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Just a bunch of grapes? Liminality and the experiences of  
adult visitors to NHS acute medical and surgical wards in  
England

Janet Elizabeth Underwood

A thesis submitted to the University of Huddersfield in  
partial fulfilment of the requirements for the degree of  
Doctor of Philosophy

The University of Huddersfield

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## **Abstract.**

In this thesis, I argue that the practice of visiting patients on the more general acute medical and surgical wards in National Health Service hospitals in England has been under-researched and is frequently overlooked by policy. This is despite the large number of written complaints received annually about NHS acute hospital care services in England.

The thesis commences with an extensive examination of the contextual influences on hospital visitors' experiences and expectations. This is followed by a detailed account of the qualitative research, using semi-structured interviews, with participants who had been hospital visitors. Visiting experiences were described as a journey through the patient's admission, hospital stay and discharge or death. This journey was identified as a time of liminality (van Gennep 1960) with the visitors' everyday routines and structures suspended and transitions to be made. Liminality and its core features identified by Turner (1974) therefore provided a theoretical framework through which to explore the data.

The analysis resulted in the identification of extensions to the understandings of liminality when applied to the hospital-visiting scenario. In turn, the use of liminality, as central to the theoretical framework, provided richer interpretations of hospital visitors' experiences and so adds to the knowledge about the practice of hospital visiting. Evidence is therefore provided to support future policy, training and professional education improvements and to suggest measures to improve hospital visiting experiences. These improvements, especially in terms of hospital hospitality, effective communication and improved discharge management, could increase hospital visitors' satisfaction and reduce the costs to the NHS incurred by responding to the high volume of written complaints.

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**List of abbreviations.**

A&E	Accident and Emergency
BSA	British Sociological Association
CAB	Citizens Advice Bureau
CCTV	Closed Circuit Television
CHI	Commission for Healthcare Improvement
CJD	Creutzfeldt-Jakob Disease
DoH	Department of Health
GP	General Practitioner
HIV/AIDS	Human Immunodeficiency Virus/Auto Immune Deficiency Syndrome
ICT	Information and Communication Technologies
MRSA	Methicillin-resistant Staphylococcus Aureus
NHS	National Health Service
NICE	National Institute for Health and Clinical Excellence
PCT	Primary Care Trusts
RCN	Royal College of Nursing

## Glossary of terms associated with liminality

- 
- **Anti-structure** - The force wielded by *communitas* to challenge existing social structures to bring about change (Turner 1969).
- **Communitas** - The term used by Turner (1969) to mean the sense of comradeship, mutual support and added strength developing amongst the 'community' of liminal personae. Has a dialectical relationship with structure.
- **Juniors** - See liminal personae.
- **Liminality** - The term coined by van Gennep (1960) to describe the interim stage of transition. Later described by Turner (1969) as being 'betwixt and between' two ways of being. Has many characteristics of which the most prominent in this thesis are loss of status, total obedience, ambiguity and betwixt and between, uncertainty and *communitas*.
- **Liminal personae** - Those people who are passing through a liminal situation also referred to as juniors (Turner 1969). Also referred to as 'neophytes'.
- **Masters of ceremony** - The experienced overseers who guide the safe passage of liminal personae (van Gennep 1960). Also referred to as seniors by Turner (1969).
- **Re-incorporation** - The return to society but with altered status.
- **Seniors** - See masters of ceremony.
- **Separation** - The removal or rupture from the everyday
- **Structure** - The hierarchical, organisational political, economic and legal forces which order a society or institution (Turner 1969). Has a dialectical relationship with *communitas*.
- **Total obedience** - Refers more to humility and passive behaviour in this thesis rather than blind obedience.
- **Transition** - The process of moving from one way of being to another.

# Chapter 1. Introducing the research.

## 1.1. Personal interest and the start of the research journey.

My work as a registered nurse on a combined medical and surgical ward in an ethnically diverse National Health Service (NHS) hospital trust in a Midlands city permitted me, on less busy shifts, to observe some of the rituals and practices occurring during hospital visiting times. I began to realise that fluctuating workloads were influencing how my colleagues and I interacted with patients' visitors. Some days we had time to chat and build up a relationship with them. When a visitor was upset, and we had time to offer words of comfort and a cup of tea, we felt we were making a difference. When the ward was quiet, a visitor asking many questions could be considered a concerned, loving and responsible relative. When the ward was less busy, it was also easy to bend the rules and permit several visitors at each bedside.

On other shifts, we were so busy trying to manage a heavy workload that visiting times seemed to pass by, almost unnoticed. During the maelstrom of a hectic shift, a visitor asking many questions could be a hindrance to our effective provision of patient care. When we were under pressure, with patients' lives literally 'in our hands', many visitors at each bedside meant more bodies to negotiate in gaining access to patients in confined spaces. If we were too physically and emotionally exhausted to offer yet more emotional support, we felt dispirited. Then there were the times we had to down tools and deal with visitors' complaints, anxieties, suspicions and mistrust, which often seemed to be influenced by the media.

Approaching my retirement, and in the early years of the Coalition government (2010-2015), I began to experience declining staff numbers on the wards and an ever-increasing burden of paperwork. Reports, form-filling and audits were demanding more time in the drive to achieve continuity of effective patient care and maintain standards set by professional organisations and local trust and national policies. Considering my forthcoming transition into retirement from nursing and my ambitions to progress further in social science research, I began to question how the visitors might be experiencing their 'visiting times' and coping with some of the inconsistencies we were presenting. I also began to observe visitors' behaviour patterns, saw that I was finding more questions than answers and wondered whether this was a suitable subject for research. An initial literature search revealed a startling paucity of qualitative research into hospital visitors' experiences to the more general acute wards (rather than specialist units such as maternity, rehabilitation of intensive care) in NHS hospitals in England, and so my research journey began.

Hospital visitors slot into one or more of four categories: 'patients' visitors' who are friends

and family; 'public visitors' include the clergy, entertainers and sports personalities who have no direct involvement with the hospital; 'house visitors' who are associated with the hospital, for example, management or financial benefactors; and 'official visitors' such as government inspectors (Mooney and Reinartz 2009: 8). This thesis focuses on the category of visitors which sparked my initial, and continuing, interest, the 'patients' visitors' to the more general acute medical and surgical wards, and asks the question:

### **What are the experiences of adult visitors to NHS acute medical and surgical wards in England?**

To answer the research question, I asked the following three subsidiary questions

1. How does the wider social context influence hospital visitors' experiences?
2. What do visitors' stories about their experiences tell us about hospital visiting?
3. Why and in what ways do visitors resist or adapt to the policies, customs and practices of hospital visiting?

### **1.2. The need for, and aims of this research.**

[Sociology] is an attempt to study, in as scientific and systematic way as possible, how societies operate. This means trying to 'stand back' from society a little – watching, recording, measuring, evaluating and interpreting what is going on, and trying to explain how and why so many of the things we all take for granted about society come to be as they are (Thompson 1982: 1-2).

Most people, at some time in their lives, will experience being hospital patients or visitors. Despite this commonality, there has been little enquiry, or, as Thompson (1982) suggests above, a 'standing back', into hospital visiting experiences in England. In undertaking this research, I have interrogated the taken-for-granted features of hospital visiting to the more general NHS wards and, in representing the experiences of hospital visitors in England, add to the knowledge about this activity and its meanings.

This research also has financial relevance. In the year April 2014 - March 2015 there were 18,703,016 finished inpatient consultant episodes in NHS hospitals in England. Of these, 6,560,415 were day cases. These figures equate to 12,142,601 patient 'nights' in an NHS hospital acute bed in England<sup>1</sup>. There is no count of the numbers of people who have visited these patients. In the same year, there were 205,000 written complaints (or 562 per day)

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<sup>1</sup> Retrieved 1/10/2015 from <http://www.hscic.gov.uk/catalogue/PUB17794/prov-mont-hes-admi-outp-ae-April%202014%20to%20March%202015-rep.pdf> (2015-2016 figures not available at the time of writing in Sept 2016)

about the NHS. Of these, the greatest proportion, 120,778, were about inpatient acute care. These figures take no account of verbal complaints expressed about NHS hospitals and resolved locally on the wards. The NICE (2015) *Violence and Aggression Update edition*<sup>2</sup> states that in the year 2011-2012 there were 16,475 reported cases of violence or aggression towards NHS acute hospital staff. The costs of managing complaints and aggression are not available in the public domain, but their sheer volume implies a huge price in terms of human resources and financial cost. If hospital visitors had a better experience, there might be a potential for the reduction of costly complaints and acts of aggression. For example, those research participants who received a cup of tea on the wards perceived that the hospital staff were offering a higher quality care to themselves and the patients.

A further relevance of the research is that of policy making. National government and the Department of Health leave the determination of visiting policies to individual trusts<sup>3</sup>. Although most trusts and some other organisations, for example, NHS Choices<sup>4</sup>, publish guidelines for visitors, very few make their visitor policies available. The NHS does, though, seek feedback from patients on discharge via the Friends and Family Test (NHS Choices<sup>5</sup>). The lack of empirical inquiry into the visitors' experiences and little or no definitive policy guidance to the hospital trusts and staff suggest an omission in policy making. A further aim of this research is to contribute towards rectifying that omission.

As the analysis demonstrates, there are also some features of hospital staff behaviour which hospital visitors find disturbing. These include the nurses' tendency to overlook the patients' visitors, the withholding of the norms of hospitality and the inconsistency in the information provided by doctors and nurses. The evidence base provided by this thesis could inform professional training and education purposes.

Despite the fact that so many people experience it, hospital visiting seems to be an almost 'invisible' practice and this demands further investigation. So, the aims of the research are:

- To extend the knowledge about the experience of being a hospital visitor.
- To add to the understanding of liminality.
- To interrogate positive and negative experiences to identify ways to cater for visitors' needs and thus provide evidence for visitors' policies and staff training and education.

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<sup>2</sup> Retrieved 11/10/2016 from <https://www.nice.org.uk/guidance/ng10/evidence/full-guideline-70830253> This report does not distinguish between acts of aggression from patients and visitors.

<sup>3</sup> Appendix 1

<sup>4</sup> Appendix 2. Retrieved 4/11/2015 from <http://www.nhs.uk/NHSEngland/AboutNHSservices/NHShospitals/Pages/visitors.aspx>

<sup>5</sup> Retrieved 1/10/2015 from <http://www.nhs.uk/NHSEngland/AboutNHSservices/Pages/nhs-friends-and-family-test.aspx>

### **1.3. What (little) is already known and the direction of the thesis.**

Due to the small amount of existing literature about the qualitative nature of hospital visitors' experiences to the more general acute medical and surgical wards in English NHS hospitals, this section introduces some of the relevant research from around the world. I then examine the small body of literature about visiting practices in English hospitals, which, I argue, justifies the need for further research on this subject and provides a starting point for this thesis.

Internationally, there is a substantial amount of literature referring to hospital visiting to the more specialised areas in hospitals, such as intensive care units (Blanchard 1995; Verhaega et al 2005; Obringer et al 2012) or paediatric wards (Callery 1997; Coyne 2006). There is also a limited inquiry into other specialities such as palliative care, maternity or rehabilitation. Whitis (1994) and Fisher et al (2008) describe visiting practices and experiences to the general wards in the North American hospital system. From Australia, O'Connor et al (2012) carried out an extensive literature review to determine the environmental and spatial impacts on hospitalisation outcomes. Within their results they note that patients' family needs are often overlooked, especially in the provision of privacy, toilets, waiting rooms and telephone facilities.

Finland, especially, but also the Scandinavian countries, appear to have a much greater interest in the caring for, and the support of family members of patients. Consequently, there is more research from these countries into hospital visitors' perspectives of their experiences (for example, Åstedt-Kurki et al 1997, 2001; Mattila et al 2014). These provide a contrast with Segaric and Hall's (2015) research into the nurse, patient and family relationships in the Canadian hospital system, where the demands of an ageing demography, medical and technological advances and rising costs have created similar problems to those in England, which I discuss in chapter two. This results in Canadian nurses gaining less job satisfaction, families experiencing a greater burden of care and their needs as hospital visitors often being underestimated (Segaric and Hall 2015). Similarly, in Germany, hospitals appear to pay scant attention to family needs, with families mostly considered as a system within which the demise of one family member impacts negatively on all other family members<sup>6</sup> (Pinkert et al 2013).

The work from overseas, while being informative and comprehensive, does emphasise the inter-nation differences in health care cultures, professional education and hospital processes. In addition, social and cultural practices, contexts and expectations appear to vary internationally. Any over-dependence on the results of the international academy could therefore adversely bias this research into English hospital visiting.

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<sup>6</sup> Finch (2007) suggests that family system theory is now less frequently used.

Most research into hospital visiting in English hospitals has employed quantitative methods and concentrated on visitor rules and whether or not visiting hours should be restricted (Bates 2002; Hoban 2004; Tanner 2005; Taylor 2008). Time restrictions are deemed necessary to protect patients' rest, enable nurses to complete their tasks (Hoban 2004) and lower the risk of infection (Plowright 2007)<sup>7</sup>, with the consensus being that nurses apply the rules. Although Webb's (2007) research extends to the consideration of visitors' opinions, she treats patients' and visitors' perspectives as in unison. She also concentrates less on the emotional and more on practicalities such as the organisation of care, the ward environment and the ability of staff to care and provide adequate information.

Green et al (2012) published a more recent qualitative study, which includes both the hospital patients' and visitors' perspectives, as part of their membership of the Older People Researching Social Issues group. Their study differs from my own in several ways. Theirs was a study by older people, using focus groups, to determine both older patients' and older visitors' experiences and needs. My research concentrates on the stories of hospital visitors' experiences as told by them in semi-structured, individual interviews. Green et al (2012) involve participants in the age range of 50-90, with the largest number aged 80-89. I have included hospital visitors within the age range of the early 20s to early 80s and so at different stages in the lifecycle and with age-related perspectives of their experiences. Green et al also focused on one geographic region in England - North Lancashire and South Cumbria. My research involved a larger geographic area, from London to the north of England, in which there are more variables in terms of social demographics, epidemiology, public and private transport facilities and hospital trusts' policies and procedures.

More specifically, Green et al (2012) present their research more as a factual description of their participants' experiences and needs. As the research questions already demonstrate, and as will be developed throughout the thesis, my critical engagement travels from the wider contextual influences to the most intensely personal and private relationships and emotions. Using the theoretical framework of liminality, I explore how visitors experience the disruptions to their everyday routines and relationships and how they struggle to adapt to new and unfamiliar hospital norms, rules and processes. I also demonstrate how the research participants exercised their autonomy and, sometimes inadvertently, resisted or transgressed both implicit and explicit hospital customs and experienced unexpected and unwelcome consequences as contestations of power and knowledge were brought into play.

As I discuss in chapter two, the context of hospital visiting within the National Health Service has changed significantly since its formation with an increasing informality on the wards and the influences of neoliberal policies encouraging greater personal assumption of responsibility (Newman and Vidler 2006). Nevertheless, despite being written some 55 years ago, Menzies

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<sup>7</sup> Here, Plowright is referring to critical care units.

Lyth's (1960) seminal work on nurses' psychological defence mechanisms includes a passing reference to hospital visitors and still bears relevance to 21st century visitor experiences:

Patients and relatives showed appreciation, gratitude, affection, respect; a touching relief that the hospital coped; helpfulness and concern for the nurses [...] Relatives could also be demanding and critical, the more so because they resented the feeling that hospitalisation implied inadequacies in themselves. They envied nurses their skill and jealously resented the nurses' intimate contact with 'their' patient (Menzies Lyth 1960: 441-442).

The quote above provides a more psychoanalytic perspective of visitors' behaviour and, in addition to a fleeting first glimpse of unwritten rules of hospital visiting, a sense of the intensely personal and emotionally infused experiences that the participants' accounts describe in this thesis. Boyd's (1960) letter to the British Medical Journal provides a contrast to Menzies Lyth's work. In this, he demonstrates how hospital staff might have perceived visitors less sympathetically:

At least four times a week [...] the wards are invaded by hordes of visitors, coughing, sneezing, some doubtless with boils and blains, and probably some with open tuberculosis. After an orgy of hugging, kissing, nose scratching and pawing of patients and blankets, they disappear leaving the wards in a state comparable to a downtown saloon (Boyd 20/2/1960: 563).

Menzies Lyth (1960) and Boyd (1960) also provide an early example of the practical and physical versus emotional and psychological dualisms, which still abound today. Within the thesis, I suggest that these dualisms originate from Cartesian theory and Merleau-Ponty's understandings of the mind and body. Cartesian theory posits a mind/body split with primacy accorded to the mind (Leder 1984; Williams and Bendelow 1996). Merleau-Ponty subverts Cartesian theory and accords primacy to the body's sensory perceptions, which are then interpreted cognitively (Leder 1984). These dualisms also arise from the differing epistemologies involved in objective, quantitative, natural scientific, experimental research and those of subjective, interpretive, qualitative sociological inquiry. As I discuss throughout the thesis, although adhering to qualitative methodology, by bridging these dualisms, or removing the gap between the two perspectives, I aim to provide a more holistic understanding of visitors' experiences. I achieve this by using thematic analysis, which Boyzatis (1998) suggests is suitable for both qualitative and quantitative research methods. Thus the discussions in the thesis range from the practicalities of the hospital environment to the emotional turbulence of uncertainty.

It is noteworthy that although the NHS, hospitals and the medical and nursing professions have changed dramatically since 1960, Menzies Lyth's comments and Boyd's employment of a discourse of visitors posing infection risks still prevail in the context of hospital visiting and are demonstrated in the thesis. These infection risks are prominent features of nursing education, hospital policies and medical texts. However, these texts also differ substantially from the broad sweep of social scientific literature I employ. The former demonstrate guidance or regulation on what ought to be rather than what is. Peterborough and Stamford Visiting policy (2006)<sup>8</sup> provides such an example when describing its aims for managing visiting times:

The policy for Patient Visiting at Peterborough and Stamford Hospitals aims to balance the therapeutic effect of patients spending time with relatives, carers and friends with the patients' need for rest and the need for clinical staff to manage the ward and care safely and efficiently [...]

The policy gives staff the authority to manage visiting in a way that provides appropriate access for patients to their family and friends while at the same time protecting confidentiality, security, privacy and rest.

The intended focus of this research is on *what is* and *visitors' accounts of their experiences*. For the differences in linguistic style between the policy document above and visitors' accounts and their emotional involvement to be better understood, the participant, James' reasons for visiting his mother in hospital are cited below:

**James:** I suppose duty in a sense - when she was only going to be there for a couple of days. Obviously, when it turned into a couple of weeks because of the complication, and it was a bit more, sort of, erm, comfort thing for her, I guess. Sort of trying to get her through it.

Consequently, although I examine policy documents in more detail in chapter two, I also examine hospital visitors' telling of their stories about their experiences. This in-depth exploration provides new knowledge about hospital visiting; especially in terms of how hospital regulations and practices influence visitors' experiences and lead them to try to adapt or resist the structures within the hospital environment. Put simply, in this introductory chapter, but expanded in later chapters, here I interpret structures as the norms, rules, positions, classifications, hierarchies and obligations within social institutions (Turner 1969). These structures might be implicit or explicit, but institutional social *mores* are powerful

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<sup>8</sup> See Appendix 3. Retrieved 20/5/2015 from:  
[http://www.peterboroughandstamford.nhs.uk/\\_files/policies/133\\_patient\\_visiting\\_2\\_.pdf](http://www.peterboroughandstamford.nhs.uk/_files/policies/133_patient_visiting_2_.pdf)

influences on social behaviour and can be, and are, also resisted when people exercise their agency.

#### **1.4. The research participants: researcher reflexivity, participants' voices and my voice.**

Having introduced the research, its questions and aims and noted existing literature about hospital visiting experiences, in following chapters, I draw attention to the political and power implications at play in healthcare policymaking, the hospital environment, the media and in academia. These, I argue, have prevented visitors' stories from being granted space in dominant discourses. The thesis also demonstrates the profound sense of loss of status, disempowerment and marginalisation, or, even, a sense of being invisible, experienced by the research participants. Therefore, contrary to much research convention, I enhance the prominence to this research of the participants by introducing them at the beginning of the thesis. I then discuss researcher reflexivity and the use of my own voice and the participants' voices for a joint production of knowledge.

##### ***1.4.1. The Participants***

**Amanda and James** are both professionals, in their early 30s and took part in the pilot study. They visited James' mother together, following her elective admission for orthopaedic surgery in a North Lincolnshire hospital. Although husband and wife, they told their stories separately in their home.

**Winnie and Jim** are husband and wife, aged mid-60s and both retired. They visited Jim's mother in a Midlands city hospital following her elective admission for orthopaedic surgery. As the pilot study recordings revealed discrepancies in participants' recall, Winnie and Jim were also interviewed separately and in their home. Winnie is disabled, walks with the aid of furniture at home and is wheelchair dependent outside the home. Jim is a retired policeman.

**Molly** is a shop assistant and is in her early 20s. Molly's grandfather was an emergency admission to hospital following an accident. Molly travelled to northern England to support her emotionally fragile grandmother while her grandfather was in the hospital. Molly chose to take part in an interview in her home.

**Sue** is in her 40s and a teacher. She described two recent hospital admissions for her elderly father in two different hospitals within the same Trust in the Midlands. One admission was elective and the other was an emergency admission following a stroke. Sue opted to tell me her story in a quiet corner of a country public house.

**Jane** is in her 50s. She talked about visiting her husband in a Midlands hospital following his emergency admission due to a sudden, life-threatening collapse. She is a housewife and mother of four young adult children and chose to take part in the research in her home.

**Liz** visited her husband in a Midlands hospital. Liz, aged mid-60s, is retired, did not disclose a former occupation and opted to come to my home to tell her story. Her husband had two emergency admissions within a few weeks due to cardiac problems.

**Sally** is in her early 60s, retired and married to Dave. Sally initially chose to talk in her home about a visit to her husband when he had two overnight stays in hospital following planned procedures. She then spontaneously introduced several other hospital visiting experiences. Most of the visits she described took place in hospitals within the Midlands.

**Meg** is Dave's sister and in her 60s. A retired teacher, she discussed her visits to her aged mother who was in a Midlands hospital following an emergency admission. Meg's interview took place in Sally and Dave's home.

**Dave** is approaching retirement, Meg's brother and Sally's husband. He is in his 60s. Dave talked in his home about visiting his mother in the hospital. Dave owns a business.

**Danny** is in his 40s and did not disclose his occupation. He talked in his home about his visits to his grandfather after his emergency admission to a Midlands hospital following a catastrophic stroke. Danny, during his formative years, had lived with his grandfather and they had a very close relationship.

**Gill** is in her early 60s. She has been her husband's main carer for almost twenty years following his accident. Her husband has had many admissions to various hospitals in the Midlands. Gill mostly spoke about her husband's most recent admission following his collapse. She chose to come to my home for the interview.

**Nina** is a registered nurse, in her 30s, and described, in my home, her visiting experiences to her mother. There were three separate admissions; two of which were emergencies. One of the emergency admissions led to the third planned admission for surgery. Two of the admissions were to the same hospital in which Nina works.

**Winston**, early 80s, is a retired production worker who emigrated in his youth from one of the poorer Caribbean islands. He took an early retirement/redundancy package, and he and his wife returned to the Caribbean. As their health failed and because they no longer felt 'at home' in the Caribbean they returned to England a few years ago. He talked primarily about

his wife's elective admission to a Midlands hospital for orthopaedic surgery but also described his hospital experiences in the Caribbean.

**Ed** is in his late 30s. He was born and spent his younger years in the Philippines before his family moved to Canada. He is a student in England and talked about his visits to his sister and his friend in London hospitals. Both had been admitted via A&E. Ed chose to tell his story at his place of work.

**Ruth** is in her mid-50s and spoke about her visits to her daughter who was in a Midlands hospital for major surgery. Ruth works with antiques and chose to take part in the research in her home.

#### **1.4.2. Researcher reflexivity and voice.**

The knowledge produced by research is assumed to be **situated**, meaning that claims which are made can refer only to the specific circumstances of place, time and participants in which the research was conducted. It is **contingent**, in that these claims, therefore, do not have the status of stable and enduring truth. The researcher acknowledges the **reflexivity** of the research process and the non-neutrality of research texts [...] For all these reasons the knowledge produced by research is, inevitably partial (Taylor 2003: 319 original emphasis).

Here, Taylor acknowledges the variations arising from the different voices and situations involved in qualitative research. She also draws my attention to the tool of researcher reflexivity for acknowledging my own influences on my research activities and writing. In this section, I therefore explain my understandings and uses of both reflexivity and voices and their intersections throughout the thesis.

Reflexivity is 'the capacity to reflect on our role in generating research knowledge' (Ali et al 2004: 25) and can counter challenges of bias and lack of validity in qualitative research (Grbich 2004). It is an acknowledgement by the researcher of his or her 'socio-historical locations, including the values and interests that these locations confer upon them' (Hammersley and Atkinson 2007:15). As Hammersley and Atkinson (2007) suggest, reflexivity is an acknowledgement that the researcher cannot stand outside of the social world being investigated and will always bring their personal influences to bear on the research.

My own socio-historic locations are multiple and varied. I am white, late middle aged, a student, a wife, mother and grandmother. I have visited significant others in NHS hospitals, been a patient and a registered nurse. My social science studies and work as a nurse have reinforced my respect for social diversity. My nursing career commenced in 1970 when the ethos of the welfare state still prevailed and patients and visitors had far less autonomy and

access to medical knowledge than today. The Neoliberal ideologies of the Thatcher years and more recent governments were yet to come. Strict ward sisters and matrons regulated the hospital wards and the delivery of nursing care.

I left the nursing profession in 1974 and did not return until 2002. By this time, nursing had undergone significant changes. By 2002, also, the media were regularly criticising the NHS and the nursing profession for poor care. I was perhaps in a unique position of being able to compare two very different models of nursing care. It would be easy to succumb to persuasive and adverse media headlines and indulge, through rose-tinted spectacles, in a nostalgic yearning for the practices of the 1970's. I have, though, concentrated on the research participants' accounts of 21st century hospital visiting without attempting to introduce my own comparisons across the decades and my own experiences of hospital visiting times. In this, I benefitted from my retirement from nursing some eighteen months into this study as this meant I became increasingly distanced from the ward environment and nursing practice. By 'stepping back' from frontline nursing I was able, for example, to be open to, recognise and respect the distress the participants experienced by being overlooked at the nurses' station, their confusion about chairs or their frequent mention of something as seemingly banal as a 'cup of tea'. Thus, for example, I was able to recognise that, professionally, I had become desensitised to hospital norms of (in)hospitality without considering the potential for visitors' additional discomfort or distress.

Furthermore, Hammersley and Atkinson (2007) note that reflexivity should involve an awareness of the political implications at stake. As they suggest, the publication of unpalatable research results can deter future potential participants or incline gatekeepers to refuse access for researchers following on. Similarly, researcher values affect the knowledge produced, which, in turn, influences policies and practices (Hammersley and Atkinson 2007). As such, had I not used reflexivity to be open to participants' expressions of their experiences, my own desensitisation to hospital hospitality shortcomings could have precluded my recognition of the participants' consequent confusion and distress. This would have prevented policy recommendations and my failure to achieve one of the research aims.

However, reflexivity also has an important role in facilitating the voices of those groups on the margins or politically oppressed (Ali et al 2004). This is particularly pertinent to the thesis as, throughout, I argue that hospital visitors have traditionally been mostly marginalised, with difficulty in getting their voices heard. My starting point for setting out how my own voice and the research participants' voices are represented throughout the thesis is Rector-Aranda's (2014: 807) following definition:

Voice is a versatile term, used in research to describe the ability, mode and/or right of individuals or groups to make their ideas, opinions, emotions,

perspectives and needs known to others. Similarly, to voice is to make such an expression, while to give voice is to allow or support that expression (Rector-Aranda 2014: 807)

As I expand further in chapter four, I am influenced by postmodern research methods. This means that I write in my own voice in order to establish my authoritative ownership of the thesis (Gbrich 2004). This is despite the long-held tradition that writing in the third person emphasises the objectivity and value-free nature of research (Webb 1992). As Webb (1992) further argues, the production of knowledge is a social activity and can never be separated completely from the social world and thus always involves some element of values and bias – but even more so when writing about interpretative research such as this thesis.

Whereas writing in the third person can often result in ‘stilted’ and ‘excruciatingly tortuous sentences’ (Webb 1992: 747), Gough (2008) suggests that it can also be understood as the researcher abnegating responsibility for the more confrontational or less acceptable comments made in the report. Davies (2012: 747) extends these comments by demonstrating how the use of the first person can connect the ‘intuitive with the intellectual’ and represent the ‘tensions, nuances, complexities, confusions and unclear thoughts’ which occur in research processes.

Therefore, in using the first person, I am not only seeking to establish my ownership of the thesis but also acknowledge my responsibility for my research activities and the twists and turns involved in completing this thesis. But my aim, too, has been to facilitate space for, or ‘give voice’ (Rector-Aranda 2014: 807) to, the participants to describe their experiences in their own words (Gbrich 2004). However, Rector-Aranda’s definition also alerts for a need for researcher reflexivity and methodological and ethical dilemmas when considering ‘giving voice’ throughout the research processes.

My decision to use semi-structured interviews creates the first ethical dilemma and the need to mitigate possible researcher power and consequent participant disempowerment. My excessively rigid adherence to an interview schedule and inept responses could stifle the participants’ attempts to voice those experiences that seemed most relevant to them. On the other hand, total lack of structure could lead to accusations of lack of focus as researcher and participants wander widely ‘off topic’.

This then leads to a second dilemma when analysing the data. In qualitative research, data analysis demands interpretation of the participants’ expressions in order to achieve deeper and richer meanings of experiences. As I discuss throughout the thesis, qualitative research using semi-structured interviews results in the researcher’s interpretation of the participants’ interpretation of their experiences – or an exercise of double hermeneutics (Smith et al 2009).

The weakness here is, as I argue, that interpretations and their descriptions, by participants and researchers, are influenced by the many variables in our different life experiences, social positions, linguistic skills, accuracy of recall, or, even, our own censorship of what to tell and how to tell it.

This need for reflexivity and ethical dilemmas continued in the writing of the thesis. When transcribing the interview recordings, I used Jeffersonian<sup>9</sup> notations to indicate participants' indrawn or exhaled breaths, their hesitations, word emphasis etc. When writing the thesis, I selected some transcription extracts, discarded others and removed the Jeffersonian notations for easier reading. Here, the practicalities of writing a word-limited and more easily read thesis could be considered privileged at the expense of the participants' voices being fully heard.

I suggest that these juxtapositions and tensions of researcher's voice, participants' voices, reflexivity and interpretative vagaries are pragmatically resolved by Taylor's (2003: 319 words cited at the beginning of this section. These are reinforced by Fabian's (2012) later comments and her pragmatic acknowledgement of unavoidable inequalities in power relationships in the research processes and variations in interpretations. Fabian (2012) further suggests that including different voices serves to illuminate the multiple and constructed realities of experiences and their interpretations. It is, however, the combination of the researcher's voice, reflexivity and interpretations, on the one hand, with the participants' voices and interpretations of their experiences, on the other, which, through a process of joint collaboration, produces knowledge (Fabian 2012).

## **1.5. The structure of the thesis**

In the interests of a more coherent representation of my research activities, I present them here in linear form whereas, consistent with most qualitative research, they formed an iterative progression. So, after the first few interviews, I paused for reflection, preliminary analysis and attempts at writing about emergent themes. This iterative process meant that, for example, 'bringing back matrons' emerged as a possible theme during the first interviews, but was eventually discounted, as I discuss in chapter three. Also, all of the participants were describing their experiences as a removal from their everyday with the suspension of their norms of rules, values, roles, priorities and activities. They were, in effect, describing what I came to understand as periods of liminality. Knowing little about this idea, I returned, again, to searching the literature for its conceptual foundations, characteristics and use in sociological inquiry and, more specifically, in the health care arena.

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<sup>9</sup> Retrieved 24/2/2017 from <http://www2.le.ac.uk/departments/psychology/research/child-mental-health/cara-1/faqs/jefferson>

The thesis is therefore structured to follow on from this introductory chapter as follows:

Chapter two begins to answer the first research subsidiary question, which asks how the wider social context influences hospital visitors' experiences. The structures explored demonstrate their potential to give rise to visitors' feelings of invisibility, ambiguity and being betwixt and between the world 'outside of hospital' and that 'within the hospital'. Local policy documents and national advisory notices also demonstrate that visitors are seen as potentially disruptive and posing threats to the smooth running of hospitals. This means policies are directed towards managing visitors rather than welcoming them. In effect, all of these consequences provide the first indications that the hospitalisation of a significant other is a liminal event; with hospital, visitors positioned as liminal personae.

The chapter commences by detailing the epidemiological, technological and demographic changes that have occurred over the decades and how these, in turn, are increasing demands, expectations and costs of the NHS. I consider how successive governments have introduced policies and reforms to adapt to these changing circumstances. Despite these political and policy concerns with the NHS, hospital scandals have become a frequent feature in the news media and have led to yet more policies and undermined public trust. This further prompts the question of whether policy reforms are a cause or a result of these scandals. I next examine how technology has influenced visitors' experiences and suggest that the use and availability of the Internet can both facilitate a voice but can also silence dissent and complaint. I also question to what extent a constant and enduring stream of multiple genres of hospital-related stories within popular culture influence hospital visitors' experiences and expectations. I conclude that the fascination with hospital-related popular culture only partially prepares people for the emotional turbulence they experience when confronted by the reality of being a hospital visitor. In the final section of the chapter, I probe the language and content of policies and documents that are directed at individuals in the hospital context. I complement this by an exploration of how these policies might be enacted in hospital hospitality and to what extent neoliberal intentions for responsabilised, 'consumer' citizens with choices are experienced by hospital visitors.

Chapter three describes the theoretical and conceptual underpinnings for the research arising from a wide-ranging literature search. I begin by considering some of the key definitions, the benefits and the disadvantages of utilising theoretical frameworks. I then set out the thesis' theoretical framework, with liminality as the overarching theory. This leads to a discussion of the origins of liminality (van Gennep 1960). Turner (1969) describes many features of liminality and, to achieve better coherence, I group those most relevant to the thesis into five core themes: loss of status; total obedience; uncertainty; ambiguity and betwixt and between; and structure and communitas. These themes are then adjusted to be more relevant to 21st century social life and used to support liminality in the theoretical framework. I also consider

more recent developments and contemporary comment about liminality and its application to research in the health care arena.

As the thesis centres on what participants' stories might tell about hospital visiting experience, I next focus on 'storytelling' and 'experience'. Sense making and meanings of experiences are achieved through the listening to and telling of stories (Bruner 1986; Turner 1986), so I commence with an examination of the literature that identifies some of the most salient points of storytelling. These include the differing purposes of storytelling in the social world. I also note suggestions that the involvement of power and politics moves some stories to the peripheries for their telling, whereas others occupy a more central stage. I then define my conceptualisation of 'experience' and discuss the literature that supports this. The literature reviewed also supports the identification of the close relationships between experiences, storytelling and liminality and so confirmed the value and relevance of all three within the theoretical framework to structure and guide the thesis.

Chapter four details my methodological journey and begins with the philosophical and theoretical foundations of my decision to use qualitative research. I also demonstrate my adherence to ethical principles and my commitment to good research practice to ensure I would 'do the right thing' (Le Voi 2006: 180). This was to protect the safety and wellbeing of the participants and myself and the integrity of the research. My journey also involved moving from a rather hazy research proposal to the sharpening of focus and the fixing of the research questions. After describing this, I discuss the fieldwork and the associated activities of a pilot study, recruitment and its difficulties, interviews and the field diary. An account follows of my use of thematic analysis and the different stages involved. I bring my own standpoint to the research by next considering my use of reflexivity and the role it played in my research. Using Finlay's (2012) five lenses for the reflexive interviewer, I work through an extract from one of the interviews and my corresponding field notes. This exercise also demonstrates the value of reflexivity for deeper and richer interpretations. I conclude the chapter by considering the divided opinions in academia about the use of empathy in qualitative research. This was of particular relevance for me, as a retired nurse carrying out research, as I had long used empathy as a tool to direct my professional practice. I conclude that used and acknowledged judiciously, empathy also has a role to play in both fieldwork and data analysis.

Chapter five is the first of the chapters to detail the research analysis and findings. This chapter builds on chapter two and responds to the first two research questions: 'What are the contextual influences on hospital visiting experiences? What do the participants' stories tell about hospital visiting experiences?' The focus of this chapter is the beginning of the participants' stories and their first experiences of liminality and hospital visiting. The first two sections set the scene of the hospital visitor scenario as described by the participants and their descriptions of the various difficulties they encountered. These challenges demonstrate

multiple intersections as they cluster under the headings of the five core themes of the theoretical framework.

The first section commences with the time before hospital admission and, for some of the participants, that heart-stopping phone call which informed of an acute medical emergency and resulted in a dash to the hospital to 'be there' for the patient. However, not all of the participants were involved in emergency admissions and so experienced a less sudden, but equally disturbing, rupture from their everyday and consequent movement into liminality. The second section examines how, in these first hours, the participants confront on-going challenges, which often seem to arise from hospital inhospitality. Here, the lens of liminality is used to highlight the participants' experiences of marginalisation, exclusion and 'invisibility'. The participants' first attempts at demonstrating total obedience, one of the core themes, are also noted. I concentrate in the third section on the core theme of uncertainty of liminality and the efforts the participants made to reduce it by seeking information. The analysis also demonstrates that visitors, too, have information to offer and there are also conceptual links between information and status.

Chapter six augments the previous chapter by continuing to respond to the second research question, which asks what the participants' stories tell about hospital visiting experiences. The discussions also respond to the third question asking, 'Why and in what ways visitors resist or adapt to the policies, customs and practices of hospital visiting?' This chapter concentrates on the liminality of hospital visiting at a time when the participants' responses to the rupture from their everyday and their first encounters with the hospital have subsided. I begin with a focus on the core theme of loss of status and how some of the participants implied their acceptance of this. I then consider the circumstances that prompted them to resist and risk the label of 'problem visitors'. My focus in the second section is the core theme of structure and *communitas*. I note that, within the developing *communitas*, the participants' talk of subtle negotiations in developing a visitors' hierarchy at the patient's bedside. Although not all the participants enjoyed a strong *communitas*, the analysis demonstrates its benefits in encouraging mutual support and the power to challenge perceived faults in the hospital structures. I conclude the chapter by considering the visitors' experiences of the core theme, 'betwixt and between'. This analysis then leads to further developments in the understandings of liminality, which include identification of a continuum of being more or less involved in the patient's illness trajectory. I also identify the visitors' ontological experiences of being between their own body and that of the patient.

Chapter seven responds to all three research questions, as the context of hospital policies, visitors' experiences and adapting and resistance feature throughout. The focus is on the endings of the participants' stories and the patient's death or discharge, which might have been considered as an end to the visitors' liminality. However, as the analysis developed, the

data proved otherwise in some cases. The first section explores the temporal uncertainties experienced by the participants. Their accounts describe the pressures and disruptions to their time and their yearning for an end to their visitor role. Other time-associated uncertainties arise from being kept waiting before being able to leave the hospital. As the next section illustrates, though, challenges, difficulties and frustrations also continued into the day of discharge. Here, the visitors describe their struggles arising from blurred boundaries of responsibility. The final section explores the participants' accounts of the time after discharge. Their experiences of exiting liminality varied considerably and so I asked why this should be. Answering this question reveals, again, the value of the use of the lens of liminality for analysis, as it highlights the role of structure and *communitas* in assisting participants through their intense experiences. Significantly, the data also suggests further nuances of liminality, which appear to have hitherto been less definitively acknowledged.

In the concluding chapter eight, I synthesise and evaluate the different components of the thesis chapters to demonstrate how I have answered the overarching research question, 'What are the experiences of adult visitors to NHS acute medical and surgical wards in England?' After reiterating the research aims, I detail how these have been achieved. I met the first aim to add to the knowledge about hospital visiting experiences by answering the three research subsidiary questions. I present a table of the key research findings of the research and then discuss them in more detail. I begin by appraising the contextual influences described in chapter two in combination with the data analysis. By doing this, I demonstrate how the participants' stories reveal more about the implicit rules, customs and practices, which are, arguably, unique to the hospital-visiting scenario. I then synthesise the literature and the participants' stories to demonstrate how and why visitors might adapt or resist the structures they encountered in the hospitals. In turn, the participants' accounts illustrate the relevance of the concept of *communitas* and the power it can afford hospital visitors.

In the fourth section, I detail the extensions, provided by the thesis, to the knowledge of liminality. The achievement of the third aim, to interrogate positive and negative experiences to identify ways to cater for visitors' needs, is then demonstrated. I suggest some policy, training and education reforms, which could improve hospital visitors' experiences. I then set out some areas for future research before reflecting about the research limitations and methodological issues.

## **Chapter 2. The contextual influences on hospital visitors' experiences.**

The NHS has a unique institutional history, which makes it a cultural and political totem...Continual reform, popular appeal and complexity produce a labyrinthine set of relations between the NHS and other actors: government, professional associations, public and 'private' partners, competitors, NHS employees, patients, other members of the public and the media. (Morrell and Hewison 2013: 62).

### **2.1. Introduction.**

To determine how the social context influences hospital visitors' experiences, I now investigate how continual changes and complexity have created the 'labyrinthine set of relations' identified by Morrell and Hewison (2013: 62). I explore five contextual themes: the national political context; hospital scandals and their repercussion; the use of the internet and social media; hospitals in popular culture; and local influences of policies and their enactment within hospital hospitality, responsibility and choice. These contextual influences are all interrelated and were chosen because of their potential for the greatest impact on hospital visitors' experiences. The extent to which these themes are a result or a cause of hospital visitors' growing loss of confidence in, and an increasing suspicion of, the care provision by the NHS is debatable. Paradoxically, this growing mistrust is occurring at a time of increasing life expectancy and ever-extending medical knowledge and expertise. Other consistent themes emerge from within these overlapping contextual influences. These include the marginalisation of hospital visitors, who find themselves between the social world outside of the hospital and that within and are often perceived as troublesome and in need of active management and supervision rather than a welcome. These are all features of liminality as described by van Gennep (1960) and Turner (1969).

The chapter begins by concentrating on the national political context and how medical advances, changing epidemiology and an ageing demography affect the demands for and costs of quality care from the NHS. This focus reveals the many reforms made in attempts to resolve the tensions between escalating financial pressures and increasing demands for and the maintenance of an efficient health care system. From Thatcher's neoliberalism, Labour's third way policies, the Conservative-Liberal Democrat coalition's austerity measures and forward into the current Conservative government's policies, these reforms have often proved controversial. Politicians find themselves between the competing tensions of cost and quality and the need to satisfy an increasingly better informed, responsabilised and demanding public (Newman and Vidler 2006), from whom they need electoral support.

I follow this examination of the political context with an exploration of hospital scandals, which have so undermined public confidence; more so as the news media seem to report them extensively. The poor care at the Mid Staffordshire Trust and the consequent Francis Reports (2010a; 2010b; 2013a; 2013b; 2015) are explored in greater detail because the repercussions continue in both the policy-making arena and for hospital visitors' experiences. As Evans (2014) suggests, the political responses to hospital scandals have been to increase regulation and professional accountability, audits, in-depth inspections and paperwork within NHS institutions. In turn, these measures, it is argued, have resulted in more work for staff, struggling with a declining workforce, at a time when the national economy and hospital trust finances are under immense strain (Evans 2014).

The review of contextual influences continues by examining the potential of the Internet and social media to permit, for visitors, the gathering and exchanges of information and support. Here, there is a suggestion that these newer forms of communication might empower hospital visitors by providing a platform for their voices and equip them with medical knowledge. However, I also challenge some potential assumptions and suggest limitations, which may silence visitors and so begin to identify an ambiguity of status, which shapes the hospital visitor experience and continues through the following chapters.

My discussion then moves from the visitors' more active engagement with communication technologies to their reception of healthcare-related popular culture, which, initially, might seem a more passive activity. Despite changes in the format over the decades, hospital related popular culture continues to entertain mass audiences. This enduring popularity caused me to question the extent to which this genre might educate, entertain or influence hospital visitors' attitudes, expectations and behaviour. I conclude that it provides cultural narratives from which participants can make sense of their experiences. However, I also suggest that popular culture engenders a fear and fascination (Mooney et al 2000) and a further undermining of trust.

Having established this wider social context, my attention turns to the influences of policies as experienced at a local level by hospital visitors. My comparison of the differing terminologies and linguistic styles of a Trust visiting policy document, a visitors' charter and an American policy document demonstrates how visitors might be considered as 'outsiders' and pose threats of disruption to ward processes in English NHS hospitals. I then explore how these policies are enacted in the local context in terms of the (in)hospitality offered to visitors. Policy and literature combine to reveal further occasions when visitors experience a feeling of marginalisation and other emotional and physical challenges. Inadequate hospitality is often accompanied by visitors' perceptions of a lack of forthcoming empathy and care from hospital staff. I present possible psychological causes for these perceived transgressions by hospital staff of normative hospitality rules. The section concludes with a consideration of some of the

dilemmas and disagreements, which neoliberal policies of choice and responsibility might engender.

I conclude the chapter by suggesting that many of the contextual influences create a scenario in which hospital visitors encounter challenges, which cohere with the features of liminality as described by Van Gennep (1960) and Turner (1969, 1974). Liminality is therefore identified as central to the theoretical framework for the thesis, as I discuss further in the following chapters.

## **2.2. The changing demographic, medical and epidemiological context and political responses.**

On 2 June 1948, just before the launch of the National Health Service (NHS) Aneurin Bevan addressed the Royal College of Nursing (RCN) conference. With remarkable prescience, he observed that post-war shortages and austerity were indicative of the need for the introduction of the NHS, that expectations of the service would always exceed capacity and resources should be used expediently (BMJ 1948 unnamed author). These remarks have echoed through the decades as fluctuating fortunes of the national economy, technological developments, and social, demographic and epidemiological changes have since influenced NHS reforms and, therefore, the context of hospital visiting.

The continuing development of the NHS has been influenced by the challenging demographic changes of increasing life expectancy, which Table 1 demonstrates:

	Male life expectancy at birth (years)	Female life expectancy at birth (years)
1948	65.9	70.3
1988	72.4	78.1
2008	77.6 NB 63.5 years healthy life expectancy	81.7 NB 65.7 years healthy life expectancy

Table 1. UK rising life expectancy since 1948 (Figures from The Office of National Statistics)

It is possible to calculate from the figures above that, towards the end of life, there is now an average responsibility of both care and cost to the state, kinship groups or individuals of 14.1 years for males and 16 years for females. However, these figures do not include illness and social determinants such as lifestyle choices, socio-economic status, occupation, ethnicity or regional variations.

Medical advances (in addition to other social factors) have facilitated this increased life expectancy. These advances include technological developments (for example, scanning machines or keyhole surgery equipment) and drug development (such as antibiotics and vaccinations). As a result, inpatient episodes have moved from lengthy hospitalisation due to acute life-threatening illnesses caused by accidental injury or infectious diseases (for example poliomyelitis or scarlet fever), towards the management of long-term, chronic diseases, such as diabetes or heart conditions (Nettleton 1995: 11), with shorter stays<sup>10</sup>. These technological, medical, demographic and epidemiological changes have meant ever-increasing costs for the NHS as evidenced in Table 2:

Year	Expenditure	Expenditure as percentage of gross domestic product
1950/1951 (adjusted for inflation to be equivalent to 2010/2011 prices)	£11.7 billion	3.5%
2010/2011	£121 billion	8.2%

Table 2. NHS spending in 1950/1951 and 2010/2011 (Harker 2012)

The NHS was restructured in 1973, 1982, 1990, 1994, 1999, 2002, 2006 and 2012-2013<sup>11</sup> Steger and Roy (2010) advise that the most political, ideological and far-reaching reforms to hospital provision were introduced during the Thatcher years (1979-1990) in response to perceived failures in the welfare state and economic and industrial turbulence. They also suggest that Thatcher's enthusiasm for neoliberalism led to the centrality of individual choice and responsibility in these reforms.

The aims of the welfare state were the provision of homes, health and health care, education and social security for all (Briggs 1961), paid for by high taxation with governments regulating and controlling the markets and money flows into and out of the country (Steger and Roy 2010). In contrast, as Steger and Roy (2010) further describe, neoliberalism promoted individualism, entrepreneurship and greater emphasis on family values. These reforms also included lower taxation, a free market with less government intervention in the provisions of social security and welfare. Another feature of neoliberalism, in the context of health care, is

<sup>10</sup>. Despite the demise of some infections, the risks and challenges of newer, more threatening infectious diseases remain. Examples include antibiotic-resistant bacteria such as MRSA or viruses such as new variant CJD, HIV/AIDS or hepatitis C. Further risks emanate from globalisation and the rapid transmission of viral illnesses, such as Ebola or swine flu, with risks of pandemics and high mortality. There is also increasing concern about the growing resistance of bacteria to antibiotics.

<sup>11</sup>. Retrieved 6/2/2015 from <http://nhstimeline.nuffieldtrust.org.uk/>

the emphasis on citizens becoming active and expert consumer-patients, with choices and responsibilities for their self-care and health promotion (Nettleton 2007). Throughout the thesis, I will argue that hospital visitors are also increasingly responsabilised and more aware of their agency. Such policies have resulted in visitors mounting a tentative resistance to those structures that attempt to marginalise them.

The National Health Service and Community Care Act (1991) introduced a *quasi*-market into the NHS<sup>12</sup>. Rivett (no date) notes how this Act was instrumental in separating, for the first time, the providers of care (hospitals) from the commissioners of care (general practitioner fund holders or local health authorities). This Act, Rivett continues, resulted in hospitals being grouped into trusts to compete in terms of costs, care, standards and waiting lists, which the Conservative Government, led by John Major, intended to result in greater efficiency. Also, in 1991, the Major Government introduced the 'Patient's Charter', detailing the rights of patients as 'customers' in health care establishments, including hospitals<sup>13</sup>. In 1992, the Government introduced a scheme for incorporating private finance into a program for hospital rebuilding (Hellowell and Pollock 2009). Notably, amongst these many reforms, I have been unable to find any mention of hospital visitors or hospital visiting policies.

When New Labour swept to power in 1997, Third Way policies were instigated, with a pledge to abandon the internal market in health care (The Labour Party Manifesto 1997<sup>14</sup>). The Third Way rejected the extremes of both Conservative neoliberalism and old Labour democratic socialism but embraced four key values: community; equality of opportunity; responsibility; and accountability (Dickson 1999). Individuals were to assume greater responsibility for their health, employment and family welfare with policy support from the Government. Organisations were to be accountable, and their performances would be measured (Dickson 1999). In effect, the Third Way was to be 'neoliberalism with a human face' with the state and the private sector working in greater partnership with responsabilised, informed and self-motivated citizens regarded as 'consumers' (Sturgeon 2014: 409).

After their first years in power, the Labour Government, contrary to earlier promises, began to expand market influences in the NHS with public-private partnerships (Bennet 2005, Newman and Vidler 2006). Primary Care Trusts (PCTs) were formed to commission care from hospital trusts in 2001. In 2003-2004, payment by results (PbR) was introduced (Department of Health (DoH 2012a). Hospitals were paid in accordance with their achievements and productivity (DoH 2012b). The intention was to support patient choice, reward hospitals' efficiency, reduce waiting lists and remove the focus from the provider-purchaser split towards quality and innovation (DoH 2012b). In 2004, as part of this on-going privatisation, the first

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<sup>12</sup> Retrieved 6/2/2015 from <http://nhstimeline.nuffieldtrust.org.uk/>

<sup>13</sup> Retrieved 6/2/2015 from <http://nhstimeline.nuffieldtrust.org.uk/>

<sup>14</sup> Retrieved 4/12/2015 from <http://www.politicsresources.net/area/uk/man/lab97.htm>

legally and financially autonomous hospital foundation trusts were introduced<sup>15</sup>. As I will later argue, all of these reforms, mostly involving targets, regulation and audits, could, nevertheless, be accused of having significant adverse consequences for patients and their visitors.

