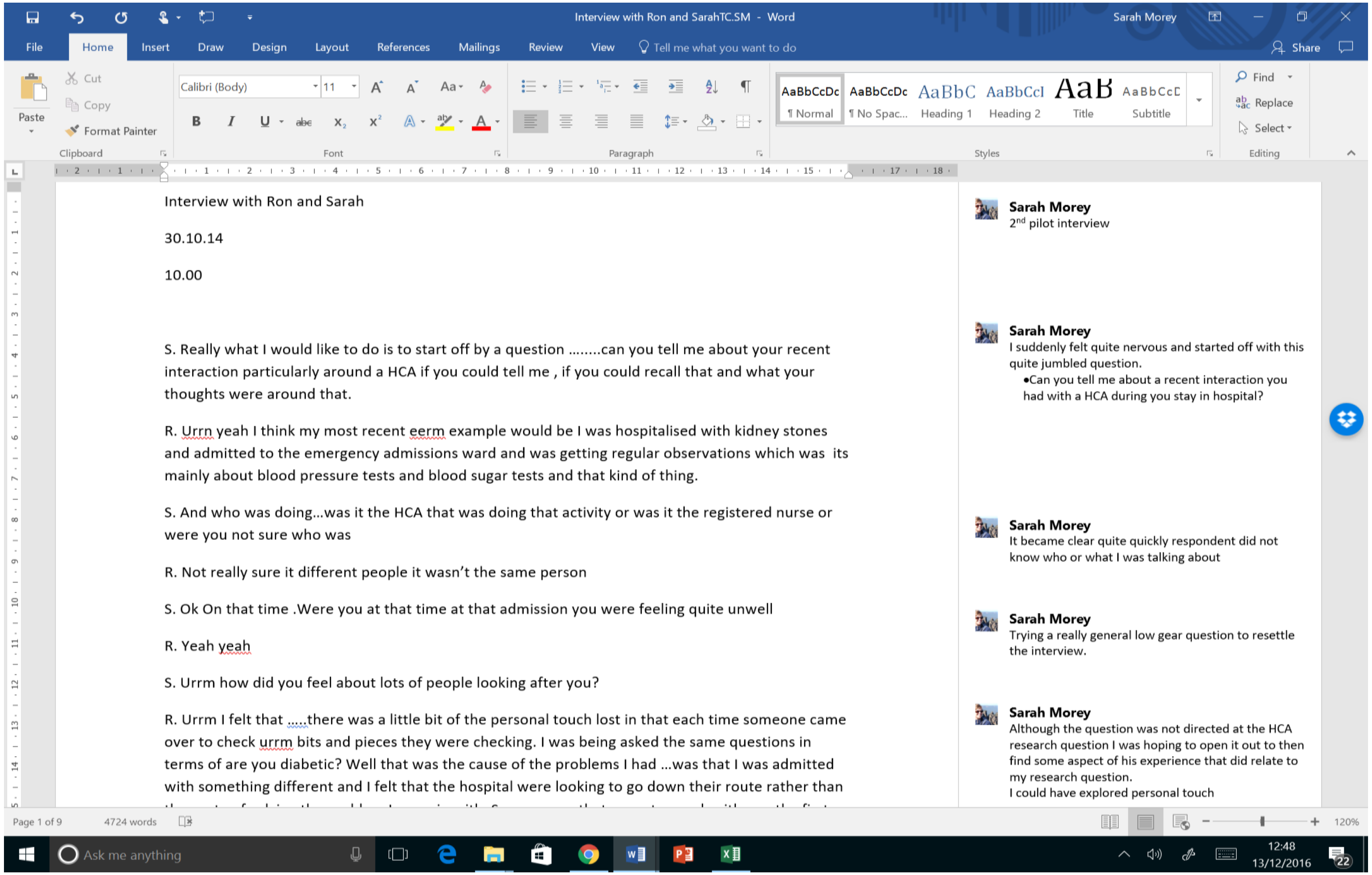
Sarah Morey AS what was it about that that

Sarah Morey Explained has been referred to

Sarah Morey AS my interpretation could have

Sarah Morey I could have probed here as she

Sarah Morey I needed some context here to



Interview with Ron and Sarah

30.10.14

10.00

S. Really what I would like to do is to start off by a question ……..can you tell me about your recent interaction particularly around a HCA if you could tell me , if you could recall that and what your thoughts were around that.

R. Urrn yeah I think my most recent eerm example would be I was hospitalised with kidney stones and admitted to the emergency admissions ward and was getting regular observations which was its mainly about blood pressure tests and blood sugar tests and that kind of thing.

S. And who was doing…was it the HCA that was doing that activity or was it the registered nurse or were you not sure who was

R. Not really sure it different people it wasn't the same person

S. Ok On that time .Were you at that time at that admission you were feeling quite unwell

R. Yeah yeah

S. Urrm how did you feel about lots of people looking after you?

R. Urrm I felt that …..there was a little bit of the personal touch lost in that each time someone came over to check urrm bits and pieces they were checking. I was being asked the same questions in terms of are you diabetic? Well that was the cause of the problems I had …was that I was admitted with something different and I felt that the hospital were looking to go down their route rather than

Sarah Morey
2nd pilot interview

Sarah Morey
I suddenly felt quite nervous and started off with this quite jumbled question.