Towards the end of the New Labour years, *The NHS Constitution. The NHS belongs to us all* (2009)<sup>16</sup> was launched. This document details the rights and responsibilities of NHS staff, patients and the public, the principles and values of the NHS and pledges to the public from the NHS. The move to greater responsabilisation of an informed public, choice and the involvement of the private sector within the NHS was continuing.

Between 2010 and 2015 the Coalition Government implemented a range of austerity measures to address Britain's economic crisis. Despite the 'ring-fencing' of the NHS from these austerity-associated funding cuts, there were considerable financial constraints. The controversial Health and Social Care Act 2012 introduced further reform and restructuring of the NHS<sup>17</sup>. This Act introduced:

[C]linical led commissioning [...] [with] provider regulation to support innovative services... a greater voice for patients [...] a new focus for public health... greater accountability locally and nationally [...] [and] [...] streamlined arms-length bodies [...] reducing unnecessary tiers of management (DoH 2012b: 1).

General practitioners (GPs) were organised into clinical commissioning groups and became pivotal in arranging secondary care for their patients from 'any qualified provider' (Speed and Gabe 2013). Three bodies were to oversee the reformed NHS: The Care Quality Commission would inspect care standards; Monitor would supervise costs; and the NHS Commissioning Board would monitor efficacy (Speed and Gabe 2013). The National Institute for Clinical Excellence<sup>18</sup> (NICE), established in 1999, would continue to advise and regulate the use, cost effectiveness and efficacy of therapeutic interventions. The march towards Morrell and Hewison's (2013: 62) 'labyrinthine relations' and complexity continued.

Ham et al (2015), in their report of the Coalition handling of the NHS, suggest that although the Health and Social Care Act 2012 increased marketisation within the NHS, it was not as extensive as initially feared. They did, though, suggest that the reforms were 'distracting and

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<sup>15</sup> Retrieved 9/2/2015 from [www.nhs.history.net](http://www.nhs.history.net)

<sup>16</sup> The Constitution is, by law, to be renewed every ten years and revised at least every three years. In effect, revisions occurred in 2010, 2012, 2013 and 2015.

<sup>17</sup> Retrieved 4/9/2015 from [http://www.kingsfund.org.uk/sites/files/kf/field/field\\_publication\\_file/autumn-statement-briefing-2014.pdf](http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/autumn-statement-briefing-2014.pdf)

<sup>18</sup> Later known as National Institute for Health and Clinical Excellence, and, since the 2012 Health and Social Care Act, as the National Institute for Health and Care Excellence (<https://www.nice.org.uk>). NICE now also guides health promotion and Social Services.

damaging', with the new systems of governance and accountability being 'complex and confusing' (p24). *The autumn statement: NHS funding* (The Kings Fund 2014) also suggests that 60% of hospital trusts were in budgetary deficit. Causes of these deficits include a substantial reduction in financing and the increased costs of more nurses on the 'front line' as a response to the Francis reports on the Mid-Staffordshire Trust scandal. There have also been increasing numbers attending hospital Accident and Emergency (A&E) departments, due, in part, to poor access to GP services. Results of these financial constraints, it was argued, include increased waiting times, a reduction in quality of care and 'back-room' staff cuts (The Kings Fund 2014).

Writing in the middle of 2016, Dunn et al (2016) suggest that the NHS budget deficit for 2015-2016 is an unaudited £1.85 billion<sup>19</sup>. The Carter Review final report (2016)<sup>20</sup> has identified key areas for increasing efficiency and productivity in acute hospitals. One area of concern and the extra cost is the delayed transfer of patients from acute hospital care facilities to home or other places of care. These delayed discharges also feature in the participants' stories and are exemplified in chapter seven. However, Murray (2016) notes in his blog that the projected savings from possible reforms identified in the Carter Review are £5bn by 2020, whereas the Government requires savings of £20bn. As Murray (2016) further states, the proposed measures include a subtle shift in emphasis from the recommendations of the Francis Reports (2010a, 2010b, 2013a, 2013b and 2015) for 'safe staffing levels' to secure patients' wellbeing to 'best practice staffing levels' to save money. The availability of extra staff is, furthermore, compromised by a shortage of nurses and doctors in England. Weaver (2016)<sup>21</sup> reports a 60% increase in doctors' and a 50% increase in nurses' unfilled posts (equating to a shortage of 24,000 nurses) with trusts finding it necessary to increase recruitment from overseas. Junior doctors have taken damaging industrial action throughout the year and the June 2016 European Union Referendum result has created extra uncertainty for overseas recruitment. The NHS problems are continuing, patient care appears vulnerable and therefore visitors' continuing anxieties remain justified.

This section has therefore begun to answer the first research question, which asks what the contextual influences are on hospital visitors' experiences. Examination of the NHS history and changes in ideologies and policies provide a backdrop of the national political context, which, as the following sections demonstrate, impacts on the expectations and experiences of hospital visitors. Within these political manoeuvres, hospital visitors appear to have received little explicit attention at national government level. Also, despite politicians' avowed best

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<sup>19</sup> Retrieved 21/9/2016 from [http://www.kingsfund.org.uk/sites/files/kf/field/field\\_publication\\_file/Deficits\\_in\\_the\\_NHS\\_Kings\\_Fund\\_July\\_2016\\_1.pdf](http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/Deficits_in_the_NHS_Kings_Fund_July_2016_1.pdf)

<sup>20</sup> <https://www.gov.uk/government/news/review-shows-how-nhs-hospitals-can-save-money-and-improve-care>

<sup>21</sup> Retrieved 26/3/2016 from <http://www.theguardian.com/society/2016/feb/29/nhs-nurse-shortages-to-last-another-four-years>

intentions for the NHS, the many policy reforms stand accused of having unforeseen adverse consequences for patients and visitors as an exploration of recent examples of hospital scandals demonstrates in the next section.

### **2.3. Scandals – cause or result of policy?**

The many healthcare scandals of recent years have undermined public confidence (McCrae 2013), resulting in political action and policy reforms. I now consider how these scandals and the resulting political responses influence the experiences of hospital visitors and have led to their loss of trust, greater anxiety and increased perceptions of a need for their vigilance of care and treatment standards on behalf of the patients. In turn, I detail the resulting shifts in policy towards a greater inclusion of relatives and carers.

The litany of hospital scandals dates back to, at least, 1991 and nurse Beverley Allitt's murder and injury of children in her care<sup>22</sup>. More recent scandals involving hospitalised adults include the Mid Staffordshire Hospital Trust's catalogue of poor care; Colchester Hospital's falsification of patients' cancer care records and its bullying of whistle-blowers; and the murder of two patients and intentional injury to eighteen others with insulin-contaminated saline at Stepping Hill Hospital. As the discussion demonstrates, care quality scandals also raise questions about whether the burden of meeting an increasing number of policies, targets, audits, inspections and reports detract hospital staff from delivering good quality care. In the context of this debate, Gubb (2009) argues that the meeting of targets assume primacy over high-quality patient care whereas Bevan (2009) suggests that government targets provide hard evidence of and incentives for real improvements.

#### **2.3.1. *The Mid-Staffordshire Hospital Trust scandal.***

I have selected, for further examination, the scandal of poor care at the Mid Staffordshire Hospital Trust, the subsequent inquiries and resulting Francis Reports (2010a, 2010b, 2013a, 2013b and 2015) for three reasons. First, it was the collective efforts of a group of hospital visitors that brought this scandal into the public domain. Second, it is arguably one of the biggest and more recent NHS scandals with continuing repercussions and influences on policy-making and the experiences of hospital visitors. Third, the inquiries and Francis Reports were continuing throughout the participants' hospital visiting experiences and during the research fieldwork. I was, therefore, aware that this well-publicised scandal could have potentially influenced the participants' understandings of their role as hospital visitors and their experiences.

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<sup>22</sup> Details of this case were accessed at [www.biography/people/com](http://www.biography/people/com)

The General Secretary of the RCN raised the first concerns about care at the Mid Staffordshire Hospital Trust in 1999 when she criticised its proposed reduction of senior nursing staff<sup>23</sup>. Despite continuing complaints of inadequate staffing levels and lowered standards of care, in 2003 the Trust achieved a two-star rating (out of a possible three) from the Commission for Healthcare Improvement (CHI)<sup>24</sup>. A year later, the newly organised Healthcare Commission (HCC) issued the heavily indebted Trust a zero star rating. Multiple complaints continued and included allegations of: inadequate care; low and ever reducing staffing levels; rising budget deficits; bullying; and raised mortality rates across several clinical specialities<sup>25</sup>. Staff later reported the falsification of their records and threats of dismissal for breaching Government targets or for reporting adverse incidents such as dangerously inadequate staffing levels. Nevertheless, Foundation Trust status was awarded in 2008.

In 2007, hospital visitor, Julia Bailey, described the Mid Staffordshire Hospital as, 'like a Third World Country hospital' (Blake 2010). Ms Bailey alleged that having been dropped by a nurse, her mother subsequently died from her injuries. Ms Bailey maintained a 24-hour vigil for her mother and witnessed the low standards of patient care in the hospital. Having advertised locally, she made contact with other hospital visitors who had seen poor standards of care in the hospital. As a result, the movement, *Cure the NHS*, was formed with the intention of bringing NHS poor care and unnecessary deaths into public awareness.

An independent (private) inquiry, chaired by Sir Robert Francis, commenced in 2009, with the preliminary report issued in 2010. Following pressure from *Cure the NHS*, the newly elected Coalition Government launched an independent public inquiry; again under the leadership of Sir Robert Francis. The many reports of poor care and unnecessary deaths include the following randomly selected example:

The patient was admitted to Stafford Hospital for a colonoscopy and discharged six days later. However, due to severe vomiting, she was readmitted to hospital and underwent surgery for a hernia. During her recovery, she developed bedsores, and a special mattress was provided, but she is believed to have developed MRSA, and she deteriorated. Her husband attended the hospital for six hours a day to care for his wife, as he believed she was being badly treated. Regular monitoring was stopped and morphine was administered to the patient

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<sup>23</sup> The timeline for the Mid Staffordshire Trust scandal was retrieved 17/2/2105 from [www.curethenhs.co.uk](http://www.curethenhs.co.uk)

<sup>24</sup> In 2001 the CHI was instigated; to be superseded by the Health Care Commission in 2004 and the Care Quality Commission in 2009. This organisation is charged with inspecting, rating and regulating health care providers, including hospitals.

<sup>25</sup> The higher death rates were consistently attributed towards coding errors. Coding is the designation of a particular code to the various causes for hospital admission and informs epidemiological statistics.

who died a week later. Source: Independent case notes review/MP (The Francis Report 2013a vol. 2: 29).

Although this evidence is in the third person, rather than first, the description demonstrates the physical and mental stresses hospital visitors might experience beyond the expected concerns for the patients' recovery. Andrew Lansley, the former Health Secretary, vindicated visitors' vigilance and responsibility in the introduction to the executive summary of the subsequent Francis Report (2013)<sup>26</sup>:

This was a failure of the Trust first and foremost, but it is also a natural failure of the regulatory and supervisory system, which should have secured the quality and safety of patient care. Why did it have to take a determined group of families to expose those failings and campaign tirelessly for answers? I pay tribute again to the work of Julie Bailey and *Cure the NHS*, rightly supported by Members in this House (2013: 15).

This vigilance and determination somewhat reflect a speech delivered in 2003 by Harry Cayton, Director for Patients and the Public at the Department of Health (cited in Newman and Vidler 2006; Sturgeon 2014). Cayton refers to 'the lying down patients of the past' and 'the standing up consumers of the future'. Here, Cayton would seem to be referring to the transitions to informed, 'consumer' patients with choices, evoked by neoliberalism. Arguably, *Cure the NHS* demonstrates that hospital visitors, similarly informed and with diminished confidence in the NHS, are also 'standing up' and 'demanding' and, so, finding a voice.

The Francis Reports (2010a, 2010b, 2013a, 2013b and 2015) resulting from the inquiries attribute many of the failings to the Mid Staffordshire Hospital Trust's corporate interest. They demonstrate that, instead of focusing on patient care, the Trust prioritised government targets in the drive to achieve Foundation Trust status. There were findings of failings in the culture and management, lack of transparency and reluctance to involve the patients, relatives and wider community in care provision. The Francis Report Recommendations (2013b) proposed 290 actions for improving patient care and the *Freedom to Speak Up* report (Francis 2015) concentrates on protecting whistleblowers and encouraging and supporting transparency, accountability and good practice within healthcare settings. The Francis Reports (2010a; 2010b; 2013a; 2013b; 2015) were published amidst much media comment, with the 2013a report coinciding with the research fieldwork. It is, therefore, unsurprising that many of the participants expressed their concerns about poor hospital care and their awareness of a need for their vigilance on behalf of the patients.

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<sup>26</sup> Retrieved 7/8/2016 from [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/279124/0947.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/279124/0947.pdf)

### **2.3.2. Repercussions of the Mid Staffordshire Hospital Trust scandal for hospital visitors.**

A more public and formal response to the Francis reports was provided by the Berwick Report (2013: 4)<sup>27</sup>, which was commissioned in order to 'distil for the Government and the NHS lessons learned and to specify changes needed'. Of particular relevance for the thesis are the recommendations that carers and relatives should be more involved in care delivery and be prepared to establish relationships with staff. Relatives and carers should also share their situations with health workers and raise the alert when care is inadequate. This document therefore both legitimises and shifts greater responsibility for vigilance onto hospital visitors. These recommendations do, though, underscore the visitors' competing demands of their everyday and their responsibilities for the patient in hospital. Also, this establishment of relationships and monitoring of care by visitors is, as discussed later in this chapter, often thwarted by restricted visiting hours, shorter hospital stays and staff workloads and shift patterns.

One solution to this dilemma, often employed on behalf of those in care homes or receiving care at home, is the deployment of covert surveillance cameras. Whereas Closed Circuit Television (CCTV) in public places in hospitals has long monitored the public, people are becoming increasingly aware of possibilities for using this technology to oversee staff in areas of care delivery. Although, so far, this covert filming appears to have been less frequently used in NHS hospitals, there have been isolated cases, which have come to media attention. For example, in 2005 registered nurse, Margaret Hayward, caused controversy by her covert filming of care conditions in an NHS hospital for the BBC television programme, *Panorama* (Edemariam 2009)<sup>28</sup>. Similarly, in 2013, Binny Clarke employed CCTV to monitor and capture on film the poor care given to her husband in a Kent Hospital as she was becoming alarmed by the deterioration in his health, which she noticed each time she visited (Edwards 2013)<sup>29</sup>.

In response to this use of surveillance technology, different organisations with vested interests have published policy documents and guidance. For example, the Care Quality Commission (CCQ) (2015) issued a leaflet entitled '*Thinking about using a hidden camera or other equipment to monitor someone's care*'<sup>30</sup>. In this, the CCQ suggests alternatives to covert filming. Notably, though, rather than condemning the use of hidden cameras, the CQC advises how to avoid possible infringements on people's rights and privacy.

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<sup>27</sup> The Berwick report was published after the fieldwork was completed.

<sup>28</sup> Retrieved 18/05/2016 from <http://www.theguardian.com/society/2009/nov/14/margaret-haywood-double-agent>

<sup>29</sup> <http://www.dailymail.co.uk/news/article-2515983/Abuse-brain-damaged-Grant-Clarke-left-urine-NHS-hospital-caught-camera.html>

<sup>30</sup> Retrieved 18/05/2016 from [http://www.cqc.org.uk/sites/default/files/20150212\\_public\\_surveillance\\_leaflet](http://www.cqc.org.uk/sites/default/files/20150212_public_surveillance_leaflet)

The suspicions aroused by hospital scandals have resulted in visitors assuming greater responsibility for monitoring patients' care. Improvements in technology and its easier affordability and availability are facilitating the increasing use of this surveillance. In the following section, I explore how hospital visitors use information and communication technology (ICT) to assist their overseeing of care provision.

## **2.4. Visitors' usage of ICT.**

The website of *Cure the NHS* demonstrates how technological advances have provided newer opportunities for visitors to 'find a voice' and express their concerns or praise, to gain support and access information. After first considering the more traditional routes that visitors might take to complain, raise queries or express their gratitude, I point to the influences of newer Information and Communication Technologies (ICT) on hospital visitors' experiences and some assumptions and interpretations, which suggest these voices might still be silenced or not heard.

As noted in chapter one, dissatisfaction with hospital inpatient acute care services results in a high number of complaints<sup>31</sup> with no accounting for the costs of handling them<sup>32</sup>. It is also unclear how many of these complaints are from patients themselves or from friends and family members who have visited in hospital and how many complaints are resolved informally on the wards and not included in the statistics. Other channels for complaining include Patient Information and Liaison Services (PILS), local Members of Parliament, the Parliamentary and Health Service Ombudsman, or, in instances of patient harm, legal services. Other, less formal, pathways include using the news media on radio, television, Internet and in the press. News reporting can sometimes result in sensationalist headlines, such as: '*Thousands die of thirst and poor care*' (Flanagan and Donnelly 2014). Seale (2002) accuses such headlines of 'tabloidisation', which can result in exaggeration, fear mongering and the undermining of public confidence. However, Houldcroft (2003: 89) suggests that news sources can also inform, prompt open debate and swifter official action and expose those issues the Government may wish 'to sweep under the carpet'.

A newer technological development has been the facilitation of easier communication by mobile telephones, which often have integral cameras and access to the Internet and, as NHS Choices<sup>33</sup> informs, are now owned by 95% of the population. Hospitals banned the use of early mobile phones on their premises due to fears of their interference with life-saving medical equipment. However, the current advice is for visitors not to use them in clinical areas and, to protect confidentiality, not to take photographs of other patients (NHS Choices).

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<sup>31</sup> Retrieved 30/09/2015 from [www.hscis.gov.uk](http://www.hscis.gov.uk)

<sup>32</sup> Appendix 4

<sup>33</sup> Retrieved 26/08/2015 from <http://www.nhs.uk/chq/pages/2146.aspx?CategoryID=68&SubCategoryID=162>

The almost universal ownership of mobile telephones suggests that it might be difficult to enforce this advice. The research participants confirmed this in their interviews as they welcomed the ability to contact the hospitalised significant other for updates. Likewise, my professional experience has underscored the need for patients to feel connected to home and family.

The widespread availability of the Internet has also provided many different opportunities for visitors. Through this medium visitors can express their concerns or gratitude and access information. Most hospital trusts have communications staff to administer blogs, Twitter and Facebook sites upon which hospital visitors and patients can post comments. Movements and organisations, which aim to provide a voice for hospital patients and visitors and have websites, include *Patient Opinion*, *The Patients' Association*, *Healthwatch UK* and *Carers UK*. There are also illness-specific organisations including the *British Heart Foundation*, *Action on Pain* and *Headway*<sup>34</sup>. *Just visiting*<sup>35</sup> is a not-for-profit organisation. Its website facilitates a virtual, on-line and individual 'room' where visitors and patients can communicate. Notably, there are at least two websites, which, more specifically, are aimed at countering negative or sensationalist comment. *Big up the NHS*<sup>36</sup> (set up by an NHS professional) warns that negative press both damages the NHS and risks 'causing real harm to real people'. *NHS Choices* also hosts the website *'Behind the Headlines'*<sup>37</sup> to provide a 'guide to the science that makes the news'.

However, this use of the Internet is not without problems and controversies. Although there has been inquiry into patients', carers' and health professionals' use of the Internet and social media (for example Eckler et al 2010; Antheunis et al 2013; Moorhead et al 2013), there appears to be little research engaging with hospital visitors' usage. Within the healthcare arena generally, Antheunis et al (2013) suggest that the main motives for using the Internet and social media are for gathering information and support, improving relationships between patients and healthcare professionals and the promotion of self-management of illnesses (and thereby controlling costs).

More specifically, James et al (2007) and Dolce (2011) researched information seeking by cancer patients and their carers. James et al (2007) suggest that carers are more likely than

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<sup>34</sup> Patient Opinion accessed 22/05/2015 at [www.patientopinion.ork.uk](http://www.patientopinion.ork.uk)  
The Patients Association accessed 22/05/2015 at [www.patients-association.org.uk](http://www.patients-association.org.uk)  
Healthwatch accessed 22/05/2015 at [www.healthwatch.co.uk](http://www.healthwatch.co.uk)  
Carers UK accessed 22/05/2015 at [www.carersuk.org](http://www.carersuk.org)  
British Heart Foundation accessed 22/05/2015 at [www.bhf.org.uk](http://www.bhf.org.uk)  
Headway accessed 22/05/2015 at [www.headway.org.uk](http://www.headway.org.uk)  
Action on Pain accessed 22/05/2015 at [www.Action-on-pain.co.uk](http://www.Action-on-pain.co.uk)

<sup>35</sup> Just visiting accessed 22/05/2015 at <https://www.justvisiting.com>

<sup>36</sup> Retrieved 22/05/2015 from [www.bigupthenhs.com](http://www.bigupthenhs.com)

<sup>37</sup> Behind the headlines retrieved 29/2/2016 from <http://www.nhs.uk/news/Pages/about-behind-the-headlines.aspx>

the patients to turn to the Internet for information. Dolce (2011: 358) notes that 'disenchantment' with medical care is 'experienced as both an antecedent and consequence of Internet information seeking' by patients and their carers. Thus, while the Internet can empower by encouraging collaboration and increasing knowledge, it can also foster dissatisfaction (Dolce 2011).

Moorhead et al (2013) also point out discrepancies in the use of the Internet and social media; with younger people, those from lower income households and women more likely to use it. They further propose various limitations of the use of health-related websites and social media. These include security, privacy and confidentiality issues. Other problems are concerns about the quality of the information provided, the possibility of unknown authors and the risk that the public will utilise the Internet rather than seek essential medical advice (Moorhead et al 2013).

Furthermore, Broom (2005) recognises the extent to which the Internet has facilitated an unprecedented access to medical knowledge and a greater awareness of the availability of alternative therapies. This, he argues, has resulted in the demystification of traditional scientific medicine and a better-informed public that is prepared to take greater responsibility and be active participants in care and treatment plans. Broom's research further demonstrates that while some medical practitioners welcome these developments, others might consider that their professional status, knowledge and power are being challenged, with resulting disrupted relationships. This notion of discord in the medical encounter, therefore, contradicts Antheunis et al's (2013) suggestion cited earlier<sup>38</sup>.

Although Broom (2005) does not consider family or friends' searches on the Internet, his research does signal a possibility that hospital visitors might feel reluctant or too intimidated to challenge the long-held dominance of the medical profession. Arguably there is also an extra reticence in information-giving to visitors by hospital staff in discussions about the patient's illness in his or her absence and ethical issues of patient confidentiality and autonomy are at stake. However, when the patient is present, the visitors are more likely to be on the periphery of the consultation as an emotional support for the patient rather than actively engaged, as the research participant, Gill, powerfully describes in chapter five.

I would further suggest that opportunities for 'being seen and heard' do not take into account significant, varied and unacknowledged assumptions and interpretations which might also contribute to the silencing of visitors' voices. For example, as this thesis later demonstrates, possible factors for deterring visitors' complaints include fear of retribution<sup>39</sup> or ostracism, time pressures and a sense of 'moving on' after the hospital experience. Visitors might also

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<sup>38</sup> Broom was writing eight years prior to Antheunis et al (2013) when technology was not so advanced and prevalent.

<sup>39</sup> The NHS Constitution pledges that complaints will be investigated without retribution.

assume, possibly incorrectly, that their more public, on-line comments will be read and that the hospitals will take appropriate action. Visitors may also misinterpret the information and advice they encounter. Finally, not everyone has access to newer technologies or the ability to use them. However, as later discussions of communities and structure reveal, it is the challenge to existing practices, which can lead to real improvements in service provision.

This section, therefore, exposes tensions between hospital professionals, academics and visitors as they grapple with the complexities of social relationships across the platforms provided by newer technologies. Although there are more immediate opportunities for visitors to express their concerns, challenge medical dominance and gain information, they remain, to some extent, silenced and, as such, are in an ambiguous position. This ambiguity is further indicated in the following section, which explores the influences of popular culture on hospital visitors' experiences.

## **2.5. Popular culture: fear and fascination.**

Solomon (2016) proposes the centrality of storytelling in medicine and suggests that patients' stories provide a pathway for doctors to achieve a diagnosis. In turn, doctors draw upon medical discourses to present this diagnosis and treatment options to the patient and relatives. However, Solomon, talking about literature dating back to the times of the Ancient Greeks, further adds:

The division between humanism and science is recent, an Enlightenment idea, a Cartesian duality, and like many such ideas, it served at first to advance a discourse it may now impede. The two modes of thought are now too often posed as opposites rather than as twin vocabularies for the same reality.

Any serious illness is a medical event but is lived in narrative terms. As religion has lost its ground to secularism and the split between body and soul has come to feel metaphoric rather than literal, some people have rooted themselves in scientific explanations of the world, whilst others seek truth in art, literature or even political idealism. Students bifurcate early, pursuing a medical track or a literary/humanist one (2016: 3)

Solomon's words underpin my identification of the centrality of storytelling in this thesis, which I discuss in detail in the following chapter. His words add support to my identification in chapter one of the chasm between the practical and physical on the one hand, and the emotional and psychological on the other. Solomon continues by noting how some doctors are attempting to bridge this void by publishing their stories of their professional experiences. I, therefore, questioned whether other genres of hospital-related popular culture might

similarly facilitate a middle ground between the 'medical' and the 'literary, humanist track'. I also asked to what extent representations in popular culture might influence hospital visitors' expectations and experiences. These queries were answered by, first, examining the production of popular culture and, second, by reviewing some of the literature about its reception by audiences. These explorations reveal that the use of stereotypes has prevailed through the decades and that hospital drama is often exaggerated for entertainment value. This creates both a public 'fear and fascination' (Mooney et al 2000) with the hospital-related popular culture which might, only in part, prepare people for their role as hospital visitors.

There is a multiplicity of genres in popular culture concerned with medicine and health (Burton 2005) and hospitals, more specifically. These genres span many decades and demonstrate an enduring popularity with audiences. Examples of television soaps are *Emergency Ward 10* of the 1950s and 1960s, through *Dr Kildare* in the 1960s, *Angels* in the 1970s and 1980s. 'Getting On' is a 21st century dark comedy series and the present day genre of soaps include *Holby City*, *Casualty* and *Doctors*. Films shown in cinemas and on television date back to (at least) the *Doctor in the House* (1954), *Carry on Nurse*, *Doctor and Matron* series (1960s and 1970s), *Twice Round the Daffodils* (1962), *The Doctor* (1991) and continue into the 21<sup>st</sup> century with *Infection* (2004) and *The Waiting Room* (2012). *24 Hours in A&E* and *One Born Every Minute* are contemporary 'fly-on-the-wall' hospital documentaries. Books range from Monica Dickens' (1942) autobiography, *One Pair of Feet*, Mills and Boon hospital romances, American hospital dramas such as *Nothing Lasts Forever* (Sheldon 1994) and *My Sister's Keeper* (Picoult 2004) and the emerging genre of doctors' stories identified by Solomon (2016). Magazines, such as *Take a Break* and the news media publish real life health stories. All of these representations are designed to inform, educate, entertain, reassure or arouse the emotions (Seale 2002). Hetsroni (2009) alerts to inaccuracies, for entertainment value, of patient demographics, epidemiology and illness outcomes, which undermine public trust and engender greater fear.

Referring to the news media, Kitzinger (2000: 61) coins the term 'media templates' which, she suggests, facilitate the creation and dissemination of news stories. These templates arise from events that attract so much media and public interest that they provide shorthand for referring to similar occurrences. Long after the news media have moved onto other topics, media templates continue to carry meanings and associations for the public. Just as Kitzinger (2000) gives the example of the Cleveland child abuse scandal, I suggest that the Mid Staffordshire Hospital scandal and following Francis reports provide a media template for the representations of poor quality care provision in NHS hospitals. This is borne out by headlines such as 'Welsh hospital scandal bigger than Mid Staffs' (Halle and Grimston 2014) or 'Francis: patient advocacy more fragmented than at time of Mid Staffs scandal' (Hazell 2014).

Moving from news reporting to fictional representations of hospitals, Kitzinger's (2000) media template tool appears to be replaced by the use of stereotypes. As Bridges (1990) notes, stereotypes can inform policy-making and the allocation of resources and influence service users' expectations and demands. Comparison of *Dr Kildare* with *Holby City* reveals a marked change in stereotypical representations of hospital staff over the decades. Jacobs (2015) argues that these representations have moved through distinct phases. The stereotype of an individual, dedicated and infallible doctor in, for example, *Dr Kildare*, shifted in the 1970s and 1980s to a focus on hospital teams and their internal conflicts (Jacobs 2015). Medical and social problems were also represented as inter-related and doctors were no longer seen as heroes. Jacobs (2015) adds that contemporary dramas are concerned with morals, the medicalisation of everyday lifestyles and health scares. Doctors still make mistakes but are represented as more reflective (Jacobs 2015). In her concentration on the changing representations of nurses in films, Hallam (2002) notes the progression from stereotypical and vocational 'angels' and 'doctors' handmaidens' in the 1950s, 'battle-axe matrons' of the 1960s to patients' advocates and professionals from the 1980's onwards. Forming part of the title of this thesis, '*Just a bunch of grapes?*' alludes to stereotypical visitor behaviour patterns. However, a literature search revealed no academic comment about hospital visitor stereotypes. This led to my exploration of how hospital visitors are represented in popular culture.

My starting point was Causely's (1997) poem<sup>40</sup>, *Ten types of hospital visitor* and the visitor stereotypes he represents. An extract of Causely's fourth 'type' is below:

The fourth attempts to cheer  
His aged mother with light jokes  
Menacing as shell-splinters.  
'They'll soon have you jumping around  
Like a gazelle,' he says  
'Playing in the football team.'  
Quite undeterred by the sight of kilos  
Of plaster, chains, lifting gear,  
A pair of lethally designed crutches [...]  
At these unlikely prophecies  
The old lady stares fearfully  
At her sick, sick offspring  
Thinking he has lost his reason –  
Which, alas, seems to be the case.

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<sup>40</sup> See Appendix 5 for complete poem.

In this verse, Causely has identified the stereotype of the hapless visitor who is experiencing social discomfort in an unfamiliar situation. Feeling awkward and unable to find the right words to encourage and support the patient, the visitor resorts to improbable platitudes. This is a stereotypical hospital-visiting scenario, which is often represented on seaside postcards as the following cartoon image demonstrates<sup>41</sup>:

*A cartoon representation of the stereotypical hapless problem visitor*



"You're looking well."

Such cartoons and many of Causely's 'types' therefore provide examples of, and warn against inappropriate 'problem visitor' behaviour. As a contrast, Causely's (1997) sixth verse describes the ideal visitor type in the following way:

The sixth visitor says little,  
Breathes reassurance,  
Smiles securely [...]  
Talks quietly to the Sister  
Out of sight, out of earshot of the patient.  
Arrives punctually as a tide.  
Does not stay the whole hour.  
Even when she has gone  
The patient seems to sense her there:  
An upholding  
Presence

This sixth visitor appears to understand intuitively the role of the 'good visitor'. This theme of good or problem visitor is developed throughout the thesis and is demonstrated as a powerful influence on visitors' expectations and behaviour patterns. As will be discussed in chapters

<sup>41</sup> Retrieved 14/7/2016 from [http://www.toonpool.com/cartoons/TP0118healthhospital\\_27766](http://www.toonpool.com/cartoons/TP0118healthhospital_27766)

five, six and seven, this theme was also reflected in how participants told their stories. For comparison, an image of good visitors is shown<sup>42</sup>:

*The stereotypical loving family bearing gifts as good visitors.*



These representations point to the, often implicit, social expectations, rules and practices, which bear down on hospital visitors. There are pitfalls for those who are unprepared for their unaccustomed role in an unfamiliar environment.

Therefore there are historical and culturally and socially contingent stereotypes, media-templates, images, representations and dramatic license employed in the production of hospital-related popular culture. Also, the enduring popularity and multiplicity of the different genres suggest that they provide cultural narratives upon which hospital visitors can draw to inform their behaviour, expectations and their own storytelling. Cultural narratives are defined as:

[S]tories that help a community structure and assign meaning to its history and existence. Cultural narratives include creation stories, which tell a story about the community's origins, and fables, which help teach moral values and ethical behaviour. Cultural narratives help a community reinforce societal norms, preserve its history and strengthen its identity through shared knowledge and experience<sup>43</sup>.

In terms of the reception of these narratives, Livingstone (2004) notes that audiences are ever changing and have been variously understood by their appropriation of popular health culture. Audiences might be educated and informed or passively entertained (for example Davin

<sup>42</sup> Retrieved 21/9/2016 14/7/2016 from <http://www.almaterhospital.com/wp-content/uploads/2013/01/visiting.jpg>

<sup>43</sup> Retrieved 14/7/2016 from <https://www.reference.com/art-literature/cultural-narrative-52d444828583ec01>

2000, Seale 2002) or their attitudes and behaviour might be influenced (Lee and Taylor 2014). Other factors such as age, ethnicity, gender or class (Burton 2005) or 'analytic competencies, social practices and material circumstances' (Livingstone 2004:79) can also shape audience interpretations of the representations. These interpretations might also lead to alternative conclusions by the audiences to those intended by the producers, or they may utilise the content to inform, construct and experiment with possible self-identities and roles (Seale 2003).

Furthermore, Hetsroni (2009) draws on cultivation theory to demonstrate that the recurring patterns in hospital genres lead people to internalise the messages being given as true representations of the real world. Giddens (1991:169) also warns of the consequences of this interrelationship of fiction and the real world. He suggests that an over-exposure to, and excessive familiarity with fictional representations of crises can result in the psychological self-defence mechanism of 'reality inversion'. This occurs when the presenting crisis feels less real than those enjoyed in the familiarity of popular culture.

Audiences, nevertheless, remain consistently fascinated by medical stories (Davin 2000). Part of this fascination arises from the entertainment value caused by emotional responses deliberately triggered by the producers (Seale 2002). As noted earlier, fear becomes one of these emotions invoked as audiences are confronted by stories that are exaggerated (Hetsroni 2009) for entertainment value. Such stories involve less common illnesses and injuries but do remind the audiences that even rare misfortunes can and do happen (Hetsroni 2009). 'Fear and fascination' is the term Mooney et al (2000) use in the context of the public response to media representations of crime. There are examples of the term's use in other disciplines, for example: anthropology (Agutter et al 2013), music (Parsonage 2007) and human infertility (Burr 2009). This fear and fascination and the reinforcement of cultural narratives suggest that popular culture might also help to provide the bridge between the literary, humanist and medical track identified by Solomon (2016).

However, the research data suggest that the participants experienced an overwhelming flood of emotions when confronted, in an alien environment, with the stark reality of the messiness of illness associated with the malfunctioning body of a significant other. This often resulted in an all-consuming preoccupation with the patient's illness trajectory and consequent anxieties, fears and uncertainty. In this reality, hospital visitors are caught between the 'literary/humanist' track of the popular culture they enjoy in the comforts of their own homes and the 'medical track' with which they are confronted.

This section establishes the role of cultural narratives in providing hospital visitors with the tools to make some sense of their situation and to later draw upon to tell their stories about their experiences. This central relevance of storytelling is explored further in the following

chapter. My discussion also demonstrates that the exaggerations of the news media reports and the misrepresentations in popular culture of hospitals, their care and illnesses can engender fear. Arguably, this fear, in common with hospital scandals, undermines visitors' trust, increases their suspicion and engenders perceptions of a greater need for their vigilance on behalf of the patient. Vigilance can, though, only be exercised within the constraints of hospital regulations, which I next explore.

## **2.6. The implications of policies and practices in the hospital environment: (in)hospitality, responsibility, control and choice.**

[We are required] to think about how to discern the parameters and targets of social policy, and whose values should underwrite and shape these boundaries of legitimacy [...] How do we decide whose interests to privilege at what moments in, for example, the social relations of care in familial or public settings? (Lewis 2000: 2).

Lewis' words reverberate throughout this section, in which I consider the more local impacts and influences of hospital visiting policies. With reference to Lewis' quote, hospital trusts, charged by the DoH with managing their visiting policies, are also caught between the competing demands of the interests of diverse groups including staff, patients, visitors, government inspectors, politicians and accountants. The abnegation of responsibility for visiting time regulation by the DoH can be attributed to at least two possible reasons. First, hospital visiting, and the visitors themselves, may be considered insignificant and overlooked by the DoH. Second, the decision to devolve the regulation of visiting times to local trusts is consistent with neoliberal policies to reduce central control. Whichever, this results in visiting time variations from trust to trust, hospital to hospital within the same trust and, even, from ward to ward in the same hospital. For visitors, this inconsistency can create extra uncertainty and logistical difficulties in arranging transport and time away from domestic, leisure or work commitments.

With such little attention accorded the by central government to hospital visitors and their needs, I review part of a national policy document that involves hospital visitors and the advice to visitors provided nationally by the Citizens Advice Bureau (CAB). I then examine local policies and their immediate impact on hospital visitors' experiences. This involves a comparison of the differing linguistic styles of a local policy document, a hospital trust's visitors' charter and a document published for guiding American hospital visiting policy. Following this, I consider how policies and practices might be enacted locally in the hospitals within the context of hospitality and neoliberal policies of encouraging responsibilised consumer citizens. This section therefore further demonstrates the tensions identified by Lewis (2000).

### **2.6.1. Policies and practices.**

I found only one guidance issued from central government pertaining to hospital visitors and this was buried deep within DoH Building Note 00-03 (2013: 32). This outlines standards for relatives' room/interview room/counselling room/ patients' sitting room on the general wards:

3.112. A non-threatening ambience should be used through the use of domestic-type furniture, for example, sofas or easy chairs. All upholstered furniture must be easy to clean and impervious.

3.113. Telephone and network/internet access should be provided to allow for future change of use.

3.114. A clinical wash-hand basin and gel dispenser may be provided to allow for clinical use of the room.

Despite recognition of the need for 'ambience', the clinical aspects and the readiness with which the room might be removed from visitors' use predominate. This lack of priority for visitors' interests does not bode well for their comfort and convenience.

The random application of visiting time restrictions further disrupts visitors' convenience. For example, hospitals might enforce rules that are more stringent and restrictions during epidemics of influenza or norovirus. Alternatively, hospitals might relax these restrictions during bank holidays and religious festivities such as Christmas or Diwali. To address possible confusion the Citizens Advice Bureau<sup>44</sup> website describes some of the rights and rules for visitors and patients in the following way:

Most hospitals have visiting hours during which visits to patients can be made. A person has no automatic right to visit you, and your doctor may decide that visits would be detrimental to your health. There is usually also a limit to the number of people who can visit at any one time. The restrictions on visits from children are the same as those for other visitors. If someone wishes to visit you outside visiting hours, they should discuss this with the ward sister. If they cannot get permission from the ward sister, they should contact the hospital administrator if they wish to pursue the matter<sup>45</sup>.

Visiting times and restrictions, overseen by nurses, can, therefore, be inconsistent and hospital visitors and patients have no legal rights to see each other. Thus the interests of the patients and staff appear to be 'privileged' (Lewis 2000:2) at the expense of meeting the visitors' needs.

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<sup>44</sup> An organization that advises on citizenship rights, and options for resolution of problems

<sup>45</sup> <https://www.citizensadvice.org.uk/healthcare/nhs-healthcare/nhs-patients-rights>

Given the minimal amount of central policy for hospital visiting, I have selected three policy documents for comparison. Each document has a contrasting linguistic style and is intended for different audiences and demonstrates how policy makers might perceive visitors. These three documents, available in the public arena, are:

- *Peterborough and Stamford Hospitals Foundation Trust Visiting Policy (2014)*<sup>46</sup>
- The University Hospitals of Leicester Trust booklet, *The Visitors' Charter*<sup>47</sup>
- An American policy document published by the Institute for Patient and Family-Centred Care (IFPCC 2010), *Changing hospital 'visiting' policies and practices: Supporting family presence and participation.*

Peterborough and Stamford Hospitals Foundation Trust is one of the few trusts that publish its visiting policy document on the Internet. Its policy is, as a formal document, the least 'visitor' friendly and is produced from the perspective of hospital staff concerned with the management of hospital visiting. It is written entirely in English and the following is an extract of relevant key points:

Peterborough and Stamford Hospitals NHS Foundation Trust (PSHFT) actively encourages visiting and the involvement of carers while patients are in the hospital.

At all times the Ward Manager or deputy can use their discretion in the best interests of the patient for whom they are caring.

The policy gives staff the authority to manage visiting in a way that provides appropriate access for the patient's family and friends while at the same time protecting confidentiality, security, privacy and rest.

Anyone who is feeling unwell, has a cold or has had any diarrhoea and/or vomiting within the previous 48 hours is asked to refrain from entering the inpatient ward areas.

Like the waiting room policy discussed earlier, this document can be accused of tokenism in respect of the active encouragement of visitors and accommodation of their needs. The language is formal, politically correct and authoritative and visitors are seen as outsiders who pose infection risks and might be disruptive to patients' best interests and so need active management. Of particular note is the difference accorded to carers in the 2014 PSHFT policy and its 2006 edition:

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<sup>46</sup> appendix 3

<sup>47</sup> Retrieved 2/1/2016 from:

<http://www.library.leicestershospitals.nhs.uk/pubscheme/Documents/Services%20we%20offer/Patient%20information/General%20information/Visitors'%20Charter%20-%20University%20Hospitals%20of%20Leicester%20information%20leaflet.pdf>

Visitors are encouraged to be present for specific treatments when they are involved in giving continuing care, for example, to help the patient at meal times. If the patient wishes, visitors may be present for consultant /medical rounds by prior arrangement (2006, page number unavailable)<sup>48</sup>.

In line with our Carers' Charter, we will give you a choice on whether you wish to take on / continue with the role of carer whilst the person is in hospital and ensure that you are given the access and support necessary to enable you to provide care should you so choose. We will waive the restrictions on visiting hours to enable you to support the person you care for at meal times and with their personal hygiene needs, should you wish to (Carers' Charter - 2320). Where appropriate visitors will be welcomed at mealtimes to assist and encourage patients with their meals (2014: 6).

These changes reflect the slowly increasing awareness of carers' needs in both hospital and community and the many documents published in recent years by public agencies. These include the Berwick Report (2013 section 3.2), as discussed earlier in this chapter, and the *Carers Strategy: Second National Action Plan 2014-2016*<sup>49</sup> (DoH: 2016). Although this paves the way for an important group of hospital visitors to be better accommodated, there remain many other visitors who might be denied this welcome.

Many trusts publish their guidance for visitors. The University Hospitals of Leicester Trust has produced an advisory leaflet titled, *The Visitors' Charter* (2011). This has a simpler and less authoritarian linguistic style than the policy document and, to demonstrate this, an extract appears below:

This visitors' charter aims to explain what you can expect from us during your visit and what we would like from you in return.

We understand the important role visitors can play in the well-being of our patients and we will try to be flexible to your needs.

Our priority is caring for our patients. Please be respectful when visiting, our patients are ill and need their rest (p2).

Always follow any infection prevention and control instructions from staff.

We try to create a calm, restful environment for our patients so noise should be kept to a minimum (p4). We will be polite and courteous to you at all times and

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<sup>48</sup> Retrieved 12/1/2016 from [http://www.peterboroughhandstamford.nhs.uk/\\_files/policies/133\\_\\_patient\\_visiting\\_\\_2\\_.pdf](http://www.peterboroughhandstamford.nhs.uk/_files/policies/133__patient_visiting__2_.pdf)

<sup>49</sup> Retrieved 1/1/2016 from [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/368478/Carers\\_Strategy\\_-\\_Second\\_National\\_Action\\_Plan\\_2014\\_-\\_2016.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/368478/Carers_Strategy_-_Second_National_Action_Plan_2014_-_2016.pdf)

we ask that you show the same consideration to us, our patients and other visitors (p5).

Unlike the policy, the charter appears more attuned to visitors' experiences, with an offer to provide a copy in alternative languages or Braille. The linguistic style is more conciliatory, addresses the visitor directly and implies a partnership with the visitor in the care and wellbeing of the patient. However, again, there are connotations of visitors being outsiders who pose infection risks and disruptive potential. Also, the term consistently used is 'our patients' which implies that the hospital has wrested ownership of the patient from friends and family. This contested ownership is discussed later in the thesis.

The policy documents examined so far all include an element of ambiguity, which, Best (2012) suggests, permits a flexibility and discretion for hospital managers in their application of the rules. This ambiguity, therefore, privileges the interest of hospital staff rather than the patients' and visitors' needs to see each other. As a contrast, the American IPFCC (2010) document acknowledges:

Current 'visiting' policies in many of our nation's hospitals, even for traditionally defined 'families', are inappropriately restrictive, costly, put patients at risk, and contribute to emotional suffering for both the patient and family (p2) [...]

As well as changing the language typically used in 'visiting' policies, it is equally important to revise many of the rules and practices that limit the times and places families and other 'partners in care' are able to provide support (p3).

This document privileges the interests (Lewis 2000) of the visitors by acknowledging the multiple and diverse rules which compound their difficulties. As noted in chapter one, these obstacles were also identified by O'Conner et al (2012) and reinforce Lewis' (2000) warning against overlooking the centrality of family members in the provision of care.

The linguistic styles of the Peterborough policy and the Patients' Charter suggest that the challenges identified in the American document remain insufficiently acknowledged by English hospital trusts and visitors remain marginalised and their needs often overlooked. To determine the extent to which this occurs, I next explore hospital (in)hospitality and how visitors might be welcomed or overlooked.

### **2.6.2. Hospital (in)hospitality.**

As hospital care has become more centralised (Ham 2014) in the cities, visitors' challenges often begin with long and difficult journeys. Public transport timetables may be inappropriate for visiting times and train stations or bus stops might be at a distance from the hospitals. Those travelling by car can encounter navigational and car parking difficulties. Hospital

parking charges and rules, set by individual trusts, are a cause of much resentment with, for example, the charges seen as a 'tax on illness' (Benjamin 2007)<sup>50</sup>. In 2014, the Hospital Car Parking Charges (Abolition) Bill was introduced into Parliament but prorogued due to the imminent 2015 General Election<sup>51</sup>. However, the DoH issued guidance to trusts on fairer charges and updated its recommendations in October 2015<sup>52</sup>.

The next challenge for visitors is to find the correct ward. Hospital signage can be difficult to follow, especially for the visually impaired, those who speak little English, have poor literacy skills or little knowledge of medical terminology as the following photograph taken in a London hospital demonstrates<sup>53</sup>:



An example of a hospital sign. *Source: Flickr commons*

In addition to difficult signage, multiple entrance/exit points create further orientation difficulties and there can also be difficulties in locating support services such as receptions, restaurants, toilets and shops (Bitgood 1988). These supporting services are often situated near the main entrance but at a distance from the wards.

<sup>50</sup> The University Hospitals of Leicester raised in excess of £3m for the year 2014-2015 (Donnelly 2015) Retrieved 20/6/2016 from <http://www.telegraph.co.uk/news/health/news/12062569/Hospitals-rake-in-more-than-3m-each-from-parking-fees-including-for-the-disabled.html>

<sup>51</sup> Retrieved 11/10/2016 from <http://services.parliament.uk/bills/2014-15/hospitalcarparkingchargesabolition.html>

<sup>52</sup> <https://www.gov.uk/government/publications/nhs-patient-visitor-and-staff-car-parking-principles/nhs-patient-visitor-and-staff-car-parking-principles>

<sup>53</sup> <https://www.flickr.com/photos/carolblondon/6501167281/in/photolist-aUubx4-nboaww-okoWvE-k15SpH-5MUnmM-oxJ4Rs-ecQnyC-bectVv-qSsitB-rwFbvm-dJYCS1-9wAEbz-9mizfg-dLeKkR-7Ss4eE-jSjNAk-nsSqAe-kt8u2t-5MEyb3-7RVgjD-6vFuYE-oBTJ22-kt7M9X-j6jnK6-ecJhJa-3wvG3q-nasZoV-bA5sL2-bejZTV-ekjBTJ-6vBgRn-gyRXW3-5MU52X-9xuKiE-kFvbqQ-dJTknP-ekdSH8-bjqymD-9ivRim-dPTvTh-b616a2-kx7kNF-pr2azh-dZmZuo-9wzGJf-e6n5AD-akXpHM-dQdt9m-rUJREL-e6u4hc>

On arrival at the ward, visitors have to find the patient. This can be made more difficult by the practice of repositioning beds within the ward or even between wards. This movement of beds is according to clinical needs and the pressure to accommodate new admissions. The public has also demanded single sex wards. This demand has been politically sanctioned but it has created an extra logistical difficulty in achieving efficient bed management, which involves complex negotiations between bed co-ordinators, ward nursing staff and doctors. My professional experience is those visitors' needs and opinions about bed movements are rarely, if ever, considered. Finally, the visitors have to find chairs to sit on. These chairs are usually stackable, plastic and uncomfortable. As the participants later confirm, the space around the patients' bed is often limited and, during visiting times, the chairs, equipment of adjacent patients, and also their visitors, can encroach on the bed area with a resulting loss of privacy.

Taking a break from the bedside for refreshment can often be impossible because it involves a lengthy trek to the restaurant, or, as one participant notes, because it 'eats into your [*permitted visiting*] time'. Hospital restaurants and shops may sometimes be closed during evening or weekend visiting times and also unaffordable for some visitors. In the absence of any policy for visitor hospitality, it is left to the ward staff's discretion whether visitors will be included in the patients' 'tea rounds' and offered refreshment. As Fox (2005: 312) somewhat ironically notes:

Tea is still believed, by English people of all classes, to have miraculous properties. A cup of tea can cure, or at least significantly alleviate, almost all minor physical ailments and indispositions, from a headache to a scraped knee. Tea is also an essential remedy for all social and psychological ills, from a bruised ego to the trauma of divorce or bereavement. This magical drink can be used effectively as a sedative or a stimulant.

My research, however, suggests that a cup of tea is far more symbolic as it implies welcome and inclusion and, yet, it was infrequently offered to the research participants.

Therefore, hospital visitors are often unlikely to receive the traditional welcome and practicalities of shelter<sup>54</sup>, comfort and the provision of refreshments most often associated with hospitality (Lashley 2000). This may be because hospital hospitality occupies an ambiguous position somewhere between the two traditionally understood concepts of either private or commercial hospitality (King 1995; Brotherton 1999; Lashley 2008). Patten (1994) suggests a useful third category of 'professional or therapeutic hospitality' for defining hospitality in American private hospitals but this does not appear to fully address the

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<sup>54</sup> In this case, I also propose a metaphorical 'shelter' from anxieties

ambiguity visitors might experience in NHS hospitals in England, where care is free at the point of need.

This ambiguity identified in hospital hospitality exposes visitors to the imposition of a different, and possibly unique, contextual set of hospital values, customs and practices which would seem to 'privilege' (Lewis 2000: 2) the smooth running of the ward rather than visitors' needs. Darke and Gurney's (2001) work on the tacit rules for hosting the impromptu, uninvited guest – or 'putting up' – provides some examples of social and cultural practices and rules which could equally apply to hospital visiting times. As hospital visitors are, likewise, uninvited guests, tolerated rather than welcomed and without the refreshments and comfort associated with hospitality (Lashley 2000), Darke and Gurney's (2001: 85) analysis seems apposite:

As the guests have initiated the visit they are expected not to complain at discomfort, poor facilities or lack of privacy [...] Guests who are put up should observe rules such as, a) be restrained in consuming household resources (telephone, milk, toilet roll etc) [and] b) avoid breaking anything.