- Can you tell me about a recent interaction you had with a HCA during you stay in hospital?

Sarah Morey
It became clear quite quickly respondent did not know who or what I was talking about

Sarah Morey
Trying a really general low gear question to resettle the interview.

Sarah Morey
Although the question was not directed at the HCA research question I was hoping to open it out to then find some aspect of his experience that did relate to my research question.
I could have explored personal touch

Screen shot 1&2: illustrating reflective work on improving interview technique

Appendix 10

Layout of 6 bedded bays

Observational notes.

The long corridor took the visitor to the ward past 4 bays of 6 on the left and 3 cubicles on the right. The nurse’s station was situated at the end of the ward where the ward rounds were being discussed and where there were a large number of staff.

These staff included clinical nurse specialists (I knew this or worked it out as the dialogue exchanged between ward nurses and these specialist roles was different to the ward nurse to ward nurse dialogue), ward nurses, and medics of numerous ranks.

Appendix 11

Sample of Reflective notes on interview locations

I did not notice staff notice/identification board inside or outside the ward. There were no leaflets in any of the bay areas or notices within the bay area giving this information.

10.1.15 13.00 Ward xx. The end of the ward was busy, lots of discussion and consultation going on. Phone ringing several times during my “waiting” at the nurse’s station for the ward sister and then the S/N. As you walked through the ward area there was an increase in the number of staff as you moved towards the nurse’s station. On several journeys up and down the ward there were no nurses noted at any time in any of the bays other than when I left S/N who had helped organise the interviews was doing the drug round and was within the bay.

During the interviews the curtains were around each of the participants so I was not aware of anyone entering each of the bays. There was some activity late on during the interview due to cleaning within the bay.

I cannot say that no one entered the bay while I was interviewing but I “heard” no dialogue between staff or any patient in the bay during the interviews.

Times that the interviews took place were Friday lunch time and Monday morning. I recognise that these are prime ward round times before and after the weekend, diverting activity away from the bedside and more activity at the nurse’s station and white board. There may well be times when there is rather more activity within bays and cubicles outside of these times that was not observed.

The ward was clean, tidy, patients appeared well cared for, there was no smell, no excessive noise and there was an air of control and calmness around the place.

I considered the potential for the interview conversation to be over heard and considered if each of the participant was also aware. Were participants concerned that any negative expressions would be met with reprisal from staff, was there an overwhelming sense of gratitude that rendered any thoughts of negativity obsolete, dismissed, disregarded or erased?

In comparison the OPD settings were “confidential” due to the interviews being held in one of the consulting rooms. Were these participants any less likely to express negative views? Looking back, I didn’t think so. Analysis of the data from both an inpatient more open interview and the OPD there was a fair balance between them both expressing positivity. I wondered therefore if this was not necessarily down to immediacy of the dialogue between me and the participant but was at a higher level where there was a sense of debt, or gratitude that transcended the interview.

Appendix 12a

Reflective notes on feedback session redesign.

I planned and scheduled two feedback sessions for the first week in August 2015 one for each site. Following recruitment from OPD across both sites these feedback sessions were to be held 7 days after the initial recruitment.

A large number of patients were approached and eventually I had commitment from 20 patients in total to attend either one or the other venue. Participants were given clear instructions as to the location, a letter of introduction and an information sheet about the research.

Nearly all of the patients approached were polite and listened to why I wanted to talk to them. I approached a number of patients with varying age, ethnicity and gender from what I could observe from the waiting area. Those that wanted to listen were interested and responded with positive comments similar to the following:

"I would like to help." "I can see the value of this and how important it will be." "I would like to contribute to this"

It was therefore with some surprise that no one turned up for either feedback session and I needed to reflect on why.

Reflections on my approach:

I did feel very apprehensive before I started to approach patients as the waiting rooms were really quiet and others could hear what I was saying. This was not necessarily a bad thing. I reasoned if they really did not want to attend they had time before I came over to make their excuses or prefer not to talk to me. I did however feel it was a big ask for patients to come back into hospital. The building may represent something significant and difficult for them in their own life. Perhaps my empathetic perception was somehow portrayed?

My other concern was that those who were local, were retired and relatively active were the ones saying they would attend. The 20 that said they would attend were of an average age of 65 plus and retired. For some patients, there was desire to contribute, they wanted to feedback and felt it was their duty to do so, altruistically. If this altruism waivered over the week, then perhaps they felt less inclined to return.

Possible solutions: I was also concerned about coercion and was perhaps less forceful than I could have been, I therefore considered adopting a form that would get potential participants to “commit” which looked something like the following:

Name/Number	Age category	Gender	Ethnicity	Site 1	Site 2

This was to address the participants saying yes because they want to please and the social acceptability by giving them a form to “commit” to may get them to be more truthful about their intentions.

Alternatively, I considered employing the University patient group. Could I consider a lunchtime after warfarin OPD clinic? Patients are usually in every week for bloods and are used to waiting however efficient the phlebotomy service is. There is a real problem however with this as patient flow cannot be interrupted.

I could however still access both inpatient and OPD for participants and so I pursued the idea of “presenting” a number of findings to some participants in OPD individually. The interview would be different but not the access, timing and location. An application was sent to the University ethics panel for approval which was granted.

The feedback session “presentation” of findings interviews involved 3 individual patients and were completed in October 2015.

Appendix 12b sample questions and quotes from feedback sessions

Georgie (FB 2)

I. "They come and talk to you for as long as they can" that's something else that somebody said.

R: Yes I suppose they've got to go round everyone but yes, they do spend time with you.

I: And what is it about here?

R: Well just got more faith in them. I know that I had what happened to me but touch wood they fixed my stomach.

I: Okay.

R: And I was so bad – and I was so grateful for what they done…

Johnny (FB 3)

I: So as I said I've conducted a number of interviews. I've got some findings here, just some quotes and references that patients have said. It's just really to find out whether you agree or disagree, or if you've got anything to add to that. Now do you know who the healthcare assistant is?

R: Not particularly.

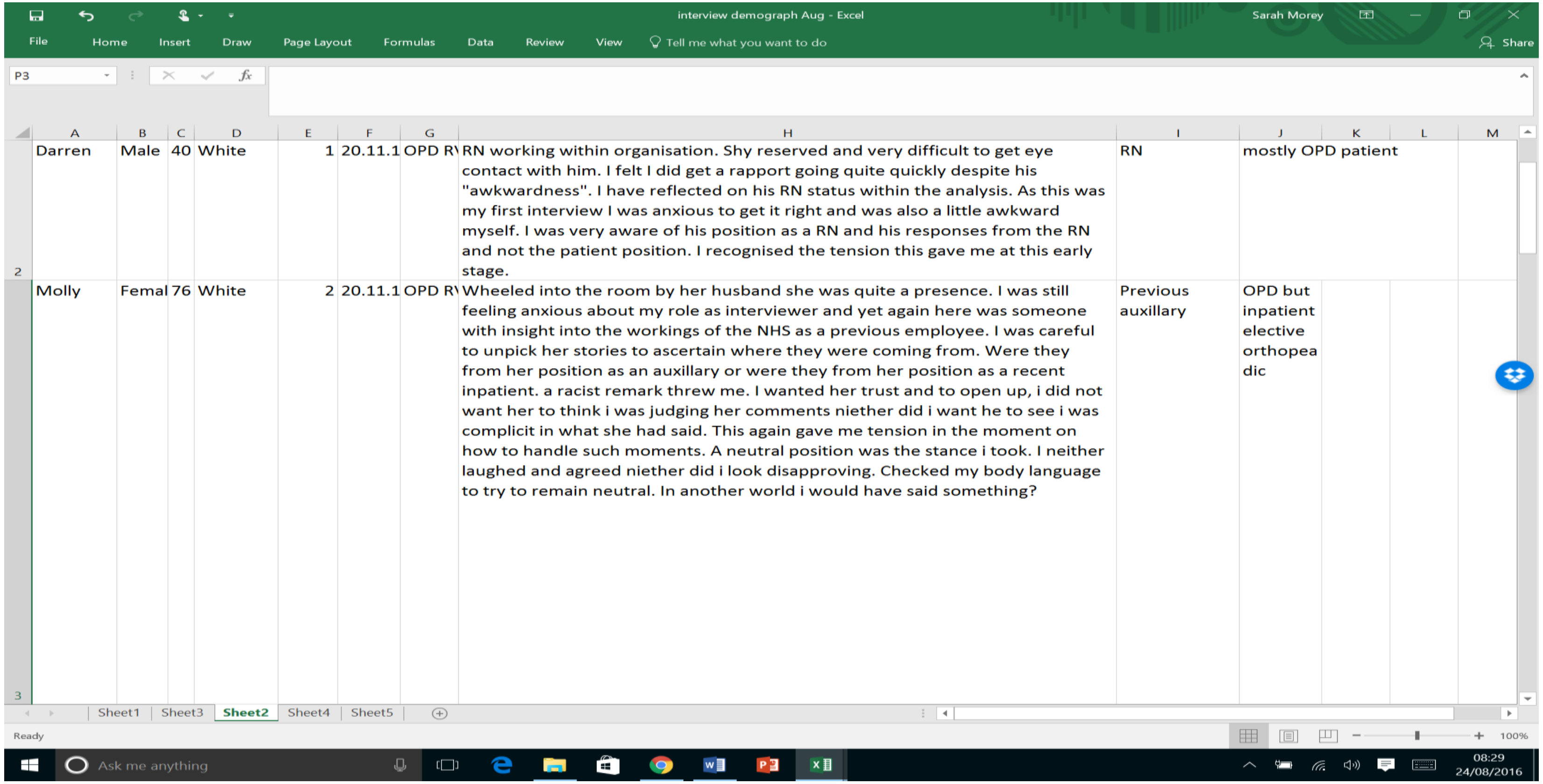
I: Okay, so they're the nursing staff that are dressed in white with the brown epaulettes on. Does that make sense who they are now?

R: It used to be auxiliary nurses.

I: More than duty. Somebody said they're gifted, I know I can rely on them, their caring is unreal.