Accordingly, the research participants, attempting to comply with similar, implicit hospitality rules, report a reluctance to complain formally to staff during visiting times about being requested to leave, their perceptions of poor care, lack of privacy and infringements of their expectations of comfort and refreshment. As will be demonstrated, these are common complaints arising from the research data.

Telfer's (2001) discussion of host and guest roles demonstrates a further ambiguity in determining the status of the hospital visitor. The patient might be the host and the visitor the guest, as in a private hospitality setting. Or, the hospital might be the host and the patient the guest, as in commercial hospitality, with no definitive role for the visitor. Hospital visitors could also be considered as indirect guests in that they compose a transient population and are visiting the patients who are resident guests (Severt et al 2008).

The results of this role ambiguity become more pertinent when considering Burgess' (1982) observation of the similarities of hospitality and gift exchange. He argues that both impose identities on the giver and receiver, are represented and reinforced by symbols, often have connotations of reciprocity and are influenced by social and cultural values, rules and conventions. As Burgess (1982) further suggests, these features are perhaps more exaggerated in the initial transactions of bargaining for identity and power. This is the time when relationships have yet to fully develop and so there is a greater social distance between those interacting (Burgess 1982). The encouragement of more positive relationships and closer social distance are now seen as a priority by many organisations, including hospitals,

and this is attempted by using first names or encouraging management to have a more public presence (Burgess 1982).

However, the development of relationships between staff and visitors requires time, which is one element in short supply on hospital wards. The research participants tell of their own time pressures brought about by attempting to incorporate time-limited hospital visiting into the everyday schedule of home, leisure and work commitments. Shorter hospital stays further compromise relationship development. Time pressures for hospital staff are exacerbated by fluctuating shift patterns and heavy workloads. This adversely affects staff capacity 'to identify visitors' needs and provide suitable hospitality' (Burgess 1982: 55).

Analysis of the data further suggests that dissatisfaction arises when visitors encounter staff who appear to demonstrate little hospitality, empathy or, even, acknowledgement of them. This dissatisfaction can sometimes be expressed in terms of abuse or aggression (Severt et al 2008). Hospital staff might respond by resorting to the tactics demanded by the emotional labour (Hochschild 1983) that is needed to comply with professional and hospital standards. These tactics include distancing (or depersonalising) themselves as targets of the abuse or acting with an appropriate sensitivity that they no longer feel (Hochschild 1983). 'Burnout' is the 'long-term cost' of this emotional labour and can lead to a refusal to continue acting and a prolonged numbing of feeling, which ultimately leads to an inability to correctly interpret the social world (Hochschild 1983:188). Thus visitors might be misinterpreting staff self-protection mechanisms as an alienating lack of empathy and welcome.

Role ambiguities and minimal hospitality, often accompanied by loss of confidence in hospital care and being viewed as threatening or dangerous 'Other', consequently have the potential to pervade visitors' interactions with ward staff. As will be shown in following chapters, the participants, attempting to be 'good visitors' (Lorber 1975) and conforming with Darke and Gurney's (2001) rules for the put-up guests, report their reluctance to complain about the poor hospitality offered to them and their perceptions of poor care afforded to the patient. This reluctance is brought into direct tension with neoliberal ideologies, which have arguably created informed and responsabilised citizens with choices as I next discuss.

### ***2.6.3. Neoliberalism: responsibility and choice.***

As noted, neoliberal ideologies have accorded responsibilities and choices to consumer-citizens. Visitors' more personal, private and, arguably, more easily met responsibilities include the practicalities of ensuring the patient has clean clothes to wear and the arrangement of a schedule of visiting to ensure regular and continued emotional and practical support for the patient. A more difficult responsibility, which may be seen as a threat by the hospital staff, is that of monitoring care provision and illness and recovery trajectories.

However, hospital visitors do not equally assume responsibilities. Finch and Mason (1993) describe family responsibilities and commitments as being constantly negotiated with a felt need for excuses, such as distance, work, incompetence or prior family commitments, to be accepted and legitimised by others. Visitors may also be prompted to act within normative guidelines and a sense of 'the proper thing to do' (Finch 1989: 144). Failure to meet responsibilities can produce feelings of guilt (Berndsen and Manstead 2007). Finch (1989: 138) identifies a 'hierarchy of obligations' within the family, especially when providing care: '[the] spouse has the strongest obligation, then daughters followed by daughters-in-law, then sons, then other relatives'. This hierarchy became evident as my research progressed and also correlates with the gendered nature of caring which has traditionally been seen as women's work (McDowell et al 2005, Russell 2007, Simon 2011, Barnes 2012). The hierarchies negotiated and developed do not cohere with inheritance and intestacy laws (The Probate Department)<sup>55</sup>. As law does not define 'next-of-kin', hospital trusts now ask patients, with capacity and on admission, to nominate someone as first point of contact (Advice Now)<sup>56</sup>. This nominated person, in the absence of Power of Attorney, will be asked to make choices if the patient loses the capacity to make them.

Choices and decision-making by hospital visitors appear also to be under-researched with little relevant literature. Most academic comment is confined to the selection of a care home (Ryan and Scullion 2000) or consideration of end-of-life plans for patients, such as whether to resuscitate (Elliott and Olver 2008) or donate organs (Sque et al 2006). However, the rhetoric associated with 'consumer' citizen and 'choice' does mean that the public now demonstrates rising expectations of care, cleanliness, prompt attention and knowledgeable doctors able to provide a cure (Bowling et al 2012). Giving citizens consumer status can also result in tensions between professional judgments, patients' and family expectations and balanced budgets (Clarke et al 2007).

Further potential tensions relating to policies of choice and responsibility arise from The Human Rights Act (1998), which includes the 'right to control who sees and touches your body' (Equality and Human Rights Commission)<sup>57</sup>. This is carried through into the NHS Constitution 2013. Giving too much choice, control and responsibility to the visitors undermines the patients' ownership of their own bodies and contravenes the law.

This section has therefore demonstrated the contextual impact on hospital visitors' experiences within the locality of the hospital wards. It has permitted identification of omissions in policies and guidelines for staff and the degree of hospitality to be afforded to the

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<sup>55</sup> <http://theprobatedepartment.co.uk/rules-of-intestacy/>

<sup>56</sup> [www.advicenow.org.uk](http://www.advicenow.org.uk) An independent, charitable website providing free legal advice

<sup>57</sup> Retrieved 5/9/2015 from <http://www.equalityhumanrights.com/your-rights/human-rights/what-are-human-rights/human-rights-act/respect-your-private-and-family-life>

visitors, whose role appears ambiguous. This often leads visitors to perceive a potentially distressing lack of empathy, welcome and care from the staff. Neoliberal policies, with the intention of fostering choice, control and responsibility, have also created dilemmas, possible disagreements, contestations of personal responsibilities and reinforced the ambiguities and uncertainties associated with the visitors' role.

## **2.7. Conclusion.**

I explored Morrell and Hewison's (2013: 62) 'labyrinthine set of relations' in this chapter in order to set out the context of hospital visiting and its influences on visitors' experiences. I reviewed five categories: the political responses to changing demographics, epidemiology and technological developments; hospital scandals; internet and communication technologies; popular culture; and how policies are enacted locally, especially in terms of hospitality, responsibility and choice. This meant that, despite the initial suggestion that they were inter-related, I examined each category in the chapter as a discreet feature with little mention of its intersection with others. In this conclusion, I address this by bringing these categories together to fully demonstrate the interrelationships and mutual constitution identified by Morrell and Hewison (2013) at the beginning of the chapter.

In the first section, I focussed on government policy changes as a response to ever-increasing demands on the NHS. Successive governments have had overall responsibility for both health care and the national budget but have been torn by these competing demands and their awareness of a need for success in both areas to satisfy the electorate. This has resulted in many reforms and the introduction of audits, targets, inspections and controls within the NHS. This then prompted the question of whether these measures have distracted hospital staff from their provision of quality care and resulted in scandals. However, these measures were also introduced after repetitive scandals and medical errors and so could be considered as central to improving care.

The Francis reports (2010a, 2010b, 2013, 2015) on the Mid Staffordshire Hospital Trust scandal of poor care, bullying and falsified audits have had major repercussions on policies and the organisation and delivery of care in hospitals. One such consequence is the recommendation by the Berwick Report (2013), which appears to have legitimised the greater involvement of the patients' family and friends who are carers. This improvement is seen later in the chapter in the contrasting statements made by the Peterborough and Stamford Hospital NHS Foundation Trust in their policy documents for 2006 and 2014. There has also been an increased inclusion of carers and awareness of their needs (Berwick Report 2013; *Carers Strategy: Second National Action Plan 2014-2016*). Nevertheless, non-carer visitors appear to be still marginalised and viewed by policy makers as disruptive, threatening, an infection risk and in need of management.

Hospital scandals, such as the Mid Staffordshire Hospital Trust scandal, also appear to have undermined public trust and confidence in hospital staff, policies and processes. These scandals, accompanied by neoliberal policies of responsabilisation, have created, for visitors', a felt need for vigilance on behalf of the patient. This impetus to monitor care delivery is further emphasised by the news media and sensationalist headlines (Seale 2002). Exaggerations of popular culture (Hetsroni 2009) and hospital staff represented as members of confrontational teams and capable of negligence and/or mistakes (Jacobs 2015) encourage further mistrust.

Vigilance and any resulting actions taken by the visitors are, though, thwarted by hospital policies, which restrict visiting times and more implicit forces such as fear of retribution, lack of time or, for some, a wish to move on after the patient has left the hospital. Increasingly, technology is permitting a more remote monitoring of care delivery and illness trajectory. Also, as *Cure the NHS* demonstrated, visitors are more able to utilise ICT to mount a collective challenge to hospital knowledge, authority and/or poor care. ICT also opens up newer channels for accessing information or expressing complaints or gratitude. Nevertheless, ambiguities prevail and hospital visitors find themselves needing to assume responsibility but having little choice and involvement with the patients' illness trajectories as professional codes of conduct, the Human Rights Act (1998) and the NHS Constitution all demand patient confidentiality and autonomy.

This ambiguity and the experience of being caught between opposing structures pervade the whole thesis and was first identified in the epistemological gap between the medical/scientific/physical and the emotional/psychological in chapter one. In this chapter, Solomon (2016) reinforces this void with his understanding of the separation of the medical and the literary/humanism tracks in storytelling. Solomon's suggests that doctors' own publications might provide a bridge between these tracks and this led to me to question the extent to which popular culture might inform and influence hospital visitors' expectations and experiences. However, the literature and the research data analysis support the conclusion that popular culture only partially prepares visitors for their experiences.

I again addressed ambiguity in the discussions of hospital hospitality. Hospital visitors seem not to fit neatly into the category of either domestic or commercial guest and some of Darke and Gurney's (2001) rules for the impromptu, uninvited guest appear more apposite. The exploration of the hospital environment, policies and practices of hospitality demonstrate that the interests of the visitors are less privileged (Lewis 2000) than the perceived need to manage and control them. The visitor's potential to be disruptive and threatening might also lead hospital staff to resort to psychological defence mechanisms associated with emotional labour (Hochschild 1983). The inability of staff to act empathetically is understood by visitors as a lack of welcome. This increases visitors' dissatisfaction and sense of marginalisation.

Therefore, this chapter reaches beyond answering the first research question of setting out the contextual influences on hospital visitors' experiences. It also begins to confirm the relevance of storytelling to this thesis. Furthermore, the discussions in this chapter also demonstrate how the structures, in terms of political, social and cultural forces, bear down on hospital visitors' experiences, which involve many of the features of liminality as defined by van Gennep (1960) and Turner (1969). Liminality, experiences and storytelling became the focus of attention when reviewing the literature in the following chapter.

## **Chapter 3. Searching the literature for theoretical and conceptual foundations.**

### **3.1. Introduction.**

In a life history [...] the distinction is between life as lived (reality), life as experienced (experience), and life as told (expression) (Bruner 1986: 6)

I explored the literature to identify multidisciplinary concepts and theories that would be an effective conceptual and theoretical foundation to guide my research. This approach developed my understanding of contextual influences as I set out in the previous chapter. I now detail the role of the literature in informing my analysis of the research interviews to answer the two further research questions. These are: 'What do visitors' stories about their experiences tell us about hospital visiting?' and 'Why and in what ways do visitors resist or adapt to the policies, customs and practices of hospital visiting?'

I begin by discussing the literature, which I used to define and support the use of theoretical frameworks but I also detail some of the possible problems that might occur when constructing and applying them. I then set out my theoretical framework, with participants' stories about their experiences' informing liminality as the central theory. This framework also incorporates five core themes, which were prominent in the developing data analysis and also corresponded with features of liminality identified by Turner (1969).

My focus then moved to 'life as lived' (Bruner 1986: 6 as cited above) by hospital visitors. For this, I explored the literature about liminality, commencing with the early work by the anthropologists, van Gennep (1960) and Turner (1969). I also read extensively about the five core themes in the theoretical framework. These five themes, slightly adapted to meet characteristics of 21st century social life in England, are: loss of status and being out of place; total obedience and being a good visitor; uncertainty; ambiguity and the sense of being betwixt and between; structure and communitas. Following my consideration of the literature about these core themes, I examined the more contemporary literature for newer understandings of liminality and its application to research in the healthcare arena.

I also searched the literature about storytelling, or 'life as told' (Bruner 1986: 2). In chapter two I discussed how stories in popular culture might influence hospital visitors' experiences and expectations. Here, I detail the literature that enhanced my understanding of the role of storytelling for both the research participants and my research. Having noted the mutual constitution of stories and experience, I next employed the literature from across different disciplines to guide and support my conceptualisation of 'life as experienced' (Bruner 1986:2).

My discussion about experience commences by drawing on the philosophical and phenomenological theories and concepts I encountered. From these, I was also able to recognise the central relevance of 'time' to 'experience'. From this reading I was able to understand that there are different nuances of 'experience' that the English language fails to deliver but which in Spanish are described as *vivencia* and *experiencia* and, in German as *Erlebnis* and *Erfahrung* (Rosa and González 2013). Dilthey's work (1976 cited in Turner 1986) on *Erlebnis* profoundly influenced Turner's (1986) anthropological understanding of experience. This proved to be significant for this thesis as it justified the integration of liminality, storytelling, and experience within the theoretical framework.

### 3.2. The theoretical framework.

As Grant and Osanloo (2014: 12) suggest, a 'theoretical framework provides the foundation from which all knowledge is constructed'. In this section, I draw on the literature to detail the benefits to which Grant and Osanloo (2014) allude, but I also remain alert to possible disadvantages. I then provide a diagram and an explanation of the thesis theoretical framework.

Lewis (2004: 164) below defines theories as:

[T]he overarching, general frameworks of explanation that make claims to providing coherent interpretations about the causes, manifestations, effects and modes of connection between types of phenomena. They rely upon, but are wider than concepts precisely because they attempt to *explain* rather than just group and define phenomena. [...] [T]heoretical perspectives dictate which concepts and which definitions of them should be used in social analysis (original italics).

Lewis (2004) further adds the caveat that theories order a hierarchy of concepts with some more privileged than others. This suggestion assumes greater relevance in chapter five where I note a developing conceptual hierarchy for liminality arising from the participants' stories. Furthermore Lewis' (2004) definition supports Anfara's (2008: 871) following description of what a theoretical framework is (and what it is not) in the following way:

[T]he term 'theoretical framework' does not have a clear and consistent definition; [...] it is defined as any empirical or quasi-empirical theory of social and/or psychological processes, at a variety of levels (e.g., grand, mid-range, and explanatory), that can be applied to the understanding of phenomena. This definition of theoretical frameworks excludes what some writers have called paradigms of social research (e.g. postpositivist, constructivist, critical, feminist).

It also does not consider methodological issues or approaches to be synonymous with theoretical frameworks (e.g., narrative analysis, systems analysis, symbolic interactionism).

Examples of what is meant by theories that can be applied as “lenses” to study phenomena might include Vygotskian learning theory, micropolitical theory, class reproduction theory, job choice theory, social capital, cultural capital, liminality, transformational learning theory, the arena model of policy innovation, and grief theory, to name only a few.

Anfara's (2008) acknowledgement of inconsistencies in defining a theoretical framework implies a flexibility, which accords with the iterative nature of my research processes. His words also explicitly add support to my identification of liminality as both central to a theoretical framework and also its possibilities as a lens for further examining the data. As Anfara (2008) further suggests, my experiences were that my theoretical framework facilitated a more systematic and focused reading of the literature and a more orderly and in-depth analysis of the research data. Thomassen's (2009: 16) work also validated my use of liminality (informed by participants' storytelling of their experiences) by suggesting that ‘the ‘betwixt and between’ feature of liminality... opens up spaces for possible uses... far beyond that which Turner had suggested’. These words, as will be demonstrated, are particularly relevant for some of the discussion in this chapter and the analysis chapters and also for the research aim of adding to the knowledge about liminality.

However, theoretical frameworks might conceal or lead to overlooking other concepts within the data (Anfara 2008; Grbich 2004). They can also be difficult to select, construct or apply and so provoke the temptation of ‘forcing preconceptions on the findings’ (Grant and Osanloo 2014: 16). Similarly, Braun and Clarke (2012: 65), although discussing thematic analysis, also warn against forcing analysis into ‘coherence’.

Mindful of these pitfalls, two codes, ‘luck’ and ‘bringing back matrons’ arose from the data, which, although mentioned by some participants, were inconsistent across the interviews. They also did not cohere<sup>58</sup> with liminality and the five core themes used in the framework. As such, I eventually discarded them. The code, ‘needing to get there’ to the patient also did not initially seem to fit the framework. But it was so consistently and powerfully described that, mindful to neither overlook (Anfara 2008; Grbich 2004) it nor discard it, I continued to include it within my analysis without ‘forcing it into coherence’ (Braun and Clarke 2012: 65). It was only in the later stages of data analysis that I identified ‘needing to get there’ as relevant to

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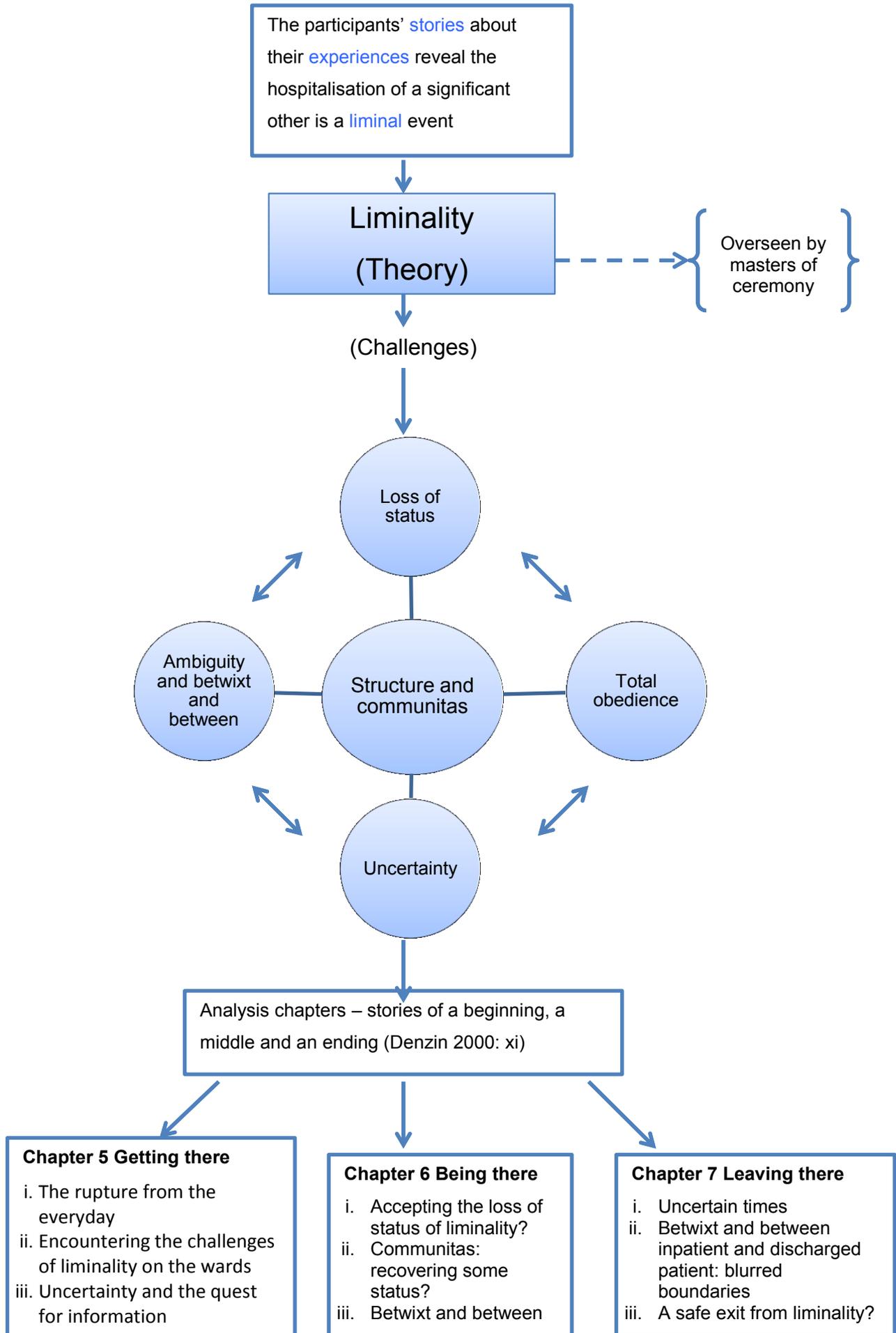
<sup>58</sup> ‘Luck’ was identified as more a figure of speech such as ‘luckily’ or ‘fortunately’ and ‘bringing back matrons’ was suggested more as a disciplinary measure for ward staff.

the 'betwixt and between' feature of liminality. The theoretical framework of liminality, which underpins this thesis, is shown in diagram 1, which I explain as follows:

As indicated in diagram 1, the central theory, informed by the participant's stories about hospital visiting experiences, is that of liminality. In liminality, the participants encountered many challenges. These difficulties cluster within the intersecting core themes, which are detailed in the diagram, underpin the data analysis and correspond to features of liminality identified by Turner (1969). I extended and adapted these themes to both incorporate the codes that emerged from the data analysis and to be more relevant to 21st century English social and cultural lifestyles. Structure and *communitas* are shown at the centre as a bulwark against the unsettling nature of the challenges induced by the other four themes, as I discuss in this chapter. I then represent the analysis and respond to the research questions according to the participants' stories about their journey through their experiences as hospital visitors: 'a beginning'; 'a middle'; and 'an ending' (Denzin 2000: xi).

With the theoretical framework thus established, I proceed in the following sections to detail the literature that informed my understandings of its core components, beginning with liminality.

**Diagram 1. The theoretical framework.**



### 3.3. Liminality.

For this review of the literature about liminality and 'life as lived' (Bruner 1986: 6), I commence with a resumé of van Gennep's (1960) early work and Turner's (1969) detailed description of its features. I also discuss the literature that underpins the five core themes. I then examine the contemporary literature for newer developments in the understandings of liminality and its application to research in the healthcare arena.

#### 3.3.1. *Van Gennep and Turner: The foundations of liminality.*

The anthropologist, van Gennep (1960) coined the term 'liminality' to represent the interim stage of tribal rites of life-course transitions. These rites, he observed, involved three distinct stages: separation from society; the interim, liminal period of being marginalised and on the threshold (*limen* in Latin = threshold) of transition; and reincorporation into society with altered status. Van Gennep (1960) also observed that tribal elders, as masters of ceremony, supervised those who were experiencing the liminality. The discussions so far in the thesis indicate that hospital visitors' experience a rupture from their everyday routines and find themselves in a different social world of unfamiliar rules, values and practices, where changes in the patients' health status might imply future lifestyle, role and relationship transitions for all involved.

Turner (1969) extends van Gennep's (1960) work with an in-depth exploration of liminality and its characteristics. He describes some of the challenges in the following way:

The ordeals and humiliations, often of a grossly physiological character, to which neophytes are submitted represent partly a destruction of the previous status and partly a tempering of their essence in order to prepare them to cope with their new responsibilities and restrain them in advance from abusing their new privileges. They have to be shown that in themselves they are clay or dust, mere matter, whose form is impressed on them by society (p90).

I understand Turner's (1969) words to mean that liminal personae in tribal rites encounter character-building physical and emotional challenges, which would emphasise their loss of status, a silencing of their voices and ensure their total obedience to the authority of a 'total community'<sup>59</sup> (p89). Turner (1969: 81) defines this total obedience as an obligation for liminal personae to demonstrate, from their position of lacking knowledge, 'passive and humble' behaviour and 'to obey their instructors implicitly'.

However, Turner was describing archaic tribal rites in the middle of the last century. For example, he describes the challenges presented to the 'chief-elect', which included dressing him in 'nothing but a ragged waistcloth', slashing his left arm and applying a crude dressing and

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<sup>59</sup> Here I understand the hospital as a total community

then publically haranguing and humiliating him (1969: 86). This description is clearly not relevant to contemporary social life in England. I have therefore interpreted 'challenges' as the difficulties the participants met in the hospital environment and beyond. These difficulties arise from the intersection of four of the five core themes; uncertainty, loss of status, ambiguity and being betwixt, and total obedience.

Furthermore, for better coherence between the core themes and contemporary 21st century England, I have conceptualised total obedience by overlooking the demand to 'obey their instructors implicitly'. Instead, I have concentrated more on the requirement for 'passive and humble behaviour' (Turner 1969: 81) in combination with the dualism of 'good visitor - problem visitor', which is a powerful theme emerging from the data analysis. This conceptualisation corresponds better to the prevailing neoliberal ideologies of autonomy, choice and responsibility as discussed in chapter two<sup>60</sup>. Similarly, 'lack of knowledge' becomes problematical when considering the discussions in chapter two of the access to knowledge provided by ICT. I have therefore interpreted 'lack of knowledge' as uncertainty and a need for information, difficulty in understanding medical discourses and also the lack of *savoir-faire* in the hospital environment, as exemplified by the postcard and Causely's (1997) poem in chapter two.

Like van Gennep (1960), Turner also recognises the role of 'seniors', or masters of ceremony, in ensuring the wellbeing of the liminal personae:

Seniors take the responsibility for actually making the changes prescribed by custom; they, at least, have the satisfaction of taking the initiative. But juniors, with less understanding of the social rationale of such changes, find that their expectations with regard to the behaviour of seniors towards them are falsified by reality during times of change. From their structural perspective, therefore, the changed behaviour of their parents and other elders seems threatening and even mendacious. [...] Thus while the behaviour of seniors is within the power of that age group – and to some extent the structures they promote are for them predictable – the same behaviour and changes are beyond the power of the juniors either to grasp or prevent (1969: 164).

Although Turner (1969: 164) is describing tribal rites of passage, I suggest that his observations are relevant to the hospital-visiting scenario. The hospital staff are the seniors who 'know' the structures, and visitors are the juniors who are unable to 'grasp or prevent' the many implicit and explicit rules and medical discourses and practices of their new environment.

Turner also places emphasis on structure for which he provides the following definition:

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<sup>60</sup> I acknowledge that total obedience is expected in some institutions such as prisons or monasteries.

[A] structured, differentiated, and often hierarchical system of politico-legal-economic positions with many types of evaluation, separating men in terms of 'more' or 'less' (p82).

Structures also reflect the rules, customs, practices, policies and values of a society. However, structures are always in a state of flux and can be contested by the collective power of 'antistructure'. Turner exemplifies this with his reference to teenagers, being between childhood and adulthood, and their testing of the social *mores* in developed countries over the past decades. Turner (1969) also coined the term 'communitas' for 'antistructure' to describe the social cohesion, mutual support, emotional bonds and collective strength arising from the shared predicament of liminality. Communitas can also have positive effects, as the emotional arousal caused by liminality can lead to creativity and the revitalisation or reformation of existing structures (Turner 1969). The collective power of *Cure the NHS* to challenge poor care by the Mid Staffordshire Hospital Trust discussed in chapter two provides such an example.

The communitas of the archaic tribes observed by Turner (1969) did not take into account the technological advances of modern transport, mobile telephones and computers in the 21st century social world, which permit easy access (physically or digitally) to others. Instead, Turner (1969: 95) talks of a segregated 'seclusion lodge' and shelters for the neophytes in transition and so seems to suggest a confined space for communitas, with the physical co-presence of all the liminal personae. But he also describes, at length, the many variations in communitas among<sup>61</sup> the tribes he studied and the changes in the features of communitas brought about social change. I have therefore conceptualised communitas as the social bonding and mutual support prompted by the physical co-presence of those visiting kinship group members and friends at the patient's bedside. I excluded those communicating solely via ICT with the patients and bedside visitors from my considerations of communitas in the data analysis. This exclusion was because this group of virtual visitors was not subjected to hospital structures, nor struggling with the hospital environment and were not confronting the full impact of the physical manifestations of illness.

The five core themes of the theoretical framework are next explored in greater detail, commencing with the loss of status and being out of place.

### **3.3.2. Loss of status and being 'out of place'.**

For I believe that ideas about separating, purifying, demarcating and punishing transgressions have as their main function to impose system on an inherently untidy experience. It is only by exaggerating the difference between within and

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<sup>61</sup> Turner (1969) also discussed institutional communitas in the context of, for examples, monastic orders, or the communitas of social groups which challenge authority such as the Hippies of the 1960's. In these cases, communitas was not associated with transitions.

without, above and below, male and female, with and against, that a semblance of order is created (Douglas 1966: 15)

[*Liminal personae*] elude or slip through the network of classifications that normally locate states and positions in cultural space. Liminal entities are neither here nor there; they are betwixt and between the positions assigned and arrayed by law, custom, convention and ceremonial [...] Secular distinctions of rank and status disappear or are homogenized' (*sic*) (Turner 1974: 81).

Douglas' (1966) and Turner's (1974) words signal potential tensions for hospital staff, concerned with maintaining the structure on the wards, and hospital visitors, who are on the threshold of transitions brought about by the illnesses of their significant other. I now draw on the literature to support the identification of hospital visitors' sense of their loss of status, being 'invisible' and 'out of place'. After this, I discuss these features in the context of inclusion and exclusion on the wards and the concepts of psychological ownership and territoriality.

As already illustrated in chapter two, the hospital structures often cause visitors to feel marginalised. Visitors do not wear the uniform or symbols denoting 'staff' nor the nightclothes of 'patient' and are therefore not readily categorised. Anything or anyone that is non-categorisable has no rightful place and, so, is untidy and has the potential to be disruptive, dangerous and polluting (Douglas 1966). A further consequence is that it is human nature to overlook that, which cannot be readily categorised (Turner 1969). Being overlooked by ward staff causes hospital visitors to experience their sense of being 'invisible' or 'out of place' and increases their feelings of lost status. Turner (1969) describes this as a structural, rather than a physical, invisibility. Arguably, this also provides some explanation for the lack of attention given to hospital visitors in the national policy and social science research, as discussed in the first two chapters of this thesis and the participants' stories in later chapters.

These two features, loss of status and being out of place, led to my consideration of the politics of place (Sibley 1995; Wakefield 2002) and practices of boundaries and exclusions in institutions, such as hospitals, and how they might affect hospital visitors' experiences. My professional experience and the exploration of contextual influences and themes beginning to emerge from the data pointed to many possible sites of manifestations and contestations of power, status and control in hospitals. Two areas on the hospital wards, the nurses' station and the patient's bed space, featured more prominently in the visitors' stories and I now discuss the associated literature.

Practices of inclusion or exclusion occur at the nurses' stations due to unwritten rules and the physical and symbolic barrier of the desk. Nurses' stations are central, multi-purpose and a place for multi-team collaboration (Gum et al 2012). They are sites of rites of passage for those entering the ward and, so, a barrier between public and private ward processes (Wakefield

2002) and places where nurses spend the greatest part of their time (Hendrich et al 2008). In the context of design, nurses' stations have also been described as 'hubs of activity where nurses gather to work individually, collaborate or socialize [*sic*]' (Chiang 2010: 1).

Although ward staff enter the area behind the nurses' station, hospital visitors, wishing to get information or express observations, requests, gratitude or complaints, must wait in front of the desk for an acknowledgement from the staff behind it. Further criticisms of nursing station practices, therefore, include Carpenter's (1997) complaint of excessive waiting for attention and Rayner's (2008) suggestion that nurses' stations are places for nurses to gossip and keep away from patients. In this context, Pope (2010) also notes that these gathering points on the wards are sites of too much noise. It is therefore perhaps unsurprising that the participants express their criticisms and their feelings of exclusion and being overlooked or 'invisible' when hoping for assistance at the nurses' station.

To explain this dissension about the value and uses of nurses' stations, I drew on Goffman's (1971) dramaturgical theory. From this, I was able to recognise that visitors and nurses might interpret the area behind the nurses' station differently. Nurses demonstrate, by their socialising in this area, that they perceive it more as 'backstage'. Visitors, however, interpret this space behind the nurses' station as a continuation of the ward and, therefore, 'front stage'. Visitors, witnessing backstage behaviour in the perceived front stage area, judge that the staff are socialising inappropriately and unprofessionally and, so, their behaviour is 'out of place' (Douglas 1966). These differing interpretations provide the first example of visitors, as juniors, or liminal personae, being unable to 'grasp or prevent' (Turner 1969: 164) their loss of their status, which the 'seniors' are imposing by excluding and overlooking them.

In addition to the politics of exclusion at the nurses' station, for hospital visitors, loss of status also implies a loss of control and ownership of the patient, space and place. Examination of policy documents in chapter two demonstrated that The University Hospital of Leicester Visitors' Charter assumes ownership of the hospitalised significant other as 'our patient'. In the same chapter, the movement of patients and their beds from ward to ward provides an example of the loss of control of space and place. As will be demonstrated in chapter five by the participant, Ed and by Jim in chapter seven, there are implicit rules and common practices by which most hospital staff assume a right of unlimited entry to the patient's bed areas. Visitors' movements around the ward are, though, confined to access and exit pathways to and from 'their' patient's bedside and attendance at the nurses' station.

Further rules are implied in the research title and mentioned in chapter two in the context of the stereotypical behaviour of visitors bearing gifts. Mauss' (1990) seminal work establishes the demands and obligations of reciprocity in gift-giving. Komter (2007: 93-94) succinctly sums up the work on this practice that has since been published:

Gift exchange has a variety of functions, for instance, economic, social, moral, religious, aesthetic, juridical ones. [...] In addition to expressions of love, friendship or respect, gifts can be used for less nobler purposes such as to manipulate, flatter, bribe, deceive, humiliate, dominate, offend, hurt, or even kill in the case of the poisoned cup.

Gift giving by visitors to the patients might, therefore, originate from more than simple acts of kindness and, arguably, can represent resistance and, thus, displays of status, psychological ownership and territoriality.

Brown et al (2005) distinguish between psychological ownership and territoriality, with the former referring to feelings of possession towards an object, knowledge, idea or a person. This notion of 'mine' demonstrates such a close connection with the target that it becomes part of the self. When others lay claim to 'mine' there is an affective response due to the undermining of control, self-identity and possession (Pierce et al 2003). Nursing has evolved from the task-orientation of care noted by Menzies Lyth (1960) to the stated aims for holistic, patient-centred care with nurses being responsible for the total care needs of a smaller group of patients (Walsh 2002). This all-embracing responsibility for patients could lead nurses to feel a professional psychological ownership of them which, in turn, is brought into tension with the visitors' sense of ownership of the patients, as recognised by Menzies Lyth (1960) and cited in chapter one. As Pierce et al (2003: 93) confirm:

[R]esponsibility for a target, either perceived or real, leads to feelings of ownership. As the person is held or feels responsible for a target, he or she begins to invest himself or herself into that target through the energy, care, and concern extended.

Territoriality refers to behaviour that arises from this sense of possession (Brown et al 2005). It is manifest in the animal world, for example, by guard dogs and their aggressive defence of territory (Hayter 1981). The possession or ownership of a territory fulfils the need to have some sense of control, efficacy, self-identity (Brown et al 2005), security, autonomy (Hayter 1981), privacy and belonging (Wu et al 2014). Of particular salience for hospital visitors, Brown et al (2005) suggest that it is harder to mark, or personalise, and maintain those territories that have more ambiguous boundaries, transient populations or involve new incomers, who are unfamiliar with unwritten rules. These features are all applicable to the patients' bed areas where the boundaries are marked only by curtains. Wu et al (2014) also note the difficulties in establishing territory where ownership of the space is ambiguous, as in hospitals. Behaviour patterns attributed to territoriality include claiming, establishing and marking the area, maintaining it and defending it against infringement by others, often with a glare or expressions of anger or frustration (Brown et al 2005). All of these behaviours also involve issues of power and politics within institutions (Brown et al 2005).

These concepts of psychological ownership, territoriality and personalisation, therefore, offered explanations for hospital visitors' attempts to mark the bedside area as a territory with gifts of flowers and personal paraphernalia. Visitors might also counter their threatened ownership of the patient's body by, for example, signing a plaster cast or contributing to their personal care. The need to possess, mark and defend a territory also explains the distress and frustration expressed at an impromptu removal of the patient to another ward and a new bed area to be marked as a territory. Marking ownership and territory can then be considered as contestation and resistance to hospital ownership of the patient and power and control of place and space, as visitors attempt to resist the loss of status accompanying liminality.

With my attention thus drawn to contestations of power, I next explore the literature for academic comment about total obedience as an expectation of liminal personae (Turner 1969).

### **3.3.3. Total obedience and being a good visitor.**

In this section I detail the literature which underpins my conceptualisation of total obedience as combining 'passive and humble' behaviour (Turner 1969: 81) with the theme, inspired by Lorber (1975), of 'good visitor - problem visitor'. I also consider the psychological explanations of the need to be considered a 'good visitor'. I then detail some of the potential difficulties and dilemmas of liminality involved in the transition from everyday roles and identities to the role of 'good' or 'problem' hospital visitor.

Lorber's (1975) seminal research into 'good patients and problem patients' provides the starting point for this discussion. I first mentioned this dualism, in the context of good visitor - problem visitor and associated behaviour in the discussions of visitor stereotypes in chapter two. Lorber (1975) suggests that hospital staff consider those patients who are compliant, non-critical, cooperative and submissive as 'good patients'. 'Problem patients' are those who loudly vocalise their demands and complaints and seek to assert their autonomy. Although Lorber (1975) was writing about North American hospitals at a time when patients were expected to relinquish more autonomy than today, my analysis suggests that her work remains relevant to the consideration of visitors' loss of status and expectations of their total obedience.

This notion of 'being a good visitor' becomes more pertinent and understandable when exploring the literature about 'being liked'. Blumber (1969) suggests that 'being liked' results in enemies doing less harm and friends doing more for us. Whereas Srivastava and Beer (2005) consider that 'being liked' supports or promotes positive self-evaluations, Baumeister and Leary (1995) suggest that it fulfils the basic human need to belong. Therefore, in interactions with ward staff, hospital visitors may be powerfully driven to demonstrate total obedience in their desire to be less marginalised and be considered as 'good visitors'. This results in acts of pro-social behaviour, such as their demonstration of care for the patient, displaying a good family (Finch 2007), acknowledging the nurses' heavy workload and, sometimes, bearing gifts for the staff.

In contrast to 'being liked', ostracism is being ignored and excluded and results in 'social pain' and reflection (Williams and Nida 2011: 71). This social pain prompts behaviour patterns of compliance and attempts for re-inclusion. Ostracism, with no chance of re-inclusion, can also result in retaliation (Williams and Nida 2011). My reading of Lorber's research (1975) leads me to argue that hospital staff might similarly judge visitors as a problem if they transgress implicit and explicit hospital rules, make unreasonable demands and complain. As the discussions in chapter two have already shown, retaliation (aka complaining) consequently becomes much more difficult and often the last resort<sup>62</sup>. Therefore the fear of ostracism is also a powerful driver of pro-social behaviour. This good visitor-problem visitor dualism inevitably leads to the ambiguity of liminality as visitors' experience a sense of responsibility and a need for greater vigilance as they monitor the patient's care and illness trajectory. When they perceive unmet needs in 'their' patient and make requests, demands or complaints, they understand their risk of being labelled as problem visitors.

The tensions between the good or problem visitor role also lead to questions about how visitors might deal with the transition from their everyday roles and identities to that of hospital visitor. Simpson and Carroll's (2008) work was particularly insightful because they focus on the mutual constitution of role and identity and their mutability. They also note that these features operate within the dualism of structure and agency wherein there are elements of conflict, self-determination and transition.

Furthermore, Ashforth et al (2000) propose that within these processes of transition, boundaries of a specific role and identity might vary in permeability and the degree to which they can be integrated with pre-existing roles and identities. Flexible and permeable boundaries will result in ambiguity (Ashforth et al 2000). Hospital visitors who are also nurses or carers might experience this ambiguity if, in their need to be considered as a good visitor, they are obliged to relinquish their everyday caring responsibilities to hospital staff. Alternatively, where there is a marked contrast between different roles, the transition from one to the other is potentially problematic (Ashforth et al 2000). This means that, for example, the professional used to being in control of his or her workplace environment might find it difficult to display the passivity of total obedience as described by Turner (1969) in order to be a 'good visitor'.

This movement, or transition, from one role to another, therefore, involves boundary crossing and liminality (Ashforth et al 2000). In considering Beech's (2011) discussion of the processes and liminal practices involved in identity reconstruction, I also invoke Simpson and Carroll's (2008) work on the mutual constitution of roles and identities and the structure-agency dualism. Drawing on Beech (2011), I recognised that the hospital visitors' transition between identities and roles involves the interplay between the self/agency and the context/structure dualism. As

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<sup>62</sup> Patients Association Report 2014: 45% complainants were relatives or friends of patient, 50% of all complainants worried about adverse repercussions on patient care, 66% found the process stressful, 55% were dissatisfied with final response and only 20% felt they had received an honest and open reply.

Beech (2011) further suggests, where agency prevails, there is the liminal practice of experimentation with available identities (and, I suggest, roles). With dominant structures, the liminal practice involves a slow recognition of the identity being imposed. When agency and structure have similar influence there occurs a liminal space of self-questioning before action (Beech 2011). Thus, I conclude that hospital visitors might accept the role and identity of good visitor imposed on them by the contextual influences, discussed in chapter two, and their need to be liked and included. They might pause and consider their position. Or they might exercise their agency and try to resist the behaviour patterns being demanded of them and risk the label of 'problem visitor' and greater marginalisation.

Therefore, irrespective of the strength and permeability of the boundaries between everyday roles and the hospital visitor role, there is the potential for difficulties. There are, for the hospital visitor, powerful structural and social psychological forces at play in promoting accordance with the characteristics of a 'good visitor'. However, even in their liminality, hospital visitors can, and do, cease to demonstrate the 'passive and humble behaviour' (Turner 1969: 81) of total obedience and, so, exercise their agency and become 'problem visitors'. As the analysis chapters reveal, this resistance can incur significant emotional discomfort. The movement between the everyday role and the visitor role, when viewed as a transition, invokes liminality with all of the ambiguities and uncertainties involved. I next consider the literature about the third core theme of uncertainty, which was identified by Turner (1969) as a feature of liminality.

#### **3.3.4. *The uncertainty of liminality.***

As Szokolczai (2009: 148) suggests, liminality is the movement from the certain 'taken-for-granted forms and limits' to 'a situation where anything can happen' within a 'delicate, uncertain, malleable state that alters the very core of one's being'. It is unsurprising that liminal personae express their uncertainty in the sense of having not only 'lost [the] road map' but also 'lost [the] road', as stated at a public lecture by Stenner (2011). Medical terminology and the norms involved in their new role as hospital visitors in an unfamiliar environment also cause more uncertainty. As already identified, there is much potential for hospital visitors to feel uncertain about their future.

There are many theories and much literature dealing with uncertainty and associated coping strategies (for example Maslow 1963; Mishel 1988; Babrow et al 1998; McCormick 2002; Brashers et al 2002; Penrod 2007). I selected Folkman's (2010) study for further consideration because she links uncertainty with the concepts of time, hope and loss of control. These features appear consistently throughout the participants' interviews. As I have already discussed the loss of both status and control of space, place and the patient, I present my exploration of uncertainty in the context of the loss of control of time. The participants' experiences of loss of control of time included being kept waiting and anxieties about the patients' illness trajectories and possible feared futures. Accessing reliable information about their future was a means for the visitors in coping with some of this uncertainty. However, the

discussion demonstrates that this coping strategy might, ultimately, be counterproductive as it might extinguish hope.

Folkman (2010: 903) suggests that uncertainty in illness often has temporal, event, efficacy and outcome dimensions. That is, there is a lack of certainty about 'when something will happen, what will happen, what can be done' and what the result might be. Uncertainty also has a conceptual link with stress. Folkman describes stress as arising from the evaluation of a situation as unmanageable, with few options for gaining control, and diminished hope. This definition implies a central role for time, the ability to control it and concerns about the future, which might often be informed by events in the past.

Furthermore, Zerubavel (1979) concludes that hospital-organised time takes precedence over patients' and visitors' time in the interests of the smooth running of hospitals. This primacy of time for hospital processes also introduces a suggestion of power imbalances, which may be particularly manifest in the time hospital visitors and patients are 'kept waiting' (Schwartz 1974). Gasparini (1995: 30, 31) confirms the transitional time of waiting and the associated uncertainty:

[Waiting is] interstitial time [...] at the crossroads, not only of the present and future but also of certainty and uncertainty and inextricably linked with expectation.

Thus 'waiting at the crossroads' can also be considered as a sharply defined micro-event of liminality for the visitors within their over-arching liminality<sup>63</sup>. In addition to the practical aspects of waiting, such as costs or loss of productivity, there are social psychological factors. Those who are kept waiting understand that their time is less valuable and that they have less social worth (Schwartz 1974; Zerubavel 1987).

Two studies, in particular, provided insights into how hospital visitors might experience and try to cope with the unsettling features of liminality in their enforced waiting and, so, gave guidance for the analysis. Trimm and Sandford (2010) explore the waiting experience of families whose significant others were undergoing surgery. In this situation, family members in an American hospital waiting room attempted to maintain a balanced equilibrium by 'focusing on the patient; passing the time; an interplay of thoughts and feelings; and giving/receiving support' (p 441). Åkerström's (1997) study investigates the different expectations and perspectives that patients and staff hold for judging the severity of emergencies in a Swedish emergency and accident department. The more critically ill patients received priority treatment, and the less severely ill were forced to wait. A lengthy wait caused expressions of hostility, anger and aggression. Both of these studies clearly bear relevance for the thesis but in different ways. Trimm and Sandford (2010) underline both the emotional element that might be experienced by hospital visitors in their waiting and also the concept of mutual support, which also features in the participants'

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<sup>63</sup>These sharply defined liminal events within an overall liminality are discussed later in this chapter and demonstrated by the participants in the analysis chapters.

accounts and accords with Turner's notion of *communitas*<sup>64</sup>. Åkerström (1997), like Zerubavel (1987), draws attention to differences between hospital staff and visitors in their perspectives of time. From the literature reviewed, I was able to understand that the micro-liminal event of being kept waiting is infused with uncertainty and its concomitant emotions which need to be managed.

Folkman (2010) identifies more theoretically informed coping strategies for managing these emotional responses to uncertainty. Strategies can be meaning-focussed and, so, include drawing on personal values, beliefs, goals, or past experiences. Or, they may be emotion-focussed aimed at regulating negative emotions by seeking emotional support, denial or distancing oneself from the problem. The third group of coping strategies are problem-focussed and include information gathering. As my discussion in chapter two has already revealed, information seeking appears to be part of the carer's (and I would suggest, more generally, the hospital visitor's) role and has been facilitated in recent years by the Internet and its provision of ready access to information and knowledge.

I also illustrated the potential tensions arising from hospital visitors' attempts to research diagnoses and other relevant facts associated with the patient's illness in chapter two. However, Maslow's (1963) words identify the tensions between the 'need to know and a fear of knowing':

What you don't know has power over you; knowing it brings it under your control and makes it subject to your choice. Ignorance makes real choice impossible ... (p116).

[T]he unfamiliar, the vaguely perceived, the mysterious, the hidden, the unexpected are all apt to be threatening. One way of rendering them familiar, predictable, manageable, controllable; ie unthreatening, and harmless is to know and to understand them (p121).

[T]he lack of curiosity can be an active or a passive expression of anxiety and fear. That is, we can seek knowledge in order to reduce anxiety and we can also avoid knowing in order to reduce anxiety (p122).

Linking these words with Folkman's (2010) work on hope suggests that, for hospital visitors, sometimes knowing might also extinguish the very hope that she identifies as another strategy for coping with uncertainty. Hope diminishes with poorer prognoses but to retain and enhance it, people will reappraise the facts and knowledge presented to them (Folkman 2010).

The literature reviewed therefore added to the richness of my developing analysis by contributing psychological concepts for the interpretation of the uncertainty of liminality and the temporal aspects of visitors' stories. Thus I was able to understand how visitors' experiences

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<sup>64</sup> *Communitas* will later be discussed in detail

might cope with the stresses of the hospitalisation of a significant other and their fears and hopes for their future. These fears and hopes are intrinsically bound with the sick body of the patient. The concentration on the well-being of the patient's body is carried into the following section in which I investigate another core theme - ambiguity and being betwixt and between (Turner 1969).

### **3.3.5. *Ambiguity and being betwixt and between.***

Here, I begin by defining 'ambiguity' and then examine how it might be experienced in the hospital visiting scenario. My focus then moves to a conceptualisation of the state of being 'betwixt and between', from which ambiguities can arise. My reading of the associated literature resulted an extension of the understanding of the betwixt and between of liminality, as I then detail.

Ambiguity occurs when there are two or more interpretations of the meanings of an event (Weick 2015). Often linked with uncertainty, which results in a quest for information, ambiguity is, instead, a search for meaning (Van Stralen 2015). Visitors' susceptibility to ambiguities occurs throughout this thesis. For example, in the discussion of hospital hospitality in chapter two, the ambiguous status of visitors within the hospital scenario was explored. My discussions so far in this chapter have also demonstrated that ambiguity can arise from differences between staff and visitor understandings of time or place and the conflicting demands of being a 'good visitor' and, yet, being prepared to challenge perceived failings in care. As Nettleton et al (2014) describe in their study of levels of unconsciousness and as the participant, Jane, demonstrates in chapter five, visitors might encounter further disturbing ambiguities in the medical diagnoses and treatment plans offered by hospital staff.

With an absence of further literature about hospital visitors' experiences of ambiguity, Meyerson's (1990) study of social workers in hospitals provides an indication of other forces which give rise to the ambiguities experienced by hospital visitors. She suggests that in hospitals, ambiguity can arise from 'lack of clarity' in hospital structures, with many people having multiple interpretations and ideas. Ambiguity can also originate from 'irreconcilable contradictions' (Meyerson 1990: 297) between different ideologies such as those arising from the tenets of neoliberalism and the Welfare State, or between the medical model of care and the holistic, patient-centred model.

These ambiguities, Meyerson continues, provoke the responses of confusion, ambivalence, and a humorous cynicism. Confusion is often judged as a sign of an undesirable of weakness. To conceal this, people will attempt to display signs of power and their ability to cope with their experiences (Meyerson 1990). In chapter five the participant, Gill, exemplifies this by describing the need to 'power dress' to cope with or resist hospital structures. Ambivalence, Meyerson (1990) continues, is an emotional response to ambiguity and is likely to occur in circumstances of competing ideologies. Contradictions in behaviour or speech are often indicative of

ambivalence (Meyerson 1990). In chapter five Ed, from overseas, illustrates this with rapid contradictions of his criticisms of the NHS. Gill and Ed, therefore, provide examples of how my extensive reading of the literature facilitated deeper and richer interpretations of the data. The participant, Amanda, considered but rejected the third response of humorous cynicism. This response was less explicit in the data, but Meyerson (1990: 38) suggests that it arises from experiencing contradictory emotions such as 'hope and hopelessness'.