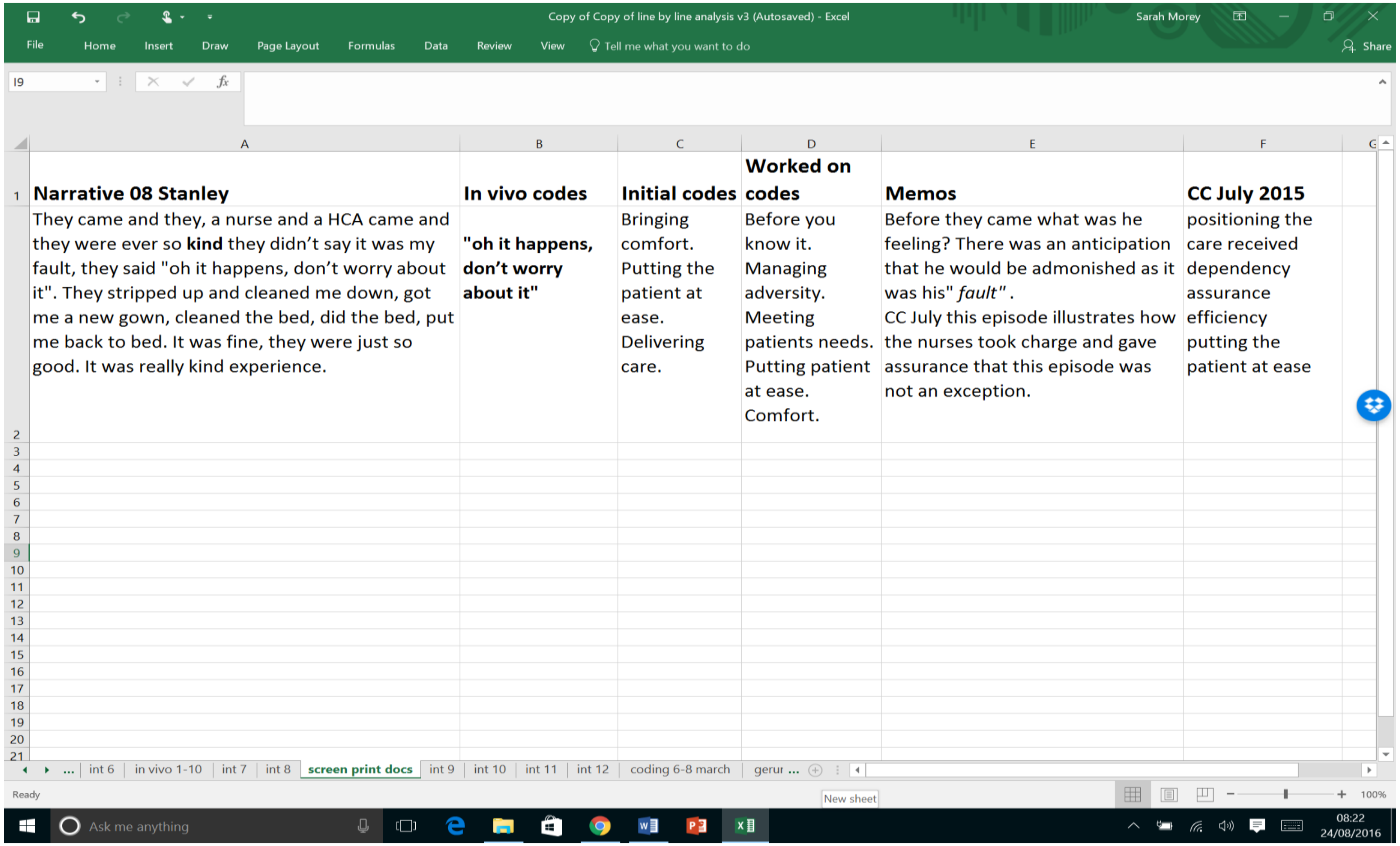
R: Yes. Yes, if you get the same ones and you manage to get to know them a little bit, yes.