The ambiguity experienced by hospital visitors can also arise from the liminal state of being 'betwixt and between' (Turner 1969) social structures. Perhaps obviously, hospital visitors find themselves between their work, domestic and leisure obligations with their need to be at the patient's bedside. When in the hospital, visitors have thoughts and concerns about events, people and demands in the everyday world. Away from the hospital, they worry about what might be happening to the patient in their absence.

My focus now shifts to a less recognised component of being 'betwixt and between' and begins with an exploration of the literature, which suggests that doctors, nurses and hospital visitors have different understandings of the patient's bodily manifestations of illness. Cartesian theory, which remains entrenched in western doctors' education and practice (Leder 1984, Williams and Bendelow 1996), is mechanistic and reductionist (Cunningham 2001) and accords primacy to thought and consciousness. The body is understood as a secondary appendage (Williams and Bendelow 1996) and objectified as a machine, a system of organs and devoid of any intention or will of its own (Leder 1984). Cartesian theory therefore suggests that the body can be tested, analysed, experimented upon and repaired (Leder 1984). I have witnessed the results of this medical model in my professional career with patients being referred to in such terms as 'the hernia in bed five'.

In contrast to the medical model, the nursing literature in England proposes a more inclusive holistic model of patient centred care, which embraces the biological, sociological and psychological (commonly referred to as biopsychosocial) needs of the patient (Walsh 2002). This should extend nursing practice to the care of the physical and emotional needs and experiences of others in the patients' social networks. As demonstrated in the introductory chapter, this varies from country to country with little academic literature hitherto devoted to hospital visitors' experiences in England. This absence would seem to support the suggestion that the biopsychosocial model is not yet consistently employed in its entirety in English NHS hospitals.

However, Merleau-Ponty's (1962) subversion of Cartesian theory by prioritising the embodied nature of being-in-the-world and the primacy of sensory perception provides an introduction to how hospital visitors might experience their own body and that of the patient at visiting times. Merleau-Ponty distinguishes between the subjective body, which is the lived body of *me/mine* and the objective body of the *other* (Finlay 2006). There is a tendency to mostly overlook *my*

body in daily actions and interactions until it malfunctions due to illness or injury, in which case *my* body also becomes an object for *me* on which to focus (Finlay 2006). With greater attention accorded to the malfunctioning body of the significant other, there is consequently a tendency for visitors to overlook the needs of their own body – until, that is, it protests, demonstrates feelings of hunger, thirst or tiredness and the visitors become unwell.

This inter-relationship between the visitors' and patients' bodies can be explored further by first considering Morgan's (2011) work on family practices and then more contemporary comment about Merleau-Ponty's concept of intercorporeality. Morgan (2011:90) states that to talk of the body:

[I]s to talk of separateness and distinction - my body and your body [...] embodiment is therefore relational in that not only do I have a body but I also acknowledge that the Other has a body'.

Morgan (2011) further suggests that, over the life course, family members accumulate an intimate knowledge of each other's bodies, which extends beyond a 'gaze' and includes all the senses and shared memories. There is an understanding of the meanings behind expressions, gestures, and body language and family members are more likely to monitor each other's body and note changes as part of caring (Morgan 2011).

I consider, though, that in emphasising 'separateness and distinction' between '*my*' body and '*your*' body, Morgan (2011) does not sufficiently address that particular closing of the gap afforded by the hospitalisation of a significant other. The participants talk of an all-consuming preoccupation with that patient's sick body at this time. For further explanation of how visitors might experience their own and the patients' bodies, I was drawn, first, to more contemporary understandings of Merleau-Ponty's (1962) concept of 'intercorporeality'. Tanaka (2015) defines this as the relationship of *my* body with the body of the *other* and this is based on our perceptions. So, for example, when we meet someone who smiles at us, we return a smile. Csordas (2008) likewise attributes the apparent contagion of yawning to intercorporeality.

Greater insight into this closing of the gap between two bodies is provided by Churchill (2012) and his promotion of the need for a 'second person perspective' for nurses to fully appreciate, understand and deliver the care needed by a patient. In first person singular mode *I* can only imagine how the *other* might be experiencing his/her own body and its circumstances by utilising my experiences as the basis of cognition and interpretation. This might, as Churchill suggests, result in health care workers leaving meals, drinks or call bells out of the patient's reach. Moving into the second person perspective, *I* come to an 'embodied way of knowing' *you* (2012: 3). That is, *I* move beyond what *I* have formally learned, and 'feel' with *my* own body senses the experiences of *your* body within the process of empathy. Only by engaging in this second person perspective can the other's pain, discomfort or body needs be fully recognised

and cared for. Moreover, and crucially for understanding hospital visitors' experiences, Churchill (2012:7) suggests that this second person perspectivity can lead to:

[T]hat special moment within the "first person plural" experience when we experience the call to step out of ourselves to enjoin the other in a simple moment of being-with.

These 'being-with' experiences are similar to the experiences some of the participants describe in their interview when the visitor becomes 'we' with the patient and seem to feel their own physical state and emotions and those of the patient. They are, effectively, moving to betwixt and between their own body and that of their significant other. The objective gaze at the *other's* body implied by Morgan (2011) and Finlay (2006) becomes a subjective experience of both bodies simultaneously. As chapter six demonstrates the consequences are described as 'I was feeling incredibly sick. I was really dizzy and disorientated' and 'I can't handle. It makes me mad'. These comments imply that this experience is not 'a special moment' (Churchill 2007: 7). It extends beyond the natural compassion of 'being with' or the intercorporeality of reacting to and with the body of the *other*. It is, I suggest, a phenomenon of an altered ontology and is a profoundly distressing and confusing moment of being betwixt and between the body of self and that of the patient when pain and distress are jointly experienced.

It was by combining my reading of the literature and the data analysis that I was able to recognise this phenomenon of being betwixt and between two bodies. Without the data, I would not have recognised this phenomenon and sought more information. Without the literature, I would have not have understood it. Of significance for this study, this ontological position of being between the body of self and other has not been identified in any of the literature I have encountered. In addition to the theoretical framework of liminality adding to the knowledge about hospital visiting, the research therefore also suggests a further understanding of liminality.

The features described so far point to a rather dismal picture of liminality with many 'chastening' challenges (Turner 1974: 91). However, Turner also notes the power of *communitas* and so I next consider this final core theme of the theoretical framework and how visitors might draw strength and support from it to deal with the many challenges they encounter.

### **3.3.6. Structure, *communitas* and more contemporary understandings of liminality.**

A blog by Stenner and Clinch (2013)<sup>65</sup> permits greater appreciation of the dialectical nature of *communitas* and structure and its application to 21st century social research rather than anthropological studies of tribal rites in the middle of the last century. In this blog they discuss Sewell's (1992) book about the French Revolution and how he understood events and structures:

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<sup>65</sup> Retrieved 9/1/2016 from <http://www.open.ac.uk/ccig/dialogues/blogs/thinking-about-affectivity-and-liminality-together>

Structures are composed of modes of power, distributions of resources, and cultural schemas, which provide meaning and 'know-how' to social actors. Events are sequences of occurrences that result in the transformations of structures. Events re-articulate structures, but such re-articulation presupposes a prior rupture through which structures become dislocated. We propose that events in Sewell's sense can be thought of as transformative actions that occur in liminal situations. That is to say, they are liminal enactments and occurrences that take place in situations that, to borrow a phrase from Victor Turner, exist betwixt and between more orderly and structured circumstances (no page number given).

These words facilitated my recognition of how event and structure might be interpreted from the visitors' perspective rather than from my experience as a researcher or as a nurse, accustomed to wards being highly structured places, as I next explain.

The event of hospital admission of a significant other causes a rupture from the structure and 'know-how' (Stenner and Clinch 2013) of the visitor's everyday domestic, work and leisure routines. In hospital, that same 'know-how' is undermined by unfamiliar, different, and often inconsistent structures. During this time visitors are between the structure of their everyday as they knew it and an everyday they are yet to know but in the fearful awareness that a transition is imminent. The existing hospital structures can be considered, I argue, as 'holding structures' in that they 'hold' – in both terms of support and regulation - the visitors in their suspension from their everyday structure and in liminality. In effect, the ward staff enact hospital structures in the form of policies and processes and, as such, fulfil the role of 'masters of ceremony' (van Gennep 1960) or 'seniors' (Turner 1969) in guiding the visitors.

Szakolczai (2009) brings further understanding by suggesting that it is the liminal stages of the process after leaving the old structure and before achieving the new structure that comprises an experience. Stenner (2015) also stresses that in this liminal stage of experience, and, flooded with the emotions associated with great uncertainty, people need 'stable institutions' or 'concrete individuals for guidance' (p156). This further supports my suggestion that hospital structures, as institutions, both hold, (support) and regulate (guide) the visitors. However, institutions do not always provide the support, or structure, needed in times of crisis (Szakolczai 2009) and in its absence liminality can become destructive (Stenner 2015).

Thinking about 'liminality' as 'an experience' or 'event' also provides the backdrop for engaging further with Stenner's (2015) differentiation between staged and unstaged liminality. He likens staged liminality to 'digging your own hole' (p3). That is, it is carefully planned and ritualised but still presents challenges and the unexpected. Unstaged liminality 'fall[s] on you like a storm' (Stenner 2015: 3) as all known structures of the everyday fall away. The crux of Stenner's hypothesis is that there is a 'zone of inter(re)ference between these ideal types' of staged and

unstaged liminality. Stenner explains that the affectivity aroused by unstaged liminality provokes rituals, which, in turn, propel this chaotic experience into a more manageable staged liminality. Staged liminality can also become unstaged when the unexpected occurs. To exemplify this, Stenner (2015), in his analogy of digging a hole, describes the possibility of the sides caving in.

This acknowledgement of different 'types' of liminality and the inter(re)ference bears direct relevance to my analysis and the nature of hospital visiting. The participants' accounts suggest that they initially considered an elective admission as staged. However, such staging was fragile and easily disrupted by incidents on the wards as diverse and seemingly minimal as lack of empathy from staff, movements of patients to other wards or a patient's unexpected deterioration. The experience then readily moves from staged to unstaged liminality. As expected, the participants' accounts of an emergency admission, as one of 'life's jolts' (Ibarra 2007), correspond with Stenner's (2015) unstaged liminality.

Unstaged liminality invokes a flood of emotions, which might be assuaged by the rituals of ward practices and processes (Stenner 2015). These processes introduce a structure and support until the visitors' *communitas* develops and they establish their own rituals and new norms as they move into staged liminality. The slow emergence of their own 'know how' (Stenner and Clinch 2013) and the strength of mutual support then gives the visitors the wherewithal to challenge faults they identify in the ward structures. This, Turner (1969) argues, defines *communitas* as 'antistructure' and can precipitate reform or improvements in structure.

Further support for the use of liminality in this thesis was provided by exploring the contemporary literature for the examples of the successful application of liminality in healthcare research (Martin-McDonald and Biernoff 2002; Little et al 1998; A. Kelly 2008; Bruce et al 2014). However, there appears to be little attention to my identification of micro-episodes of intense liminality experienced in the overall liminal experience or event. Thomassen's (2009: 6) interpretation of van Gennep's work does add some support for this variability of liminality as follows:

Van Gennep also noted that the rites of separation, transition, and incorporation are not equally important or elaborated in specific rituals and that the tripartite structure is sometimes reduplicated in the transitional period itself [...] By no means did he try to press all ritual forms into one explanatory framework.

Thomassen (2009) also advises that Turner's later work on liminality provides understanding of how a liminal state can become 'fixed' over long periods with the norms of social life seemingly suspended for an indefinite time. The relevance of this is further demonstrated by the analysis in chapter seven of the participants' differing experiences of their exit from liminality.

As the main research question asks about hospital visitors' experiences, Szakolczai's (2009) understanding of liminality as the experience, or event, of the time between leaving the old structure and before reincorporation into the new structure seems very apposite for this thesis. The following discussion, therefore, considers the literature that reveals the roles of storytelling about experiences.

### **3.4. Integrating liminality with storytelling and experience.**

With liminality and the five core themes of the theoretical framework now established, I begin this section by detailing the literature which defines 'storytelling' and informed my analysis of the 'life as told' in Bruner's (1986: 6) quote at the beginning of this chapter. I continue by providing a synopsis of the literature to provide a foundation for a more precise understanding of 'life as experienced' (Bruner 1986:6) in the context of this thesis. I then consider Turner's (1986) later work which conceptually and theoretically informed my integration of experience and storytelling with liminality in the theoretical framework and guided and structured my data analysis and this thesis.

One of the research questions asks specifically what visitors' stories might tell about the experiences of hospital visiting. It is by the participants' telling of their stories of visiting experiences that meaning and sense making can be achieved (Bruner 1986, Turner 1986) - by the participants, readers of this thesis and me. 'Stories' and 'narratives' are often used as interchangeable terms but in this thesis I refer to Denzin's (2000: xi) definition:

Narrative is a telling, a performance event, the process of making or telling a story. A story is an account involving the narration of a series of events in a plotted sequence which unfolds in time. A story and a narrative are nearly equivalent terms. A story has a beginning, a middle and an ending. Stories have certain basic structural features, including narrators, plots, settings, characters, crises and resolutions. Experience, if it is to be remembered, and represented, must be contained in a story, which is narrated. We have no direct access to experience as such. We can only study experience through its representations, through the ways stories are told.

Therefore the stories, as products of narration, were the central focus as I sought to interpret the research participants' experiences as hospital visitors, with the term 'narrative' being assigned to a method of sociological analysis (Hargreaves et al 2010).

Storytelling is essential to our social existence, and it seems that humans need to tell their stories but that these stories have many purposes (Kearney 2002). Bruner (1986) further proposes that some stories are told in more central and prominent arena, such as the media or lectures and are used to justify policy. Other stories are excluded or marginalised for their

expression. Bruner's comments reflect the lack of academic literature and research into hospital visitors' stories and the argument presented throughout this thesis that visitors have also been marginalised or, even, excluded from policy, academic enquiry and professional considerations on the hospital wards. These omissions suggest that there are issues of power at play, which Freeman (2000) demonstrates by discussing the difficulties in resisting meta-narratives of inevitable decline in old age. Plummer (1995) also suggests that, in their telling, stories can either challenge or comply with power. Drawing on Freeman (2000) and Plummer (1995), I came to recognise the participants' attempts, both by the act of storytelling itself and in their stories about their experiences, to resist the meta-narratives of their marginalised positions and the stereotyping of their behaviour. These observations are therefore pertinent to the third subsidiary research question which asks why and in what ways visitors resist or adapt to the policies, customs and practices of hospital visiting - both while visiting and in their telling of these experiences.

My reading of Finch (2007) established a further role of storytelling and insight for my analysis. She suggests that family members employ practices of display to demonstrate and confirm their successful, family-like relationships. Significantly for this thesis, Finch further adds that tools for the displaying family include the telling of stories and the giving of gifts. These displays are intense in times of transition when family relationships and dynamics are subject to disruption, occur within direct interactions, and with a desire for positive feedback from those witnessing them (Finch 2007). As the following chapters demonstrate, I was able to recognise the participants' display of their families as they were describing their (inter)actions in hospitals.

I was also interested in the role of storytelling in the health care arena. Hargreaves et al (2010) suggest that stories refer to descriptions of particular episodes and demonstrate our identities. Storytelling is also instrumental in helping sense making of stressful events - for ourselves and others (Hargreaves et al 2010). Bradby et al (2009) discuss the facilitation by stories of judgements and assessments. As such, patients' stories about their signs, symptoms and past medical history play an integral role for doctors in their arrival at a medical diagnosis. This is despite the primacy given in the medical arena to presenting physical signs and symptoms. As I argue later in this chapter, significant others also have their stories to tell. Visitors' stories are often based on their longer intimacy with the patient and his or her body (Morgan 2011) and can facilitate or confirm at best, or confound at worst, doctors' interpretations of signs and symptoms and achievement of a diagnosis. This becomes salient in chapter five when the participant, Gill, describes her efforts to supply information about her husband to the doctors.

This dualism between confirmation and confounding is significant as stories about the same episode, but told by different people, might differ according to the tellers' differing perspectives arising from their positions, roles and relationships in the social world (Andrews et al 2000; Kearney 2002). So, events may be differently interpreted (Hargreaves et al 2010). There are also stories that cannot be told, as exemplified by those with poor articulation who cannot give

full expression to their experiences (Hargreaves et al 2010). As the teller is the final censor in just what is related or withheld, there are also stories that are not told (Bruner 1986, Hargreaves et al 2010). As I note in the following chapter and in the research findings, memory and false recall also influence the content of stories (Wengraf 2001).

Furthermore, Bruner (1986: 6) begins to provide the link between storytelling and 'life as experienced' by noting their interrelationship: 'Experience is culturally constructed, while understanding presupposes experiences.' Bruner's words are reflected, in chapter two, in the demonstration of the potential for current cultural narratives and representations to shape hospital visitors' expectations and experiences. The experiences of others, however, can only be understood from within the repertoire of our experiences.

For the purpose of the research, I conceptualised experience by acknowledging the centrality of time and drew on theories and concepts from within the disciplines of phenomenology, philosophy, social psychology and anthropology. During my literature search, I came to recognise most elements of experiences are initially perceived via the senses and that these perceptions are then interpreted cognitively and subsequently influence meanings, emotions and behaviour. Social and cultural factors and experience are mutually constitutive in that each shapes interpretations and expressions of the other. This results in the multiple realities associated with the many differing stories about the same phenomenon. I now explore the literature that supports and extends this initial conceptualisation.

My review of the literature about experience begins by drawing on aspects of Husserlian phenomenological theory, which confirms the relevance of the participants' past experiences in shaping their understanding of their 'present' of hospital visiting and their concerns about the future. Using music as an example, Husserlian theory posits that it is impossible to acknowledge a melody by listening to each note in isolation (Dostal 1993). It is only by listening to the preceding notes, the 'now' note and the following notes that the melody can be appreciated (Dostal 1993). Likewise, a consciousness of past experiences (retentions) informs the present, and past and present join to form anticipations (protentions) of the future (Muzzetto 2006, Adam 2004). Retentions and protentions are only experienced in the present, whereas memories are only experienced with a reference to the past and hopes and expectations are the 'conscious focusing on some imagined future event' (Dostal 1993:147).

In providing the further understanding of Husserlian theory, M. R. Kelly (2008) defines his proposition of three levels of consciousness of time: objective consciousness of time; consciousness of internal time; and subjective consciousness of time. Giving an example of a fifty-minute lecture, Kelly suggests that objectively the lecture is experienced as lasting for fifty minutes of clock time. Subjectively, it may be experienced as a longer or shorter duration. The consciousness of internal time permits assimilation of both the subjective and objective experience of time and the possible nuances between the two. So, for visitors, visiting time is,

objectively, a measured number of hours in which, subjectively, time might pass quickly or drag interminably. It is the visitor's consciousness of internal time, which allows integration of both.

The subjective dimensions of time also feature in Torre's (2007) work on metaphors for time. He proposes that these metaphors most often fall into three categories: time as a resource; time as an environment; and time as the horizon. Time as a resource is particularly salient for hospital visitors who need or must make time to visit and incorporate this extra activity within busy schedules of work, domestic and leisure commitments. Torre's second category of time as an environment proposes distinctions between experiences and *an* experience. Torre describes a static and repetitive passive endurance of experiences such as the routine humdrum of the everyday. This is in contrast to the dynamic explosiveness of *an* experience, which, for the participants, was the life's jolt (Ibarra 2007) of the hospitalisation of a significant other - more so if this was preceded by sudden and unexpected collapse and an emergency dash to hospital. Within this explosiveness, as Torre (2007) further suggests, the participants had the choice of whether to adapt to events or resist - a theme which is central to the third research question and is discussed throughout the thesis.

The third type of temporal metaphor is that of time as a horizon, although this horizon is never reached and can only be viewed and contemplated from the present (Torre 2007). Like Bruner (1986), Turner (1986) and Husserlian theory (Dostal 1993), Torre confirms the relevance of both the past and the future to the establishment of meaning within the present. This also has the important implications for understanding time in the context of the visiting experience, as I illustrate in later discussions of the participants' uncertainty or their experiences of excessive waiting.

Whereas Husserlian theory provided a useful starting point for considering the relevance of time to experiences, his proposal that phenomenology involves psychological reduction was less appealing. For this, Husserl suggests that to see the essence of a phenomenon or experience, the researcher should bracket out all factors that might influence research processes (Aspers 2010). My standpoint is that my values, experiences, personality and social positions are an integral and non-separable part of me, such that psychological reduction is impossible. This reflects Heidegger's work which suggests that, as we are already inescapably embedded in the world, bracketing is impossible and we can only know and understand an experience through *Dasein*, which is our own 'situatedness' within, and understanding of, the life-world (Smith et al 2009; Aspers 2010).

Of further relevance for my understanding of experience was the primacy of sensory perception proposed later by Merleau-Ponty (1962). The body senses of sight, smell, touch, hearing and taste perceive the world. Cognition, memory and awareness of social and cultural values permit a sense making of these sensory perceptions (Merleau-Ponty 1962). This explains the participants' descriptions of their responses to the immediacy of their sensory perceptions when

physically confronted by the messiness of illness as demonstrated in later chapters and was first discussed in chapter two.

These phenomenological theories of Husserl, Heidegger and Merleau-Ponty cohere with one of the three pathways suggested by Rosa and González (2013) for theorising 'experience'. Similar to Torre (2007) they consider the phenomenological pathway of experience as a flow of consciousness of, and within the personal environment and most often concerned with the routine, humdrum of the everyday. When experience (in English) refers to 'something personally encountered, undergone or lived through'<sup>66</sup>, the Spanish and German languages employ two different terms to explain the nuances between Rosa and González' (2013) other two pathways. The Spanish *experiencia* and German *Erfahrung* refer to objective experience, which is concerned with 'cognition of the experienced object', sensation and feelings that can be manipulated or controlled in experiments. The Spanish *vivencia* and German *Erlebnis* describe experience as a 'lived, immediate, subjective quality that involves the self' and is more concerned with 'sense-making and meanings' (Rosa and González 2013: 396-397). These distinctions are important for this research as they clearly signal that it is experience as *vivencia* or *Erlebnis* that is the focus of the participants' stories.

However, it is the profound influence on the anthropologist, Turner (1986), of Dilthey's (1976) work on '*Erlebnis*' that provides the connections with liminality and storytelling and was to prove highly significant in establishing a theoretical and conceptual foundation for this thesis. Turner (1986) demonstrates Dilthey's understanding of 'mere experience' as 'passive endurance and acceptance of events' within the routine and humdrum. An experience, or *Erlebnis*, is distinguishable from the everyday routine and humdrum and is:

[F]ormative and transformative, that is, distinguishable, isolable sequences of external events and internal responses to them such as initiations into new lifeways... These experiences that erupt from or disrupt routinized [sic], repetitive, behaviour begin with shocks of pain or pleasure. Such shocks are evocative: they summon up precedents and likenesses from the conscious or unconscious past... What happens next is an anxious need to find meanings in what has disconcerted us...and converted mere experience into an experience (Turner 1986: 35-36).

Therefore the features of *Erlebnis*, as an experience, correspond to those characteristics Turner himself ascribes to transitions, such as those brought about by the hospitalisation of a significant other.

It is the recognition of the suspension of the participants' everyday routine that allowed me to understand the hospitalisation of a significant other as 'an experience'. Moreover, drawing again on Dilthey, Turner (1986: 35) notes that an experience has a 'temporal or processual

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<sup>66</sup> Merriam-Webster on-line Dictionary cited in Rosa and González 2013: 396

structure – [i/t] 'process[es] through distinguishable stages'. These notions of procession, transformation and stages also conform to van Gennep's (1960) understanding of the three stages of the rituals accompanying life's transitions and, especially, the interim stage of liminality. Turner (1986) also refers to Dilthey's (1976) suggestion that there is a human need to express these experiences. As the expressions of experiences in this thesis are in the form of storytelling, Turner's (1986) work, therefore, provided the links between the three main components of the theoretical framework: liminality; storytelling; and experiences. This, I argue, justifies the integration of all three in the theoretical framework.

### **3.5. Conclusion.**

The paucity of existing research or literature about hospital visiting experiences in English NHS hospital general wards provided the stimulus to interrogate literature from across disciplinary boundaries. These disciplines include anthropology, philosophy, sociology, social psychology and nursing and, as I now conclude, my extensive reading has produced a chapter that is pivotal to the whole thesis.

The theoretical framework set out in this chapter and supported by the literature (Grant and Grbich 2004; Lewis 2004; Anfara 2008; Braun and Clark 2012; Osanloo 2014) is central to the whole thesis in that it intersected with the first chapters, structured this chapter, the data analysis and the thesis as a whole. Features of liminality were identified as emanating from contextual influences in the previous chapters and from my early interpretations of the interview transcripts as detailed in following chapters. Therefore liminality was used as the overarching theory to develop the theoretical framework presented in this chapter. This framework provided the organisation of this chapter and a lens for deeper interpretations of the data analysis as I discuss in following chapters.

The central role of this chapter is also demonstrated by the results of combining the literature with the contextual influences discussed in chapter two. This meant that I was able to comprehend that the liminal characteristics of liminality during archaic tribal rituals described by Turner (1969) needed some conceptual adjustment for their successful application to 21st century research. In doing this, I was steadfastly aware of Grant and Osanloo's (2014: 16) warning not to 'forc[e my] preconceptions on the findings'. Instead, I permitted a dialectical relationship between the themes emerging from the data analysis and the literature, which included Turner's (1969) descriptions of the features of liminality and more contemporary literature. This resulted, for example, in the 'total obedience' of liminality being amended to accommodate the neoliberal policies of responsibility and autonomy, as described in chapter two. Therefore, I conceptualised the theme of total obedience as a combination of Turner's (1969: 81) requisite for 'passive and humble' (Turner 1969: 81) behaviour with the dualism of good visitor - problem visitor derived from Lorber's (1975) work on patient types. I conclude that, even in liminality, hospital visitors can exercise their agency.

The centrality of this chapter is further demonstrated by the guidance I derived from the literature to effectively analyse the data which features in later chapters. Thus, I have mentioned theories and concepts as diverse as psychological ownership, being liked, ambiguity, inclusion and exclusion and uncertainty. These all assisted in my interrogation and interpretation of the participants' stories about their experiences. Arguably one of the most significant results of combining the literature with the data analysis is my identification of a nuanced difference in the current understandings of the betwixt and between of liminality. The experience of being ontologically between the body of self and other has not appeared in the literature I have encountered and so suggests an example of adding to the knowledge about liminality.

Experiences and stories about them also feature in the theoretical framework and the collection and mode of analysis of research participants' stories feature in the following chapter. From a reading of associated literature, I recognised the multiplicity of roles of storytelling (Bruner 1986; Turner 1986; Kearney 2002; Finch 2007; Bradby et al 2009; Hargreaves et al 2010) and the power issues involved (Bruner 1986; Plummer 1995; Freeman 2000). I also noted the mutual constitution of stories and experiences (Bruner 1986). This led to my consideration of the literature about 'experience' and the central relevance of time (Dostal 1993; Adam 2004; Muzzetto 2004; Torre 2007; M. R. Kelly 2008)

Torre's (2007) work on time's metaphors also introduces the distinction between experiences as the humdrum everyday and an experience as a rupture from the everyday in which there is a choice between adapting to, or resisting, events. This relates to one of the subsidiary research questions. Moreover, I had earlier noted that Szokolczai (2009) suggests that an experience occurs in the liminal space between leaving the humdrum everyday and later returning to an altered everyday. I then established that an experience could also be considered as Dilthey's *Erlebnis* (Turner 1986, Rosa and González 2013). The processual nature of an experience similarly invokes liminality and prompts storytelling (Turner 1986). I was then able to successfully integrate the three major components of the theoretical framework, which structured my research activities, reading and the organisation of this thesis. This exemplifies the iterative nature of qualitative research and confirms the pivotal role of this chapter.

The theoretical framework organised this literature review and is now taken forwards into further chapters; with my focus of the next chapter on the theory and practice involved in the fieldwork and data analysis.

## **Chapter 4. Researching hospital visitors' experiences.**

### **4.1. Introducing the research journey.**

This chapter begins with the theory and philosophy that underpinned and guided my decisions to use qualitative research to achieve a deeper and richer interpretation of hospital visitors' experiences. I note how many of the decisions made cohere with postmodern research methods but I also acknowledge possible problems associated with taking this position. I counter long-standing criticisms of qualitative research by demonstrating my awareness of the requisites for preserving research integrity and also confirm my commitment to ethical principles. I then describe the progression from research proposal to finally settling the research questions.

My focus then shifts to the fieldwork activities where I detail the small pilot study and the advantages it afforded. I describe the processes and challenges of participant recruitment and set out the rationale for the use of the semi-structured, digitally recorded interviews. I provide extracts from my research field diary and details of the different stages of the thematic analysis of the data, which was informed by Braun and Clarke (2012).

I conclude the chapter by acknowledging the importance of reflexivity to qualitative research. I then carry out a reflexive exercise on a transcript extract and my corresponding field notes, and, so, demonstrate the further insight this revealed. Finally, I critique the use of empathy in qualitative research by, again, considering an extract from the data and my responses.

### **4.2. Guiding theory.**

The research presented here is qualitative and underpinned by an interpretive epistemology and recognition that the knowledge gained is 'partial, situated [the research context] and relative [to the researchers' subjectivity]' (Taylor 2003: 12). Qualitative research seeks deeper and richer interpretations and meanings of social situations, behaviours, interactions and practices (Schensul 2008). This leads to an ontological acknowledgement of the socially constructed nature of multiple realities and the influence of the many cultural and social processes brought to bear on the research (Taylor 2003).

Liminality, as central to the theoretical framework, coheres with Grbich's (2004) description of the characteristics of postmodern research, which permits the voices of those on the margins to be heard, whereas they have hitherto been silenced (Grbich 2004). In further accordance with the tenets of postmodern inquiry as described by Grbich (2004), this research is small-scale but in-depth. It also does not rely on meta-theories and acknowledges that the participants have multiple subjectivities and identities and differing views and perspectives of equal value. As with postmodern research, I write in the first person and the participants describe their

experiences in their own voices. Furthermore, I acknowledge my own and the participants' influences on the research. My reflexivity is therefore integral to establishing the research integrity and, arguably, more important than attempting to achieve scientific validity (Grbich 2004).

Criticisms of postmodern research include charges of being 'pretentious, lightweight and anti-Enlightenment' (Baert et al 2011: 478). Agger (2007: 443) suggests that it 'angers and agitates people' and is 'difficult' and 'abstract'. Grbich (2004) also advises that it can create experiences of alienation and suspicion for social scientists. Similar to Anfara's (2008) comments in the previous discussion about theoretical frameworks, Grbich (2004) also warns that postmodern research involves acknowledging that no single theory can adequately define a social phenomenon and can omit alternative understandings.

In the following section, I defend my stance and counter these criticisms by detailing how I followed best practice to preserve the research integrity. I also confirm my commitment to ethical principles.

### **4.3. 'Doing the right thing.'**

As noted, 'doing the right thing' (Le Voi 2006: 180) involves two interweaving, but essential, themes. The first is good research practice and the second is that of adhering to ethical principles to preserve the research integrity and my own and the participant's personal safety and wellbeing.

I incorporated Yardley's (2000) suggested qualities for protecting research integrity. Whereas Yardley (2000) suggests that reliability and validity are of less significance for qualitative research methods, Silverman (2005) accords them greater relevance. I therefore also discuss his recommendations for ensuring validity and reliability and the ways in which I was able to meet them. Yardley's (2000) first essential quality is that of sensitivity to context. To achieve this requisite, I read extensively and have presented the most relevant contextual influences on hospital visitors' experiences in chapter two. As the diary entries later reveal, I was also sensitive to the contexts of the interviews and how they might have consequently influenced the interactions between myself and the research participants and their decisions about what to reveal about their experiences.

Yardley's (2000) second essential quality consists of commitment and rigour. I have demonstrated my commitment with five and a half years of studying hospital visitors' experiences. My sustained attention to detail in this thesis and my adherence to Yardley's (2000) and Silverman's (2005) recommendations for good research practice are evidence of my rigorous approach. I also acknowledge the possible influences of my own professional, social and cultural background as that of being white, late middle age, a woman and (now) a retired

nurse. However, at times, my professional experience as a registered nurse was helpful in understanding what the visitors were trying to describe. So, for example, in chapter three, I was able to identify nurses' stations as a site of power where there are politics of inclusion and exclusion.

The third quality demands transparency and coherence and is concerned with the presentation of the research. The theoretical framework of liminality, as described in chapter three, has proved essential to achieving an orderly procession and structure in both carrying out the research and in the presentation of this thesis. For transparency, I set out the detail of the research processes later in this chapter. Also, the philosophy underpinning the research methodology was discussed earlier in this chapter and my relationships with participants, and possible influences, are expressed and accompanied by a section on my understanding of reflexivity and how it extended and improved my analysis.

Yardley's (2000) fourth quality concerns the theoretical, practical and socio-cultural impact and the importance of the research. Through my critical engagement with the literature and the data, I have attempted to demonstrate my 'standing back' (Thompson 1982: 1-2) to illuminate the often 'taken for granted' features of hospital visiting. In addition to the provision of coherence, the theoretical framework of liminality is demonstrated as a powerful lens through which to analyse the data and reveal new knowledge about hospital visiting. In turn, the interpretation of the participants' stories added to the knowledge about liminality. In chapter eight I reflect on how this thesis might influence professional education, training and policy and I have recently had a paper (Underwood 2016 forthcoming), stemming from this research, accepted for publication in a nursing journal<sup>67</sup>. I have also presented the research live (Underwood 2015; 2016) and pre-filmed to academic audiences.

In contrast to Yardley (2000), Silverman (2005) places greater emphasis on the need to demonstrate the validity and reliability of qualitative research. He suggests any, or all, of: constant comparison; noting deviant cases; coding by more than one person; triangulation; and respondent validation. Informally, I adhered to the constant comparison method and the noting of deviant cases. I also discussed emergent themes at great length with my supervision team. Triangulation was made possible by my personal diaries, observations and experiences in my professional role as a nurse and, on occasion, as a visitor myself. Also, as will be discussed later, the participant Nina is a registered nurse and provided rich detail from her perspectives as a nurse, as a visitor and as a nurse/visitor.

'Doing the right thing' (Le Voi 2006: 180) also involved ensuring rigorous research practices to meet formal ethical requisites. I stored the research data in compliance with the requisites of The Caldicott Guardians and Data Protection Act (1989), The Open University and the University of Huddersfield regulations to ensure participant confidentiality and anonymity. I also

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<sup>67</sup> See Appendix 13

read extensively about research ethics and produced a written report of my understanding of ethical principles. Thus, for example, I was able to appreciate the controversial suggestion that ethical demands might restrict researcher freedom and, consequently, have an adverse impact on the production of knowledge (Juritzen et al 2011) as researchers may avoid more sensitive topics in the interests of obtaining approval from ethical review boards (Boden et al 2009). Nevertheless, I obtained ethical approval for my research from The Open University Human Research Ethics Committee<sup>68</sup>. As a novice researcher, I also followed the guidance provided by the British Sociological Association (BSA) (2002)<sup>69</sup> in order to uphold requirements detailed within the categories of: professional integrity; relationships of trust and integrity; and relationships and responsibilities to participants<sup>70</sup>.

With reference to professional integrity, I recognised my own competency limitations and followed my supervisors' guidance at all times when designing the research, conducting the fieldwork and analysis and writing the thesis. To ensure my safety, my husband was always at home (in another room) during the interviews. If I met participants elsewhere, I carried a mobile phone and told my husband where I was going and what time to expect my return.

Relationships of trust included assurances to the participants of anonymity, privacy and confidentiality. The participants were all made aware<sup>68</sup> that they were contributing towards research for a Ph.D, possible risks and benefits, and I gave no promises of consequent future changes in NHS policies or processes. As already discussed, I have also been consistently aware of the need to preserve the integrity of the research.

My relationships and responsibilities to the participants were also a priority and also intended to preserve their psychological wellbeing. Before each interview, the participants and I spent some time getting to know each other. I provided them with an information leaflet about the research<sup>72</sup>, obtained their signed consent and emphasised their rights to withdraw or stop the recording and retract any statements. I also adopted a professional, but friendly, approach aimed at building rapport and trust with the participants before beginning the interviews..

Throughout the interviews I was aware that the participants could be revisiting very private and emotionally disturbing events with the potential for consequent psychological distress. I therefore attempted to minimise any such emotional turbulence by being a 'focussed listener' (Corbin and Morse 2003), demonstrating my empathic understanding but refraining from giving advice, providing solutions or making value or moral judgements (Gabb 2010) and, if necessary, offering a pause in the interview (Corbin and Morse 2003). After each interview, I and the participants engaged in a 'debrief'. This meant that the participants could discuss their

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<sup>68</sup> Appendix 4

<sup>69</sup> Retrieved 26/10/2011 from <http://www.brit.soc.co.uk/about/equality/statement-of-ethical-practice.aspx>

<sup>70</sup> As my research was self-funded, the categories referring to influences from or obligations to sponsors or funders was not relevant

<sup>72</sup> Appendices 6 & 7

experiences of the interview processes, express any concerns and achieve their emotional equilibrium before I left (Corbin and Morse 2003). I provided the participants with my supervisors' and my own contact details in case they wished to discuss the interview further, retract any statement or were experiencing further distress. Shortly after the interviews I contacted the participants to thank them for taking part and to check that they were suffering no lasting problems (Corbin and Morse 2003). None of the participants reported any prolonged distress and several described the experience as cathartic, a means of sense-making or an opportunity for being heard as further suggested by Corbin and Morse (2003).

An additional requirement of the Ethics Committee was that at least 20% of the research participants should come from an under-developed or developing country and/or not have English as a first language. By achieving this, I gained additional insights to the research findings. For example, Ed, originally from the Philippines, but now a Canadian citizen, who has acquired fluent North American English, talked about the language difficulties of overseas visitors in English hospitals. Winston, from one of the poorer Caribbean islands, detailed the differences in his experiences of hospitals on his island and in England.

Therefore 'doing the right thing' has been uppermost in my mind during all my research activities. Having determined these principles underlying good research practice, I next demonstrate how I fixed the research questions to achieve the research aims.

#### **4.4. Fixing the research questions.**

As Hsiung (2010) suggests, asking 'why' questions alone involves establishing causal relationships and is more appropriate to quantitative research methods of controlled experiments and counting. He also proposes that 'what' questions alone lead to descriptive accounts. Richer accounts of a phenomenon result from probing the multiple layers of meaning, tensions, patterns and interconnections (Hsiung 2010). I now describe the process involved in fixing the research questions in order to probe these multiple layers of meanings. Through this, I was able to achieve my aims of presenting a critical engagement with the data and a comprehensive account of hospital visitors' experiences.

Fixing the research questions was an iterative process with the questions becoming more focused as the research activities evolved. As Scotland, Wales and Northern Ireland have their own health administrations and policies, and as I was working in an English NHS hospital on a combined medical and surgical ward, it seemed a natural progression to focus on English NHS hospitals. With my sociological interests aroused, it was but a small step to recognising that I needed to explore the structures, or contextual features, that influence visitors' expectations and experiences. So, it was easy to set my first subsidiary question, which asks, 'How does the wider social context influence hospital visitors' experiences?'

My initial intention was to use Foucauldian discourse analysis of texts and documents in the public domain to establish power and knowledge relationships. However, this and other discourse analytic traditions (Wetherell 2001) did not permit engagement with the totality of the visiting experiences that I was seeking. It was my aim to tease out entanglements, commonalities and variations, the practical and material, the sociological and emotional, the unwritten rules and the unidentified or hitherto commonly understood, but rarely overtly challenged, aspects of hospital visiting. I came to understand that participants' accounts would be best termed as their stories. I was then able to set the second subsidiary question asking, 'What do visitors' stories about their experiences tell us about hospital visiting?' Within these questions, the term 'influence' did not imply passive acceptance by the participants, and, already aware of issues of power, I then asked, 'Why and in what ways do visitors resist or adapt to the policies, customs and practices of hospital visiting?'

In fixing the questions, the iterative nature of the research is further demonstrated. My acknowledgement of unfamiliar rules, policies and norms supported my earlier identification of liminality as an overarching theme and then in its development into the theoretical framework for my thesis. This framework then provided structure and a guide for my research activities involved in data collection and analysis, which I detail in the following section.

#### **4.5. The fieldwork.**

I now detail the different activities involved in carrying out the research. The fieldwork began with a small pilot study, which provided valuable experience as I later demonstrate. I then describe the participant recruitment and some of the obstacles encountered. These participants were all invited to take part in semi-structured, digitally recorded interviews, which I transcribed verbatim. Alongside the interviewing, I also maintained a field diary. Examples of the diary entries not only demonstrate the contextual influences of the interviews (Yardley 2000) and my subjective experiences, they also show how I was beginning to identify key themes (Braun and Clarke 2012), including liminality.

##### **4.5.1. The pilot study.**

The pilot project afforded the opportunity to confirm the method of data collection. It also gave me practice in interviewing, the chance to test the initial interview schedule and experience of the process for gaining ethical approval. I obtained informed consent from the participants<sup>74</sup> prior to the semi-structured, digitally recorded interviews with two people (a husband and his wife) who were known to me<sup>75</sup>. As with all of the interviews, I transcribed the pilot study interviews verbatim.

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<sup>74</sup> Appendix 5.

<sup>75</sup> I preferred to do this 'practice interviewing' with people known to me and with whom I would feel more comfortable as I practiced and developed a new skill.

An unforeseen consequence of the pilot study was the extra dimensions that the two participants revealed. The participants, Amanda and James had visited the same patient together but took part in the interviews separately. Their accounts accentuated many differences. For example, they had differing relationships with the patient, and also with my role of interviewer. There were discrepancies in their recall, fluency of description, and the foci of their individual attention when they visited. In effect, they were each narrating their reality of visiting the same patient, at the same time in the same hospital (Grbich 2004). Consequently, I also carried out individual interviews with the two husband and wife couples, who later took part in the research. I next describe the recruitment processes.

#### **4.5.2. Recruitment.**

'Word of mouth', posters in local surgeries, an article in the local magazine and a 'snowballing' process were utilised for recruitment. The criteria for recruitment were:

- The participants should be adults.
- The patient visited was an adult and not in a specialised unit such as Intensive Care.
- The visit should have occurred within the last year.
- The visit should have been to an NHS hospital in England.

I set the time limit because I anticipated that those potential participants might remember their experiences of recent visiting episodes more clearly. As the research demonstrates, though, the participants recalled other significant hospitalisation events from several years ago. The participants' full recall was an early indication that their experiences were so memorable that they could be later described as liminal events involving ruptures from the everyday and familiar norms. A second reason for setting this time limit was to avoid potentially confounding factors of the many political, economic and demographic changes that have occurred in recent years, as detailed in chapter two.

I also aimed to recruit people from the different social categories of age, gender or ethnicity and visiting patients with whom they had varied kinship or friendship relationships. The exclusion of minors was to achieve a more bounded research and to avoid ethical and methodological implications involved in including children in research.

The recruitment difficulties were varied. My initial intention was to recruit research participants within my workplace. Despite indications of support and approval from my more immediate managers, the Hospital Trust Human Resource department, 'as gatekeepers' (Hammersley and Atkinson 2007: 104), insisted on retaining intellectual property rights for my work and, so, control over any following publications. Negotiations between the Open University legal advice team and the Trust's human resources department were unsuccessful. So, I recruited from the wider community. The unforeseen advantage of this was that participants had visited different

hospitals in different parts of the country. These more varied experiences yielded a broader overview of the enactment of policies and practices in English hospitals.

I also encountered further problems. Most of the participants who volunteered were female. However, this could also be considered a preliminary research result as it demonstrates that visiting has particular significance, in some way, for women. The second problem was finding participants from a 'developing country' or those for whom English is not their first language. Local adverts and posters brought forward no volunteers in this category. Here, 'word of mouth' worked as others introduced me to their acquaintances. Also, an insufficient number of people who had visited in the previous year volunteered. I, therefore, extended the time limit to two years to achieve an adequate number of participants. This extended time limit appears to have had little impact on the interviews as participants' provided well-remembered details of their experiences.

Corresponding with our ageing demography and the higher demands made on the NHS by older people, I also initially encountered more participants who had visited elderly patients. I therefore later carried out purposive recruitment (Tonkiss 2004) and sought those visiting younger people. This strategy brought different perspectives to the research. Ed, visiting his sister and a friend, Ruth, visiting her daughter and Sally talking about visits to her husband, mother and son provided some rich data. For example, in chapter six, Sally expresses differences in her approach when visiting her husband and her son, and Ruth describes her concern about her daughter but was content to move to a secondary position in the visitors' hierarchy after her son-in-law.

#### **4.5.3. *The Interviews.***

In the discussions of popular culture, I noted how hospital visitors, as audiences, might listen, watch or read stories to make meanings and sense of experiences (Bruner 1986; Turner 1986). In this chapter, the participants' storytelling becomes the medium for data collection and analysis. As Holstein and Gubrium (2003: 6) state:

It would be difficult to imagine how an experience of any kind could be conveyed except in narrative format, in terms that structure events into distinct plots, themes, and forms of characterisation. Consequently, according to this view, we must leave our research efforts open to respondents' stories if we are to understand respondents' experiences in, and on, their own terms, leading to less formal control in the interview process.

My employer NHS Trust, and the constraints it would place on publishing the research results directly influenced my decision to use semi-structured interviews for data collection. I was unable to carry out overt ethnographic observations on the wards and covert, insider

observation compromises ethical principles such as informed consent (Hammersley and Atkinson 2007) and my professional codes of practice.

Whereas structured interviews use standardised interview schedules, are most commonly associated with quantitative research and aimed at reducing variables (Bloch 2004), semi-structured interviews are more suited to an interpretive epistemology (Byrne 2004).

Traditionally, qualitative research interviews have been defined as in-depth conversations, specifically designed for gaining or improving knowledge (Wengraf 2001). As Byrne (2004) further suggests, semi-structured interviews are conducted with the researcher having a list of open-ended questions, which are introduced as the conversation develops. There is also flexibility for the listening researcher to pursue other topics of interest that the participants might introduce.

There have been accusations of asymmetry in the power relationships between interviewer and the disempowered 'respondent' (Holstein and Gubrium 2003). Other acknowledged problems include details of past experiences being misremembered or forgotten, concealed, or re-interpreted with reformed conclusions (Wengraf 2001). Plummer (1995) suggests that stories are constantly reformulated and refined in their telling. The changes made are influenced by cultural and social expectations, the context of their telling, prevailing dominant discourses and their consumption and interpretation by others. This means that their meanings are never finally fixed (Plummer 1995) and can be considered to bear methodological implications for all qualitative interview research. Borer and Fontana (2012) also argue that there is now widespread knowledge about different types of interviews (for example, job interviews, research interviews, market research interviews). Therefore, there has been the creation of 'an interview society' equipped with 'interview repertoires' and 'prepared sound bites' (Borer and Fontana 2012: 46). Byrne (2004) also draws attention to researcher bias and a, possibly unintentional, misrepresentation of the data.

However, as Bruner (1986:10) states, and thereby justifies the continuing relevance of stories to social science research more generally and to my thesis more specifically:

[E]xpressions<sup>76</sup> are not only naturally occurring units of meaning but are also periods of heightened activity when a society's presuppositions are most exposed, when core values are expressed, and even when the symbolism is most apparent. Even if the events in the expression are not contiguous in time and space, they do have a coherence based in meaning.

Furthermore, my earlier discussion on postmodern research provides an alternative, but convincing, understanding of qualitative research interviews, which is assimilated within and

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<sup>76</sup> With the term 'expressions', Bruner is referring to the multiplicity of culturally contingent vehicles for telling about experiences. These include storying, theatre, art or drama.

throughout my research. So, I aimed to minimise possible accusations of asymmetry in power dynamics (Holstein and Gubrium 2003; Borer and Fontana 2012). To achieve an equal interaction, I went beyond informing participants of their rights to pause or stop the recordings or retract statements to extending to them the choice of venue, date and time for our meeting. I had a checklist of topics<sup>77</sup>, but I also listened carefully and gave the participants the opportunity to discuss other features that were of obvious significance for them.

This tactic resulted in Winston, who is a Jehovah Witness, talking at length about his religious beliefs and how they might be either overlooked or accommodated in the hospital. Jim, as a retired policeman, discusses hospital security and Gill describes the heart-breaking loneliness and frustration of caring for someone with dementia. Although these topics have not assumed a central relevance in this thesis, they all added an extra and deeper richness to my understanding of the varied nature of hospital visitors' experiences. I also reflected on how the participants were influenced by their personal and social contexts in determining what to say, how to say it and, crucially, what might be left unsaid.

Also, postmodern research shifts the position of the participants as passive respondents. Instead, it acknowledges that participants and researcher are engaged in a collaboration to produce meanings and understandings of an experience (Holstein and Gubrium 2003). Gill exemplifies this in chapter five when she draws attention to 'medi-speak' and how difficult it is for lay people to understand medical terminology. Her expressed reason for volunteering for the research was to improve hospital visiting experiences for others. She was effectively using the interview to highlight difficulties that she had encountered, but which she considered were avoidable.

Difficulties encountered during the interviews were varied. Some participants were more articulate and fluent than others, although recall appeared not to be a problem. In today's time-pressured society, I was acutely aware of the constraints this imposed on some of the participants in their storytelling. I also sometimes had to gently draw the participants back to the main focus of the research.

I conducted seventeen interviews with the participants detailed in chapter one. Although I had designed an interview schedule, I hoped for participants' own rich descriptions, and, becoming more confident, I used this schedule as merely a checklist for ensuring those topics, which seemed most relevant, were discussed. Each interview lasted between one and two hours, no participants withdrew from the research and only one requested a break during the recording due to distress. Adhering to the concept of theoretical saturation, I realised by the last interviews that I was receiving reinforcement of existing themes, rather than hearing about new phenomena. Throughout my research, I maintained a diary, extracts from which are shown in the following section.

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#### **4.5.4. Field diary.**

Sensitivity to context involves many facets, including the circumstances of the fieldwork (Yardley 2000). My reflections and experiences recorded in my research diary proved to be a valuable tool as, for example, I recalled the frustrations I encountered. For example:

Snow everywhere! Had to cancel interviews again.

I also noted my understanding of the relationships I was establishing with the participants:

She comes across as confident and energetic.... It was easy to establish a relationship.

And the unexpected:

Went to do my 7<sup>th</sup> interview today. When I got there his wife and sister also wanted to take part [...] I did not want to upset anyone by declining [...] By this time I was beginning to feel pretty tired and suggested that I left them to have their lunch to return another day but he wanted to continue.

I was also able to refer to the diary to recall a more phenomenological understanding of my experiences of the interviews:

She alternated between tears and anger as she spoke at length to me. Hers was the longest interview to date [...] I felt totally drained – exhausted. Some of the stuff she told me, and her emotions, were hard to accommodate. It has been a cold, wet day – the second in a row and it all felt very bleak.

Finally, I also noted themes as they were beginning to emerge and would eventually inform questioning in following interviews:

Husband was more concise and less able to talk about feelings etc. Is this a man thing?

I realised that, in a sense, their loved ones were partly lost to them as they were moved from their homes to behind institutional walls; into an uncertain and vulnerable unknown where access to them [the patients] was limited. Visiting is to make sure they are ok but unnatural.

As a result [...] I have become interested in transitions, roles, cross-domain role transitions and identity, together with liminality. I wonder if my research can be narrowed down more to this?

Thus, the diary was, in addition to the recordings, a reminder of the interview settings and the stories told for use in analysing the data, which I now discuss.

#### **4.6. Data analysis.**

I considered and discounted alternative qualitative research methods for analysis. For example, the traditions of discourse analysis (Wetherell 2001) and the different approaches to phenomenological analysis did not accommodate the broad spectrum of features involved in hospital visiting experiences that I was seeking.

My decision to use the thematic analysis as described by Braun and Clarke (2012) was due to varied reasons. First, Braun and Clarke (2012) provide a coherent structure for analysing the data. Thematic analysis also permits flexibility to incorporate both the social/cultural/emotional and the material/medical aspects (Boyzatis 1998) of hospital visiting. I realised, too, that, in the early days of fieldwork and analysis, I was handling the data intuitively and this seemed to cohere with Braun and Clarke's (2012) analytic structure. Diagram 3 illustrates the progression of my data analysis through the structure provided by Braun and Clarke (2012: 60-69)

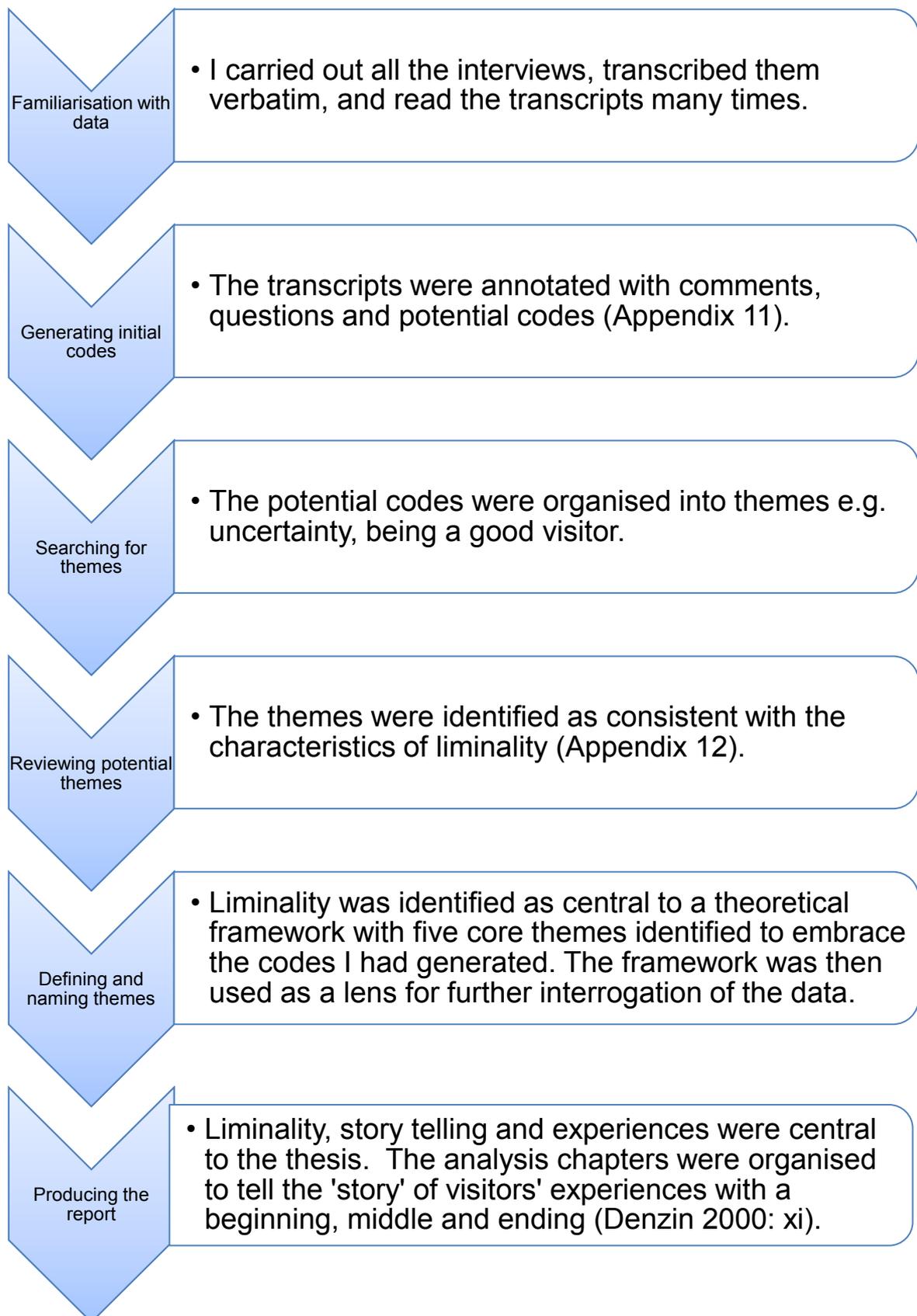


Diagram 2. The six steps of thematic analysis (Braun and Clarke 2012)

The data analysis was an iterative exercise, with each interview suggesting (or sometimes discounting) codes and themes for further exploration in successive interviews. Codes identified in following transcripts were then sought in previously coded transcripts to ensure I had not overlooked them. So, there was a continual reworking of the interview transcripts until the coding and the clustering of codes into themes was complete. As my research diary entries demonstrate, I came to recognise that the participants were implicitly, but consistently, describing the hospitalisation of a significant as a liminal event. As described in chapter three, liminality formed the centre of the theoretical framework and a lens for probing the transcripts for deeper and richer interpretations.

Within this process of analysis, deviant cases (Silverman 2005) provided additional insight. For example, Amanda's story about her hand gel use was inconsistent with the other participants' descriptions. From this, I identified the need to be judged a good visitor. This code was eventually absorbed into the core theme of 'total obedience'. Free association further enriched the analysis. Consideration of the colloquialisms and social and cultural *mores* associated with a simple cup of tea, for example, led to my identification of the theme '(in)hospitality'. My continued writing about the analysis and themes also assisted in my reflections and interpretations of the data (van Manen 1997).

Throughout the data analysis I remained aware of Bruner's warning below:

The interpretive process, however, always operates on two distinct levels: the people we study interpret their own experience in expressive forms, and we, in turn, through our fieldwork, interpret these expressions for a home audience (Bruner 1986: 10).

With Bruner's (1986) words in mind, I was aware that my interpretations, founded in my life experiences, values and social positions, could introduce a bias into the analysis. In order to counteract this and to preserve the integrity of the research, I employed the tool of reflexivity (Yardley 2000; Grbich 2004) as I demonstrate in the following section..

#### **4.7. The reflexive researcher.**

In the introductory chapter I discussed the use of researcher reflexivity to counteract my possible influences on the research processes. To demonstrate the power of reflexivity as a research tool, in this section, I use Finlay's (2012) five lenses for the reflexive researcher to conduct a theoretically informed reflexive exercise. To do this, I reflected on one short extract from an interview transcript and another from my related field notes. I follow this with a critique of the questionable use of empathy in qualitative research and again reflect on a transcript extract to determine my standpoint on this issue.

#### **4.7.1. A reflexive exercise.**

Having established the role of reflexivity, I now demonstrate my use of it. For this, I used Finlay's (2012) guidance to work through a transcript extract and my associated notes. The extract is from Sue's transcribed interview in which she is telling me about an episode of her father's experience of faecal incontinence.

**Sue:** They'd given him three enemas on one night, left him to, obviously, evacuate his bowels and he was left until the next morning. And when he woke up and, obviously one of those big large nappies they put on elderly men, he was covered up to here (pointing to neck) with poo.

**Janet:** Oh nooo (whispered).

**Sue:** All the way down to his knees. Erm, so the level of care there was appalling.

**Janet:** Did you do anything about it?

**Sue:** Erm we didn't do anything officially but my father was quite *compos mentis* that morning so he became very angry with the nursing staff and he apologised to all the other men in the bay cos he said the stench was appalling. And erm, and luckily a lovely nurse erm said, 'Frank, you know, we need to get you sorted out. Let's get you to the shower.' And she took him to the shower and she just completely hosed him down. But he said that was very degrading, very humiliating to wake up in that mess.

My notes about this interview were:

Sue needed a sufficient command of articulation and expression to permit me some understanding of her feelings and experiences. She may have repressed, retained or misremembered elements of these feelings for many reasons or, even, exaggerated them to make a point. She may have felt ashamed of her feelings, she may have forgotten them or she may not have recognised them. Alternatively, she may only have related this particular episode because she knew my professional status and expected understanding (or something else I have not recognised) from me. Similarly, there are vagaries in my understandings of her expressions of her experience. In her 'telling', I recall my own first encounter with faecal incontinence and how I was affected. However, subsequently, I have had much experience of dealing with patients' incontinence, such that I no longer experience that initial shock. Sue was also talking about her parent – someone I have not met and with whom I have no emotional attachment. Finally, I need sufficient articulation to re-describe Sue's expression of her experience. My representations of Sue's experience can only, therefore, be partial and directed by my own experiences and understandings. These differing possibilities for

interpretation alert to the need for researcher reflexivity whilst attempting to interpret and represent the experiences of others.

Finlay's (2012: 318) five lenses for researcher reflexivity are listed below:

(1) Strategic reflexivity looks through a lens focused on methodological/ epistemological aspects; (2) contextual-discursive reflexivity examines situational and sociocultural elements; (3) embodied reflexivity focuses on the embodied felt sense and the gestural duet between interviewer and interviewee; (4) relational reflexivity examines the intersubjective, interpersonal realm; and (5) ethical reflexivity monitors processual aspects and power dynamics, enabling the possible ethical implications to be revealed.

I now employ Finlay's lenses to extend my reflexivity beyond my initial notes.

For *strategic reflexivity*, I have already defined my reasons for choosing a qualitative methodology and the accompanying method and data analysis. As with all the interviews, I tried to adopt an approach, which was friendly and open but, simultaneously, professional, with comments and questions suitably phrased for Sue's emotional comfort and ease of response. Sue's interview was the fourth (including those in the two pilot studies) interview and I still lacked confidence in my interview techniques. Sue, as a teacher, had already demonstrated her knowledge by alluding to her experience of conducting research. Her research expertise, apparently greater than mine, accentuated my anxiety but also my determination 'to get it right'.

From my further reflection, I was able to understand that Sue, as an articulate and professional woman and aware of possible power imbalances, was, perhaps subconsciously, drawing my attention to her research skills to reduce power asymmetry (Holstein and Gubrium 2003; Borer and Fontana 2012).

Nevertheless, Sue's body language and gestures when she talked about the incontinence episode provoked an instant response from me, followed by a closed question, which was prompted by my anxiety, 'Did you do anything about it?' Fortunately, Sue expanded her reply. As the interviews progressed, I became more relaxed. My growing confidence meant that I was able to sit with the participants as they sought to describe their experiences more fully. This involved allowing silences, asking more open questions, using phrases or tokens of agreement, and asking for further explanation.

The second lens of contextual-discursive reflexivity involves reflection 'of both the research *situation* and the broader *structural* (sociocultural) domain' and seeks to identify 'hidden stories' (Finlay 2012: 321). My notes refer to the influences my professional status might have brought

to bear on the research. However, here there are also other dominant discourses at play, which could have, without a reflexive exercise, remained unacknowledged.

First, Sue is calling on the discourses of incontinence, to which she and I both allude and which Ungerson (1986: 75) defines:

The successful imposition of that order [toilet training] is of enormous symbolic as well as practical importance – it is, like the development of speech, a most significant indicator that the baby is human and can impose his or her own control on himself and his or her environment, and enjoy social interaction with other humans. The further implication is that the breakdown at any age of this particular order is also of enormous significance. It immediately sets the incontinent person apart as not properly human – or, at the very least, not properly adult; the temptation for the carer, particularly a woman who has struggled in the past to impose that order on her children, is to categorise the *whole* incontinent person as child or a failed human being, with possibly disastrous consequences for the whole caring relationship between carer and cared for.

Ungerson's (1986) words alerted me to how the discourse of incontinence might be leading Sue to see her father as a 'child' with a 'big nappy' at best or even a 'failed human'. Sue's words, *'But he said that was very degrading, very humiliating to wake up in that mess'* caused me to reflect further. I question whether Sue is attributing to her father her private, almost inadmissible thoughts about his new status of degradation and failed human. *'And she took him to the shower and she just completely hosed him down'* adds to my suspicions because, here, Sue seems to be implying that her father has been dehumanised into an object, perhaps a car, to be hosed down.

Sue also calls upon the discourse of inadequate nursing care. At the time of her interview, there was much media reporting of NHS hospitals' poor standards of care and, as I later demonstrate, she and her family were very concerned about this. My spontaneous reaction, 'oh nooo [*whispered*]' demands reflection. I might be calling on the same discourses of poor nursing care; I could be remembering my early experiences of abhorrence when confronted by incontinence; I might be attempting to disassociate myself from such acts of nursing neglect; or I might, too, be calling on the discourses of incontinence. However, my recollection of that moment is that I was thinking of my experiences with hospital policies and processes that result in overnight low staffing numbers. The consequent time pressures and heavy workload for nurses might have contributed to this situation for Sue's father.

Finally, Sue is also referring to gendered and age differences in practices of care as she talks of *'big, large nappies'* they put on *'elderly men'*. I question whether this might imply that she thinks

there are other, more aesthetic, incontinence aids for women and younger people. Or, she might associate incontinence with *'elderly men'* only.

Finlay's (2012: 323) third lens of embodied reflexive empathy concerns how the researcher feels a corporeal empathy with the participant, as she writes:

[A]n interviewer's empathy is not just about an emotional knowing but a felt, embodied experience that helps us understand our participants [...] I suggest that it can be fruitful to engage reflexively with our participant's lived body, our own body, and our embodied intersubjective relationship with the participant.

Using this embodied reflexivity, I was able to experience with Sue the *'nappy'*, *'the 'appalling and degrading stench'*, *'the mess'* and the *'humiliation'* she was physically feeling for her father's plight. After this, the *'lovely nurse'* *'hosed'* him down and, with order and propriety reasserted, her father was returned as an adult person again and sufficiently *'compos mentis'* to apologise. Sue pointed to her body to demonstrate the extent of the incontinence and expressed her disgust facially. I was in no doubt that this incident, although Sue did not witness it herself, was a profound and shocking experience for her. It seemed to signal her transition from thinking of her father as a fit and active man, to whom she could turn in times of trouble, to a frail, aged gentleman seeking help and support from her.

The fourth lens, relational reflexivity, was particularly salient for me. This lens focuses on the relationships between the researcher and participant and acknowledges that this is *'emergent, situated and negotiated'* (Finlay 2012: 134). Therefore I needed to consider how much Sue and I were influencing each other during the interview and how much of our social and cultural histories we were bringing to, or concealing from, the interview. Sue had been informed of my professional status before we first met and, unlike some of the participants, she was bringing that knowledge with her. My concern was that those participants who knew of my profession were tailoring their replies accordingly as is, possibly, demonstrated by the following two extracts:

**Winnie (aware of my profession):** Um, the nurses seemed to be having to do everything, I mean the poor nurses were even, one patient was gerring [sic] out of bed and the nurses had to wipe down and wash the bed [...] You know, I mean, that 20 minutes, half an hour would have changed a dressing on somebody, which is a specialist job. Wiping the bed is not. You don't train for all those years only to wipe the bed. An' I felt quite sorry for them really because, especially the two that were there most of the time, because they were running round, doing everything.

**Gill (not aware of my profession):** And I'll be quite specific about that because none of these nurses show any deference. They don't show any deference to the

needs of their patients, to the requirements of their patients in terms of – [...] just civility.

When coding, I remained vigilant for possible bias in the accounts of those participants who were aware of my profession. However, as Sue's extract shows, even being aware, she felt sufficiently confident to describe the care accorded to her father as 'appalling'. Finlay (2012) further notes, 'There are multiple interacting 'selves' or subjectivities involved' (p324). So, Sue and I were also there as daughters, mothers or professionals in addition to participant and researcher.

The dilemma of whether to inform research participants of my professional status became even more pertinent when using the final lens of ethical reflexivity (Finlay 2012). Finlay stresses that ethical practice should continue throughout the research processes and not just at the beginning. The (non)disclosure of my profession therefore also created an ethical dilemma. I did not want to introduce bias but neither did I wish to deceive. Instead, I took a pragmatic approach and, if directly asked, I informed the participants of my profession. Interestingly, despite my concerns, Gill told me during her debrief that she suspected I worked for the NHS as a nurse.

The unrecorded 'debrief' also involved ethical dilemmas as this was a time for the participant to talk about their experiences of the interview and any concerns or problems they might have wished to discuss with me. However, the participants often talked about things they had forgotten or omitted to say during the recording. The dilemma was whether to use their interesting, but unrecorded comments. I resolved this by seeking permission to restart the recorder or to use a passing comment.

Finlay (2012) also discusses the handling of emotional intensity. I was concerned about this because I did not wish to cause any unnecessary distress. When I realised that a participant, was becoming upset, I always suggested a break in recording. Only one participant agreed to this. Others, who were visibly upset, opted to carry on. However, for me, this emotional intensity was, surprisingly, bilateral. It was by listening to Meg describing her '*incredible*' and '*overwhelming sadness*' at the loss of her much-loved mother and noting how her eyes filled with tears that I reconnected with the emotions I experienced when I lost a parent. I was thus able to understand that consideration of empathy might provide a more phenomenological or 'felt' understanding of hospital visitors' experiences and decided to explore its value as a research tool.

#### **4.7.2. Empathy.**

All of the participants described, and often expressed in the interview, their emotional responses to the hospitalisation of their significant other. Reflexivity led to my recognition that I was also affected by the participants' verbal and physical expressions of emotion. Although I had used

empathy to guide my professional practice, I began to consider how much it could, or should, take a role in social science research.

Empathy is defined as ‘an emotional reaction congruent with another person’s feeling’ (Vitaglione and Barnett 2003: 302). Empathy can be variously considered through the lens of the drama-cultural, symbolic interactionism, psychoanalytic and neurological theories (Turner and Stets 2005). From the symbolic interactionism theory, empathic role-taking emotions ‘are evoked by mentally placing oneself in another’s position and feeling what the other feels or what one would feel in such a position’ (Shott 2008: 117). Keen (2006) determines the difference between empathy and sympathy in the following way:

<b>Empathy</b>	<b>Sympathy</b>
I feel what you feel	I feel supportive
<i>I feel your pain</i>	<i>I feel pity for your pain</i>

Distinguishing empathy from sympathy (Keen 2006: 209)

There are ethical considerations involved in an over-reliance on empathy in qualitative research. Social science ethical standards demand researchers’ acknowledgement of their responsibility for the ‘physical, social and psychological well-being’ of research participants (BSA 2002: 2). Charges of manipulation and misuse of power by the researcher arise from both the use of empathy to develop a more open and disclosing relationship with the participant and writing rhetorically to arouse empathy in the reader (Watson 2009). Empathy might both silence the participant and impose the researcher’s values on him or her (Watson 2009).

However, the academic literature also supports the use of empathy in research. Empathy facilitates a deeper understanding of participants’ interpretations, but the researcher should remain sufficiently objective in order to prevent over-identification (Given 2008). Similarly, van der Riet (2008) proposes a combination of the outsider approach to understanding the broader context and an empathic approach for interpreting the intricacies of a participant’s experience. Decrying the more positivist epistemologies, Alma and Smaling (2006: 204), although describing participatory research, suggest a working definition of empathic understanding as a tool:

Empathic understanding is placing oneself imaginatively in another’s experiential world while feeling into her or his experiences with the aim of comprehending these experiences.

These differing positions on the use of empathy, therefore, provided a conundrum. To determine the value of empathy, I carried out a reflexive exercise on a short extract from Molly’s transcript. Molly is a young, single woman in her 20s and, below, she describes an incident

when she was visiting her grandfather in the hospital. Her interview was one of the first to be conducted, at a time when I was still experiencing a lack of confidence:

**Molly:** I think the pyjamas they gave him were ever so tight because he's quite a big bloke and they were very tight around his bottom, his bottom half, and he actually said that, excuse me (*laugh*) his testicles were black and blue because the, erm, the pyjama bottoms they'd given him were too tight and they said they were the biggest ones they had available at the time.

**Janet:** How did that make you feel?

**Molly:** That made him feel embarrassed. That made me feel embarrassed 'cos he told me. And I'm his granddaughter (*laugh*).

**Janet:** I can feel, see you're embarrassed telling me about it.

**Molly:** Yeah, it was incredibly embarrassing (*eyes watering and blushing*)

**Janet:** Aaawww.

**Molly:** I felt more embarrassed for him than myself, obviously.

**Janet:** Yeah, did you feel that he'd got his own bit of territory there?

Here Molly is talking about her empathic embarrassment *for* her grandfather. She was feeling his pain, discomfort and embarrassment being caused by the tight pyjamas. However, hospitalisation has prompted Molly's grandfather to transgress an implicit code of appropriateness that had previously existed in their relationship. He talked about personal problems with Molly, which, as 'granddaughter' and a young, single woman, she found an inappropriate disruption to their relationship dynamics. Therefore Molly felt embarrassed *by* her grandfather. She is also displaying this embarrassment *during her interview by* relating his explicit description of his discomfort. I am invoked into feeling Molly's embarrassment. Noting Molly's words, her blushing and her watering eyes, I show my concern for her wellbeing, 'aaawww' and then abruptly change the topic of conversation.

This rapid change of topic can be interpreted in several ways: as a silencing of Molly to relieve my embarrassment; a change of topic to avoid Molly's further discomfort and possible tears; or my ineptitude in one of the first interviews. Likewise, my demeanour, appearance, position, age or many other attributes might be causing Molly more embarrassment in the telling of her experience. As Watson (2009: 114) suggests, 'We should subject our empathetic responses to rigorous scrutiny, be suspicious of empathy, don't encourage it (it'll make it worse)'.

Exploration of the literature failed to yield a definitive answer about the use and role of empathy in research. On the one hand, it permits an active engagement with the participants and the intricacies of their stories and watchfulness for their wellbeing. On the other hand, empathy stands accused of manipulation and the abuse of power. My standpoint is that my feelings of empathy are, to a large extent, as involuntary as any other emotion. While doing the fieldwork, this was more so when I had shared a similar experience (Gair 2012), such as that when talking

to Meg. To be allowed to feel into others' experiences and touch their feelings with them is a privilege, which can only assist the interpretative nature of the research. However, with both the nurse and researcher role, I think it is incumbent on the professional to limit the extent to which empathy should be indulged and physically expressed. An interview which disintegrates into, say, both researcher and participant in floods of tears would be inappropriate and irresponsible researcher practice. Here Hochschild's (1983) suggested demands for the public management of emotions apply equally for nurse and researcher.

#### **4.8. Conclusion.**

In this chapter, I have set out the main processes of the research. I have engaged with the theory and rationale underpinning my decision to carry out qualitative research and employ semi-structured interviews. I also detail the main problems, debates and controversies, which arose during my research. These were as diverse as recruitment difficulties to whether empathy should be used in social science research. I also set out the criteria for recruitment, the interview structure and the pathway I took in carrying out a thematic analysis.

In these activities, Grbich's (2004) discussion about postmodern research was salient. She, like Bruner (1986), mentioned in chapter three, draws attention to the silencing of those who are on the margins. My decision to follow the tenets of postmodern research is, therefore, relevant to my on-going argument that hospital visitors' voices have, except *Cure the NHS*, hitherto been largely unheard. More specifically, this marginalisation and loss of status are features of liminality. The theoretical framework provided by liminality and the five core themes provided a more in-depth and structured analysis of the data, which, in turn, informed the knowledge of liminality and hospital visiting experiences. I next detail this analysis in the following three chapters.

## **Chapter 5. Getting 'there': entering liminality.**

### **5.1. Introduction.**

I now present the results of the analysis of the participants' stories about their hospital visiting experiences in this and the following two chapters. Consistent with the tenets of postmodern research, the participants contribute in their own words. Each chapter represents the different stages of their journeys. As such, this chapter deals with the participants' first encounters with the hospitals they visited. Chapter six focuses on the following days and, for some participants, weeks of being a hospital visitor. In chapter seven, I concentrate on the discharge process and the exit from liminality. I also apply the theoretical framework of liminality as a lens and a guide throughout.

The analysis begins with my interpretations of the participants' stories as a rupture from the everyday, the need to get 'there' to the patient and their entry into liminality. I use the first two sections of this chapter to set out the diverse physical and emotional challenges, which the participants faced in the first hours of the hospitalisation of a significant other. Many of these difficulties continued throughout the hospital stay and included overcoming the logistical problems involved in satisfying an overwhelming need to be with the patient in the hospital.

On the wards, the participants' did not receive the signs of hospitality that they would have hoped or expected. Instead, they reveal more of the difficulties they encountered as they engaged in the practical difficulties of 'scouting' for chairs to sit on in the confined spaces at the patient's bedside. They also describe other more emotional challenges as they struggled to overcome their sense of invisibility and marginalisation, their loss of status and their attempts to overcome these by being judged as good visitors.

This interrogation of the data about those first few hours led to my recognition that the challenges faced by the participants were introducing the features I later identified as core themes within the theoretical framework of liminality as I set out in chapter three. Although all of these themes are mentioned in these first two sections, two of them, loss of status and total obedience assume greater prominence. In the third section, I begin to single out the core themes and explore the experiences of uncertainty and how the participants attempted to cope with this by seeking out information, providing it to the hospital staff or, for some, its denial.

This chapter addresses the first two research questions asking how the wider social context influences hospital visitors' experiences and begins to consider what visitors' stories tell about these experiences.

### **5.2. The rupture from the everyday.**

[The everyday is] 'ordinary in the sense that it is not imbued with any special religious, ritual or magical significance [...] how we get along on a day to day basis [...] between the rhythms of regular working life and the occasions when these are punctuated by special events, holidays or celebrations' (Bennet and Watson 2002: x).

In such ways, Bennet and Watson (2002) describe the everyday, which, for the research participants, was suspended by the hospitalisation of a significant other and superseded by a period of liminality.

The modes of and reasons for hospital admissions were multiple and varied. For some participants, it was due to the sudden, and sometimes life-threatening, collapse of the patient in their presence - one of life's 'jolts' (Ibarra 2007). For others, the disruption to the everyday was prompted by a telephone call informing of an emergency admission of a significant other. Then, there were those who were dealing with elective admissions for routine procedures.

Whatever the cause, all the participants recall the day of admission in detail as they relate their experiences. Unsurprisingly, the emergency admissions, or the 'explosions' (Torre 2007), involved greater emotional turmoil and are recalled with more dramatic detail. For example, Nina, a senior staff nurse on a busy NHS ward, received a telephone call from her father at 07.20 hours, as she entered the hospital car park for the start of a twelve-hour shift. As an only child of elderly parents, Nina feels responsible for their welfare. On this occasion, her mother became very poorly at home, and her father telephoned her for advice, as she describes:

**Nina:** I thought, 'What do I do? What do I do? I've got a long day at work. What do I do?' Went into work. I said, 'Who's in charge?' to somebody. I think I was [*in charge*], but I think [*deputy ward sister*] was on management. She was there. I said, 'Clare, I need to go home.' And I started crying. 'I need to go.' She said, 'What's the matter, what's happened?' I said, 'There's something wrong with my mum. I don't know what it is but I've got to go.' And Clare, being as she is, 'Fine, go, just go. Don't worry, just go.' So I went. Got back to the car park, rang my Dad again. Said, 'Any changes?' He says, 'No, what's happening?' I says, 'I'm coming'.

For Nina, unstaged liminality 'fell on [her] like a storm' (Stenner 2015: 9 forthcoming). She was torn between her work commitments and her obligations to her parents. Her sense of shock and those first minutes of being unable to formulate a plan are palpable: '*What do I do? What do I do?*' By the time she reached her ward, she had acknowledged that she must get to her parents.

Here, Nina is demonstrating her filial responsibilities and obligations (Finch 1989; Finch and Mason 1993). However, Nina, in common with other participants, seems to be expressing something more. Her tears and the repetition of her 'need to go', suggest that 'getting there' for her mother was almost a non-negotiable, inexplicable urge. Her words to her father 'I'm coming' are a triumphant announcement that she has overcome the first of many challenges of liminality and has successfully achieved leave of absence from work to satisfy this urge to get 'there' to her parents.

All those participants who had close relationships with the patient reveal this need to get there, but it is especially intense in a medical emergency. In reply to my request for reasons for this, Meg states, '*It wasn't a question. It just wasn't a question. [She] loved us to bits and so needed to see us really. Erm, we needed to see her*'. Molly also teases out the difference between need, family obligation and reciprocation, '*It was a want and it was a responsibility of mine. I felt like I owed it to them anyway*'. Sally's words below describes the toll of not 'being there' when she was at home and aware that her husband was undergoing a surgical procedure:

**Sally:** I can't eat. That's one thing. Er, my stomach just churns. Erm. I, I, I just seem to go round and round not actually doing anything but you know it, it, it, you can't sort of sit and concentrate.

Sally is describing the uncomfortable state of being betwixt and between. Although her thoughts were with her husband in the hospital, physically she was at home. Her description suggests that it might be more manageable to be with the hospitalised significant other and in the full knowledge of what is happening. Sally's words therefore illustrate another deeper layer of meaning to the visitor's overwhelming need to go to the hospital.

However, 'getting there' to the patient's bedside posed further logistical challenges for all. Centralisation of hospital care means that most of the participants had longer journeys than they would have wished. Traffic queues, irregular public transport with mismatched connections and inappropriate timetables, difficult navigation, expensive car journeys and car parking costs all added to the challenges they experienced. Hospital parking charges are universally resented by all of those who had to pay. For some, there was also the added difficulty of estimating how much parking time to pay for in advance. An overpayment was non-refundable, and an underpayment created the fear of car clamping. Consequently, there were the added challenges of monitoring time and repeated trips from the ward and back to the car park to pay for extra hours of parking. Others experienced the dilemma of having insufficient change for the parking meters. Those exempt from parking charges due to disability and the users of public transport often faced greater logistical difficulties. However, they considered parking costs a deterrent for unauthorised use of the hospital parking facilities by the general public and suggested that the extra income gained could benefit patient care.

One of the participants using public transport was Winston, in his eighties, unable to drive, and living fifteen miles from the city hospital. His ninety-minute journey from home to his wife's bedside was fraught with challenges, including taking two buses. Despite this, Winston found the navigational difficulties in the hospital more problematic as he tried to find his wife, who was in the hospital for routine surgery. Like other participants, Winston became disorientated in the vast and confusing spaces of the hospital buildings, as he describes below:

**Winston:** You may get directed to where you want to go, and, again, you could get lost on the way even though you're handed a piece of paper with directions. Sometimes you find you're gone and you're past where, it's, exactly you gotta go [...] I lost. Like if you're in a jungle and your worrying, 'Well which way did I come.' Like, should I say, in a maze? You know, you've got in a maze. And you keep, wondering, 'Which way should I turn? Where is the entrance?' That's how I feel, lost, you know. It's terrible there when you get lost.

**Janet:** Who did you ask the way of?

**Winston:** I may meet somebody out, either a nurse or a porter or somebody. Anybody I get hold of that coming my way. Even, maybe, sometimes, a visitor themself.

Winston describes a mounting panic as he reached out to anyone at all for assistance and assumed (arguably, incorrectly) that all hospital staff could give him guidance out of his jungle, or maze. Winston, in his distress and panic, is providing an example of reality inversion (Giddens 1991) as discussed in chapter two. He initially attributes these feelings of disorientation to other visitors, '*like you're in a jungle*'. '*I lost*', in its brevity and the first person, signifies both his capitulation and his ownership of his total despair of finding his way unaided. Moreover, '*I lost*' was not being at home with his wife and certainly not being in the familiarity of his 'everyday'. Winston was physically lost in the hospital corridors, but also metaphorically 'lost' in his liminality. Even in its brevity, '*I lost*' resonates with Stenner's (2011) seminar in which he suggests liminal personae have not only 'lost [the] road map' but also 'lost [the] road'.

Unlike Winston, Danny drove himself to the hospital following a telephone call from his mother informing of his grandfather's catastrophic stroke. Danny had a close emotional bond with his grandfather and was desperate to get 'there' to be with him. He describes below his frustration of being stuck in a traffic queue as he tried to enter the hospital car park:

**Danny:** I actually thought about actually pulling the car over and actually just going in because you know, he'd had a stroke and within that, you know, forty-five minutes, he could have passed away. And I may never have seen him. So, it was a big issue, you know, it was a real big issue. You know, there was a lotta, a lot of pressure. All I wanted to do was actually get the car parked and go and see him and, you know, with that traffic jam, I couldn't actually do that.

However, on arrival at the ward this desperate urge to be there suddenly dissipated:

**Danny:** I couldn't actually go in, to be honest with you, I couldn't go in initially to see him. I was at the ward but I couldn't go in. I couldn't bring myself to go in to actually see him. It, it took me a good few, a good few hours to actually go into the, into the ward to actually see him. [...] I felt I must go and see him because obviously at the time he could actually pass away at any time. [...] And I wanted to really remember him as he was rather than as he was in that bed.

Danny's words demonstrate one distinctly individual threshold experience within a longer overall liminal event, which started with his mother's phone call and ended with his grandfather's funeral. Although Danny easily found the ward, his account of '*going in*' is very evocative. The agonised hovering at the ward threshold demonstrates the ambivalence of ambiguity (Meyerson 1990). He had been driven by his desperate need to 'be there' and, yet, he was afraid of his possible emotional pain and distress, which would arise from confronting the altered physical state of his grandfather. He was suspended, torn even, between the fit and active grandfather of all his childhood memories and the dying grandfather. 'Going in' would bring him face to face with an unwelcome transition and a forced acceptance of a new reality of shifting relationships and altering family dynamics. It was a fearful time for Danny in his liminality, despite his earlier rush to 'go there' to be with, and for, his grandfather.

Also, Danny is indicating more aspects of the ambiguity of liminality in the form of tensions between his emotions; his apprehension and reluctance to 'go in' competing with his sense of obligation and his awareness of what a good visitor should do. These were still being played out in the interview, as it was only towards the end that Danny managed to talk about this personal threshold dilemma. His reticence in describing this incident could be further interpreted as his regret or, even, embarrassment and concerns about how I might judge his actions. Danny and I were passing acquaintances before his interview, and he also knew of my professional status. As a consequence, he was, possibly, more aware and attentive to his self-presentation (Goffman 1971). He also wanted, or needed, my approval of him as a good visitor and is demonstrating the need to be liked, as discussed in chapter three (Blumberg 1969; Baumeister and Leary 1995; Srivastava and Beer 2005; Williams and Nida 2011).

Means of entering the wards differed. Ruth had to identify herself via an intercom system before gaining entry through a locked door. Others appreciated a greeting from staff members, who either escorted them or directed them to the patient's bed. Jim, a retired policeman, with a consequent greater interest in security, questions whether permitting unlimited access to the wards compromises patient and staff safety. On the wards, some did not know where the patient's bed was situated and needed directions from staff. As Sue explains:

**Sue:** And a very convoluted way of getting to that particular ward, which was signposted eventually but when you came on to the ward erm very hard to locate my father. It was a little bit like a rabbit warren. Corridors off onto other corridors. And nobody at the nurses' station when you first get there and having to hang around for a few minutes. And then when somebody did come to the nurse's station, they asked, obviously, asked for his name and then they just pointed in a general direction. So I ended up going twice round the loop trying to find it. So, it's just not so organised and didn't appear to be so personal. I thought perhaps the nurse would take me round and actually show me where he was physically.

Sue's 'convoluted way of getting to the ward' implies that she, like Winston, might have also got lost but had possibly not endured the same panic. Instead, Sue's use of the metaphor, 'rabbit warren', invokes a sense of both increasing complexity and space around her diminishing as she entered the ward. Just as Danny was unable to 'go in', Sue felt prohibited from entering the ward without permission and she also needed directions to her father's bedside. Her '*hanging around*' is an apposite phrase for her sense of suspension between the world of 'outside' and that of 'in hospital'. She was, like Danny, experiencing a shorter and more exaggerated period of micro-liminality within a longer liminal event.

It is possible to tease out, in addition to the state of being 'betwixt and between', further core themes that Sue is expressing about her position as a liminal persona. She implies her total obedience in her tacit acknowledgement of the unwritten rule that she needed permission to enter the ward. The lack of attention from the nursing staff confirms her loss of status. Her uncertainty reverberates throughout the account and extends beyond her navigational problems and difficulty in locating her father. Her use of the first person singular, 'I' implies she was alone on this occasion, and without the mutual support she might have experienced from a *communitas*, which could have minimised this uncertainty.

One aspect of arrival at the ward entrance was the same for all the participants. This was the marking of boundaries by infection prevention and control measures, which included the 'ritual' of the mandatory use of hand gel. Although infection control is of vital importance in hospitals, the use of hand gels might also be otherwise interpreted as an indication of the polluting and dangerous characteristic of liminal personae (Turner 1969). Ruth and Amanda recall their differing experiences below:

**Ruth:** Erm, the hand gel sanitisers were there for people to use. I know I don't have a problem using them. I don't want to make anybody ill going in. You know. Didn't bother me in the least. In fact, we often complained, we see people walk in and walk past them and I said, 'Excuse me, can't you read?'

**Amanda:** I think there was a sign and we were very good, we washed our hands. They had a sign saying 'wash your hands in alcohol gel' before you went. Oh. No, we didn't. No that's a lie. No, we didn't do it and then the nurses came and then we realised that actually, we hadn't done it so we pinched some at the end of the bed.

**Janet.** Did you feel guilty for not having done that as well?

**Amanda.** Yeah. But I hadn't touched anything so I was fine.

Amanda's initial statement that they 'were very good', as they used the hand gel, is suddenly retracted. She makes her transgression appear worse by 'telling a lie' and then 'pinching' some hand gel. I reinforce and agree that she was possibly a problem visitor by asking if, and therefore suggesting, she might be feeling guilty<sup>79</sup>. Amanda briefly acknowledges her guilt but then immediately dismisses it with her next remark, '*But I hadn't touched anything so I was fine.*' So, even while voluntarily acknowledging her transgressions, ultimately she tries to reposition herself as a good visitor, as discussed in chapter three. In contrast, Ruth, not only emphasises her status as a good visitor by using the hand gel and acknowledging its importance in controlling infection, she then reinforces this by telling how she challenged those visitors who were not complying and, so, unlike her, were problem visitors.

Sometimes the participants, without being forewarned and despite being designated next of kin, arrived on the wards only to find that their significant other had been moved to another ward. Three participants were perturbed to find that the ward staff did not know the patients' whereabouts in the hospitals. This movement, or 'outlying', of patients is a measure taken by hospital staff to facilitate smooth 'bed management' as described in chapter two. Nina describes her experience of this:

**Nina:** So, anyway, went in the next morning. It was about 10 or something like that. 'Where is she?' She [*the nurse*] says, 'Ooh, we've moved her.' She said, 'Don't worry', she said, 'we've just moved her across the way.' She says, 'Cos she came back with a PCA<sup>80</sup>,' and she said, 'There were no trained staff on last night to deal with PCA's.' I says, 'Oh, ok then.' Erm, she says, 'But she's fine, as far as I know, she's fine. It's just that she had the PCA and she needed to go to 22 across the way.' I thought, 'Oh, ok.' I said, 'Will they mind me going across?' She said, 'Oh no, it's fine. I've told you it's fine.' So I went across. She was in the first bed. It was like a Nightingale ward [.....] Nurses' station at the top. Mum was right by the nurses' station. I thought, 'That's not good'.

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<sup>79</sup> Amanda had already spoken of her feelings of guilt for not visiting frequently. It is important to note that Amanda was the first interview of the pilot project and well known to me and aware of my profession. This might have influenced her comments

<sup>80</sup> PCA – patient controlled analgesia. Patients self-administer small doses of intravenous morphine as required. Extra training, beyond registration, is required and nurse competency must be demonstrated before assuming responsibility for this form of pain management.

Nina had arranged to visit her mother outside of visiting hours on the first postoperative morning. In their brevity, her words, '*Where is she?*' reverberate with her shock at realising her mother was not on the ward. Nina's consternation must have been evident because she relates how the nurse repeatedly attempted to minimise the event by telling her not to worry, her mother is '*fine*' (as far as she is aware), and she has only been moved '*just across the way*'. The significance of Nina's '*Oh, ok then*' is questionable. Superficially, it appears to be indicative of her understanding and acceptance of the situation. However, the tone of Nina's voice could also signal her displeasure because no one had informed her about the ward change. 'Ok' might also be demonstrating relief in knowing that her mother's absence was not due to serious complications following a complicated surgical procedure which had meant, at best, a move to Intensive Care or, at worst, her death.

The lens of liminality permits further interpretations of Nina's account. Nina works in the same hospital, but different ward, in which her mother was a patient. Assumptions that her 'know how' (Stenner and Clinch 2013) of the hospital processes would diminish her uncertainty are erroneous. Instead, her awareness of the hospital practice of moving patients around the wards did little to protect her when confronted personally, rather than professionally, with this situation. Her uncertainty increased because she could no longer assume that her mother was recovering from surgery as expected. Her experience of the inconsistencies in the application of visitor rules from ward to ward undermined her confidence that she would be permitted to see her mother outside of normal visiting times as previously agreed. She understood that she would have to accord total obedience to the rules as applied on the new ward. Her recognition of an unwritten rule that the sickest patient is positioned nearer to the nurses' station further reinforced her uncertainty.

Also, Nina was aware of the symbolic indications of her diminished status. Despite being a nurse, her mother's stated next-of-kin and first point of contact, she had not received notification of her mother's movement to another ward. Nina's experiences point to hospitals extending their control of time (Zerubavel 1979) to include control of space and place with similar consequences; lack of self-worth and loss of status. Nina had to consequently familiarise herself with another new environment and establish her status with different staff members and also assist in establishing a new 'territory' (Hayter 1981; Brown et al 2005; Wu et al 2014).

In common with other participants, once Nina arrived at the new ward she received little acknowledgement or welcome and faced further challenges. Hospital (in)hospitality, therefore, becomes the focus of the following section.

### 5.3. Encountering challenges of liminality on the wards: hospital (in)hospitality.

This section reveals that the features of hospitality, identified by Lashley (2008) as the provision of shelter<sup>81</sup>, comfort and refreshment (Lashley 2008), varied considerably on the wards visited. From the first minutes on the ward, the participants' stories demonstrate the inconsistencies of hospital hospitality afforded to visitors. The participants encountered challenges, which emphasised the core themes of loss of status and total obedience.

When the participants finally reached the bedside, the first practical challenge was often the difficulty in finding chairs. Amanda and James independently mentioned this problem, which James resolved by fetching some chairs from the patients' day room:

**James:** Erm. Er, we had to squeeze down the side of, of the beds er but not vastly.

**Janet:** Were they that close?

**James:** Well sort of, well when once you got the chair kinda of there, there wasn't any more, any more room on that side. I mean they had the two visitors rule.

**Amanda:** Well James picking up the – in the visiting room where you're supposed to get all the chairs from, it's a day room and a dumping ground for the spare chairs. He did pick up the visitors', the patients chairs rather than the little plastic chairs for the visitors [laugh]

**Janet:** [laugh] So James had broken a rule?

**Amanda:** So he had broken a rule and got a bit embarrassed but we sat with it and then took it back afterwards but no one was around so it was fine [...] Erm I don't know if they have to clean them anymore, but, yeah, it was quite funny. Made a joke of that.

The two stories of the same event provide rich interpretations. James had undertaken to fetch chairs for him and Amanda to sit on at his mother's bedside. Mistakenly, he picked up the bulkier and heavier patients' armchairs rather than the smaller, portable and plastic visitors' chairs. James does not tell me about this transgression of implicit visiting rules. Amanda, on the contrary, describes the situation in much greater detail with the acknowledgement that James was a potential problem visitor and the family teasing he had to endure.

James and Amanda are therefore illustrating how two people might interpret the same event and their different understandings of their reality and experiences (Kearney 2002) as noted in

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<sup>81</sup> For this chapter I understand shelter to mean the respite from weather conditions and from anxiety, stress or physical harm

chapter three. However, it could also be that James, having already endured family teasing, chose to censor and withhold the detail of his *faux pas* from his account (Bruner 1986, Hargreaves et al 2010). He might also have forgotten the detail (Wengraf 2001). I would also suggest that James might have withheld the information so that he did not present himself to me as a problem visitor nor have to revisit his embarrassment. Amanda, on the other hand, had nothing to lose in her telling and everything to gain. Her laughter when telling the story denotes her relief at being able to demonstrate some little 'know how' (Stenner and Clinch 2013) within her liminal situation and, in this instance, her compliance as a good visitor. Notably, though, she still ends her description by assuring me of her on-going support for her husband, James, and that it '*was fine*'.

Both Jane and Jim also describe the challenge of a lack of chairs:

**Jane:** I would look up the ward and see, you know, where there was an empty chair, where I could go and pinch a chair from, and I just wanted to tap somebody on the shoulder and say, 'Is it ok if I take this chair?' I felt really awkward about that, 'cos I felt as though the chair belonged to them.

**Jim:** There's never enough seats, you [go] scouting around the ward for somewhere to sit, to find seats to sit, especially if everybody's got visitors at the bed. Even if it's only two people at each bed, there weren't eight seats available<sup>82</sup>.

Jane is describing her first hours of liminality and the role of visitor. She acknowledged her perceptions of other visitors' possessiveness of chairs and her understanding that, by taking one, she would be pinching, or depriving the 'owners' of what was rightfully theirs. She is demonstrating her sense that she would have been infringing other visitors' psychological ownership of the chairs and the territorial boundaries they were affirming at 'their' patient's bedside (Hayter 1981; Pierce et al 2003; Brown et al 2005; Wu et al 2014).

Due to her reluctance to ask for a chair, Jane later recalls standing for hours at her husband's bedside on that first day while waiting for the doctors. No member of the ward staff offered her a chair. Jim reports that he went 'scouting around' for chairs. Other participants use metaphors such as 'hunting', or 'fighting' for chairs. Metaphors and idioms are a dominant feature in the healthcare arena, with language and place being mutually constitutive (Gesler 1999). By teasing out these metaphors, it is possible to recognise that the visitors were experiencing the scarcity of chairs as a 'struggle', which, in turn, contributed towards the creation of a site of further problems and anxieties from which there is no shelter. This aspect of hospitality (Lashley 2008) was elusive for the participants.

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<sup>82</sup> The ward Jim visited consisted of bays. In each bay, there were 4 beds and two visitors permitted at any one time although this rule was often broken and therefore created a greater shortage of chairs.

When the participants had taken their chairs, almost as 'battle trophies', back to their bedside 'territory' they became aware of a marked lack of space and constraints on their movements and privacy. Jane illustrates this below:

**Jane:** Each time we wanted to, we had to use the bedpan or everything, I would have to shuffle the chair which was sticking out the way from the other patient's cubicle and shuffle the curtains round and, you know, I would do all of that. It's bad enough, you know, with the drip up and a chest drain and using the bed pan and the person on, on the next door on the commode, the conversations, the smell that was going on there. But each time you looked in that direction there was a person, you know, in a different circumstance, but still uncomfortable. And of course if you looked across the ward as well, you were faced with, you know, seven or eight beds and they were full and it was just all so in your face. Yeah. It was all so blank; it was all so in your face. They were all staring at me and I can't talk to my husband or I can't give him a kiss or put my arm round him or, without feeling, you know, sometimes you just as a visitor, you really want to do some of those things, don't you?

Jane invokes an image of confinement, which was compounded by an unwelcome and intrusive encroachment on *her* territory by furniture, equipment, noise and smells from the next bed space. Jane's perception of the stares from other patients and visitors served to exacerbate her loss of privacy and sense of intrusion. The stares also reinforced her status as an outsider within the social world of the hospital ward. Jane's words cohere with O'Conner et al (2012) and their conclusion that hospitals are places where the needs of visitors are often overlooked and the lack of privacy makes sustaining normal relationships difficult.

Jane's needs for privacy also drew my attention to my professional environment where most visitors, if space permits, sit facing their significant other with their backs turned as much as possible to the ward and other patients. By combining the literature, Jane's words and my professional experience, I came to understand deeper meanings for this turning away from the ward. Visitors might turn their backs to 'shut out' the unwelcome and intrusive gaze of others. They might also be attempting to set privacy and territorial boundaries. Their actions could also be indicative of the beginnings of the developing *communitas* of liminality, with the visitors turning inwards towards each other for support and excluding strangers around them on the ward.

Coincidentally, Jane and Liz are both describing behaviour on the same ward in the same hospital, and in similar circumstances but at different times. Liz describes her own territorial and privacy experiences:

**Liz:** And the privacy is a pair of curtains round you, actually, even though you can hear what's going on elsewhere. But you just, everybody, you respect, so its boundaries. It's, it's quite, quite interesting, really, how human beings cooperate in that kind of way.

These two differing accounts of the experiences of privacy and territoriality in the same ward reveal much. Jane is acknowledging a two-way gaze between herself and other patients and their visitors. These gazes are a direct challenge to territorial boundaries and privacy and possible responses to threats of boundary infringement (Brown et al 2005). Liz, on the other hand, talks of 'respect of boundaries' and 'co-operation', which suggests averted eyes and less direct observation of, and by, others.

These differences could be attributed to the different personalities of Jane and Liz and consequent differing interpretations. They could also be an indication of variations in staff, patient, visitor and illness types, which occur on hospital wards with a transient population. For example, shift patterns and staff rotation might impact on the environment as some nurses may attempt to move patients to the bathrooms for toileting purposes during visiting times. Others would make a commode available at the bedside. Recognition of this ebb and flow also corresponds with my working experiences, which I identified, from a nurse perspective, at the beginning of this thesis. It explains the unpredictability of hospital hospitality, which further exacerbates the liminal characteristics of uncertainty and the loss of status. It also invokes a destabilising ambiguity as visitors seek to establish, for themselves, a precise understanding of the hospital visitor role and the normative behaviour patterns it entails, as demonstrated by the representations in chapter two.

Danny too, describes his problem with chairs and lack of space but implicitly links these with consequent challenges to his physical and emotional well-being:

**Danny:** I wasn't comfortable there at all, you know. Had to sit on the floor because, you know, we'd only got a couple of chairs. So it wasn't catering for the actual, you know, family of the patients' needs either, if you've got a big family. Yeah, if you've got one person that's fine, you can have one chair but if you've got five or six people.

**Janet:** You can still only have one chair?

**Danny:** Yeah, you can only have one chair. But, what you end up doing is sitting on the bed or, or sitting on the windowsill or something else or standing up. That can't be very good. We did ask for more chairs. We got one more chair but we couldn't get much more in the room [...] I feel that potentially, er, there needs to be more provision for visitors to actually have an area to go to. For instance, there was a room but that whole room was for the whole of the ward. So, we're a very big, big family, so we took most of the room up.

Danny was certainly not experiencing comfort in terms of that 'self-conscious satisfaction with the relationship between one's body and the immediate environment' (Crowley 1999: 750). Physically he was discomforted by the crowded conditions and lack of seating and emotionally he was coping with changing family dynamics and being suspended between the life and death of his comatose grandfather in an unfamiliar environment.

Jane, like Danny, talks about the visitors' room:

**Jane:** [W]e were shown erm, you know, the, the waiting room, the relatives waiting room [...] And do you know, all I could think was, this is the most uncomfortable, dark, dingy, uninviting room [...] There were no tissues, there were empty pizza boxes, just stacked up on the table, there was one tiny sofa with a hole in it, the curtains were open. Erm yes, there was, um, a book case where you could have your, you know, prayer books or your bible stand, yes so that was taken care of. But just, and it was tiny. It was tiny; you couldn't possibly have more than two or three people in there without feeling very cramped.