Appendix 13 Data coding and analysis images



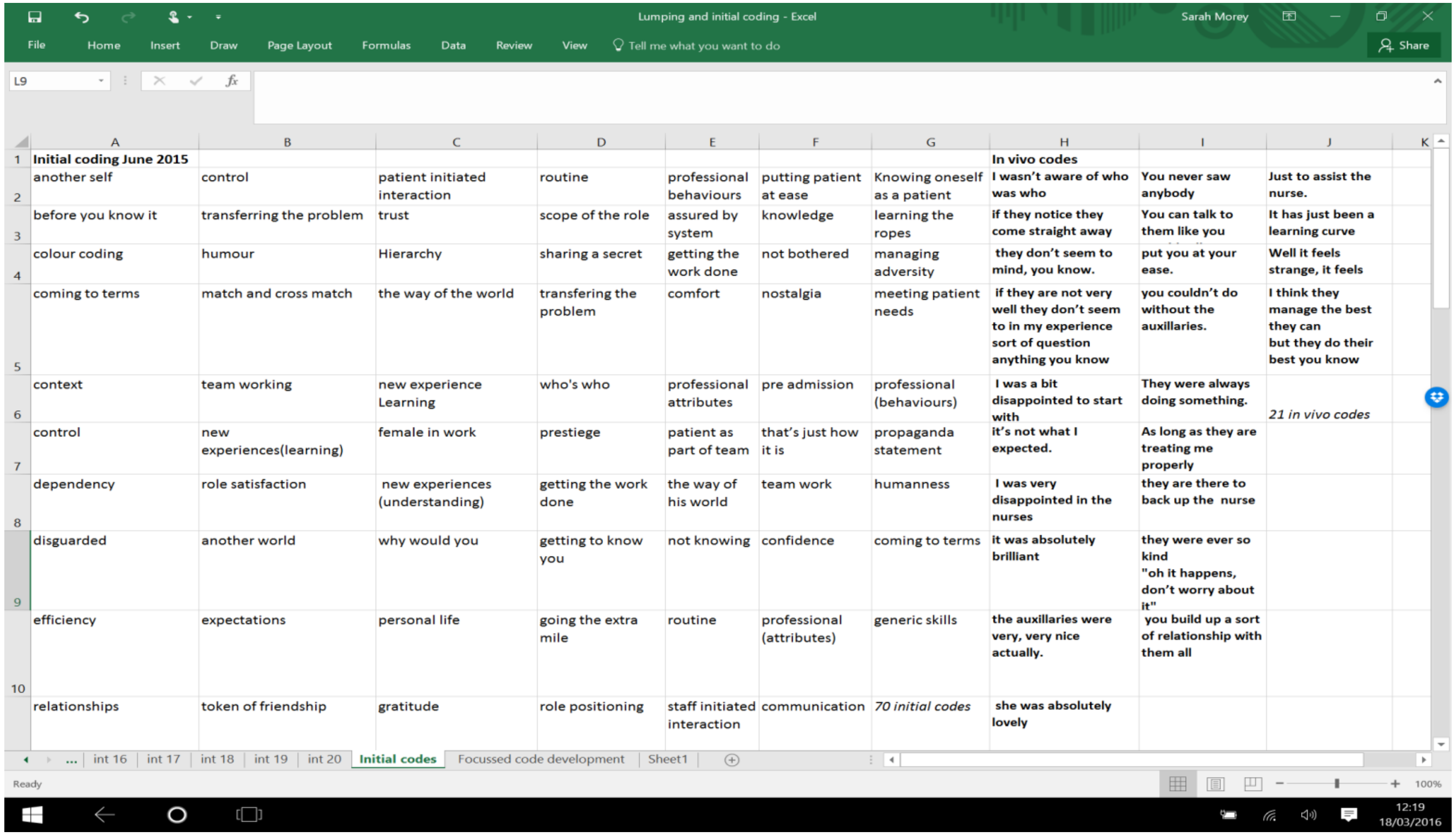
	A	B	C	D	E	F	G	H	I	J	K	L	M
2	Darren	Male	40	White	1	20.11.1	OPD R\	RN working within organisation. Shy reserved and very difficult to get eye contact with him. I felt I did get a rapport going quite quickly despite his "awkwardness". I have reflected on his RN status within the analysis. As this was my first interview I was anxious to get it right and was also a little awkward myself. I was very aware of his position as a RN and his responses from the RN and not the patient position. I recognised the tension this gave me at this early stage.	RN	mostly OPD patient			
3	Molly	Femal	76	White	2	20.11.1	OPD R\	Wheeled into the room by her husband she was quite a presence. I was still feeling anxious about my role as interviewer and yet again here was someone with insight into the workings of the NHS as a previous employee. I was careful to unpick her stories to ascertain where they were coming from. Were they from her position as an auxillary or were they from her position as a recent inpatient. a racist remark threw me. I wanted her trust and to open up, i did not want her to think i was judging her comments niether did i want he to see i was complicit in what she had said. This again gave me tension in the moment on how to handle such moments. A neutral position was the stance i took. I neither laughed and agreed niether did i look disapproving. Checked my body language to try to remain neutral. In another world i would have said something?	Previous auxillary	OPD but inpatient elective orthopeadic			

Screen shot 3: illustrating analytic/reflective memos.



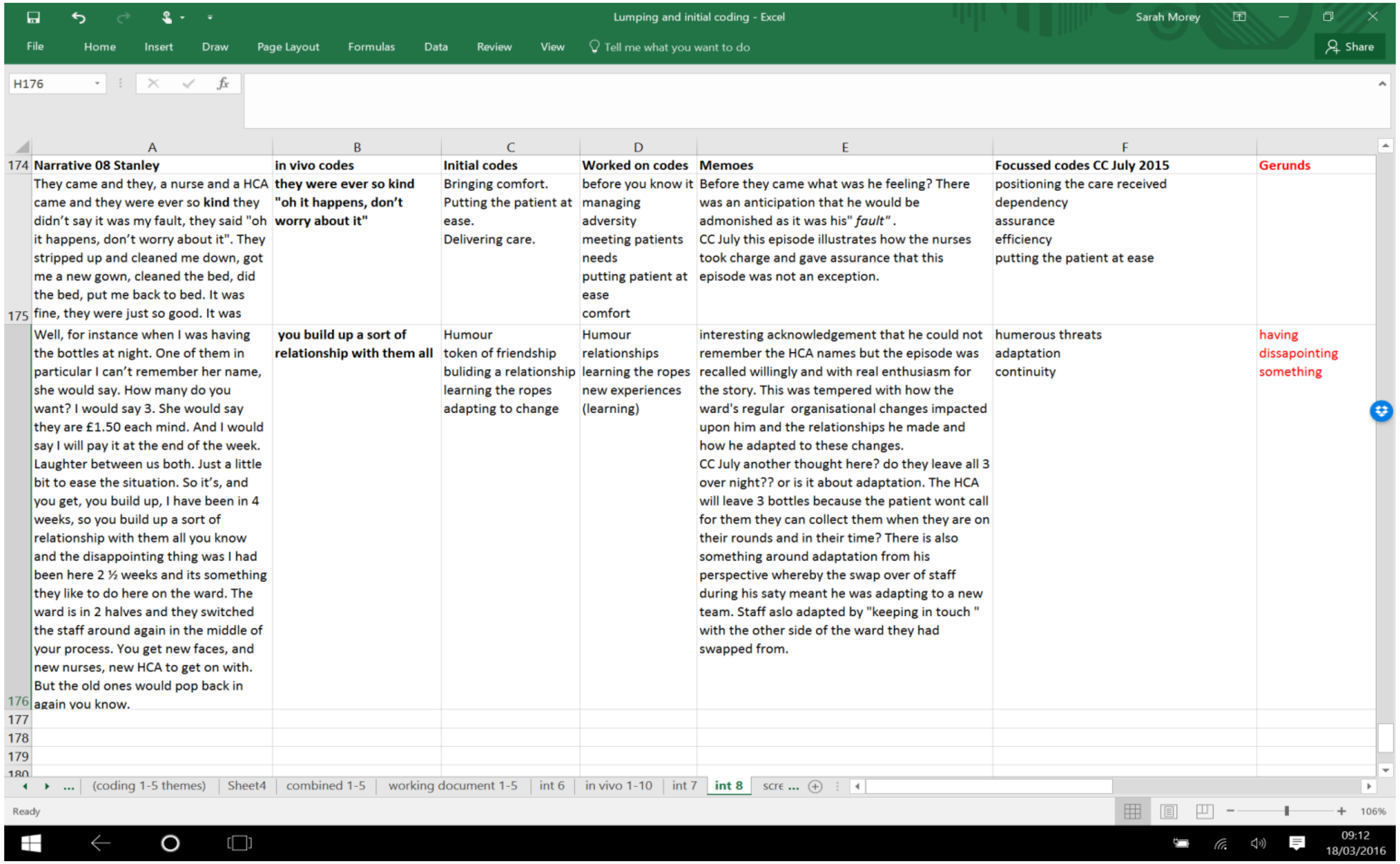
Narrative 08 Stanley	In vivo codes	Initial codes	Worked on codes	Memos	CC July 2015
They came and they, a nurse and a HCA came and they were ever so **kind** they didn't say it was my fault, they said "oh it happens, don't worry about it". They stripped up and cleaned me down, got me a new gown, cleaned the bed, did the bed, put me back to bed. It was fine, they were just so good. It was really kind experience.	**"oh it happens, don't worry about it"**	Bringing comfort. Putting the patient at ease. Delivering care.	Before you know it. Managing adversity. Meeting patients needs. Putting patient at ease. Comfort.	Before they came what was he feeling? There was an anticipation that he would be admonished as it was his" *fault*" . CC July this episode illustrates how the nurses took charge and gave assurance that this episode was not an exception.	positioning the care received dependency assurance efficiency putting the patient at ease

Screen shot 4: illustrating lumper coding, line by line analysis, mining the data for gerunds, in vivo codes and generation of initial codes.