Jane's and Danny's descriptions of the visitors' rooms, in conjunction with the participants' experiences of confinement and seating difficulties, demonstrate hospitals' lack of attention to the varied needs of visitors. They also provide further examples of the physical challenges of liminality. The participants' needs were not afforded the same privilege as that established by the comprehensive body of literature about patient comfort (for example, Kolcaba 1994; Morse et al 1994; Malinowski and Stamler 2002). This lack of attention to hospitality by the hospitals was a further symbolic reinforcement of the participants' position as liminal personae.

As already noted, experiences of inhospitality were not universal and consistent. Participants' experiences differed in terms of refreshment on the wards. Whereas some did not receive anything, others enjoyed cups of tea and, sometimes, a snack. Those receiving this hospitality were not only appreciative, but they also interpreted these gestures as indications of higher standards of care within the hospital. Meg and Winston demonstrate their praise and gratitude in the following way:

**Meg:** They gave us a piece of toast. Yeah, they used to bring us a drink. They were just, they were just wonderful.

**Winston:** You're, when they were going round doing, like, tea break, y'know, having a refreshment time, they'll come with tea and fancy cakes and things like that or even a sandwich for the patients. And the visitors, they were offered a cup of tea, or whatever. I find that was very, very good, y'know. Very generous. A lot of generosity and kindness.

For the participants, the offer of a cup of tea was a symbol of status recognition, welcome, inclusion and care by the staff. As I came to recognise, there appears to be no specific policy guidance for staff to give or withhold tea. In hospitals, junior staff, with limited power on the wards, carry out the patients' tea rounds. By 'standing back' (Thompson 1982) and reflecting on my professional experiences, I came to understand that deciding whom to include and exclude in the tea round was giving some little power to these junior staff.

Many of the participants, however, did not receive any refreshments. As Gill, accustomed to frequent episodes of hospitalisation for her disabled husband, states:

**Gill:** I need to find something to eat that's actually not going to be bad for me because I'm trying to look after me. Because if I don't look after me, I can't look after him. And nobody else is gonna look after me. And certainly, nobody in the hospital is concerned about me. So I have to find something that's appropriate for me to eat.

Gill's repetition of there being nobody to look after her is particularly poignant. When we met, she seemed to be reaching the end of her endurance after twenty years of caring for her husband. Her words call out for somebody, anybody, to look after her for once. Hospitals are expected to be places of care and, yet, Gill did not find that care and hospitality for herself. Consequently she had to leave the ward to find refreshment<sup>83</sup>. For Gill, this lack of hospitality extended to her also signifies poor care for the patients. In overlooking the care Gill seeks, the staff were also putting her physical and emotional wellbeing at risk. Gill's demise would provoke more financial burden for the NHS and another bed 'blocked' from use by another patient. This 'bed blocking' is a substantial cost to the NHS and identified by the Carter Report (2016), as discussed in chapter two.

Hospital inhospitality was even more distressing for the participants when they experienced the 'invisibility' of liminality. The question 'How do you think the staff saw you?' produced some very different responses. Sue hoped she would be seen as part of a good, caring family and Meg saw herself as a junior partner in the care of her mother. However, Jim's following reply alerts to an ambiguity of being simultaneously invisible and 'in the way':

**Jim:** Yeah, I don't think that they see you there, but I'm sure that they would rather we weren't there.

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<sup>83</sup>. Gill later makes the important observation that in the hospital restaurants or vending machines, most of the food and drinks on sale belong to the 'junk food' category. This is at a time when the Government, health care professionals and the media are consistently warning of the dangers to health of poor diet and obesity.

Others report, in greater detail, disturbing episodes of inappropriate staff behaviour, being ignored, treated rudely and being a 'nuisance' or 'interfering' at the nurses' station. Gill describes this as follows:

**Gill:** Whenever I go into any of the hospitals, I feel I'm, I'm, I'm invisible, I'm a nuisance, I'm detracting them from their work and, um, I really should know better than to interfere. 'I'm busy. I'm busy. We are, we have our computer screens, we are engaged with our computer screens. We will not make eye contact with you even over, even over the station desk'. I certainly had this on one occasion on, on CDU<sup>84</sup>, five members of staff all seated in front of computer screens and I stood at that desk for six and a half minutes before I could actually engage eye contact with one of those people. Now they were, they must have been aware of my presence because I don't travel into hospital unless I am dressed for importance. I go in heels. I go in a jacket and I go as if I mean business because otherwise, you have no chance. You have to make the power statement. You have to be, 'I will know and you will engage with me'. So you stand at that desk for six and a half minutes until somebody actually looks at you and you say, 'I'm sorry to disturb you but I need some information.'<sup>85</sup>

Like Jim and other participants, Gill, as not staff-not-patient, was experiencing the ambiguity of liminality. She was being seen as a nuisance and, yet, not seen and, so, structurally invisible (Turner 1969: 81) as discussed in chapter three. Gill covers her confusion arising from this ambiguity by stressing her '*importance*' and '*power*' (Meyerson 1990). For Gill, the hospitality rules of the 'outside world' were suspended. The lack of deference, which she might have expected as a domestic guest or as a customer, reinforced her loss of status. Wirth et al (2010) offer an explanation for Gill's expressed need for eye contact. They suggest that a direct gaze results in the sense of inclusion and being valued, which then results in increased self-esteem and a sense of control (Wirth et al 2010). Lack of eye contact caused Gill to conclude that the computer screens seemed to have more value than her. To interrupt the nurses without receiving this prior eye contact to indicate permission to speak would be to fail to demonstrate the 'passive and humble' behaviour (Turner 1969: 81) of the good visitor role.

The nurses' desk also presented a physical barrier between Gill and the staff and increased her sense of marginalisation and exclusion; a 'them and us' situation had occurred. When one person eventually looked at her, Gill's opening words were an apology for disturbing them. This apology is, though, cleverly ambiguous. It can be considered a sign of Gill's capitulation to the position of an outsider, her attempts to display 'passive and humble' behaviour (Turner 1969:

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<sup>84</sup> CDU – clinical decisions unit – a ward for patients awaiting allocation to the appropriate ward once a diagnosis has been reached.

<sup>85</sup> Just as Amanda earlier added humour as a storytelling device, Gill, like some of the other participants, demonstrates the tactic, for achieving greater effect, of attributing words to the other actors in her experiences.

81). Gill's tone of voice on the recording demonstrates that she might also be employing irony or sarcasm to emphasise that the absence of prompt attention, which she considered was her due.

In chapter three I suggested that staff and visitors have different interpretations of the area behind the nurses' station (Goffman's 1971 front or back stage). The participants' stories support this and thus demonstrate a potential cause of tension between visitors and staff and a feature, which it is 'beyond the power of the juniors [*aka visitors*] either to grasp or prevent' (Turner 1969: 164). Ed, too, speaks of the marginalising nature of staff behaviour and the expectations for visitors' total obedience at the nurses' station when he was visiting a friend and waiting for her transfer to the ward from A&E:

**Ed:** You kinda marvel as a visitor 'cos I waited, like, almost two hours and I could see the workstation from where I was sitting and the flow, it's like a beehive. It's like, you know, and, and in all the chaos there's order. That's one thing I realised [laugh]. But there's a, being also a visitor, you get an awareness to what's happening. I think certain places where people that stand, especially if you're staff or hospital, you shouldn't be joking, making noises and laughing. There could be somebody really ill [...] There's a code of conduct that you have to be more respectful.

**Janet:** When they're laughing and joking, how do you feel?

**Ed:** Well, well, one of the things they were laughing about, was, there was this woman. I never saw her, but in another room.

**Janet:** Do you think it was right that you were party to that discussion?

**Ed:** Well. It depends. I could hear them. Whether I wanna ignore them or not, I can hear them. And the fact that they were very animated in how they're saying things. You cannot, you know, you cannot help.

Ed was being kept waiting with no information about the patient's whereabouts in the hospital. An unwilling witness to an inappropriate joviality, Ed was unable to distance himself in his attempts to be a good visitor and accord with the implicit rules he recognised and which constrained his movements around the ward. As with the other participants, Ed's presence was being overlooked. He, like Gill, was experiencing the structural invisibility of liminality. His discomfiture, caused by witnessing general laughter but not being a part of the amusement, was alienating, undermined his self-worth (Klages and Wirth 2014) and emphasised his loss of status. Ed further reveals his sense of ambiguity and ambivalence by the contradictory (Meyerson 1990) terms he employs to describe his first impressions of ward activity, 'And in all the chaos there's order.'

Ed is also noting his role expectations. As a visitor, he was still able to see, hear, understand and make judgements about what was happening around him, despite his understanding that

the staff were not aware of this. Moreover, just as he recognised the implicit rules, which constrained his movements away from the frivolity, he thinks hospital staff need to be similarly circumspect in their demeanour and they should accord with a professional code of conduct. As a liminal persona, Ed, like Gill, is also unable to 'grasp or prevent' the 'seniors' behaviour (Turner 1969: 164) which continued to marginalise and exclude him<sup>86</sup>.

The participants' stories about their 'invisibility' also demonstrate their limited options for dealing with their consequent discomfort. Being ignored, as experienced by Gill, Ed and other participants, is disempowering and limits reactions to retaliation, anger or withdrawal (Geller et al 1974). The sense of 'not belonging' arouses the negative emotions of sadness and fear, which also increase social sensitivity (Molden et al 2009). However, warnings against abuse or aggression towards staff, ubiquitously displayed around NHS hospitals, and some limited awareness of accepted social norms of behaviour within the context (van der Reit 2008) preclude overt (re)action and retaliation by visitors. The participants could not withdraw because of their overwhelming need to 'be there' for the patient. At the same time, they could not protest for fear of being accused of aggressive behaviour or being judged as problem visitors. They were being forced to manage, with difficulty, their emotional responses without transgressing rules (Hochschild 1983).

Nina, talking about the day of her mother's second admission for major surgery, powerfully demonstrates this increased social sensitivity. Aware that her mother would be unable to cope emotionally with the cancellation of her operation due to lack of a bed, Nina had used her professional 'know how' (Stenner and Clinch 2013) and had confirmed the availability of a bed with the hospital bed-coordinator. When the nurse completing the admissions process mentioned the possibilities of bed shortages and operation cancellation, Nina repeated her earlier discussions. This led to a chain of adverse interactions for Nina with this nurse, the ward sister and a health care assistant. Below, Nina takes up the story in her own words:

**Nina:** And for the nurse to say that about the bed situation and to be so abrupt with me was quite upsetting. I was upset for my mum, not upset for me. I was angry for me and I wanted to say more but I knew I couldn't because I didn't want to upset my mum further. And the comment from the NA<sup>87</sup> about the wheelchair. There was absolutely no need for that. You know I was just sat, as a daughter, doing the best for my Mum as I possibly could. And that upset me, that upset me quite a lot really. It shouldn't have done, but it, it did. Because I was worried about my Mum as well. But my worry kinda took second place to me being the counsellor and the reassurer and everything else. In a way, it took my mind off my mum's operation because that was some way away down the line that I wasn't

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<sup>86</sup> These reports of professionally inappropriate behaviour at the nurses' station continue throughout the interviews and indicate a need for staff training and education, as I discuss in chapter eight.

<sup>87</sup> NA = nursing assistant

thinking about at that point. I was just thinking about. I'm trying to keep my mum calm and trying to stop the staff being angry with me, 'I'm just here, you know, I am vulnerable'. My mum was very vulnerable. I didn't think of myself as vulnerable at the time but yes, looking back, as a visitor you are vulnerable. You don't know the system, you don't know what's going on, you do rely on people to update you and give you information. If you're not given that information, you worry even more, sometimes because you might start to think, for example, 'Is the operation not going to go ahead?' If you don't get updates every few hours, is it going to be cancelled? Things like that really. So my emotions were a bit all over the place, really.

Nina combines all the different aspects of her role as daughter, visitor and nurse: her distress aroused by bruising interactions with hospital staff; her own, and her mother's, vulnerability; her disempowerment; and her uncertainty and need for information. All of these were under the shadow of a risky, major operation, if, indeed, it would 'go ahead' that day as arranged. Even though her mother's admission was planned, Nina's liminality reflects Stenner's (2015) unstaged liminality, discussed in chapter three. Nina states her concerns were primarily her mother's emotional and physical wellbeing, but her own emotional turmoil is apparent. Her earlier bruising interactions with three different members of staff caused her to conclude that she was being judged a problem visitor. The disempowerment, caused by the need to exhibit the 'passive and humble' (Turner 1969: 81) behaviour of a 'good visitor', was further reinforced by Nina's awareness that to respond as she wished could cause negative repercussions for her mother. Her identity and status as 'nurse', which initially served to underpin her confidence, was completely swept aside by the hospital staff. Her diminished resources made her feel vulnerable but angry.

In the first hours of finding themselves out of their everyday in the hospital as liminal personae, the participants experienced their sense of confidence, control and status seriously threatened by the lack of tokens of hospitality. The participants were governed by the wish to be liked (Blumberg 1969; Baumeister and Leary 1995; Srivastava and Beer 2005) as good visitors and their desire to avoid the social pain of marginalisation or exclusion (Williams and Nida 2011) as problem visitors. Their options for action to ameliorate their predicament were limited and their only resource was to continue to display their 'passive and humble' (Turner 1969: 81) behaviour.

The stories so far in the first two sections have demonstrated how the challenges of liminality give rise to the intersection of total obedience with loss of status and ambiguity and betwixt and between as conceptualised in chapter three. As such, they form a backdrop for exploring the different core themes individually. The uncertainties, inconsistent and indeterminate hospital processes and an uncertain future all added to the emotional turmoil. I next explore, in greater

detail, the core theme of uncertainty and note the ways in which the participants attempted to cope with it in the context of their quest for information.

#### **5.4. Uncertainty and the quest for information.**

As the participants reveal in this section, most of them experienced a need for consistent, coherent and up-to-date information, which seemed to afford some sense of control, lessen the loss of status and move them from the marginalised position in which they found themselves.

For some, information gathering was a pre-admission activity. Winnie, Jim and Winston all appreciated the hospital information leaflets provided before the admission of their significant other for elective surgery. Although Winnie and Jim considered the information was sufficiently comprehensive, Winston had some queries about operation risks and so contacted a friend, who is a registered nurse, for extra clarification. Ruth also talks about pre-admission information but prefers not to know (Maslow 1963) the details of her daughter's forthcoming brain surgery:

**Ruth:** She [her daughter] knew everything about the operation. She'd been on the Internet. Whereas I get on and do it. I don't want to know. I just don't want to know. Just the sheer thought of what they were going to do to her is horrific. To think that they're chopping you about, oof, no. I'm not that way at all.

This suggests that, for Ruth, in contrast to the fear and fascination (Mooney et al 2000) with hospital drama in the media, which might titillate the emotions and entertain, the stark reality and intricate detail of her daughter's impending brain surgery were far less manageable. Ruth did, though, speak to an acquaintance whose mother had undergone the same operation and felt reassured. As she says, '*My biggest worry was that she was gonna [sic] be alright. Full stop. That she was coming home.*' The detail was, for her, too emotionally challenging to process and reassurance was all she needed.

Once the patient is in the hospital, there appears to be an overwhelming need to seek information concerning what has happened, is happening and will happen and why. I asked Dave to explain his desire for information, and he responded as follows:

**Dave:** It [NHS] is organised for the benefit of the doctors, which is the expensive resource. So, trying to get information from the doctor at specific times could just be difficult. On a couple of occasions, it was almost I was asking, they were saying, 'We can't do that'. And I said, 'But, no, I would like to see them [the doctors] now please [...] So I felt, you feel a bit powerless. But then again, I can understand why, because, unless you want information, the most important thing

is, that my mother was getting the care, and, to take somebody away from that just to give you the information you want, could be thought of as selfish.

**Janet:** How important is accurate information to you?

**Dave:** Well, I think it is important, especially if somebody is really ill. Often you go in and people are well, they're just waiting for things, they're just under observation or whatever. In that scenario, information is not that important. It's when people are ill and you're not being fully informed, you get frustrated 'cos you don't know what's happening. I think often the nurses don't feel empowered to give you the information. The doctors are very busy and trying to balance it out is difficult, I think. But it is frustrating.

**Janet:** Why do you think people want the information?

**Dave:** Purely because I think they do want to know what's happening, you know. What's being done for their particular relative or friend?

**Janet:** Does it give you some sort of control?

**Dave:** Yes, yeah. And you know, in control of the whole process. You do want to know what's happening even when you can't affect the process. I think it's just knowing what's going on, not feeling as part of, unimportant, if you like.

Dave has difficulty in explaining, and perhaps, even, fully understanding, his need for information but his responses illuminate important features of information gathering, as described by other participants. Dave demonstrates an understanding of a hierarchy of information providers, with nurses and junior staff considered the least reliable informers. Like others, Dave thinks the hospital consultants are the most efficient and respected holders and communicators of information. However, the more reliable the professionals are as a source of information, the less visible and accessible they become for the visitors.

Dave is also acknowledging a 'hierarchy of illnesses'. Being hospitalised for observation or investigations is not being '*really ill*'. This hierarchy occurred in several interviews. For example, Sally, talking to me about her husband's overnight stay as a patient for a routine procedure, worried that this was too insignificant for inclusion in the research. She consequently also told me about other episodes of her hospital visiting experiences to more critically ill patients several years beforehand.

The lens provided by the theoretical framework extends the interpretation. In this extract, Dave seems to be working hard to prove to me that he was a good visitor and, although he expresses a mild form of assertiveness, he is emphasising his obedience, compliance and demonstrations of respect in the hospital. Despite his frustration, he signals his acceptance of the higher value of the doctors' time (Zerubavel 1979) but makes no comment about the lost productivity for his own business. Unlike '*selfish*' others, Dave again presents himself to me as a 'good visitor' in according primacy to patient care above his needs as a visitor. It is not until near the end of this extract when I prompt Dave about the possibility that information provides a sense of control,

that his self-presentation falters and Dave reveals his true feelings, '*Not feeling as part of, unimportant if you like*'.

Arguably, these nine words carry more meaning than all those uttered by him before. Dave stops himself from the colloquialism, '*not feeling as part of the furniture*' and substitutes '*unimportant*'. 'Part of the furniture' is being depersonalised, inanimate, a *thing* of little consequence. '*Unimportant*' is one step higher and at least an acknowledgement that he is a human being. Only by being given consistent, coherent and up to date information could Dave regain some of his lost status. But, the status he could achieve in the hospital was only ever going to be that of 'patient's son'. It would not be his professional status as a company director or his family position of husband, father and breadwinner and certainly not eldest brother and head of the wider family. Dave felt the loss of status in his liminality very keenly.

Gill likewise emphasises the role of information in securing some status. Her following account also demonstrates that hospital visitors might also have valuable information to offer to hospital staff (Hargreaves et al 2010; Bradby et al 2009). Gill's husband has dementia, and this impedes his ability to recall all aspects of his long and complicated medical history. Gill talks at length about the vital information she provided to the ambulance crew in attendance after her husband's collapse and also to the hospital staff on admission. This was either ignored or not passed on to those caring on the ward for her husband. She then describes the following incident in which she handed, to a doctor, her prepared synopsis of her husband's medical history:

**Gill:** I'm an irrelevance. [Husband's] history is an irrelevance. He didn't take any history from [husband] about previous occurrences. He didn't have, he didn't even have the courtesy to fold the piece of paper or hand it to his registrar or his SHO<sup>88</sup> and say, 'Pop that in the notes, we'll have a look at it later.' Nothing! He just handed it back to me and I thought, 'You arrogant bastard. You're not treating this person. You're just treating the body'.

Gill was attempting to provide essential information to those treating her husband. This prepared synopsis also represented her twenty difficult years as her husband's carer. The doctor's rejection also served to denigrate her years of struggle and to reinforce her liminality by marginalising her and her central (and, arguably, essential) role in the management of her husband's illnesses. It also undermined her status and self-esteem. Her lay, but extremely comprehensive, knowledge is given a lower value than the doctor's professional knowledge. Gill's resulting anger with the doctor, '*You arrogant bastard*', is obvious.

However, Gill alerts to a further problem in information seeking:

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<sup>88</sup> SHO = senior house officer. Now called FY2 (Foundation Year 2) to denote the second year of post-medical school training

**Gill:** I'm not a regular user of medispeak and each set of circumstance seems to present me with new aspects of the language.

Gill's interview is peppered with acronyms such as: FOPAL (frail older persons' assessment and liaison service), CDU (clinical decisions unit), MRSA (Methicillin-Resistant Staphylococcus Aureus), and CTPA (computed tomography of pulmonary-abdomen). As Gill illustrates, any information that is given by hospital staff is often couched within medical discourses and terminology ('medispeak') and, as such, more difficult for patients and visitors to comprehend. Gill's words epitomise the Foucauldian power-knowledge-discourse interrelationship described and exemplified so effectively by Hall (2001).

Gill, an intelligent and articulate woman, who has had some very distressing visitor experiences over the years, volunteered for the research because she hoped its publication would lead to improved experiences for others. Gill is playing an active role as the research participant in shaping knowledge to be disseminated to the wider public, as discussed in chapter four. By explicitly drawing my attention to the difficulties of medical terminology, Gill is attempting to publicise the information and communication problems visitors might encounter. Moreover, Jane, below, justifies Gill's efforts:

**Jane:** And you'd get different stories as to why it happened or what could possibly you know, 'cos, when they are investigating Marfan's Syndrome. One of the doctors had mentioned that. And of course I'd never heard of it and I just wanted that doctor, that person to go on and spend ten minutes with me. I said, 'Look you know, 'I've got two huge boys<sup>89</sup> at home.' But again I had to come home and do, ask my GP who's wonderful. I tend not to use the Internet as much as I possibly could.

**Janet:** And how did that make you feel, that you weren't getting the information?

**Jane:** Frustrated, very frustrated. And it made me want to turn to the, and I never do this, but it made me want to turn to the Internet and do a lot more research.

Jane and her husband were not receiving consistent and clear information about the possible causes for his near death experience. Here, Jane is referring to her lack of knowledge, which Turner (1969) identified as another feature of liminality. The possible diagnosis, Marfan's Syndrome, is a genetic illness. Not only would her husband's health status be permanently compromised, but also she was facing the anguish of knowing her children's health could also be questionable. Utilising Stenner's (2015: 3) words, Jane's liminality was unstaged and fell on her 'like a storm'. She was facing a sudden imposition of an unwanted transition from a secure and happy family life to an uncertain future, blighted by continuing health difficulties, which might pass down the generations. Ontologically her accustomed reality was undergoing a

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<sup>89</sup> Jane also has two daughters. Here she was referring to the height of her sons because people with Marfan's Syndrome are unusually tall.

seismic shift, and she needed structure and support from the 'masters of ceremony' - the hospital staff. But she was not getting this support in terms of the information she so desperately sought to dispel some of her uncertainty.

This uncertainty leads Jane to hint that she might have resorted to the Internet for further information. Any slivers of knowledge, no matter how she obtained it, would empower her sufficiently to afford her some sense of control. Implying, but not admitting, her use of the Internet suggests that she considers its use an illegitimate challenge to medical power and ownership of specialist knowledge (Broom 2005) as discussed in chapter two. These are the first indications of some resistance by the participants in the research findings. Getting information from another doctor, her GP, is legitimate and can be safely acknowledged without the risk of being considered a problem visitor.

Another of the core themes, loss of status, is relevant to Jane's use of the term 'stories' as it seems to signal that she was experiencing her loss of status as an adult. She suggests that she was being judged as a child, without the wherewithal to assimilate the full facts of her husband's condition in one account and was, instead, being provided with unreliable snippets, which might be contradicted later. In this liminality she, as a junior, was unable to 'grasp' (Turner 1969) that it is only by accumulating many different test results, considering the patient's medical history and presenting symptoms, performing clinical examinations and observing the illness trajectory that doctors (the seniors) can reach a diagnosis.

Similar to Jane, Danny and his family received a stream of partial information as he tells below:

**Danny:** You know they were feeding us information when they possibly could. They were all very honest with us. Which helped. It really did help. They weren't giving us false hope or anything. They actually did say, how ill he actually was and this is what's actually happened and he said his chances of survival and er. So we were quite prepared quite early on. We actually knew that and prepared ourselves for it. My mum struggled with it even though, she was told early on, she really struggled with it later on. But it didn't affect me as much as it gave me time to prepare myself. And in my mind, I knew what was going to happen. There was an acceptance, you know.

The drip feed of '*honest*' information extinguished all of Danny's hope for his grandfather's recovery. Importantly for Danny, this helped him move from the despair of no hope, through emotional self-preparation and onwards to an acceptance of his grandfather's terminal prognosis. Danny's use of 'we' and 'us' implies that this emotional journey was a joint family process. Only Danny's mother blocked the information and clung on to hope for recovery (Maslow 1963; Mishel 1988; Penrod 2007; Folkman 2010). In giving '*honest information*', the hospital staff were acting as masters of ceremony and using their structures to support and

guide Danny and most of his family towards acceptance of their imminent bereavement. This support was needed until they were able to establish *communitas* and their rituals (Stenner 2015) at the patient's bedside as discussed in chapter three. For Danny, it was his mother's insistent clutching at hope, which prevented her from successfully preparing herself like the rest of the family. Danny thinks that being unprepared causes greater struggle when faced with the reality of the transition brought about by the death of a loved family member.

The participants all report using other sources of information. For example, Jane later describes asking the patient for information. Further sources of information included other patients on the ward and other (visiting or non-visiting) kinship group members. Family and friends who work in health services were also valuable sources of information. Jane was the only participant who mentioned seeking information from the Internet. This could mean that the others chose to censor it from their accounts as they, too, thought it might be judged as an 'illegitimate' activity. Or, it could mean that searching the Internet for information is now such a common activity that it does not warrant comment.

## **5.5. Conclusion.**

This chapter begins with the participants' accounts of their overwhelming need to 'get there' to the patients' bedside. This was a very powerful and consistent theme emerging from the data analysis and was illustrated by Nina's story. However, when I asked why this need arose the participants seemed to find it difficult to find adequate words to respond. It was Sally's comment, identified in the data at a very late stage of analysis, which prompted my recognition that the trials and tribulations of 'getting there' to the patient's bedside were preferable and more manageable than staying at home, worrying and wondering about events in the hospital.

All of the participants described the hospitalisation of a significant other as a rupture from their everyday. In this respect, the emotional turbulence was, as can be expected, greater if this hospital admission was following an emergency. However, as Winston and Nina reveal, even if this rupture was due to an elective admission, the features of liminality prevail. Nina demonstrates the fragility of the staged liminality and its inter(re)ference with unstaged liminality (Stenner 2015: 3) in her account of her responses to her mother's transfer to another ward. Similarly, Winston's account of getting lost indicates his own unstaged liminality.

The focus of the first two sections was intended to foreground the many challenges that can be presented to hospital visitors as liminal personae by the admission, the hospital built environment and policies and processes. Throughout these first discussions of the data analysis, I have therefore provided an overall illustration of the hospital visiting scenario as experienced by the participants and demonstrated how the challenges encountered can, and do, translate into the five intersecting core themes in the theoretical framework. For example,

one of these themes, total obedience and being a good visitor, was established by Amanda and Ruth's discussions of their use of hand gel.

The second core theme of loss of status also prevailed throughout the chapter. It was established, for example, by the lack of hospitality, being ignored at the nurses' station and the participants' perceptions that information giving and receiving is an acknowledgement of their status. This is particularly well demonstrated in the section on uncertainty and information seeking by Gill and her response to the denigration, by the doctors, of her status as her husband's carer.

Indications of the core themes of ambiguity and being betwixt and between and *communitas* also appear in this chapter. For example, Ed demonstrates his ambiguity in the proximity of the chatter at the nurses' station and Nina describes how she was torn between competing responsibilities to her parents and her employers. *Communitas* is a theme that developed more strongly at the patients' bedside as time passes but its emergence and relevance is also evident in the first hours of being a hospital visitor.

The chapter also demonstrates other, arguably minor, concepts, or features, of liminality as described by Turner (1969) in addition to the five core themes utilised in the theoretical framework. Examples include the emotional and physical challenges of being seen as polluting or dangerous (and hence the ritual of hand cleaning) and the sense of being invisible. These, in turn, contribute to features within the core themes. These 'minor' concepts appear throughout the analysis chapters and so suggest the possibilities for creating a more elaborate, hierarchically organised theoretical framework (Lewis 2004) of liminality. My extensive reading of the literature has not revealed such a conceptual hierarchy, and so there is a glimpse in this first analysis chapter of the research into hospital visitors' experiences also adding to the knowledge of liminality.

However, the core themes are not discreet phenomena. Their intersection is, for example, demonstrated by my use of my theoretical framework of liminality to penetrate the deeper layers of Dave's account of his quest for information. In his story, I was able to detect the less explicitly expressed theme of Dave's very measured and elaborate attempt to position himself as a good visitor and restore some fragile status for himself as the patient's son.

This pre-hospitalisation relationship with the patient was accorded more respect by the ward staff than more accepted understandings of status arising from social class, wealth or employment and is explored further in the following chapter.

## Chapter 6. Being 'there': in liminality.

### 6.1. Introduction.

The participants' stories now continue with my focus on the interim stage of their liminal journeys, when the shock of the rupture from the everyday and first encounters with hospital structures has, to some extent, subsided. In this chapter, I continue to examine individual core themes and concentrate on loss of status, structure and *communitas*, and *betwixt and between*. In doing this, I answer the two subsidiary research questions which ask, 'What do visitors' stories about their experiences tell us about hospital visiting?' and 'Why and in what ways do visitors resist or adapt to the policies, customs and practices of hospital visiting?'

My discussion begins with a focus on the participants' stories about loss of status and relegation to the role of 'juniors' in the hospital environment, where the 'seniors' are the ward staff. Therefore, the relationships and interactions between participants and ward staff are also explored. Although some participants had a clear understanding of their visitor role and their imposed junior position, others experienced ambiguities. However, as juniors, many of the participants continued their earnest attempts to adapt to their unaccustomed circumstances and remain good visitors. Confusion arose when errors were made in attempts to translate pre-hospitalisation relationships into the ward scenario and distress often resulted when the participants recognised that, inadvertently, they had invited the label of problem visitors. I then consider why and how the participants demonstrated their agency and resisted some of the structural forces bearing down on them. The main causes of this dissatisfaction were contested psychological ownership, exclusion from the centrality of the patient's care and perceptions of inadequate care.

In the second section, I focus on the core theme of structure and *communitas*. As such, this section also deals with the relationships and interactions between the visitors. I begin by identifying the participants' negotiations in establishing further their position in a hierarchy at the patient's bedside. These negotiations also established a 'prime' visitor to be supported by secondary visitors. As *communitas* was developed there was the introduction of a rudimentary structure in the form of individual tasks and rituals, interdependence and mutual support. As a result, the visitors moved from a dependence on hospital structures in their unstaged liminality to their sense of a more manageable staged liminality (Stenner 2015).

I continue, in the third section, by concentrating on the participants' experiences of being '*betwixt and between*'. The participants' interactions and relationships with the patients is explored and leads to my identification of the presence of a continuum. The participants were positioned on this continuum according to their level of emotional involvement with the patient and the signs and symptoms of illness. I then interrogated the accounts of those participants who demonstrate the greatest involvement and preoccupation with the patient's body. By

considering the data and the literature, I recognised the phenomenon of being ontologically between the body of self and the body of others and therefore add a further understanding of liminality, as discussed in chapter three.

## **6.2. Accepting or resisting the loss of status of liminality.**

Multiple ambiguities arose for the participants as they and the staff attempted to define the correct category for each visitor. In this, the visitors' pre-hospital roles and their relationship with the patient were a determining factor, but mistakes and confusion occurred. The visitors also earnestly describe their attempts to negotiate between duties of overseeing care and treatment and, simultaneously, avoid being judged as a problem visitor. Sue and Nina's accounts demonstrate how they inadvertently risked becoming a problem visitor. Although this caused Nina some considerable distress, Ed's story reveals that his concerns about getting his sister's needs met outweighed these other considerations.

Below, Meg indicates her readiness to adapt to a more junior role. Her status as carer for her mother became secondary to that of hospital visitor and daughter:

**Meg:** And, and, you know, we, when we came in, if she hadn't eaten or we, encouraged her to do it. We tried to support what the hospital would be doing.

**Janet:** So you saw this almost as in partnership?

**Meg:** In partnership. Definitely. Definitely. Cos I don't think for one minute they, they hadn't got my best, my Mum's best interests at heart. And they were good, they were good. So we were there to support. They were the experts. Had we felt that we weren't getting, my mum wasn't getting the right level of care or we weren't being listened to, that situation wouldn't have lasted long, I don't think.

Meg, as the patient's daughter, is explicit about her acceptance of her junior position – unless, that is, she, perceived a decline in the standards of care given to her mother. Gill, too, is very clear about her role and status as a hospital visitor as she describes below:

**Gill:** I think to expect the visitor to, first of all, do the social visiting with an inpatient when you actually go to support them. You go to, to be their partner, you go to be the bearer of information, the carrier of information, the bearer of good will and the carrier of, erm, requests out of the hospital. You also go as a significant other and an advocate, in my case, to ensure that the care that your, my husband is getting is what you would expect. That the proposed care plan has been executed to the point where you expect it to be and that he is progressing, moving towards discharge at, at the appropriate rate. So you go to be the advocate.

Gill is combining her understanding of her duties and status as a hospital visitor. Her use of the second person, 'you', infers that the 'social visiting' applies to all hospital visitors. 'In my case' reclaims some status for herself as 'significant other and advocate' and also justifies her vigilance and readiness to intervene if her husband's care or treatment is inadequate.

Just as Gill demonstrates that her role as a carer influences her understanding of her continuing responsibilities and status in the hospital, Sally also indicates that the pre-hospitalisation relationship with the patient changes the nature of her responsibilities and her emotional responses to being a hospital visitor. Below she reflects on this:

**Sally:** I tell you the other difference I noticed, I feel different about [husband] being in the hospital to my son being there. I think you're more protective, in a way of, of your children.

For Sally, her role as a mother involves nurturing and protecting her children. In contrast, as a wife, she is a partner in a reciprocal exchange of care when required. Her husband entered the hospital on two occasions for planned procedures involving an overnight stay each time, but he was not incapacitated. Although concerned for her husband's wellbeing, she seems to feel that his continuing physical and mental capacity throughout meant that he did not need her protection or vigilance in the same way as her children did.

All three women are implying that their pre-hospitalisation roles and relationships with the patient and the mental and physical capacity of their significant other bear influences on nuanced differences in their status as hospital visitors. Therefore, when Ed talked about visiting his sister on one occasion and a friend on another I asked him to tell me about the differences in his experiences. His reply is below:

**Ed:** I find when I'm a visiting friend, I can detach myself, I'm more objective. When it comes to family, I'm more involved and you worry more and the fact that, even as a foreign visitor, I have control as a, you know, as a visitor. Visiting a friend, I'm not related to them, I'm, even the nursing staff will come to you as a visitor. But with family, you're under their full - you have the rights, they give you the signatures and everything to fill in and they ask you for more details. So, I found when I visit family, they, you invest more emotion you know. Yeah and you have the, depending on what they have, you put on a brave face.

For Ed, his status as the visitor to his sister involves two definitions – 'foreign visitor' and 'patient's visitor'. These definitions imply a double marginalisation, which pervades Ed's story. His words 'You're under their full - you have the rights' indicates that Ed stopped himself from saying, 'you're under their full control'. Ed is stating a contradiction and so reveals the ambiguity (Meyerson 1990) he was experiencing about his status. Being under full control as a

liminal persona and expected to offer total obedience to the seniors (hospital staff) seems to bear too many connotations of submission and a lowly status for Ed. 'Having rights' is cleverly reclaiming some status as 'brother' in his self-presentation to me in the interview. 'Having rights' is, for Ed, also claiming some status in a country where he is 'foreigner' and does not enjoy full citizenship rights. These 'rights', nevertheless, involved a practical and emotional burden for Ed, rather than benefits more commonly associated with the term. He had to deal with the administration involved because his sister was not entitled to free NHS health care and he had to bear a more intense emotional engagement.

In contrast, when visiting his friend Ed recognised that he was 'just a visitor' with no 'rights'. Ed is pointing to a lower position within a visitors' hierarchy. However, the establishment of a friend in a lower position in this hierarchy appears to have arisen from the tacit understandings of Ed and the ward staff and further reinforced by their minimal interactions. Ed then talks further about his later visiting experiences to his friend. His words below confirm my suggestion that hospital staff draw on pre-hospitalisation relationships with the patient to accord status. These implicit negotiations can result in errors of judgement as Ed relates:

**Ed:** I'm happy that she [a friend] wanted me there. At the same time, I was, I was feeling out of place. Cos, first of all, I'm a man. I'm not even related to her. We're just neighbours and good friends. And then the fact that this nurse was explaining like I was the husband or the brother or -.

Ed is describing his visit to a female friend who asked him to remain during a discussion about her care with a nurse. Ed understands the status of friend and husband to be very different in the context of hospital visiting. By her request for Ed to remain with her, his friend seemed to be confirming a more elevated status for him as a good friend, rather than 'just neighbour', whom she could trust. Without Ed's initial realisation, the nurse had incorrectly assumed that he was the patient's husband. So, there were differences between the nurse and Ed in their understanding of the appropriateness of his continued presence at the patient's bedside during an intensely personal discussion. This conversation also involved medication associated with the treatment of HIV (Human Immunodeficiency Virus). As the conversation developed, Ed understood that it was inappropriate for him to be present and he experienced a disorientating sense of being 'out of place' (Cresswell 2008).

In different circumstances and providing a stark contrast to Gill and Meg's certainty about their status, Nina describes her experiences of being 'out of place' (Cresswell 2008):

**Nina:** So I was still in uniform. Got to the hospital. There I am stood in this cubicle in my nurse's uniform so everybody who walks in kind of looks me up and down and looks at my badge. I tried to do my cardigan up so they can't see my

badge [laugh].... I didn't need a nursing head. I was back being daughter again.  
Bit difficult when you're in uniform.

Nina's words relate to the time after she had been called from work and was with her mother in A&E waiting for transfer to the ward. She was experiencing role ambiguity (Ashforth et al 2000) in that her uniform was symbolically positioning her in the role as a nurse and yet she understood herself to be there in the role of the daughter. Her attempts to 'hide her badge' point to her concern to be fully 'in the right place', or role, as 'daughter' and not 'nurse'. Her embarrassment seems further exacerbated by the extra interest she felt she was receiving from the hospital staff. She perceived that her being 'out of place' was also causing them some consternation and confusion. Nina again indicates her discomfort arising from role ambiguity, when she later visited her mother on the ward and found her in considerable pain:

**Nina:** So I took her drug chart to the nurses' station. There were a couple of junior doctors. Very nicely, not at all abruptly, I gave the drug chart; I put my hand out to give the drug chart to one of the junior doctors. I said, 'Would you mind writing [my mother] up for some regular pain relief, please?' I said, 'She's in terrible back pain, pain in her back.' Got the drug chart snatched out of my hand, 'Oh, you're the daughter who's a nurse aren't you?' I said, 'Yes I am a nurse, but I'm just a daughter today, can she have some pain relief written up, please, regular.' It was taken off me and I walked away. I felt really upset, really. I thought, wasn't in uniform at this time, you know, I'd not mentioned I was a nurse. All I was doing is asking for pain relief for my mum who'd not had any for like six, seven hours.

The core themes in the theoretical framework underpin the interpretation of Nina's comments. Her words, '*very nicely, not at all abruptly*' affirm to me (and is possibly a reaffirmation for herself) her status as a good visitor. Nina then reinforces this good visitor position and justifies her actions, '*all I was doing is asking for pain relief for my mum*'. However, Nina had subtly signalled her professional status by taking the drug chart to the doctor, indicated her knowledge of hospital jargon for prescribing, '*writing up*' and '*regular*', and demonstrated her nursing knowledge of the correct use of analgesia. As such, she could have been seen as a problem visitor mounting a challenge to the ward staff, medical knowledge and structural powers.

Nina's words reflect the liminal practices (Beech 2011) in her transition from her status as a nurse to that of daughter/visitor as discussed in chapter three. Initially, Nina had exercised her agency. She assumed that her status of registered nurse/daughter/visitor was sufficient for her to suggest to the doctor a more appropriate pain relief regime for her mother. The doctor replied from within his position as first, a doctor, second as a hospital employee concerned with maintaining structures and third, his 'senior' role in the interaction, '*You're the daughter who's a nurse, aren't you?*' Nina understands this as a direct challenge and a denigration of her professional status and an emphasis on her junior status. As such, structure prevailed and Nina

was 'put in her place'. She was forced to relinquish her registered nurse status; *I'm just a daughter today*'. But, as *'just a daughter'* she still retained some of her status as a visitor with kinship responsibilities, which she considered legitimated her repeated request for analgesia. Nevertheless, her resulting distress about her perceptions of her downgraded status and categorisation as a problem visitor are apparent.

Nina is also displaying her uncertainty arising from her liminal situation of being betwixt and between the roles of nurse/visitor/daughter, which are usually better segregated in her everyday (Ashforth et al 2000). The uncertainty of role ambiguity clearly influenced Nina's visiting experiences. In her storytelling, she is still attempting to make sense (Bruner 1986; Turner 1986) and reconcile, for herself, her judgement that the staff had undermined her control of the situation and positioned her as a problem visitor. Nina then describes the challenges, threats and uncertainty she might have caused the staff caring for her mother by describing her responses when, at work, a visitor who is also a nurse, comes to her ward:

**Nina:** And subconsciously I feel on guard. What are they gonna ask me? What they gonna look at. Are they gonna start reading the nursing notes? Are they gonna ask me loads of questions? And subconsciously I start going round in my head, 'Ok, erm let me think about this patient, let me'. If they come at me with anything I need to have a quick response. Where if any other visitor, I would say, 'Ooh, if you just give me a few minutes, then I'll come and have a chat with you.' And in that few minutes, I'm looking through the medical notes and trying to update myself on what I'm gonna say. I feel that if somebody's in uniform and confronting me with a question about their loved one, I somehow feel that I have to have a response, and I have to have a response there and then because they, they know what they're doing and they know what I should be doing and I need to be seen to be doing that.

Nina is confirming that ward staff draw on pre-hospitalisation roles and family-associated relationships to appropriately position and categorise visitors. *'They come at me with anything'*, *'confronting me with a question'*, *'I have to have a response there and then'* and *'I need to be seen doing that'* illustrate her sense of threat from the visitor who is associated with nursing or the medical profession. Such visitors express confidence, medical knowledge and greater autonomy rather than the 'passive and humble' behaviour related to the total obedience of liminal personae (Turner 1969: 81).

A more explicit source of tension between visitors and ward staff arises from the contestation of psychological ownership of the patient, as discussed in chapter three (Menzies Lyth 1960; Pierce et al 2003; Brown et al 2005). Below Sue talks about the provision of care by herself and her family for her father:

**Sue:** We said 'he has to have his bed raised, bed sides up.' And one time at the General again, second [hospital admission], they didn't appear to be so vigilant so before we left we raised the bed sides up ourselves to make sure. But we specifically told both wards he needed to be watched because he could wander. But I think if we hadn't said that and it wasn't in his notes, it wouldn't have been picked up on.

**Janet:** So it was almost like, erm, you were having to sort of keep an eye on everything, his medical care, his nursing care?

**Sue:** Absolutely! We did. Everything. His medical care, his nursing care, absolutely... We were able to do that but there must be lots of people that don't have the facility or the wherefore to do that. Must be, well, they wouldn't get a very good level of care, unfortunately.

Sue's mention of 'your own person' is a clear expression of the psychological ownership of the patient that runs through many of the participants' accounts and is demonstrated in this thesis. Sue is also describing the corporate efforts of her family in ensuring the wellbeing of her father and their disinclination to hand over full responsibility for this to the ward staff. In their efforts to deliver personal care to her father the family ensured that he did not present an unkempt appearance. This caring achieved a display of their activities as a 'good family' (Finch 2007). Being a 'good family' achieves a higher status than people '*that don't have the facility or the wherefore to do that*'.

The family's determination and success in their assumption of responsibility is, however, questionable. Her father, the patient, might not have wished his family members to be involved with the intimacies of his care. Similarly, the family's attempts to ensure the staff monitored her father's movements might have been interpreted as attempts to control her father and the ward team (Boudreaux 2010), rather than their natural concern for his wellbeing. There is the possibility that Sue and her family could not provide better care than the professionals on the ward. For example, hospital policy often dictates that frail and confused patients should be provided with low beds and the rails not used. This minimises the risk of serious injury should they attempt to climb over bed rails and fall from a higher bed. The potential for tensions between the ward staff and the family is considerable.

A further cause of more overt expressions of dissatisfaction for the visitors was their loss of status and exclusion from the centrality of treatment decisions and care delivery for the patient. Nina explicitly illustrates her need to be involved in and informed or consulted about her emotionally frail mother's care and treatment:

**Nina:** And I like to be involved. When it comes to my mum, yes, I do probably like to be in control because she's very vulnerable. I like to be in control so I can be part of the decision process really.

Nina's sentiment is shared, either implicitly or explicitly by all of the participants and some felt that, in this respect, their needs were met. However, others were more explicit than Nina in expressing their anger at this exclusion, as Gill illustrates:

**Gill:** It's always 'the team', isn't it? The team, the team is an exclusive. It excludes you. You're not part of the team. But you are actually. You are the team at home. You are the only bit of the team. You call on ancillaries and experts as and when. But you actually are 'The Team' at home. You are it. So when somebody else comes and says, 'Oh, I, I'll get somebody from 'the team' you think, 'Oh sod the team. I'm it. Include me in it.

The marginalisation and exclusion Nina wishes to avoid can, as Gill demonstrates, cause much anger and distress and can result in compliance or retaliation (Williams and Nida 2011). Attempts for re-inclusion might include overt demonstrations of a willingness to adapt and conform to hospital *mores* (ie the complete obedience of liminality). Others are driven to retaliation (Williams and Nida 2011) by making demands or complaints and expressions of frustration or anger, like Gill. I would suggest that, like Dave's expressed needs for information in chapter five, Gill and Nina consider that exclusion from the centrality of care implies a greater loss of status. Gill and Nina did eventually 'retaliate' (Williams and Nida 2011) and make complaints – but not until after the patients' discharge when they were less likely to be confronted with the immediate and unpleasant consequences on the wards of becoming problem visitors. As the analysis progresses, it is becoming increasingly clear that the pressures associated with the core theme for total obedience and being a good visitor are powerful influences on visitors' behaviour and actions.

However, the most prominent source of dissatisfaction in the interviews was the participants' unmet expectations of the delivery of high standards of care. Varying factors compromise nursing care. These include minimal staffing levels, high dependency patients, inexperienced staff, absenteeism, telephone calls, paperwork and dealing with difficult relatives (Haigh and Ormandy 2011). Nurses' organisation and prioritisation of care delivery do not always cohere with the visitors' wish for their significant other to be the priority. Haigh and Ormandy's (2011) research findings pose a further conundrum. Nurses perceive the time taken to deal with difficult relatives (or problem visitors) and telephone enquiries from family members as impediments to their delivery of care. These visitors, even as they demand the nurses' time and attention, therefore diminish the nurses' resources to deliver high-quality care. Below, Winnie and Danny represent the consensus of the majority of the participants, as follows:

**Winnie:** Yeah, 'cos for families coming in, they're priority -. I know there are twenty people on the ward and I know everybody's stretched and all the rest of it. But, I, the, other, as a member of the family, you do, of course you care about

everybody, but your priority is the needs of that person so when you come in they tell you that they're in pain.

**Danny:** I did feel the nurses and the doctors were very stretched there, though. Er, they missed a few times, you know, his changing hour and things like that [...] I think the schedules they were trying to actually keep were unachievable [...] You know, things like pillows propping him up. He'd fallen off of his pillow for instance. With a drip in. And we had to prop him up and there was no help or anything from the doctors or nurses.

Most of the participants also confirmed Haigh and Ormandy's (2011) attribution of failings in care to impossible workloads and time pressures for the ward team. Nevertheless, there were some who did demand or complain, resisted pressures for total obedience and risked being judged as problem visitors. But they did so in very different ways as I now illustrate.

Winnie describes how she tackled her perceptions that the elements of her mother-in-law's care were being overlooked:

**Winnie:** So when the nurse came by, I said to him, 'Look, procedures, come on,' I said, 'By the way you know, Mark, Mum says she needs her dressing changing, she needs some painkillers.' [He said] 'Yes, I'll be right with you, I'll just finish what I'm doing.' And he was as good as his word. He finished what he was doing and came back and did it [...] I don't think I pushed them. I think I reminded them.

Winnie, who consistently monitored her mother-in-law's post-operative recovery trajectory, made use of constant 'reminders' to secure the care she perceived her mother-in-law needed. 'Reminding', for Winnie, was less coercive than 'pushing' and was legitimated by her co-operation as a junior partner with the hospital staff, just as Meg earlier described. 'Reminding' therefore permits Winnie to preserve some status as a good visitor with a kinship tie with the patient. She is implying that 'reminding' is an acceptable display (Finch 2007) of the compromises she has made to settle the tensions between her responsibilities for vigilance and the requisites of being a good visitor. It is debatable whether the staff might have felt more 'pushed' than 'reminded' by Winnie, who may have been consequently perceived as an interfering and demanding problem visitor.

Danny's family took their dissatisfaction further by making a verbal complaint on the ward. He describes this as follows:

**Danny:** Yeah, we did complain about it. As I say, my, er, one of my aunties complained about it to one of the nurses, a senior nurse who was there.

**Janet:** Was that complaint taken on board?

**Danny:** I believe so. I don't know what actually happened to it, to be honest with you. But I believe it actually was taken on board. She did kick up a bit of a fuss. Which is what she should have done, she should have done. But, in general, the staff were very, you know, very helpful. They just were very stretched.

Danny, a junior kinship group member, as discussed in the following section, considered that making a complaint was the responsibility of the senior family members. His contradiction '*they were very stretched*' and then justifying the complaint, '*what she should have done*' denotes the ambiguities he was experiencing in interpreting (Meyerson 1990) either, or both, his situation on the ward and his position in the interview where he was aware of my professional status. Like other participants, he was and remains reluctant to be judged a problem visitor.

Ed demonstrates a complete lack of concern about being assertive and the possibility of being a problem visitor. The service he received might be grudging, but his demands were met:

**Ed:** Then I didn't know that there's a thing called, well, depending on where you're visiting, the louder you are, the more they seem to want, they serve you quicker. Either to get you out of the way. Just get you over with. Or somebody told me if you're too meek and quiet they forget you're there.

I interpret Ed's words in different ways. Rather than owning this assertiveness as a personal characteristic, Ed attributes it to a growing awareness that this is how visitors and patients might thrive in the NHS in England. Ed's previous experiences of hospitals had been in either the Canadian or Philippine hospital systems where the implicit 'know how' (Stenner and Clinch 2013) and different levels of assertiveness might be demanded or expected. Being 'loud' could also have been due to his emotional arousal caused by his sister's severe emergency illness. Finally, as foreigners, Ed was aware that his sister's insurance company would be responsible for her NHS costs. Ed and his sister, in this sense, were more likely to see themselves as 'customers' with associated expectations of a service more often found in the private sector. The potential for ambiguity in Ed's role and relationships with the staff was multiple and varied.

Nevertheless, other participants were satisfied with the provision of care and were, even, relieved to hand over control and responsibility to the hospital, as Sally describes below:

**Sally:** I mean, I think in a way, it's, it's like I was pleased they kept him overnight because if he'd come home, I would have been up all night watching whereas, erm, it's almost like their responsibility and not mine.