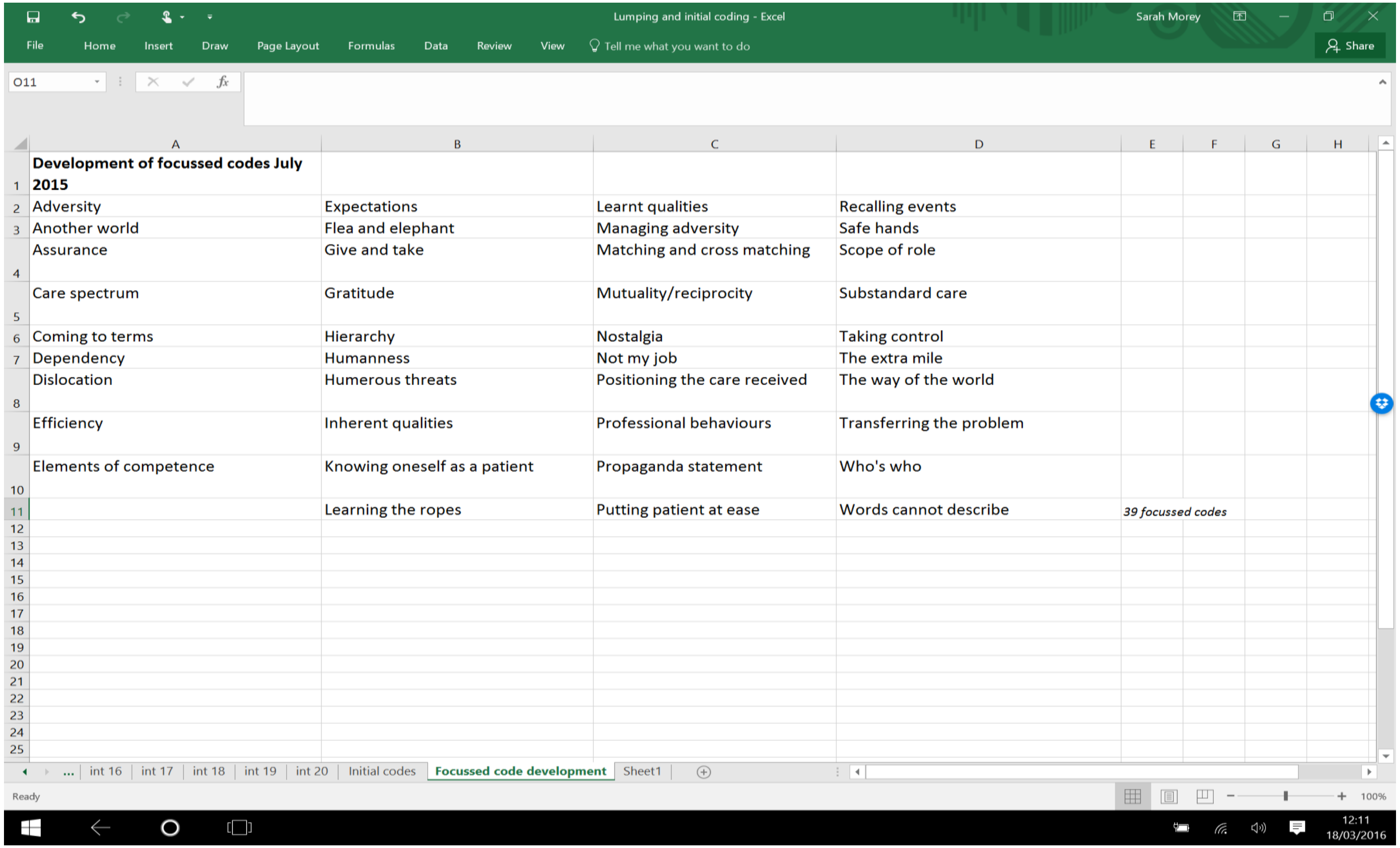
	A	B	C	D	E	F	G	H	I	J	K
1	**Initial coding June 2015**							**In vivo codes**			
2	another self	control	patient initiated interaction	routine	professional behaviours	putting patient at ease	Knowing oneself as a patient	**I wasn't aware of who was who**	**You never saw anybody**	**Just to assist the nurse.**	
3	before you know it	transferring the problem	trust	scope of the role	assured by system	knowledge	learning the ropes	**if they notice they come straight away**	**You can talk to them like you**	**It has just been a learning curve**	
4	colour coding	humour	Hierarchy	sharing a secret	getting the work done	not bothered	managing adversity	**they don't seem to mind, you know.**	**put you at your ease.**	**Well it feels strange, it feels**	
5	coming to terms	match and cross match	the way of the world	transfering the problem	comfort	nostalgia	meeting patient needs	**if they are not very well they don't seem to in my experience sort of question anything you know**	**you couldn't do without the auxillaries.**	**I think they manage the best they can but they do their best you know**	
6	context	team working	new experience Learning	who's who	professional attributes	pre admission	professional (behaviours)	**I was a bit disappointed to start with**	**They were always doing something.**	*21 in vivo codes*	
7	control	new experiences(learning)	female in work	prestiege	patient as part of team	that's just how it is	propaganda statement	**it's not what I expected.**	**As long as they are treating me properly**		
8	dependency	role satisfaction	new experiences (understanding)	getting the work done	the way of his world	team work	humanness	**I was very disappointed in the nurses**	**they are there to back up the nurse**		
9	disguarded	another world	why would you	getting to know you	not knowing	confidence	coming to terms	**it was absolutely brilliant**	**they were ever so kind "oh it happens, don't worry about it"**		
10	efficiency	expectations	personal life	going the extra mile	routine	professional (attributes)	generic skills	**the auxillaries were very, very nice actually.**	**you build up a sort of relationship with them all**		
	relationships	token of friendship	gratitude	role positioning	staff initiated interaction	communication	*70 initial codes*	**she was absolutely lovely**			

Screen shot 5: initial and in vivo codes June 2015



	A	B	C	D	E	F	
174	**Narrative 08 Stanley**	**in vivo codes**	**Initial codes**	**Worked on codes**	**Memoes**	**Focussed codes CC July 2015**	**Gerunds**
175	They came and they, a nurse and a HCA came and they were ever so **kind** they didn't say it was my fault, they said "oh it happens, don't worry about it". They stripped up and cleaned me down, got me a new gown, cleaned the bed, did the bed, put me back to bed. It was fine, they were just so good. It was	**they were ever so kind "oh it happens, don't worry about it"**	Bringing comfort. Putting the patient at ease. Delivering care.	before you know it managing adversity meeting patients needs putting patient at ease comfort	Before they came what was he feeling? There was an anticipation that he would be admonished as it was his" *fault"* . CC July this episode illustrates how the nurses took charge and gave assurance that this episode was not an exception.	positioning the care received dependency assurance efficiency putting the patient at ease	
176	Well, for instance when I was having the bottles at night. One of them in particular I can't remember her name, she would say. How many do you want? I would say 3. She would say they are £1.50 each mind. And I would say I will pay it at the end of the week. Laughter between us both. Just a little bit to ease the situation. So it's, and you get, you build up, I have been in 4 weeks, so you build up a sort of relationship with them all you know and the disappointing thing was I had been here 2 ½ weeks and its something they like to do here on the ward. The ward is in 2 halves and they switched the staff around again in the middle of your process. You get new faces, and new nurses, new HCA to get on with. But the old ones would pop back in again you know.	**you build up a sort of relationship with them all**	Humour token of friendship buliding a relationship learning the ropes adapting to change	Humour relationships learning the ropes new experiences (learning)	interesting acknowledgement that he could not remember the HCA names but the episode was recalled willingly and with real enthusiasm for the story. This was tempered with how the ward's regular organisational changes impacted upon him and the relationships he made and how he adapted to these changes. CC July another thought here? do they leave all 3 over night?? or is it about adaptation. The HCA will leave 3 bottles because the patient wont call for them they can collect them when they are on their rounds and in their time? There is also something around adaptation from his perspective whereby the swap over of staff during his saty meant he was adapting to a new team. Staff aslo adapted by "keeping in touch " with the other side of the ward they had swapped from.	humerous threats adaptation continuity	having dissapointing something
177							
178							
179							
180							

Screen shot 6: showing progression from initial coding to focussed coding and memos.



	A	B	C	D	E
1	**Development of focussed codes July 2015**				
2	Adversity	Expectations	Learnt qualities	Recalling events	
3	Another world	Flea and elephant	Managing adversity	Safe hands	
4	Assurance	Give and take	Matching and cross matching	Scope of role	
5	Care spectrum	Gratitude	Mutuality/reciprocity	Substandard care	
6	Coming to terms	Hierarchy	Nostalgia	Taking control	
7	Dependency	Humanness	Not my job	The extra mile	
8	Dislocation	Humerous threats	Positioning the care received	The way of the world	
9	Efficiency	Inherent qualities	Professional behaviours	Transferring the problem	
10	Elements of competence	Knowing oneself as a patient	Propaganda statement	Who's who	
11		Learning the ropes	Putting patient at ease	Words cannot describe	*39 focussed codes*

Screen shot 7: development of focussed codes July 2015

Appendix 14

Output from the research process

Presentation of this work at conferences has provided me with a critical audience that has enabled me to reappraise and rethink in ways otherwise would have been absent from this academic trajectory.

Date	Organisation	Presentation	Reflection
10-12th September 2014	BSA Birmingham	Forum theatre workshop	An opportunity to network across disciplines other than nursing. Offered me a unique opportunity to present a dynamic and innovative piece of work working collaboratively with social work and lay health students a different perspective was brought to my work at an early stage in my academic career. Paper accepted for Journal of Adult Protection Sept 2016 (3rd author)
29-30th May 2014	International Qualitative Research Methods Melbourne	Poster presentation. X2	Both conferences and my poster presentations at International Qualitative Methods research conference in May 2015 allowed me the perspective of positioning my research within a national and international network. Seeing where there were gaps and areas for additional work.
21st April 2015	RCN Research conference Nottingham	Presentation	The RCN conference in April 2015 provided me with further thoughts around how I would continue to apply Clarks (2005) work in my reflexive practice and continue to capture reflexive positions

			during data collection and analysis.
4th June 2015	Northumbria Health and Life Sciences conference	Presentation	An opportunity to support and network with fellow colleague
4-6th April 2016	RCN Research conference Edinburgh	Presentation	The RCN conference in April 2016 provided me with additional perspective on the contemporary patient within secondary care. A quote from a nurse researcher who sat through my presentation suggested I was working in the right way in bringing the participants voice to the fore. "you have captured through the participant quotes some really insightful observations." However, she later went on to add the following thought: "you really don't know what it's like (to be a patient) unless you have experienced it." This confirmed my view that more than ever as a nurse researcher there still remains a gap between what is known, what is heard and what is presented.
17-19th October 2016	International Qualitative Research Methods Canada	Poster presentation	Opportunity for positioning my research within a national and international network.

Glossary

For ease of use I have summarised each of the acronyms used in the following section for clarity.

- *HCA* Healthcare assistant. A term introduced to describe the assistant role when Project 2000 commenced that was designed to replace the Nursing Auxiliary, or NA. The acronym HCA will be used throughout this doctoral study for consistency of read but I will refer to other names and titles for the assistant role whenever it is specific to the literature or context.
- *HCSW* Healthcare support worker. A term introduced to address the assistant role more generically across health and social care
- *NA* Nursing Auxiliary. A term used to describe the assistant role prior to Project 2000.
- *AP* Assistant Practitioner. A term used to describe a higher level assistant role that was brought into the nursing workforce in North of England in 2002.
- *NuA* Nurse Associate. A term used to describe a new role that will working alongside the HCA. An apprenticeship model that will lead to a foundation degree.
- *RN* Registered Nurse. A term used to describe a professional registrant with the Nursing and Midwifery Council (NMC)
- *Practitioner.* A term used to identify a member of a professional group within the Health service.
- *Participant.* The term participant is synonymous with the research design and will be used throughout the thesis when referring to the contribution the participant made. Outside of the research context the participant will be known as the patient.
- *Patient.* The term used to describe the general aspect of the participant’s experience.
- *NHS.* National Health Service.
- *Secondary Care.* A term used to describe care that takes place largely within hospitals as an inpatient or from an outpatient setting.
- *Social Care.* A term used to describe organisations delivering care within patients own homes, residential or nursing homes

- *Health and Social Care.* A term used to describe care that takes place within health and social care settings.