Sally has no nursing knowledge but has had the experience of her father's sudden collapse and death from a heart attack in her kitchen. In common with other participants, despite concerns about possible inadequacies of care, she acknowledges gratefully that hospital was the 'right

place' for her husband to be following a cardiac procedure and was relieved not to have responsibility for his welfare at home. Hospitals can be understood to have more technological apparatus, greater knowledge, professional skills and life-saving competencies than available in the domestic sphere. Having a significant other in the hospital was therefore often accompanied by a sense of relief at handing over responsibility. There is thus a tension between the patient being 'in the right place' and the visitors often feeling 'out of place'.

Sue and Danny have also mentioned corporate actions of the wider family at the patient's bedside. This conforms to Turner's (1969) idea of the *communitas* of liminality. I discuss this further in the following section.

### **6.3. Structure and *communitas*: recovering some status.**

In the previous section, I noted the beginnings of a visitors' hierarchy that seemed to emerge with influence from the ward staff. In this section, I examine the participants' accounts of their interactions and relationships with other visitors at the patient's bedside, as they negotiate and come to understand their status and position within this hierarchy of visitors and the responsibilities entailed. These negotiations are also often involved in the establishment of *communitas*, which provides essential mutual support and greater power for resisting the hospital structures.

Danny illustrates the shifting characteristics and negotiations of status and responsibilities (Finch 1989; Finch and Mason 1993) among the visitors at the patient's bedside:

**Danny:** Initially I thought I'd got quite a lot [of responsibility]. Er, but then, of course, he's got a very big family so everybody else pulled in there and shared that responsibility, which was good. My mum took more responsibility than everybody else did. [...] [H]is children felt more responsibility than all the grandchildren... The grandchildren just wanted really to be there. Just making sure everything was ok and if anything needed to be done, obviously we, you know, we've got cars. We could ferry people around and everything else.

Despite the loss of status recognised as a feature of liminality (Turner 1969), Danny is confirming my identification in the previous section of a hierarchical organisation of visitors at the patient's bedside. The development of this hierarchy often involved subtle negotiations among the visitors and, in the participants' accounts, it is most commonly ordered: spouse, then adult children, and, finally, grandchildren and siblings. Relegated to the lower end of this hierarchy, Danny and his cousins, as grandchildren, seemed to adapt readily and carry out the tasks assigned to them by their parents.

Most of the participants also identified a 'prime' visitor, who is often emotionally or physically vulnerable and in almost the same, if not more, need of support and concern than the patient. The prime visitor is most often the person who is understood to have the closest emotional bond with the patient and will often spend the greatest amount of time at the bedside; even to the extent of jeopardising his or her personal wellbeing. Therefore, 'secondary visitors' assume the role of supporting this more vulnerable visitor, as Molly, a young, single woman demonstrates when she travelled north to support her emotionally frail grandmother. Molly says she offered this support whilst her grandfather was in the hospital because she did not want something *'terrible to happen to another family member'*.

Jane, Gill, Sally, Liz and Winston, as patients' spouses, and Winnie, a disabled woman in her early 60s and visiting her mother-in-law following a hip replacement, identified themselves as this 'prime visitor'. Winnie talks about these experiences:

**Winnie:** I went in every day. Erm on the Thursday, I went in twice. In the morning and the evening just to make sure, you know, that she was ok. Erm and I became ill in the hospital in the evening. But they were sweet, they were so lovely, you know, they brought me a glass of water an' they were just so nice.

Winnie's husband, Jim, has power of attorney for his mother's health decisions and, as his mother's only surviving blood relative, might have assumed this lead role. However, despite, or because of her vulnerability caused by disabilities, constant pain and wheelchair dependence, Winnie undertook the prime visitor role, visited frequently, acknowledged her responsibilities and actively supervised the care her mother-in-law received. In common with other participants, Winnie's physical and emotional welfare became secondary to the primacy of the patient's needs. Thus she was able to present herself as a good visitor at a cost to her physical wellbeing.

However, Winnie's illness might also be indicative of her subtle, possibly subconscious, and passive resistance to her loss of status in liminality. Becoming unwell, if only temporarily, would, for Winnie, regain her visibility and recover her usual position in the family dynamics as the focus of concern. Winnie's illness occurred during the patients' tea round, so it might also have been a resistance to the lack of hospitality and failure to offer her a cup of tea. Instead, the ward hostess offered a glass of water, which Winnie, somewhat doubtfully, acknowledges as a symbol of care and concern.

The shifting, negotiated and, often, gendered nature of the visitor hierarchy is consistent throughout the interviews. For example, although Jim is the patient's only surviving child, his and Winnie's tacit agreement that she should be the prime visitor suggests that it is a gendered role. Just as women are traditionally more involved with activities of care, they may also be more ready and able to engage with hospital staff in discussions about care and treatment

plans. Winston, with all his adult children living overseas, was the only male participant who readily, willingly and comfortably identified with this 'prime visitor' role and actively engaged with ward staff about his wife's illness trajectory. Ruth also demonstrates the mutability of the designation of next-of-kin. Whereas she once would have undertaken discussions with hospital staff, her daughter's marriage means that she acknowledges that her son-in-law now should do this. Instead, Ruth engaged more actively with the practicalities of caring for her daughter's baby while she was in the hospital and both granddaughter and daughter after discharge.

Some of the participants felt that the identified prime visitor was too frail to cope with, as nominated next of kin, the detailed confidential discussions with hospital staff or to be involved in making possible far-reaching decisions if the patient does not have, or loses, mental capacity. To support the 'prime' visitor, other family members took on the role of next-of-kin and emergency contact for hospital staff. For example, Nina, accustomed to taking the lead in family issues, assumed the role of 'next-of-kin' and the first point of contact during her mother's hospitalisation and saw it as a supportive action towards her elderly father.

Although Turner (1969: 81) states that liminal personae have 'no status position in a kinship system', he was an anthropologist observing archaic tribes within which membership of a kinship group denotes social status. His observations were of those who were incurring the loss of, specifically, family-associated status. In modern first world societies, kinship systems are less recognised (Jary and Jary 2000). Instead, employment, wealth, knowledge or power are more often indicators of status. It is arguably paradoxical that when 21st-century social status is undermined in the hospital-visiting scenario, a traditional, kinship status assumes greater relevance.

Arguably, though, the developing hierarchy at the bedside coheres more with the first signs of the participants' management of family relations and the organisation and allocation of tasks and responsibilities within a developing structure of their own *communitas*. Danny illustrates his own experiences below and, in doing so, provides an indication of a developing *communitas*:

**Danny:** [Y]ou're really concentrating, you know, on your issue and there's not a lot of time to actually speak to other people really. We tended to go in, er, spend an hour at a time and then we'd go for something to drink in the café and then go back again and take turns in doing it like that. But, you know, a lot of, there's a few people, towards the end, when the ward was actually filling up with more seriously ill people, so, you know, other people were having a very similar, kind of experience. And they don't really - they want to keep their emotions to themselves and they don't want to be distracted. They want to concentrate on what they're there for and, not visit to chat to other people. Be very focused on themselves and their families.

From Danny's description of the joint co-operation and negotiations within his family, it is possible to identify the emerging *communitas*, which provided emotional and practical support. In this, Danny suggests an almost complete withdrawal from the world outside the room, in which he and his family were focussing upon his dying grandfather. Interactions with those outside were utilitarian (for example, fetching nurses to tend to his grandfather or getting drinks) and not for building new relationships with, or gaining support from other visitors in similar circumstances. Danny is, therefore, suggesting that, during the liminality of family misfortunes, such as impending death or sickness, kinship group members draw closer, with bonds of mutual care and support, within a *communitas* which is intra-familial rather than inter-familial.

Within the developing *communitas*, Danny and his family began to form their rituals. These provided some sense of their own structure as they moved from unstaged to staged liminality (Stenner 2015). These rituals extended beyond establishing a hierarchy and included the coordination of rest breaks and a continuous family presence at the bedside. Within all of these activities, there was recognition of the need to be there to support and care for all concerned. Danny's words also support my suggestion in chapter five that visitors, sitting with their backs to the ward, are engaging in a withdrawal from others and a concentration on the patient and each other in the building of *communitas*. As later demonstrated in other participants' accounts, this development of structures within *communitas* can also be interpreted as an act of resistance from which challenges to hospital structures might be mounted.

Although many of the participants echoed Danny's comments, there were those for whom *communitas* was much weaker or did not occur. For example, Gill and Jane each telephoned a close friend and Winston requested practical help and emotional support from his religious community<sup>90</sup>. Ed, a student from overseas, did not have anyone to call upon for emotional or practical support when his sister, who was visiting him from Canada, was taken ill:

**Ed:** And then they had to put her in the ward because, er, I don't know what they did, cos they, was a blur of things, procedures she was doing and all that stuff. To me, after a while, I got lost with all these different things that she's doing. I said, cos her husband's back in Canada, 'I'm her only relation that's here. I'm her brother'. She's my closest sister, you imagine the worst. And the imagination, and then, and then that's how it was, 'What will I, like, tell her children if something goes wrong?' You think ahead. Just to be prepared, just in case something goes wrong. Which, you know, I know it's not a good thing to do. She's family, so you think ahead. What do you do to a point where, how do I get her body back? Things like that.

Ed's words provide a vivid description of his unstaged liminality, which was brought about by his sister's emergency admission. As Stenner (2011) suggests, Ed lost both his 'road map and the

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<sup>90</sup> My conceptualisation of *communitas* appears in chapter 3.3.1

road' in terms of uncertainty about and control of the situation. Ed's only strategy was to make plans for an uncertain future, but those plans created further anxieties and compounded his emotional arousal. The imposition of an unfamiliar and unexpected role and the isolation of being in a strange country far from home and family are apparent. Ed's situation does provide a contrast to the calmer tones used by Danny in describing his experiences, in which kinship group members and close friends were '*all pull[ing] in there and shar[ing] responsibility*'.

Turner (1969) suggests that *communitas* not only fosters mutual bonding and support but also, as *antistructure*, can challenge existing structures. Meg's experiences provide an example of this. She enjoyed a strong *communitas* with her family and describes their discussions with the doctor when the care plan for her dying mother altered without any consultation with the family:

**Meg:** She'd had a stroke and, at first it was, they said, you know, 'This is a major stroke and the prognosis is not good'. Then she went through a period of almost seeming better. Being a bit, she could actually sit one day. And then they, the physiotherapists came and they were talking about, they tried to sit her out. Got her out of bed and tried to sit her down but she couldn't do it. Couldn't talk. And they were talking about moving her to a recuperation place... I got quite anxious then. That was what made us go back to the doctors and, and say, you know, talk to us about why are we having this, why is this in the plan? Is it going to help her? And I ended up saying to him. It was my brothers and me, we all had a meeting. I said, 'She just wants to go home'. And he said, 'Well, you can do that'. And I wish they'd said, right from the start, 'You can take her home. If that's what she wants and that's what you want to do'. Without putting pressure on us.

Meg and her family were in constant attendance at the bedside and, consequently, sensitive to any changes in her mother's condition. With the care plan suddenly changed, Meg and her three brothers, from within their *communitas*, felt sufficiently empowered to challenge this medical decision. Meg did take her mother home, with family, community and palliative care service support. Her mother died peacefully four days after discharge, surrounded by her family in her home.

In different circumstances, Sue and her family were presented with a breakdown in hospital communications when a consultant confused her father with another patient and cancelled the order for the required MRI scan. Sue describes how she and her family, from within their *communitas*, managed to circumvent this confusion within the hospital structure:

**Sue:** We didn't know whether he'd had a stroke at the beginning. Obviously, you know, they would have to do the tests. And he was quite agitated and obviously my mum was quite stressed. After the first six hours, they're left for a good twenty-four hours before anything was done in terms of results. And we're quite a

proactive family, so we wanted things sorted quickly. We wanted confirmation that he'd had a stroke, to be fair. So they knew what they were treating. And unfortunately we did have a bad experience on the first day [when the scan was cancelled by mistake]. But luckily my Mum is extremely assertive. And when a person came to take my Dad to the scan machines [despite the cancellation], my Mum just said, 'Get on the wheelchair and get down there quickly and keep your mouth shut.' Which my Dad did. And we got the MRI.

Although Sue says her mother prompted her father to get onto the porter's chair, Sue talks of 'we' as a 'proactive' family. By corporately monitoring events, through their assertiveness and by keeping abreast of the developments in her father's treatment plans, the family were able to collectively, and somewhat fortuitously, take advantage of a second mistake in the hospital structures to secure the previously and erroneously cancelled scan for her father. The scan resulted in an early diagnosis and the activation of treatment.

In contrast, Sally, a lone visitor, was summoned by a doctor to discuss the plans the staff were making for her ageing mother's discharge, as she describes:

**Sally:** It was an awful journey. It was two hours from where we were living, and I did this for six weeks. And it, it came to the end and the nurse said, 'Oh the doctor wants to see you.' This doctor came and she was quite young and she said, 'Oh, your mother's fine. We're going to discharge her. If you ask for help we won't support you'.

Sally's use of the first person, 'I', suggests that she was dealing with this situation alone and felt insufficiently empowered to challenge the hospital staff. These examples confirm that *communitas* is an important facilitator of mutual support and cooperation in times of trouble. Without it, visitors might feel vulnerable, disempowered and less able to challenge the hospital structures that sometimes seem to bear down on them. However, common hospital practice is to restrict the number of visitors at the patient's bedside and limit visiting time. These restrictions may also curtail the development of *communitas* and, thereby, inhibit resistance to hospital structures. The relevance of *communitas* and structure to the safe exit from liminality is explored further in the following chapter.

#### **6.4. Betwixt and between.**

My initial coding of the data revealed the participants' senses of being torn between the competing demands of hospital visiting and their everyday. However, for some, there were more complications, as I first detail. The participants' accounts reveal a continuum in understanding the variations of their experiences of being betwixt and between. Using the literature, the theoretical framework, as discussed in chapter three and this continuum, I then

identified a deeper meaning of being betwixt and between the body of self and the patient's body as this section details further. This identification of a continuum and the experiences of being between the body of self and other add to the understandings of liminality.

In addition to supporting each other, the participants saw their role as that of both practical and emotional support for the patient. Ruth faced added complications. Her daughter was in a hospital in one city, undergoing brain surgery. Her daughter's husband was suffering a heavy cold and unable to visit his wife for a few days. Her daughter's baby became ill with a virus, and, due to dehydration, was admitted to a hospital in a different city. Ruth describes her sense of being 'betwixt and between' below:

**Ruth:** And then Josie [granddaughter] was poorly and I ended up in [hospital in one city] with Josie on the Saturday night because she was so dehydrated. She got a sickness bug and of course she'd also got a chest and throat infection and couldn't keep the penicillin down. So I ended up in [a hospital in a different city] with Josie. So, it, it was just everything at once... You know, it was, it was just with Jess and Josie - one in [one city] and one [in another]

**Janet:** Divided loyalties?

**Ruth:** Which way [to go]. Well, they're home and sorted. I stopped in the hospital with Josie. And looked after her while Gary (son-in-law) went to Jess in the end. He went back on the Sunday to see her. And I couldn't do her phone number, cos they got their phones, an' they can use their phones in the hospital. So he was on the phone to her all the while, talking to her but of course then she was getting upset cos Josie was poorly cos she wasn't there. That was the biggest thing. She was getting upset because of Josie. And she'd ring me and I would say, 'Jess, she's fine.' I said, 'I'm lying next to her, she's, she's fine. We just gotta get the fluids down her, that's all.' So teaspoon job, you know and keep, oh hours, hours. I sat with her just a teaspoon full at a time. Getting it down her.

Ruth's dilemma is obvious, '*Which way [to go]?*' Pulled between her concerns for both her daughter and her baby granddaughter, unlike the other participants, she seems to have relinquished all domestic and work obligations at that time. Her words also draw attention to the needs of the patient who is also metaphorically caught betwixt and between the hospital and the everyday. Ruth exemplifies the role of the visitor in providing emotional support in addition to practical help. Her words also signal the critical role of mobile phones for the patient and kinship group members in circumventing an imposed physical distance between them if circumstances prevent hospital visiting. Fortunately, the baby was only in the hospital for an overnight stay.

Although Ruth's desire to be with her daughter was prevented by her understanding of a greater responsibility to her baby granddaughter, Amanda below, demonstrates how the patient can cause difficulties for visitors in their experiences of being betwixt and between:

**Amanda:** She was having bowel problems as well, which is quite embarrassing. So again they came over and started doing treatment [a dressing change] to her while we were sat there and I did offer, I offered to James' mum, I said, 'Do you want me to go, shall I go and sit in the day room while they're doing it?' And she said, 'No, stay there'. But I think I would have felt more comfortable if I did. But it probably showed, probably, her being kind and showing that she sees me as part of the family rather than an external person just visiting [...] [I felt] just awkward, didn't know, you don't know where to look and you think, 'Well do you keep the conversation going or do you joke about the situation or – or not really' [...] The next patient who was very poorly, I think she was having an enema or something, they did close the curtains but it was still really loud and she was being sick as well so it wasn't very nice. She felt a bit embarrassed that she, we were there.

Amanda's discomfiture was caused by the circumstances in which she found herself. Not only was she in a marginalised position as a visitor, her words, '*Showing me that she sees me as part of the family*' point to her understanding of family relationships and how they should be enacted within the hospital visitor scenario. Amanda's husband has three sisters who, in addition to their father, were also visiting regularly. Amanda demonstrates her tacit awareness that she is lower down in the visitor hierarchy and on the peripheries of the developing *communitas*. Amanda was also experiencing an uncomfortable ambiguity arising from being betwixt and between her accustomed relationship position of 'daughter-in-law' and that being invoked by her mother-in-law as 'daughter'. Amanda considered, but appears to have dismissed, the use of humorous cynicism (Meyerson 1990) as a means to cope with her consequent discomfiture. Her sense of being out of place was exacerbated by the smells, sounds and obvious distress of the woman in the next bed to her mother-in-law.

Ruth and Amanda are therefore beginning to demonstrate the multiple dilemmas involved in being in the betwixt and between of liminality. These difficulties appear to be largely beyond their control. Whereas Ruth's 'betwixt and between' was clearly due to the wish to be with both her daughter and her granddaughter, Amanda's situation appears more complex. Her story demonstrates that the need to be with the patient, first identified in chapter five, can be differently experienced according to pre-hospitalisation relationships and on-going roles and responsibilities. Nevertheless, her mother-in-law's insistence and Amanda's need to be at the patient's bedside in support of her husband overruled her wish to be elsewhere.

Whereas Amanda was being involuntarily invoked into a closer engagement with the patient, Gill, who has already described her sense of exclusion from 'the team', describes how her husband distanced her from the centrality of his care:

**Gill:** I said, 'You don't ever think about what its like for me when you're in here.'  
[He said] 'Well it doesn't matter what happens to you. It doesn't matter, it doesn't matter what happens to you. I'm in here. I'll be alright.' And that actually was a, well that was a line in the sand for me. [...]

**Janet:** Do you want to speak to somebody every time you go?

**Gill:** Not necessarily, but I don't go every day. I've got to the point where our relationship is, erm, shall we say, it's, it's less, it's a less than perfect marriage. Let's put it like that.

Accustomed to being hospitalised, Gill's husband felt sufficiently secure to let others take over her role of carer. She, on the other hand, was marginalised and bore all the stresses of liminality and the hospital visitor role, as her accounts throughout the thesis show. To be so summarily dismissed by her husband to the margins was very painful for Gill. As such, her 'line in the sand' is an acknowledgement that her role in the hospital was to be less involved than her role at home. As she later adds, it is also recognition that her marriage is 'less than perfect' and she seems to have decided to visit her husband less often.

Similar to Amanda, Nina found herself positioned into a closer engagement with her mother's care than she would have wished. In disturbing circumstances of an absence of nurses to take her mother to the toilet, Nina was forced to step in and help her, as she describes:

**Nina:** And I just said [to somebody at the nurses" station], 'My mum's buzzing. She needs a commode.' And she was, kind of looking round for somebody. I said, 'Tell me where the commodes are, I'll go and get one myself.' She says, 'Well you can wheel her to the toilet.' I says, 'Fine I'll wheel her to the toilet.' By this time she still wasn't able to walk. She'd been in such pain. I went and got a commode [...] and wheeled her across to the toilet. Well, me and my mum don't have, never have had the sort of relationship where I get involved in personal care. She wouldn't want me to and I wouldn't want to. So I just popped her inside the bathroom area. I said, 'Will you be alright now?' She says, 'Yeah'. I says, 'Buzz when you've finished.' So she buzzed and I could see the toilet from where I was sitting at the bedside. Five minutes – nothing. I thought, 'Well, I might as well go and get her.' So I went and got her, took her back.

Nina, the nurse/visitor/daughter, again found herself experiencing an ambiguity arising from being betwixt and between her roles. The urgency of her mother's need for the toilet and the lack of staff meant that they both had to negotiate an acceptable compromise to deal with the

situation. In some ways, Nina's reluctance to deal with the more intimate details of care is similar to Amanda's wish to absent herself from her mother-in-law's bedside. There are, though, subtle differences. Amanda understood that her mother-in-law, the patient, was invoking her into a betwixt and between position. Amanda had no previous caring experiences or skills to draw upon to resolve her discomfort. Nina understood that her situation arose from the poor provision of consistent care by the hospital. Unlike Amanda, she was able to call upon her professional skills and resolved her situation more satisfactorily.

From the descriptions of Ruth, Amanda, Gill and Nina I was able to recognise a continuum of as diagram 3 illustrates:

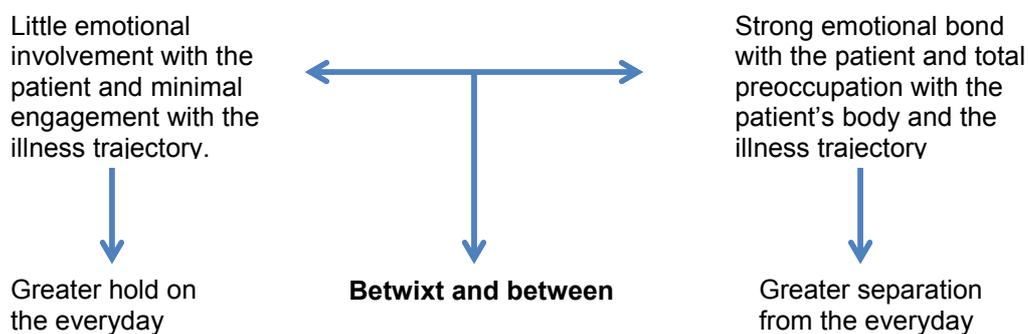


Diagram 3. The betwixt and between continuum

At one end of this continuum, there is a minimal engagement with the processes of care and treatment plans and less emotional involvement with the patient. At the other end, there is a total preoccupation with the patient's body and illness trajectory and intense emotional involvement with the patient. This engagement can be so overwhelming that, as Ruth's words demonstrate, the everyday merits little consideration. However, these women are also showing that they were involuntarily positioned on this betwixt and between continuum; whether by circumstances (Ruth), the patient (Amanda and Gill) or the hospital staff (Nina). Being allocated to a position with which they were uncomfortable seems to have created emotional responses, which were accompanied by a sense of disempowerment.

With my interest aroused, I revisited Ed's account, shown earlier in section two of this chapter. Here he demonstrated his assumed position of being at the end of the continuum with little emotional involvement with the patient and minimal engagement with the illness trajectory. Being mistakenly categorised by the nurse as 'husband' rather than 'friend', he, too, was being positioned on this continuum, with a greater engagement with the patient than he wished. Such a continuum of variations of the betwixt and between of liminality has not been acknowledged in the literature I have encountered, and so, I suggest, adds to the knowledge.

Furthermore, Ed, visiting his friend, and Amanda both demonstrate that, with a lower level of engagement with the patient's illness trajectory and, arguably, a less emotional bond with the patient, experience the betwixt and between of liminality only during the visit. Unlike the other participants, they both express a greater ontological foothold on their everyday.

I then examined the participants' at the other end of the continuum for indications of the consequences of being heavily engaged with the patient's illness trajectory and very involved emotionally with the patient. This was often demonstrated by the participants' intense preoccupation with the patient's body at the expense of their own wellbeing. This closer scrutiny revealed expressions of anger and frustration by some of the participants. Jane was cross with her husband because he did not mention presenting symptoms to the hospital staff. Winnie, likewise, was frustrated because her mother-in-law 'won't ask' for her attention to her needs. Nina several times repeats the brusque words she used to her mother.

This intensity of such emotions felt by the visitors has several possible causes. Anger might be a subconscious response to anxiety or fear. Also, Vitaglione and Barnett (2003) provide a partial explanation of these responses. They suggest that, although empathy has been traditionally considered to arouse sadness-related emotions such as sympathy, there may be an arousal of alternative responses, such as anger. This anger, Vitaglione and Barnett continue, is directed at the perpetrator of the victims' suffering. In the participants' examples, they suspected that the patients had themselves provoked, prolonged or exacerbated their illnesses in some way. The participants' then experienced the distress of seeing a loved one suffering. Their emotional response to this distress is that of anger or frustration. But, 'good visitors' should not feel angry with the patients. Knowing this, the visitors then experience feelings of guilt.

Winston expresses these conflicting emotions of anger and real concern for his wife:

**Janet:** And how did you feel when you went in and you could see she was in pain?

**Winston:** Oh well, I felt a bit pitiful for her, you know. I knew her knee used to pain her. Now it usually gets me when she's not erm, if she's out of sorts, y'know. It's like a couple of weeks ago, she wasn't very well. She had a, erm, some food poisoning. That was her fault. I says to her, 'Watch that. I don't think you should eat that.' She said, 'I'll be ok.' And next day, she had diarrhoea, she were vomiting and all of that. Oh dear, had to get doctors for her. Had to ring up for the doctors to come up and have a look at her. Well when they saw the thing happen, I just really feel for her. Like she would tell you. She says I can't handle it. That's how she puts it [laugh]. She says, 'He can't handle it, you know.' So I say it's not a matter that I can't handle it, I just don't like to see you suffer.' [Laugh].

**Janet:** What does it do to you then?

**Winston:** I feel all out of sort y'know, I feel all, you know. If - I don't know. It's a feeling I can't explain, I can't really explain it. I, I, I get all tense and I get mad with her. Let's put with her, let's put it that way. I get mad with her for being ill.

Winston is having difficulty in determining the cause of his feelings. He initially tries to express them in such a way that he might still maintain his self-presentation (Goffman 1971) as a good visitor: '*I felt a bit pitiful for her, you know*' and '*I don't like to see [her] suffer.*' However, I suggest that Winston's '*get[ting] mad with her for being ill*' derives from a stronger, but subtle, emotional process than the anger of empathy described by Vitaglione and Barnett (2003). Using the literature, I was able to recognise that Winston's all-consuming concern with his wife's sick body and his emotional bond with her meant that he had metaphorically and ontologically 'slipped' betwixt and between her body and his own, as discussed in chapter three. Winston's wife's pain effectively became his pain in what should be termed as a stronger phenomenon than the processes of intercorporeality. Unable to understand this pain and emotional turmoil, as he states, 'it get's' him.

Jane also experienced this phenomenon of being caught between her own body and that of her husband as she describes below:

**Jane:** And I took one look at him when I got there on Sunday, and this was just before lunchtime and I thought, 'You're sweating and you're hot and your eyes are rolling about in your head.' And I was cross with him because he hadn't mentioned anything to any of the staff. Erm, and he also was desperate to go to the toilet. And I asked the nurse if we could have the bedpan. So she came along within five minutes with the bedpan. Erm and I helped him use it and go to the toilet and that was when I realised there was probably something wrong with him because that just wasn't right at all.

Jane's familiarity with her husband's body permits her to instantly recognise the physical signs of his illness (Morgan 2011). However, whereas nurses help a patient *onto* a bedpan, Jane is proposing an intimate and joint action of '*we*' having a bedpan and '*I helped him use it and go to the toilet*'. Jane is, like Winston, demonstrating that aspect of liminality of being 'betwixt and between' one's own body and the body of the significant other. As Jane further informs, though, the intensity of this experience took its toll:

**Jane:** Erm so I went home and didn't sleep really, well on and off I slept a little bit. [...] I felt, because of the trauma and the lack of, lack of sleep, and I wasn't eating, and, erm, I was feeling incredibly sick. I mean, I think I came home one evening and tried to have half a tin of beans but gave them to the dog. I can't, I. And because of all of that coupled together it left me feeling as though -. Erm I was really dizzy and disorientated and I felt, I actually felt physically sick.

This profound experience of being between the body of self and that of the other was not demonstrated by all of the visitors but, in addition to the identification of the continuum of being betwixt and between, my interpretation of the participants' accounts has added nuanced and newer understandings of the betwixt and between of liminality.

## **6.5. Conclusion.**

In this chapter, I have focussed on the interim stage of the participant's journey, after the patient's admission and before imminent discharge. I explored three of the intersecting core themes of loss of status, *communitas*, and ambiguity and betwixt and between. Although this might be expected to be a time, as Sue says, of 'things sett[ling] down very well', the participants' challenges continued throughout.

My focus in the first section was the participants' experiences of their loss of status. The participants' preadmission roles and relationships with the patient and, often implicit, negotiations and interactions with ward staff resulted in an ability to derive some fragile sense of status. Those, like Meg and Sally, who seems to have adapted more successfully to this junior position, not only think they were judged as good visitors by the ward staff but also describe their experiences of less distress. Ed, who was mistakenly accorded a higher status as 'husband' than he felt able to accept, was uncomfortable. Nina, who inadvertently expressed a higher status than the hospital staff were prepared to accept, recognised that she was being judged as a problem visitor and was upset. Therefore, as in chapter five, adaptation and resistance to an altered social status also invoked the core theme of 'total obedience and being a good visitor' and demonstrates the affinity between these two themes.

I then set out the participants' accounts of their more active resistance to the loss of status and the call for total obedience. This, I suggested, was prompted by contestations of psychological ownership, exclusion from the centrality of care and treatment planning and perceptions of lowered standards of care. In such incidences, many of the participants felt ready and able to challenge the hospital structures. Sue and her family demonstrated their psychological ownership and declined to relinquish responsibility for her father to the ward staff. When they perceived failings in care, Winnie resorted to subtle reminders and Ed was prepared to stand up and shout for his demands to be met. Gill and Nina demonstrate the importance to them of being involved in the patient's care and treatment and Gill's anger at her exclusion is evident.

Whereas the first section focused on the loss of status and how it may be partially retrieved in interactions with the ward staff, the second section involved a focus on the visitors' interactions with each other and their developing *communitas*. Within this, the participants describe their development of a visitors' hierarchy, which demonstrated their organisation and management of family relationships and tasks. This hierarchy also included the identification of a prime visitor and a designated 'next of kin'. Danny illustrates how the developing *communitas* also permitted

the establishment of some rituals, which represented a temporary, fragile and somewhat rudimentary structure for the participants and effected their move from unstaged liminality to staged liminality (Stenner 2015). Therefore, *communitas* can also be understood as providing the wherewithal to resist hospital structures and from within which to reject a total loss of status. Meg, Sue and Sally provide contrasting examples. Whereas Meg and Sue enjoyed a strong *communitas* and successfully challenged hospital structures, Sally, with no *communitas* felt disempowered. Likewise, Ed, with no *communitas*, experienced a loss of control.

In the final section, I concentrated on the theme of 'ambiguity and betwixt and between' but moved beyond the obvious dilemmas arising from the competing demands of visiting and everyday responsibilities or the tensions between making demands or complaints on behalf of the patient and remaining a good visitor. Instead, I concentrated on how the participants were involved in the practical and emotional support of the patient. In doing this, I identified a continuum along which the participants were positioned according to their degree of emotional engagement with the patient and preoccupation with the sick body. Their positions on the continuum were involuntary and involved a further sense of disempowerment. Moreover, these positions on this continuum seem to be reflected in the intensity of their ontological experiences of liminality and, more specifically, the feature of being betwixt and between.

Having noted the participants' expressions of frustration or anger, I sought to interpret the accounts of those who were at the 'very involved' end of the continuum. Combining the literature with the participants' accounts, I was able to extend the knowledge of liminality by identifying that the participants were ontologically experiencing a profoundly distressing and disorientating 'betwixt and between' their own body and that of the patient.

As already demonstrated in the preceding chapter, the five core themes consistently intersect, with each implicating elements of the others to the extent that none can be considered totally in isolation. This is demonstrated further in the next chapter, which explores the latter stages of the time of being a hospital visitor and corresponds with the end of the participants' stories.

## Chapter 7. Leaving 'there': an end to liminality?

### 7.1. Introduction.

Much of the focus of this chapter is on the challenges arising from the discharge process and the differences in individual experiences of the exit from liminality. It also answers all three of the subsidiary research questions, which ask: 'How does the wider social context influence hospital visitors' experiences? What do visitors' stories about their experiences tell us about hospital visiting? Why and in what ways do visitors resist or adapt to the policies, customs and practices of hospital visiting?'

The first section details how the participants experienced the time leading up to discharge. I consider the stresses of time management and the different interpretations of the *time* of 'visiting times'. These difficulties combined to reinforce a yearning to dispense with the hospital visitors' role. But uncertainty prevailed about when that might be, leading most of the participants to ask just one question, 'How long?'

The challenges for the participants continued into the day of discharge with the four core themes of loss of status, total obedience, uncertainty, and ambiguity and being betwixt and between combining in the participants' descriptions. In this section, I also identify the ultimate loss of status - that of depersonalisation. Frustration also prevailed on discharge day as ambiguity and the betwixt and between features of liminality continued and there appeared to be no clear consensus about where hospital responsibility ended and carer or family responsibility began.

The discussion of three of the participants' letters of complaint post-discharge then leads to an exploration of the different experiences of exiting liminality. Some exited safely and achieved reincorporation into the humdrum of an altered everyday. Others experienced continuing difficulties and the participants' accounts suggest that good structure and strong *communitas* are essential for 'moving on' after a liminal event.

### 7.2. The challenges of 'time'.

Time was valuable to the participants. They describe the stresses of trying to 'save' or 'make' it as they attempted to reconcile their 'outside hospital' obligations with their 'inside hospital' visitor role. In this sense, time was a commodity (Torre 2007). They also considered time as a horizon (Torre 2007) as they experienced more uncertainty about bereavement, illness outcomes and transitions, but also longed for the patient's discharge and relief from visiting duties. Finally, they were forced to endure the time of endless waiting.

Gill's account illustrates these time pressures that can result in a longing for an end to visitor role obligations:

**Gill:** So you're combining as much as you possibly can in your 28 mile sweep, including a stressful hospital visit. You may have had an appointment with your doctor or somebody else, you may have stopped for a coffee with a friend, you may have to go shopping, you may have got frozen goods in the car, you may have come through the hospital system. You probably, because of the way the hospital operates and the difficulty in actually locating anybody to speak to, you may have overrun your car parking. The stress. And when you get back to your car, have you got a ticket on your car, have you been clamped? How -, what happens if it has? How on earth long is it going to take you to get your car extricated if it's been clamped? Where do you go to pay your ticket, is it a legal, is it a county council ticket, is it a hospital ticket? Where do you get, where do you go, who do you see? What happens if it's 8 o'clock at night? And you're coming out of the hospital? And you've had, I mean if you go into the place, you have, you don't know what you're going to need. I've gone in and found, I can't find [*husband*]. So I'm using time locating him. I haven't had anything to eat. I've got a headache coming on. And, he, I haven't got any paracetamol with me.

Gill tried to save some of the precious commodity of her time. However much she attempted to use her time judiciously, events, rules and regulations, mostly managed and controlled by the hospital staff, thwarted her and her stress mounted. Gill's descriptions illustrate the considerable emotional and physical cost of hospital visiting. Her anxieties about car parking payments reflect the financial cost. For Gill, 'time' really 'was money'. She is also articulating the core theme of betwixt and between the competing demands of being 'there' for her husband in the hospital and her everyday, domestic responsibilities. Her logistical, practical and emotional difficulties result in a yearning for her husband's discharge. However, as she indicates throughout her interview, her carer duties at home also take a heavy physical and emotional toll. Gill is, as such, facing the ambiguity of wanting an end to her visitor's role that can be brought about by her husband's discharge. But this is tempered by her awareness that his return to home would mean her resumption of the role of carer and its excessive demands.

Jim presents a different example of time as a commodity. As his mother was moving towards discharge, he became increasingly frustrated by the persistent intrusion of staff on *his* visiting time, as he describes:

**Jim:** [E]very visiting time you go there's always something they want to do as well. Now, whether that's because it's a catch-up situation during the day or whether it's because it has to be done at that time or whether it's just bad planning. And really, nothing should be happening during visiting time, except visiting. But you're

always a little bit in the way because there's always something that needs to be done. I like to move away if they want to do something [...] with her so you have to go and stand, I'll go and stand, you know, outside in the corridor or whatever. Erm, and it can impede on your visiting time and if that's, you know, maybe you can only get on one occasion.

Jim's words signal an example of Zerubavel's (1979) identification of the primacy of hospital time at the expense of the patient's or, in this thesis, the visitors' time. It also points to differences between the seniors (hospital staff) and juniors' (visitors) interpretation of visiting time in the hospital. The nurses in this example appear to have understood visiting time as a mere continuation of their shift and their responsibilities of care. Jim, however, was experiencing their delivery of care to his mother during visiting hours as a misappropriation of *his* visiting time. However, Jim also understood that any objections to the nurses' encroachment on *his* time might have denied his mother the care she needed and could have positioned him as a problem visitor. Feeling he would be out of place if he remained at the bedside, Jim was forced to wait outside. His status was being undermined, his marginalisation apparent, his total obedience ensured and, as such, his position as a liminal persona reinforced.

In different circumstances, Liz knew her husband could only return home after he had successfully had a stent inserted for his heart problems. Her words demonstrate how she, likewise, experienced her control of time being taken away as they waited for the procedure and her consequent emotional responses:

**Liz:** Well we did get quite anxious actually and the worst aspect was that he was prepared for this stent and he was quite anxious about it because we, we're very fortunate having had very good health so we'd never actually been in this situation before. So it was new to us. And the idea of having some sort of major procedure was quite worrying. And they got him sort of gowned up and all the rest of it and then they didn't go ahead with it. [...] And that was where you felt they were kind of, sort of, stringing you along, a little bit. Saying, 'Oh yes, I think it will happen', you know, and it got later and later and later in the day and nothing was happening. And then it got to 5 o'clock and you thought, 'No this isn't going to happen'. They eventually came in and said.

**Janet:** Mmm, and how did you feel?

**Liz:** Erm, I was, yes, it was quite upsetting actually because it was a little bit like you psyche yourself up to it and then it doesn't happen so you going away and you're thinking, 'Oh, another night and will it be done tomorrow?' Erm, and it wasn't done until the day after New Years Day when they had the full team on. So that was kind of 3 days, really.

The cancellation of hospital operations and investigations occurs due to many types of unforeseen circumstances such as emergencies, staff sickness or scheduled operations taking longer than expected. Despite her acknowledgement of operative risks, Liz recognised that her husband's forthcoming procedure was non-negotiable as it was essential for his recovery and continued wellbeing. In their enforced waiting, Liz was suspended in an acute phase of micro-liminality, with its accompanying ambiguity, in the overarching liminal event. Despite experiencing such uncertainty Liz is careful to express her anxieties and frustration in measured terms, '*You felt they were kind of, sort of, stringing you along, a little bit*'. By choosing her words carefully, Liz is softening her criticisms and demonstrates the ambiguity she now feels about this enforced waiting. Liz might have been highly critical of the hospital structures, which caused her such uncertainty and anxiety. However, these same structures ultimately effected the restoration of her husband's wellbeing and so she also remains grateful. By expressing this gratitude and minimising her criticisms, Liz is also maintaining her stance as a good visitor.

In contrast to Liz and her hopes for her husband's successful surgery, Danny was enduring a vigil at his grandfather's bedside and knew that there was no hope of recovery. The family spent more than a week at the hospital. Danny tells his story as follows:

**Danny:** But as it progressed into the second week, we were a bit more relaxed, to be honest with you. Because it was going to happen, you know, and it wasn't going to happen soon, it wasn't going to happen in a few hours but it could happen at any time. But, because everyone had got themselves geared up if it happened very quickly in the first week, I think it was a bit more relaxed atmosphere in the second week.

Danny is describing how he and his family moved on from the panic and disorientation of the 'explosion' (Torre 2007) of the emergency admission and became 'a bit more relaxed' and adapted (Torre 2007) to their changed circumstances. However, the unspoken question remained: how long before the inevitable happened?

The uncertainty and ambiguity of liminality caused by not knowing 'how long' is intensified in this situation of waiting for somebody to die and the sense of loss which is felt before the event, as A. Kelly (2008: 335-336) suggests:

Loss is a dynamic psychosocial space that is itself prolonged and compromises different things at different moments. These elements of loss and their proliferation eventually come to constitute torment. This proliferation intensifies the sense of loss as all encompassing and invasive [...] While at once [liminality is] a socio-cultural space, what adds to the enormity of residing in these spaces is that they are simultaneously a medical and psychological space. To be in liminality is to be in limbo, on the threshold of being here and there without socio-cultural

classification or a medical diagnosis of where 'there' is, will be, or if the ritual subjects ever make it there.

Kelly's words, referring to her experiences, also succinctly describe Danny's situation and the uncertainty that arises when doctors are unable to forecast the day and time of death. These days of waiting did, though, give Danny and his family time to 'gear up' for the inevitable.

Molly and Dave express their needs to know how long it would be until the patients' discharge:

**Molly:** Everyone's got work to get back to or, you know, whatever. But, I mean, but maybe, you know, my grandmother, she needed to know [the discharge date] because in her not knowing, meant I wasn't, you know, able to sort of plan anything. And erm, I mean, I'd already sort of stretched out of my week that I'd taken off work at the time, already stretched over that in order to stay with my grandmother and then the second week I was thinking, 'Oh, is he gonna be better soon, is he gonna be better soon?' Cos I've got work to do. I can't leave my grandmother, I can't bring her down here with me because she won't leave, leave Northumberland while granddad's in hospital.

**Dave:** I think they [visitors] do want to know what's happening, you know [...] And to know how long it's going to go on for, erm, how long, again probably selfishly, how long do I need to keep on visiting and whatever.

Here Molly is describing her experiences of being trapped in the betwixt and between of liminality. She is torn between her need to return to work in the Midlands to secure her continued employment and her recognition that, with her grandfather still in the hospital, she cannot abandon her grandmother in the north. '*Is he gonna be better soon, is he gonna be better soon?*' indicates her increasing uncertainty and desperate hopes for her grandfather's discharge so she could return to her 'everyday'. Dave's comments echo Gill's words in that the burden of combining everyday obligations with the demands of hospital visiting becomes so difficult that people need to have sight of the end of their struggles. Initially, Molly projects this need to know onto her grandmother and Dave, at first, suggests it is selfish, but anonymous, others. This lack of ownership of the need to know indicates that good visitors should not resent the time taken to visit.

On discharge day, the most common complaint expressed by the participants involved the excessive waiting for the medication to take home.

**Sally:** They told us to come, I think, it was about 10 o'clock in the morning that he would be coming home. So we got there at 10 o'clock. And of course, he, the doctors didn't come round to check and then he had to have a prescription. So we

went to the pharm-, that went down to the pharmacy. And I think it was about 4 o'clock in the afternoon by the time we came out. It was a long while, a long wait [...] We didn't know whether to go and get something to eat, or, or not, because they might say, 'Alright you can go'. It just seemed a long wait and they said that-, one of the nurses said, 'Oh, you often have to wait, you know, that's the way it is'.

**Jim:** I think it's ludicrous. I think it's appalling when you're told somebody's going to be discharged on a particular day, yes it's normally at the end of a visiting time and you're waiting hours for the medication because it's been arranged. You know, um, I just find it so strange there doesn't, there doesn't seem to be joined up thinking. I would have thought emergencies and discharges, cos if you can discharge somebody, you can free a bed up, you can get somebody else in. But if you can't discharge them then you've not got any, you can't get somebody else in the bed.

Although Sally demonstrated her obedience by arriving at the hospital at the stated time, the hospital staff seem to have made little attempt to secure her husband's medication in readiness for his discharge. Sally's repetition of the nurse's comment illustrates that the delay in dispensing medication has been so internalised by the staff as 'normal' that repercussions, in the form of visitors' loss of their status and self-worth (Schwartz 1974; Zerubavel 1987) anger and frustration are no longer fully considered. Moreover, Sally's words, echoed by other participants, indicate that the patient, now considered fit for discharge, and by association, the visitors, appear to have become structurally invisible in their liminal positions (Turner 1969), with no one seemingly concerned about their plight or their needs. Jim expresses a much greater annoyance than Sally and indicates the wider implications of a delayed discharge for efficient bed management. Such annoyance and frustration might so easily spill over into verbal aggression (Åkerström 1997).

Gill's describes her experience of discharge in the following way:

**Gill:** Chuck out! It's called, 'kicking them out.' [...] I've never had what I would describe as a smooth, organised, planned discharge. Everything seems to be a scramble. From very early on, 'He's due for discharge this afternoon', 'Yeah'. Discharge, 'We're waiting for meds. We need the room, you have to wait in the corridor'. Lug his baggage. You're no longer a person. You're a piece of baggage with ancillary baggage and all your baggage.

Arguably, Gill is confronting the ultimate loss of status in the form of depersonalisation. This treatment of people as less than a fellow human being and more as an object frequently occurs in hospitals (Haque and Waytz 2012). 'Rationalisation, standardisation and depersonalisation' of patients contribute to the smooth running of hospitals (Lorber 1975: 213 drawing on Freidson

1967). Treating a patient as a 'non-person' can also diminish social status, remove autonomy and encourage compliance (Lorber 1975). Gill's words suggest that visitors also experience this depersonalisation and her resulting anger is palpable.

However, as Nina's continuing story informs, she eventually was able to use her professional status for a benefit to herself and her mother:

**Nina:** [T]he day before discharge, went to see mum and, erm, having a little bit of insider knowledge and knowing a few things, I was talking to the pharmacist on our ward. I says, 'Oh I think' after she was asking me how Mum was, I says, 'I think she's coming out tomorrow.' I says, 'That's what I've heard.' I says, 'Obviously I don't know what time, depending on TTOs<sup>91</sup> and everything.' She says, 'Do you want me to go and check her tablets for you?' I said, 'You're allowed to? Would you?' So she went down and came back later and said, 'I've supplied everything. It's all sorted for tomorrow.'

The participants' evident frustration and Nina's ability to circumvent the delays for medication have policy implications. With computerised prescribing and dispensing of medication in hospitals, it is, I suggest, difficult to continue to condone such a commonplace inefficiency. However, the participants experienced other challenges, primarily caused by the unclear boundaries of responsibility, which I next explore.

### **7.3. Betwixt and between inpatient and discharged patient: shifting boundaries.**

Discharge concerns were of a more practical nature for some of the participants. For Winston, there was a need for adaptations within his home to facilitate his wife's mobility following her surgery. Similarly, Winnie and Jim had to be sure there was a package of care in place for Jim's mother following her discharge. Meg, too, needed support from the community palliative care team as the family, with hospital support, decided that her mother should spend the last days of her life in the familiarity and comfort of their home. However, the ambiguity arising from blurred boundaries of responsibility was another cause of frustration, as I now discuss.

Although Jim's mother already had her medication to take home when he went to collect her from hospital, he noticed that one drug had been incorrectly prescribed as he now describes:

**Jim:** Something was wrong on her medication and that's because either she hadn't told them or the question hadn't been asked about it, which I thought was odd. But that was just for my mother's things and I picked it up when I saw what

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<sup>91</sup> TTOs – medicines to take home

was on the bed and then I had to go and get the, some more medication for her from the pharmacy. [...] And that was just, fortunately, that was just 20 minutes before the pharmacy shut. Had it been shut, I would have had to come back the next day, which I didn't think would have been acceptable.

Jim had to walk from one end of the large hospital building to the other to secure the correct prescription from the pharmacy. This event occurred during a very snowy winter, and Jim and his wife lived twenty miles away from the hospital. Their journey was along country roads that can be treacherous in snow and ice and this explains his reluctance to return the following day. Jim's words demonstrate how the boundary of responsibility shifted further from the ward staff and nearer to him before his mother's discharge was complete.

Whereas most visitors had to wait with the patient for medication, Jane's husband was discharged without a prescription. Jane was visiting him when they were, unexpectedly and abruptly, told that her husband could now immediately leave the hospital and go home. Jane was annoyed about such a summary dismissal without a definitive diagnosis and her husband restored to full health. She describes her response:

**Jane:** I was thoroughly disappointed when they discharged him. [...] They simply took the chest drain out and said, 'Look, there are no medicines to give you, you're free to go.' And I, I really, really, now that did make me, and [husband] was also quite angry as well 'cos we had a chat about it in the car. And of course I'm saying to him, 'Now calm down, because I don't want, you know. I'm not turning the car round to take you back to hospital.'

Jane lives in a village some 25 miles from the hospital. Her husband woke her in the middle of the night. He was struggling for every breath and at the point of dying. She dealt with the emergency situation alone until the ambulance reached her. She then accompanied her husband in the ambulance to the hospital where he immediately entered the resuscitation room. At this point she had to wait outside in the corridor, not knowing whether she would see her husband alive again. Jane found the whole event very traumatic. Just three days later, the chest drain, which had saved his life, was removed and, with her husband clearly still unwell and with no explanations given for the cause of this emergency, they were told to go home. 'You're free to go' implies that being hospitalised is a practice of enforced confinement from which patients are 'liberated'. However, Jane also interprets these words as the hospital staff freeing themselves from continuing responsibilities of care and the provision of information to her and her husband. Still trying to make sense of her experiences and suffering from a lack of sleep, Jane was expected to undertake complete responsibility for her husband for which she felt ill prepared. For Jane, all the features of unstaged liminality, which had engulfed her, would continue after discharge. As I later discuss, this had grave consequences for her.

This determination of the point at which the hospital ceases to be responsible for the patient also features in Gill's story when she single-handedly struggled to get her physically and mentally disabled husband in his wheelchair and all of his belonging to the car:

**Gill:** If you're in hospital for a couple of weeks you can accumulate quite a lot of stuff. You can't get it all to a car and wheel a chair with a man in it in one go. You have to ferry in and out of the hospital [...] It's peeing with rain, you get in there and you're wet [...] Out to the car. It's still hissing down with rain. You put all this lot in the car. You get soaked wet again. Back into the hospital. Then you have to leg it all the way through the hospital again [...] You can't get a porter to save your life [...] Can't get a chair for a man who is being discharged as non-walking [...] Well, you've got to get him downstairs into main reception. Then you've got to leave him there. A piece of baggage, he's parked. Nobody knows who he is [...] why he is sitting there. He's just baggage. He's not a person anymore. He's just something in transit. And I am the porter. I am not allowed to park [near the entrance]. Get [husband] with the chair to the car. I have to get the chair back into the hospital. I've gotta leave the car with him in it. I can't leave it running. I can't leave the keys with him because he would just get out and get in the driving seat [...] He's upset, pissed off, angry, stroppy, because he's been shunted from pillar to post [...] And I'm pissed off because all I've actually managed to achieve is load the car up with stuff, I then have to carry in when I get to the other end.

Gill's frustration with these multiple challenges in attempting to move away from the hospital is evident. Once her husband was officially fit for discharge, they were both structurally invisible and of little or no concern to anyone in the hospital. Gill experiences this as a further loss of status and depersonalisation (Lorber 1975). The lack of established boundaries for the cessation of hospital responsibility also suggest an ambiguity. The ward staff appear to perceive that their responsibility ends at the time the patient is pronounced fit for discharge. Gill understands that hospital responsibility should continue until the patient is safely in the car for the journey home. However, '*I then have to carry in when I get to the other end*' also begins to signal that, for Gill, like Jane, continuing problems and her liminality will continue.

However, this experience was not universal. Meg and her brothers made the decision to take their dying mother home for the last days of her life. Meg talks about this experience:

**Meg:** Because, for her, I mean the support we got then, once we said we'd like to take her home. [...] The support we got was just fantastic. Absolutely fantastic. She was home the next day. And we got a proper hospital bed. She was only at home 4 days before she died. We could have brought her home sort of 10 days earlier or whatever. But time is very precious, then, isn't it? Very precious [whispered]... I wish I'd said to the doctor before, 'If there's any point you think we

can take her home, I want to do it'. But of course, they didn't know that I've got the facil- you know, I could have her downstairs or that I was willing to have her at home or anything. I just didn't have that conversation. But, yeah, visiting her, you, you get, I think it was just concern that she was in the best place possible.

Jim, Jane and Gill are therefore pointing to the ambiguities of determining exactly when hospital responsibility ceases and kinship group responsibilities recommence. The boundaries are blurred, and the exact point of discharge is not determined. The participants' describe their experiences as being betwixt and between being a visitor and their everyday. Meg's account suggests that such disturbing ambiguities are less likely to arise when hospital staff and kinship group members can jointly determine the discharge date and make plans for on-going care. This discussion also points to the pressures on hospitals to discharge patients as soon as possible to admit the next patient. These actions improve indicators of efficiency and productivity and meet the targets set by the Government as discussed in chapter two.

The ambiguities arising from blurred boundaries of responsibility at discharge led to the natural conclusion of the participants' stories and how they might have experienced the final part of their transition and reincorporation into the everyday world as I next discuss.

#### **7.4. A safe exit from liminality?**

In this section, I follow the participants' accounts of their experiences after the discharge or death of the patient. I begin by considering three of the participants' formal complaints after the patient was discharged. I then examine the participants' stories about their movements back into the everyday social world.

Sally, Nina and Gill felt so strongly about events that had occurred during the period of hospitalisation that they talked about their formal complaints. Below, Sally describes her letter writing after her mother was discharged without any arrangements for community care:

**Sally:** She'd [her mother] been in hospital for 6 weeks, she was blind, she'd had a heart attack, she'd been in intensive care and they were just sending her home. Yeah. And she [the doctor] said in fact, if I ask for help at home for her, you know, carers, they wouldn't support it. Well, she got home, she died six weeks later. And it was awful. It was a nightmare. And I did write a letter but I never posted it. But it made me feel better to write it. And I actually do wish, with hindsight, I had posted it.

Sally is describing an experience, which happened eight years before we met. She remembers this experience in vivid detail and voluntarily introduced it into the interview. Sally, like Gill and Jane in the previous section, is also illustrating different understandings of boundaries of

responsibility, with the hospital staff appearing to understand that their duty of care ceased once the patient had been declared fit for discharge with no consideration of the visitors' opinions. Here, Sally, as junior, was unable to comprehend or agree with the decisions of the seniors but, without the support of *communitas*, she felt unable to challenge the medical decision. Throughout her interview Sally emphasises her compliance and unwillingness to make a complaint in any of the times she was a hospital visitor. After her mother's death six weeks post-discharge, Sally wrote a letter, of complaint. Although this was a cathartic process, Sally now regrets not posting it. Sally's regrets, her recall and her unprompted introduction of this experience into her interview indicate some lingering remnants of liminality.

Nina talks at length about the letters of complaint she sent to the consultant and the matron responsible for the ward after her mother's discharge. She describes the matron's dismissive response to her complaints in the following way:

**Nina:** Letter from the matron. Very sorry, blah blah, that this has happened, blah blah blah. Erm, on our monthly matrix there is always seen to be stellisept at the end of the bed and we will pass on your comments to the domestics with regards to the cleanliness of the ward. As for the staff nurse who you stated was on nights, the male staff nurse. He has been spoken to and we feel that this was a misunderstanding. He did say he dropped something on the ward but because it was dark he couldn't see and it was kicked slightly. He has been spoken to about how this may be interpreted by a patient. We are sorry for any undue distress. We hope your mother has a full recovery. Thank you very much, bye bye, basically.

On this admission, Nina's mother had demanded that she was discharged - thereby just falling short of the self-discharge process. Part of the complaint concerned a registered nurse who had, in anger, kicked a dropped medicine pot across the ward. An accumulation of adverse incidents had prompted Nina's letter of complaint. The reply cleverly moves part of the claim from an inappropriate action by a nurse to Nina's mother's misinterpretation of the situation. However, as Nina's words '*blah, blah, blah*' suggest, she was very aware that she had received a standard reply, which, for her, implies little will change and her efforts in writing the letter were in vain. Nina's story does indicate that she continued to interpret her status as diminished after the discharge but, unlike Sally, she was able to use her professional knowledge to secure appropriate care for her mother in the community, with the result of a complete recovery.

Gill is a seasoned visitor and has endured many confrontations with hospital staff. She describes what happened when she complained to the Patient Information and Liaison Services (PILS):

**Gill:** I contacted the patient liaison people and said, I'm -. Well, a catalogue of idiocy! You contact them by telephone. 'We'll call you back.' Take your details.

Nobody calls you back. You contact them again. You speak to somebody else. 'Oh, we've got no record of that.' 'What, what?' This, this is documented on my [unclear word], this day, this date, this time and this person. 'Oh, she doesn't work for us anymore.' 'Ohhhh, ok, shall we start again?' 'Ok, we'll start again.' So we listen, we set up a formal meeting. We set up a meeting. And it is org-, it says on her computer, weeks, it's nothing immediate, there's nothing we can do now and whatever is going to be done is going to involve me going to the hospital. It's not. They don't come to me. It's always I have to go to them. I have to meet them on their terms. Never on my terms. There's a sense of it's always, 'We're in charge. You're, you're only bringing, you're bringing a problem to us. We're prepared to see the problem but, erm, you need, we need to know, we need to engage with this'. We get all, we get all the new speak, we get the medispeak, we get all the, all the political correctness. You walk into the hospital to meet the lady from Patient Information and Liaison and she calls me Mrs Black [not Mrs Brown]. An' I thought, 'That says it all. You have no idea who I am. I am just a name and you haven't even recorded the name correctly'.

This is a shortened extract of Gill's long account of her experiences of making complaints. In the past, she has also involved solicitors. Nevertheless, her words demonstrate the many challenges she encountered and her understanding that no one was taking ownership of her complaint. Her need to go to the hospital for the discussions, and the staff member addressing her with the wrong surname did nothing to restore, for Gill, her diminished status. She felt disempowered and, like Nina, recognised she was receiving official discourses and tokenism as a 'junior' in the interaction. Gill's dissatisfaction was exacerbated rather than assuaged.

Arguably these post-discharge complaints might also be understood as delayed resistance to the hospital structures they had encountered. Nina, who had enjoyed a strong *communitas*, was able to use her professional skills to help her mother back to recovery and so safely exited from liminality. For Gill and Sally, there was no resolution of their complaints. Sally's mother died, and Gill's husband's mental and physical deterioration continues. I concluded that they both seem to be pointing to prolonged liminality (Schouten 1991).

I, therefore, explored the data for further indications of this movement from the social world of the hospital into that of the everyday outside the hospital. Van Gennep (1960: 10) describes liminality as, 'a passage from one situation to another or from one cosmic or social world to another'. Danny, Sue and Liz have all demonstrated distinct mini episodes of a heightened sense of micro-liminality within the overarching liminal event of the hospitalisation of a significant other. Liz, below, vividly describes another such event when she moved from the social world of the ward to that outside of the hospital:

**Liz:** It did seem like another world, did seem like being on a parallel planet. One quickly lost all sense of time completely because of the environment. The fact that you've got lighting on all the time. You hardly ever, this is not, really, you don't ever look out of a window, really. So in a way you step out into the car park and see a few trees. You suddenly think, 'Oh, oh, it's still daylight. Or, 'Oh it's dark already' or, so it's, erm, it is very, this very, very strange, like being in, I now think I said, 'It's like being in a space station'.

This more intense experience of micro-liminality, described by Liz, correspond to Thomassen's (2009) interpretation, discussed in chapter three, of van Gennep's work, which acknowledges that liminal experiences are varied. Such difference in duration and intensity of liminality, both practically and emotionally, are demonstrated throughout the participants' narrations. For example, Amanda's liminality was the short duration of one visit to her mother-in-law. She returned easily to her everyday after the visit and was not involved in any discharge or aftercare arrangements. For others, as I next discuss, liminality was far more distressing and prolonged (Schouten 1991). However, these variations also demand an attempt for further interpretation, which I now discuss<sup>92</sup>.

Gill's story provides the starting point for my further examination. Her prolonged liminality (Schouten 1991) began some twenty years before her interview when her husband sustained life-threatening injuries in an accident. He has multiple co-morbidities and is now physically and mentally disabled. Gill describes the impact of the accident and her current situation below:

**Gill:** Massive impression on his life, catastrophic on mine and an immense impression on my daughter's life. [...] So we do have an odd relationship but I, I feel that I have a, I have a moral responsibility to ensure that he gets everything that he needs. So I will remain as his advocate and his carer. Er, er, but I suppose that until the end, and I don't know when that going to be, none of us knows, but he is an unwell man, let's put it like that.

Gill also informs that she and her husband made an agreement in the early days of their marriage. Her husband would secure their finances while she would care for home and family. She accepts that her marriage is now more one of convenience for her husband and, for herself, the burden of his care. To walk away from her responsibilities and look elsewhere for happiness would jeopardise her relationships with her daughter and renege on her side of the agreement. So, she continues in the betwixt and between of liminality in her family relationships and privately hopes for release from it, which she perceives will only be on her husband's death.

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<sup>92</sup> I have compiled Table 3 to demonstrate the participants' differing experiences of *communitas*, structure and exiting liminality. See Appendix 14.

She hesitates about verbalising her private, almost inadmissible, deliberations, '*Er, er, but I suppose that until the end*' and leaves the word 'death' unspoken but implied.

Liz and Jane provide comparisons to Gill's story. Like Gill's most recent hospital experience, both women also had the traumatic 'life jolt' (Ibarra 2007) of their husbands being rushed by ambulance to A&E and both men, coincidentally, became patients on the same ward but a few weeks apart. Liz, Jane and Gill can be loosely described as middle aged, middle class and articulate. Although Gill has one adult daughter, Liz and Jane both have four adult children. Unlike Gill, the only prior experience of hospitals for Jane and Liz was for childbirth. Liz and Jane both experienced sudden and enforced transitions and, coincidentally, their interviews took place within days of each other. During the interview they both describe their current situation, thoughts and emotions as follows:

**Liz:** I suppose in a way it could be that we are in a stage of denial still, I don't know. Possibly. [...] I haven't quite, I don't believe it, so I suppose that is a state of denial. While I'm telling you all this, it's a bit like a story that's happened to somebody else. It's not.

**Janet:** It's not happening to you?

**Liz:** Not really. It is at one level and that day-to-day dealing with it thing. That's all happening. That sort of like what's happening and then there comes like the other level [pointing to her head] that you use for processing things. And I suppose on that level, I am more in a state of denial. I don't know. But having said that we are sort of doing practical things like we're trying to, thinking of moving house, which I know is perhaps not good after you've had a heart attack, but, to somewhere easier, somewhere, where. We live in a very big, we've got a very big garden. And sort of, you know, just trying to simplify things a bit.

**Jane:** Even right now I feel quite sick with the whole thing because they didn't answer, you know, is the tear in his lung going to heal itself naturally? The hole they had to make, I'm assuming that heals itself naturally? Why on the Wednesday after he was discharged on the Monday, did I have a terrible experience by having to call the GP out and it was confirmed that he did have a UTI? I really wanted to question, I really wanted to go back on them and an' an' I really wanted to go back and knock on the hospital door and say, 'Why didn't you listen to what I say?' You know, am I being, but perhaps they think that every visitor, every wife, every mother is just being over cautious about, you know, the worry you place on them.

Liz's words suggest that, despite having difficulties in assimilating all that happened, she has 'moved on' from liminality and accepted the enforced transition and the implications, if not the full reality, of her husband's heart condition. She is 'looking forward' and making active plans

with her husband for their future. In contrast, Jane is still very much 'looking back'. Her only mention of the future in her interview was concerning the possibility of reoccurrence of the collapsed lung for her husband and any genetic implications for her children. Jane's 'everyday' appeared to be still suspended, she remained in a distressed and uncertain state of liminality and her anxieties about her husband and children were continuing.

Therefore, the experiences of Gill, Liz and Jane held variations. Liz and her husband received a definitive diagnosis, and he had a successful surgical intervention, which will prolong his wellbeing. As such, despite the delays for her husband's procedure, Liz seems to feel that the hospital structures provided sufficient support until her daughters arrived and their *communitas* became established<sup>93</sup>. Jane's husband also underwent a surgical procedure to relieve his life-threatening symptoms. Crucially, they received few medical explanations for these symptoms, and Jane felt profoundly upset by the lack of support extended to her by the hospital structures. Jane also distanced her children so that she could concentrate on her husband and because she also judged that he was too unwell to receive many visitors. She did not, therefore, have the advantages of *communitas*. Gill knew her husband's medical history but not the cause of his latest collapse. She reports difficulty in getting a diagnosis and support from the ward staff. Gill, like Jane, also did not have the support of *communitas* at the patient's bedside. Gill and Jane are the two participants who experienced both poor structure *and* little or no *communitas*.

I then returned to Sally's interview, which was with the intention of discussing her visits to her husband. As the previous section demonstrates, when visiting her mother she likewise experienced poor support from the hospital structures and little or no *communitas*. Sally's prolonged recall of events of visiting several years ago suggests lingering remnants of liminality. Sally, Jane and Gill seem to support a developing hypothesis that a safe and complete exit from liminality depends on good structure and strong *communitas*.

This led to my examination of the accounts of those people who experienced a good structure but no *communitas*. Ed (visiting his sister) and Winston, with their families overseas, both report receiving support from the ward staff, in the form of hospitality and information, when they visited. Sue and Nina reported strong *communitas* but failures in the structure. All four participants appear to have safely exited liminality, adjusted to the transitions and resumed the humdrum of the everyday social world.

Ed, visiting his friend, reported problems with the structure in the hospital and did not indicate any *communitas*. He appears to have exited liminal position immediately after visiting. Significantly, Ed had no kinship bond with the patient. So I explored further.

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<sup>93</sup>Throughout this discussion, I have determined the degree of *communitas*, structure and exit from liminality from what the visitors reported in their interviews.

Gill, Sally and Jane all had another commonality - that of a negative outcome for the patient and on-going health problems. However, for Danny, Meg and Dave the outcome was bereavement with, in all three cases, the death of a much-loved family member. All three report both the failings and merits of the hospital structures they encountered. They do, though, describe their experiences of a strong *communitas*. Danny describes his exit from liminality below:

**Danny:** I know what his [grandfather] attitude would be. He'd have said, 'Now stop being morbid about it. Celebrate their life and stuff like that. So. I'm like that. And it's right, as I say, I can't, we can't bring him back. You can never bring him back. You can remember him how he was, which is great. But life has to go on and he would have said that as well. You can't mope around all the time.

Danny's words provide a clear indication that, although saddened by his bereavement, he has accepted it. He has re-engaged with an everyday that now only includes memories of his grandfather. Similarly, during his interview, Dave talks about his forthcoming transition into retirement and Meg is very involved with her grandchildren. Therefore the emergency admission, close relationship with the patient and the severity of the illness and bereavements were not precursors to prolonged liminality.

Although these comparisons are from a small sample they do appear to indicate that prolonged liminality occurs when there is a close kinship bond with the patient, accompanied by a weak, unsupportive structure *and* weak or no *communitas*. This supports Stenner's (2015) acknowledgement of the damaging powers of a weak structure. But it also suggests that a good *communitas* limits this damaging power, especially when the visitor has a close emotional bond with the patient. The hospitalisation of a significant other, combined with a lack of *comunitas* and structure, result in such a traumatic experience that a safe exit from liminality becomes compromised. This is an extension of the understanding of the role of *communitas* that I have not encountered in the literature.

## **7.5. Conclusion.**

This chapter has concentrated on the last days and hours of the participants in their visitor role and the time after the patient has returned home or died. As they approached the endings of their role as hospital visitor, the pressures of being betwixt and between and the uncertainty of time increased. For some, there was a safe exit from liminality when the event of hospitalisation ceased. For others, this sense of liminality continued.

The analysis begins by exploring the central relevance of time to the participants' experiences. Gill and Jim demonstrated Torre's (2007) suggestion of time as a commodity. For Gill, there was a shortage of her time and for Jim, there was a misappropriation of his. Also, the loss of control of time prevailed throughout the participants' accounts and was pronounced during long

episodes of waiting and the uncertainty of not knowing when (Folkman 2010) a return to the everyday would happen.

On discharge day, the frustrations and challenges continued beyond waiting for medication. Gill's account demonstrates, arguably the ultimate loss of status and her depersonalisation. Also, the ambiguity of liminality prevails, as there seems to be no consensus between staff and visitors in the demarcation of boundaries of responsibility. This meant that the participants and their patient were betwixt and between the status of 'inpatient' and 'discharged patient'. The participants' accounts also seem to show that when the hospital staff decided to discharge the patient, there was a greater sense of dissatisfaction. This arose as the participants were more likely to understand that the hospital staff were prematurely divesting themselves of continuing responsibilities. When the discharge planning included collaboration with the visitors there was a greater sense of control for the participants and, consequently, greater satisfaction.

Variations in experiences of liminality, identified in earlier chapters, were further noted. My focus on the exit from liminality demonstrates that, in addition to structure, *communitas* also is relevant to a safe exit from liminality. Although I have encountered suggestions of the importance of structure (Stenner 2015), there seems to have been no acknowledgement of the role of *communitas* in avoiding a prolonged liminality in the literature I have read.

This chapter concludes the analysis. In the following chapter, I synthesise the results to show how the research aims have been achieved and the questions answered.

## Chapter 8. Conclusion.

### 8.1. Introduction.

I now synthesise the chapters of this thesis to demonstrate how I have met the research aims and answered the research questions. I continue with suggestions for further research about both liminality and hospital visitors' experiences and conclude with methodological reflections.

The research question asks, 'What are the experiences of adult visitors to NHS acute medical and surgical wards in England?' This question arose from my professional and academic interests and observations of practices during hospital visiting times in my workplace on a combined medical and surgical NHS hospital ward in England.

In chapter one, I justified the research by suggesting that more insight into the hospital visitor experience might forestall many of the complaints received by the NHS about hospitals and, more specifically, their provision of care. The evidence arising from this research could help to shape a more visitor friendly policy and so improve satisfaction. As a result, I suggested, policy changes could reduce the costs of handling complaints and dealing with aggression. I also noted the lack of qualitative research into visiting time experiences to the general wards in NHS hospitals in England and suggested that qualitative research could extend the knowledge about an activity, which most people will experience at some time in their lives.

As my research progressed, I began to understand that the participants were consistently describing their experiences of the hospitalisation of a significant other as a liminal event. Liminality then became the central theory in the theoretical framework for the thesis. The combination of extensive reading and the data analysis led to my recognition of phenomena that were providing different and new nuances to the existing body of knowledge about liminality. Therefore, the use of liminality in a theoretical framework was yielding deeper and richer interpretations of the data. In turn, the literature discussed in chapter three, and data were providing extensions to the understanding of liminality.

The aims of the research thus became:

- To extend the knowledge about the experience of being a hospital visitor.
- To add to the understanding of liminality.
- To interrogate positive and negative experiences to identify ways to cater to visitors' needs and thus provide evidence for visitors' policies and staff training and education.

The following three sections demonstrate how each of these aims has been met. I then suggest areas for further research before reflecting on the research limitations and the methodology and methods underpinning my research activities.

## **8.2. Research Aim 1: Extending the knowledge about the experience of being a hospital visitor.**

To answer the overarching research question asking, 'What are the experiences of adult visitors to NHS acute medical and surgical wards in England?' I posed the following three subsidiary questions:

- How does the wider social context influence hospital visitors' experiences?
- What do visitors' stories about their experiences tell us about hospital visiting?
- Why and in what ways do visitors resist or adapt to the policies, customs and practices of hospital visiting?

I have summarised the main findings of the research at the end of each chapter but, on the next page, I present these results in tabular form. These findings have been allocated to the five features of liminality, as described by Turner (1969), and, which corresponded with the most prominent themes arising from the data analysis. For a richer and more theoretically and conceptually informed interpretation of the data, I explored the literature about these themes in chapter three. As acknowledged throughout the thesis, Turner's (1969) features were extended slightly to fully embrace the richness of the data and the translation of his work from mid 20th century anthropological observations of archaic tribes to 21st century practices in English NHS hospitals. I have also demonstrated the intersection of these core themes throughout the thesis.

I next discuss how, in turn, I have answered each subsidiary research question and commence with a discussion of the influences of the wider social context.

<p><b>Loss of status and being 'out of place'</b></p>	<ul style="list-style-type: none"> <li>• <b>Ch 1.</b> No accounting for hospital visitor numbers and experiences on general wards – invisible practice.</li> <li>• <b>Ch 2.</b> Visitors are potentially disruptive and need to be managed.</li> <li>• <b>Ch 2, 5.</b> Invisibility at nurses' station is distressing.</li> <li>• <b>Ch 2,3,5.</b> Visitors often not accorded hospitality. Good hospitality increases satisfaction and perceptions of good care.</li> <li>• <b>Ch 3,5</b> Visitors' attempts to secure privacy, territory and psychological ownership were often in tension with ward staff.</li> <li>• <b>Ch 5.</b> Loss of status mitigated by being given information.</li> <li>• <b>Ch 3,5</b> .Carers given scant recognition. This has been improving since the fieldwork was carried out but not everyone recognises themselves as carers and not every visitor is a carer.</li> <li>• <b>Ch 6.</b> Status is influenced by pre-hospitalisation relationships with patient rather than other social categories.</li> <li>• <b>Ch 7.</b> Hospital time takes priority over visitors' time and leads to lowered self esteem.</li> <li>• <b>Ch 7.</b> Depersonalisation – the ultimate loss of status?</li> </ul>
<p><b>Total obedience and being a 'good visitor'</b></p>	<ul style="list-style-type: none"> <li>• <b>Ch 2,3,5,6,7.</b> Visitors need to be 'liked' and seen as good visitors. This need encourages pro-social behaviour.</li> <li>• <b>Ch 5.</b> Visitors sometimes involuntarily transgress rules.</li> <li>• <b>Ch 6.</b> Visitors will risk being a problem visitor if poor care is witnessed.</li> <li>• <b>Ch 6, 7.</b> Visitors find it difficult to challenge professional authority and knowledge</li> <li>• <b>Ch 7.</b> Complaining post-discharge seems to achieve little satisfaction but avoids contestations on the wards.</li> </ul>
<p><b>Uncertainty, loss of control and the quest for information</b></p>	<ul style="list-style-type: none"> <li>• <b>Ch 2</b> Informed consumers now have more information readily available, especially via the Internet but this can be seen as a challenge to medical authority.</li> <li>• <b>Ch 3</b> Knowing provides control but can extinguish hope.</li> <li>• <b>Ch 5</b> Good information provides sense of control, improved status and inclusion.</li> <li>• <b>Ch 5</b> Inconsistent and incoherent information is distressing.</li> <li>• <b>Ch 5</b> Rejection of visitors' information is distressing and compounds the loss of status.</li> <li>• <b>Ch 7.</b> Needing to know 'when?'</li> <li>• <b>Ch 7.</b> Waiting.</li> <li>• <b>Ch 7.</b> Blurred boundaries of responsibility.</li> </ul>
<p><b>Between and the sense of ambiguity</b></p>	<ul style="list-style-type: none"> <li>• <b>Ch 2.</b> Visitors are neither domestic or commercial guests.</li> <li>• <b>Ch 2,3,5,6,7.</b> Visitors caught between competing demands of being vigilant and responsible but need to be liked and not voice complaints and demands.</li> <li>• <b>Ch 2, 6.</b> Role ambiguity.</li> <li>• <b>Ch 3, 7.</b> Visitors are caught between fiction and reality</li> <li>• <b>Ch 6.</b> Continuum for intensity of involvement influences the extent of the pull towards the everyday or to the patient.</li> <li>• <b>Ch 6.</b> Visitors can be caught between their own body and that of patient .</li> <li>• <b>Ch 7.</b> Competing demands of home, work and leisure and hospital visiting.</li> <li>• <b>Ch 7.</b> Blurred boundaries of responsibility.</li> </ul>

<b>Structure and comunitas</b>	<ul style="list-style-type: none"> <li>• <b>Ch 3.</b> Hospitals provide structure to support and guide families until communitas develops.</li> <li>• <b>Ch 6.</b> Communitas is intra-family and not inter-family.</li> <li>• <b>Ch 6.</b> Subtle hierarchy develops between visitors with identification of prime visitor.</li> <li>• <b>Ch 7.</b> Good communitas seems to mitigate the damaging power of poor supporting/regulating structures. Lack of communitas and structure on the wards can lead to prolonged liminality.</li> </ul>
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Table 3. Key findings of hospital visitors' experiences corresponding to the five core themes of liminality.

**8.2.1. How does the wider social context influence hospital visitors' experiences?**

I presented potential contextual influences on hospital visitors' experiences in chapter two under the five categories of: the changing demographic, medical and epidemiological context and political responses; hospital scandals and their repercussions; visitors' use of ICT; popular culture; and the local impact of policies. I concluded chapter two by demonstrating the intersections of these five categories and suggested that they combine to present hospital visitors with many challenges. Hospital visitors, I suggested, are on the threshold of change, and, so, in liminality (van Gennep 1960), and experience the many challenges defined by Turner (1969) in his extension of van Gennep's work. These difficulties include marginalisation, ambiguity and the sense of being between home and hospital. I, therefore, suggested that I could incorporate liminality within a theoretical framework for more rigorous research practices, a lens for the data analysis and structure for the thesis. I now demonstrate how analysis results combine with my discussions in chapter two, to answer the first research question and extend knowledge about the contextual influences on hospital visitors' experiences.

I began chapter two by setting out the ever-increasing demands and expectations of the NHS in England and the different ideologies that have informed NHS policies over the decades. From this, I was able to identify the competing tensions of running a health service within the financial means of the country, providing high-quality care and keeping an informed electorate, with rising expectations and demands, satisfied. Notably, there is little direction from central Government in how hospital visitor policies should be formulated and enacted locally. This is the responsibility of hospital trusts. However, in chapter five the participants' accounts began to demonstrate the extents to which government policy still impacts on hospital visitors' experiences. For example, the decision to centralise acute secondary care services in cities, or on their outskirts, meant that the participants had lengthy, costly and, often complicated, journeys to the hospitals. In chapter seven, the pressures on hospital staff to meet efficiency targets by admitting more patients and keeping waiting lists lower meant that some of the participants' experienced inappropriate discharge processes. There was a

blurring of the boundaries of responsibility with the participants understanding that the hospital staff were prematurely divesting their responsibilities. Neoliberal policies have encouraged personal autonomy and responsibility, but throughout their experiences, the participants found these contested by the, often implicit, rules and customs with which they had to comply to be 'good visitors'.

These implicit rules caused further consternation when the participants' inadvertently failed to comply with them. This is despite their earnest attempts to be 'good visitors' which, as I suggested in chapter two, is further informed by popular culture. More specifically I suggested that stereotypes, such as those mentioned in Causely's (1997) poem or featured in magazines, brochures and postcards, could educate, inform and prepare the public for their role of hospital visitor. The participants' accounts in this respect were varied. Amanda told of James' *faux pas* of taking a patient's chair from the day room to the bedside. Although Liz talks of her recognition of boundaries and the need to avert the gaze from other patients and their visitors, Jane describes her distress when she experienced the stares of other patients and visitors who had not been aware of this unwritten rule. In chapter five, Ed recognised the implicit rules which meant he was unable to move away from the laughter at the nurses' station and Sue understood that she needed permission to enter the ward.

The on-going scarcity of central policy guidance about visiting times prompted the exploration of local policy in chapter two. This revealed that visitors are understood as potentially disruptive to the smooth running of the wards, which is another feature of liminality (Turner 1969). Consequently, hospitals appear to prioritise the management of visitors at the expense of their comfort, and the welcome and hospitality accorded to them. This lack of attention to visitors' needs continued throughout the participants' accounts, and the hospital environment was often a cause of physical and emotional discomfort for them. In chapter five, for example, the participants reported the practicalities of confusing signage, shortages of chairs to sit on, cramped conditions at the patients' bedsides, small and dingy visitors' rooms, a lack of privacy on the wards and insufficient options for refreshments.

I also considered the education of and information for hospital visitors in chapter two and my discussions of their usage of ICT. The Internet does provide many channels for visitors to gain support, information and express their comments about their experiences. Broom (2005) points to the possibility that doctors might understand visitor's use of the Internet as a challenge to their medical authority. Inconsistency in understandable information provision by the hospital staff was a disturbing experience for some of the participants. Jane, in chapter six, was particularly distressed by this and seemed to imply that she used the Internet to learn more about her husband's condition and ramifications for her family. But she also demonstrates that she considered this an illegitimate challenge to medical authority. Notably, none of the other participants declared their use of the Internet for information. I suggested

that they, too, saw the use of ICT to access medical knowledge as an illegitimate challenge to medical authority. However, I also suggested that the Internet is now so commonly used that the participants did not consider it worthy of note in their interviews. All of the participants also used other sources of information, which included asking the patient, other acquaintances who had gone through the same experiences, friends or family members who work in the nursing or medical professions, hospital leaflets and their GPs. Ruth and Danny's mother also confirmed Maslow's (1963) suggestion, noted in chapter five, that sometimes it is easier not to know.

Solomon (2016: 3) considers that the newly emerging genre of doctors' stories could bridge the gap between the 'medical track or a literary/humanist one'. I explored the possibility that other hospital-related genres in popular culture could do likewise. As the data analysis demonstrated, the participants experienced an overwhelming flood of emotions when confronted with the reality of the malfunctioning body of a significant other. This immediate reality is much harder to manage and is very different from the controlled titillation of the emotions that audiences might enjoy while sitting comfortably in their homes. The finely balanced and controlled scales of fear and fascination achieved by media production teams, and discussed in chapter two, become tipped heavily towards the former and fascination gives way to fear in the forms of an all-consuming anxiety, uncertainty and, sometimes, anger. The participants demonstrated such emotions throughout their stories about their experiences.

In the continuing discussion of popular culture, Hetseroni's (2009) research suggests an exaggeration, for entertainment value, of patient epidemiology, demographics and recovery outcomes in popular culture and this can engender fear and mistrust. Jacobs (2015) also notes the modern-day stereotypical image of doctors as fallible. Also, the research interviews all took place in the shadow of extensive media reporting of the enquiries into the Mid Staffordshire Hospital Trust scandal of poor care, bullying of staff, falsified records and poor management. The data analysis demonstrated that misrepresentations and scandals have so undermined public confidence in hospital care that hospital visitors perceive a need for their extra vigilance on behalf of the patients. However, visitors can only monitor care within the constraints of restricted visiting hours. This was particularly emphasised by Sue's account of her father's episode of incontinence in chapter four and the family's on-going attempts to maintain their responsibility for his care in chapter six.

The contextual influences on hospital visitors' experiences are therefore multiple, varied and intersecting. They also reinforce the many features of liminality, which include significant practical, physical and emotional challenges when a significant other becomes a hospital patient. Whereas the more explicit rules are understood, the participants' accounts demonstrate that there is a minefield of tacit social *mores* on the wards, to which it is harder

to conform. I discuss these further in the following sections where I summarise what that participants' stories inform about hospital visiting experiences and how they adapted to their alien environment or resisted these social rules.

### ***8.2.2. What do visitors' stories about their experiences tell us about hospital visiting?***

Chapters five, six and seven focused on the participants' stories and demonstrate that they were taking an active part in their interviews to provide me with their understandings and meanings of their experiences (Holstein and Gubrium 2003). For example, Amanda utilised humour to elaborate her story and to self-present as a visitor who knew the rules and complied (mostly) with them. Gill used the interviews in her hope that this research might contribute towards improvements in hospital care for visitors. To emphasise her storytelling (and in common with Nina in this chapter and other participants), Gill attributed words to staff members. It is, however, essential for the integrity of the research to acknowledge that the original episodes being described by the participants were not observed or recorded. There is also the possibility that the participants are likely to have misremembered the exact words the staff used and/or misinterpreted what was said (Wengraf 2001).

The most dominant theme emerging from the participants' stories was that the hospitalisation of a significant other is experienced as a rupture from the everyday and a movement into a state of liminality for kinship group members and, to a lesser extent, friends. Liminality was, therefore, central to the theoretical framework, which I described in chapter three. This framework also included the five core themes that emerged from the participants' stories and corresponded with Turner's (1969) understanding of the characteristics of liminality.

In chapter five I focussed on the beginning of the participants' stories and their first experiences of getting to the hospital and taking on the role of hospital visitor. In the first two sections, I used these stories to demonstrate the many different emotional and practical challenges arising from the hospital environment and structures. These challenges not only related to the five core themes of the theoretical framework, but they also demonstrated their multiple points of intersection. This, therefore, prepared the way for exploring the core themes individually. In the final section of this chapter, I began this examination of the individual themes, by seeking deeper interpretation of the experiences of uncertainty in those first hours and days.

I had first considered uncertainty in chapter three when I used Folkman's (2010) definition. She suggests that uncertainty is 'when something will happen, what will happen, what can be done' and what the result might be (Folkman 2010: 903). Although this definition of uncertainty prevails through the participants' stories, more subtle implications also emerged. Dave illustrated the intersection of uncertainty with the loss of status. For him, information was recognition of his status as the patient's eldest son. Gill also showed that information

giving is a two-way process and visitors have their knowledge to pass on to the doctors. The rejection of such knowledge by the doctors implied, for Gill, a rejection of her status as a carer and her many years of struggle. Danny demonstrated how consistent information could restore some sense of control by helping him prepare for his imminent bereavement. But his mother confirmed Maslow's (1963) acknowledgement that knowing extinguishes hope. Losing hope is the removal of one of the mechanisms for coping with uncertainty (Folkman 2010). Dave also drew my attention to a hierarchy of information providers, with the senior doctors considered the most reliable. Paradoxically, those members of staff, considered as the most knowledgeable and reliable sources of information, were the least visible and accessible on the wards.

However, another uncertainty became apparent in the participants' stories. Relating to the discussions of contextual influences in chapter two, the participants tell of their uncertainty arising from their lack of 'know how' (Stenner and Clinch 2013) in the hospital environment. Nina later demonstrates what is achievable with this 'know how' by her ability to circumvent the lengthy wait for the medication to take home. The use of this 'know how' came at a personal cost to Nina on other occasions when she experienced a discomfiting role ambiguity, as demonstrated in chapter six. In drawing on her professional skills, Nina was inadvertently failing to accord the 'passive and humble' (Turner's 1969: 81) behaviour expected by the seniors (ward staff) from the juniors (visitors) (Turner 1969). Nina consequently realised she might have attracted the label of problem visitor.

In chapter six I also noted the subtle interactions and negotiations between the visitors and staff. These permitted the staff to categorise visitors according to their pre-hospitalisation roles and relationships with the patient. The visitors carried this development of a hierarchy into their developing *communitas* with the establishment of a 'prime' visitor. This hierarchy then permitted the allocation of different responsibilities and tasks involved in supporting the patient and each other and, so, some small recovery of status within the kinship group.

For the third section of chapter six I concentrated on the core theme of 'betwixt and between'. In this, two new nuances in the understanding of 'betwixt and between' emerged. The first of these involved my recognition of a continuum along which ward staff, the patient or circumstances position the visitors. The second understanding arose from a combination of the literature and the data and resulted in my identification of the phenomenon of being ontologically betwixt and between the self and other. These extensions to the understanding of liminality and are discussed in more detail later in this chapter.

The final analysis chapter involved the last stage of the participants' stories as they dealt with the patient's discharge or death. The first section had a focus on 'uncertain times' and demonstrated the centrality of time for all of the participants. This involved time, as a

commodity (Torre 2007) and in in short supply, and as the horizon (Tore 2007), with the uncertainty about the date of discharge, or in terms of waiting. Further uncertainties emerged due to blurred boundaries of responsibility and led to the participants' dissatisfaction. The final section considered the participants' exit from liminality. Whereas most managed a safe exit, others were unable to move on with their lives. The data suggests that this inability to exit liminality depends on the power of *communitas* to mitigate the damaging power of unsatisfactory hospital structures.

The participants' stories demonstrate that having a significant other in a hospital can pervade every waking moment and disturb sleep patterns, appetite, concentration and even rational thought. It is a tiring, challenging, scary, stressful and profoundly disturbing experience, which they desperately want to end so that normality, whatever form that may take, can be re-established. They are, truly betwixt and between home and hospital. Their lives are suspended and their stories demonstrate all the features of the five core themes and their intersections and being betwixt and between is not just physical but also highly emotional. Most importantly, as Gill's words in chapter five demonstrate, hospital visitors are also in need of care in the ward environment and this care is often not forthcoming.

However, as Nina's story suggests, the research participants did not always display the 'passive and humble' (Turner 1969: 81) behaviour of total obedience. In the next section, I demonstrate how the third subsidiary question has been answered by considering the ways in which hospital visitors adapted or resisted policies.

### ***8.2.3. Why and in what ways do visitors resist or adapt to the policies, customs and practices of hospital visiting?***

The data analysis reveals that the greatest influence on the participants' attempts to adapt or resist hospital policies is their need to be judged as a good visitor. This need pervades their accounts and is explained in chapter three by the need to be liked (Blumberg 1969; Baumeister and Leary 1995; Srivastava and Beer 2005) rather than resist and incur the social pain of ostracism (Williams and Nida 2011). The idea of being a good visitor, I argued, supplemented and modified Turner's definition of total obedience (Turner 1969) to better reflect the 21st century social world in England where autonomy, responsibility and choice are encouraged. I, therefore, concentrated more on the participants' observance of 'passive and humble' behaviour. The second part of Turner's definition, 'Implicitly obeying instructors' (Turner 1969: 81), is more applicable to the tuition given to neophytes of the archaic tribes than to citizens in the UK with an almost instant access to knowledge to form alternative conclusions about hospital care and treatment. My more contemporary conceptualisation of 'total obedience' also permits recognition that agency and resistance to structures can, and do, occur in the social world.

The examples of being a good visitor are multiple and varied throughout the interviews. Chapter five features Ruth's challenge to visitors who did not use hand gel. In chapter six, Nina assures me she asked 'very nicely, not at all abruptly' for analgesia for her mother and in chapter seven Dave and Molly project their need to know 'how long' onto others. However, there were some occasions when the participants inadvertently transgressed the rules and risked being labelled as problem visitors. Nina's well-intentioned interventions on her mother's behalf, either to ensure a bed would be available or to request analgesia, provoked animosity from the hospital staff. Amanda and James, for example, forgot to use the hand gel but Amanda immediately repositioned themselves as being good visitors by assuring me they had not touched anything. This last example is one of many which demonstrates that the participants' desire to be judged a 'good visitor' carried on into the interviews.

In chapter six I suggested three causes of tension between the ward staff and participants, which could provoke resistance and invoke the problem visitor label: contestations of psychological ownership of the patients; the participants' marginalisation or exclusion from the centrality of patient care; and the perceptions that inadequate care was being given to the patient. I then demonstrated the ways in which the participants attempted to deal with these problems; from the constant 'reminding' from Winnie, Ed's 'shouting louder' and Nina and Gill's complaints, in chapter seven, after the patients' discharge.

I also demonstrated the power of the mutual support from within *communitas* to mount successful challenges to the hospital structures. Danny and his family were able to secure better care for his grandfather, Meg and her family were able to challenge the hospital decision to remove her mother to a care home and Sue and her family were able to circumvent breakdowns in hospital communication systems for her father to have the MRI scan he urgently needed. The data analysis and contextual influences led me to conclude that the development of *communitas*, the overseeing and supplementing of care and contestations of psychological ownership are curtailed by visiting policies that restrict the time and the number of visitors at the bedside.

#### **8.2.4. Conclusion.**

Therefore, responding to the three research questions gave a comprehensive understanding of hospital visiting experiences. By conducting an in-depth review of contextual influences and careful analysis of the data, I was able to bridge the gap between the material/ practical and the sociological/emotional. This meant that, for example, I could identify and engage with the practicalities of Winston's 'jungle' of corridors and stairs and also his emotional response of sheer panic at being lost. I could also understand that a cup of tea meant more than a drink to quench thirst. It also symbolises inclusion and welcome.

I also came to recognise that hospital visiting could be understood as a liminal event. The theoretical framework provided by liminality and the five core themes guided and structured the thesis and provided a lens for deeper and richer interpretations. The data analysis, in turn, also added to contemporary understandings of liminality and this is discussed in the following section.

### **8.3. Research aim 2: To add to the understanding of liminality.**

In chapter three, I noted Thomassen's (2009: 16) suggestion that the 'betwixt and between' feature of liminality [...] opens up spaces for possible uses [...] far beyond that which Turner had suggested'. As the thesis demonstrates, just as the theoretical framework of liminality provided a tool for researching and extending the knowledge about hospital visitors' experiences, its use also provided additions to the understandings of liminality, as I now discuss.

My starting point was to acknowledge that Van Gennep (1960) and Turner (1969) were anthropologists observing the rites of passage within archaic tribes in the middle of the twentieth century. This focus on traditional rites of passage posed some problems when translating their work on liminality into practical use in the 21st century social world in England. I modified Turner's (1969) definition of the total obedience expected of liminal personae, as discussed in the previous section. I also extended the core feature of uncertainty to include the quest for information. As noted in this chapter, the uncertainty took many forms and went beyond Folkman's (2010) definition and involved the discomfort experienced by not having the 'know how' in an alien environment.

As my discussions of the use of ICT in chapter two, and the participants' stories in chapters five and seven demonstrate, the quest for information is a significant feature of the hospital visitor's experience. My initial assumption was that this was needed to assuage uncertainty and so the two concepts became linked in the framework. However, as the analysis developed, it became increasingly evident that information is also highly relevant to other concepts such as restoring a sense of control, permitting the organisation of outside hospital obligations, or being a symbol of inclusion and the restoration of some fragile status.

Turner (1969) seemed to infer that 'loss of status' applied more to the membership of, and positions in hierarchies of tribal kinship groups rather than status conferred in contemporary England by class, employment or accumulated wealth, skills or knowledge. Therefore, I used 'loss of status' to refer to this twenty-first-century understanding. Nevertheless, kinship group membership became a feature at the patient's bedside where hierarchies developed according to pre-hospitalisation relationships with the patient. This hierarchy extended to the identification of a prime visitor who needed support from the secondary visitors. This

accordance of visitor status was subtle, changing and negotiated. Furthermore, the ward staff also seemed to get involved in these negotiations and, sometimes, made mistakes. I noted that the neophytes, described in van Gennep's (1960) and Turner's (1969) observations, experienced loss of kinship group status. In this research, with status of employment, wealth or knowledge disregarded, the participants resorted to this traditional kinship group status. Significantly, this organisation of a kinship hierarchy amongst the 'juniors' (Turner 1969) of the *communitas* of liminality in the 21st century developed world appears to have no specific acknowledgement in the literature I have read.

Also, in chapter five I drew on Lewis' (2004) to identify that the five core themes were incorporating other concepts, such as feeling invisible or being seen as disruptive or dangerous. This, I suggested, demonstrates a possibility for the design of a more elaborate and hierarchically organised conceptual framework for liminality.

In addition, new and nuanced understandings of the betwixt and between of liminality arose from the combination of the data analysis and literature. In chapter six I was able to identify a continuum along which the participants felt positioned by the patient, the ward staff or circumstances. At one end of this continuum, there were those, such as Ed visiting his friend, who had minimal emotional and practical engagement with the patient's illness trajectory. These visitors were experiencing a stronger ontological hold onto their everyday. At the other end, there were participants, like Ruth, who were so heavily involved with the events in the hospital that their previous everyday ceased to bear much relevance and their ontological experiences of liminality were much more intense. When the participants sensed their inappropriate position on this continuum of engagement with the patient, they experienced emotional turbulence. For example, Amanda felt her mother was pulling her into a greater involvement with her illness and was consequently embarrassed. Gill, on the other hand, was being pushed to a lesser involvement in his illness by her husband and was distressed. Significantly, both Gill and Amanda implied their disempowerment and an inability to resist their positions.

I then explored the stories of those participants who expressed an intense engagement with their hospitalised significant other and the body manifestations of illness. The emotional and physical responses they describe suggest they were experiencing something more severe than compassion, empathy, or second person perspective (Churchill 2012). I, therefore, combined Merleau-Ponty's (1962) understanding of intercorporeality and Churchill's (2012) third person perspective. I suggested that the overwhelming concentration on the malfunctioning body of the patient, often to the neglect of their own body, meant that some of the participants were experiencing a disorientating ontological state of being betwixt and between the body of self and that of the other. These extensions, in the form of a continuum

and the betwixt and between of two bodies, have also not featured in my extensive reading of the literature.

Another feature of liminality, which appears to have been accorded little or no recognition in the academy is that of the role of *communitas* and structure in the safe exit from liminality and a return to the everyday. Stenner (2015) notes that weak or lacking structure makes the experience of liminality destructive. However, indications arising from my data analysis suggest an extension to this understanding. Where there is a close emotional bond with the patient, *communitas* seems to be essential for mitigating the damaging power of poor structure in the hospital-visiting scenario. Weak or no structure combined with weak or no *communitas* makes the whole experience of liminality so emotionally and physically traumatic that a safe return to a new form of everyday is compromised. The result is a prolonged liminality (Schouten 1991), which, in Gill's case, has lasted for twenty years.

The methodological implications of this research are discussed in chapter four and later in this chapter, but my focus on hospital visiting experiences and the use of liminality and the five core themes as a theoretical framework have permitted my identification of extensions to the understandings of liminality. My reading of the literature was extensive and crossed disciplinary boundaries, and I have not encountered these identified extensions of the features of liminality elsewhere.

In the following section, the thesis chapters are further synthesised to demonstrate how the third research aim has been achieved.

#### **8.4. Research Aim 3: To interrogate positive and negative experiences to identify ways to cater for visitors' needs.**

In this section, I refer to the analysis of the participants' stories to establish which features of their hospital visiting experiences can be taken forward to inform future education, training and policy which will improve hospital visiting experiences.

My insight from the research suggests that staff training and teaching should aim to ensure that hospital visitors are welcomed and acknowledged on the wards and, especially, at the nurses' station. The distress the participants experienced when they felt 'invisible' or 'in the way' was very profound and was possibly unintended by the ward staff who were juggling the many demands of a heavy workload and limited time. Associated with this recommendation, I also suggest that hospital visitors should be offered a cup of tea on the wards during the patients' tea rounds. Those who were offered refreshments appreciated this hospitality and they expressed greater satisfaction with the hospitals' standard of care. To defray the extra

cost to the NHS or the hospital trusts, I would also suggest that visitors would be happy to pay a nominal sum.

My second recommendation is that hospitals ensure that there is a sufficient number of chairs for visitors. This would discourage visitors from sitting on the patients' beds and would remove the need to 'scout for chairs' as Jim tells in chapter five.

Although my professional experience is that hospital policies stipulate that next-of-kin should be notified of the transfer of the patient to another ward, the participants' accounts suggest that this does not always happen. The result is considerable distress and inconvenience for patients and their visitors. Efficient bed management, productivity, audits and finances appear to have assumed priority over patients' and visitors' emotional and practical wellbeing. At the very least, ward staff should be instructed to ensure that relatives are informed of the bed move.

The research suggests that there needs to be better co-ordination in the discharge processes. There seems to be greater satisfaction when the hospital staff involve kinship group, or carers, in discharge planning. The delays in dispensing medication to take home are a source of considerable frustration, which has the potential to escalate into abuse or aggression. As the participants describe, hospitals seem to manage the discharged patient differently. Some waited in discharge lounges; others had to wait in corridors or could continue to occupy their beds. Boundaries of responsibility were vague with a lack of consideration for the on-going needs of discharged patients' and their family members.

The data analysis also demonstrates that consistent, understandable information is imperative for visitors although this invokes a tension for staff in their attempts to maintain patient confidentiality. Dave's words point to a hierarchy of information providers. Doctors are considered more reliable communicators of information but are less accessible to visitors. Also, Jane might have experienced less distress if she had fully understood that, due to high demand, there could be delays in arranging some tests and investigations to confirm a diagnosis.

Therefore, many of the more negative experiences described by the participants seem to originate from poor communication between hospital staff and visitors. However, as Haigh and Ormandy (2011) suggest, nurses often experience tensions between spending their time delivering care and talking to anxious relatives.

A lingering concern is that is three years since the fieldwork was completed and the analysis began. So this thesis is contingent in that there have been changes within NHS hospitals in England. This is particularly pertinent when considering that, since the fieldwork, for example,

carers are more welcomed as partners in care in hospitals than during the time of the participants' visits and interviews. I remain anxious that these measures still exclude visitors who are not carers, who are temporary carers or might not recognise themselves as carers.

I now continue with recommendations arising from the thesis by suggesting areas for future research.

### **8.5. Directions for future research.**

My identification of extensions to the understandings of liminality has already demonstrated that this is fertile ground for further research. This thesis suggests several areas for further research into liminality as listed below:

- Further investigation into development of a hierarchy amongst liminal personae in *communitas*.
- Extension of Turner's (1969) features of liminality into the identification of a conceptual hierarchical framework of liminality.
- Further research to determine the inter-relationship and influences of structure and *communitas* on a safe exit from liminality.
- More research to support the continuum of levels of engagement within the *betwixt* and *between* and the consequences that might arise.
- Further research to extend the initial identification that the '*betwixt* and *between*' feature can also apply to being between two bodies – that of the self and that of the significant other – in liminality.

The insight provided by Nina's interview supplemented my own professional experience and facilitated the data analysis and the interpretation of some of the contextual features. I, therefore, suggest that there is more insight to be gained from researching hospital staff and patients' experiences of visiting times. However, as I encountered, there may be difficulties in recruitment and fieldwork in NHS properties. A second problem would be methodological. Although patients and visitors experience the hospitalisation period as a time of liminality, I would suggest that ward nurses would understand their shifts as part of their everyday. As such, liminality as an analytic lens might be inappropriate for researching ward staff experiences. Other research limitations and methodological issues arising from this research are considered more fully in the following section.

## 8.6. Research limitations and methodological reflections.

Throughout my research activities, my own reflexivity has been paramount. In accordance with Heidegger's work, I accept that I am inescapably situated in the social world and cannot escape the influences of my own experiences and values (Smith et al 2009; Aspers 2010). I acknowledge that, at times, my professional knowledge and life experiences have helped me to interpret some of the participants' stories about their experiences. I have felt, with them, the panic of getting lost in a hospital's maze of corridors or the dilemma of trying to find a patient. Similarly, I have been able to understand how and why nurses seem to ignore visitors waiting at the nurses' station in addition to the deep distress this can cause visitors.

However, I have consistently utilised reflexivity as a research tool in order to privilege the participants' perspectives rather than depend on my own socio-historical locations (Hammersley and Atkinson 2015: 15). My original intention was to research hospital visitors', patients' and nurses' experiences of hospital visiting times. In the early stages of my research I came across Silverman's (2005: 80) recommendation that 'depth rather than breadth' is more important for a single researcher project. At the same time I was encountering much literature about nurse/patient relationships and interactions. With the intention of having a more manageable and bounded project, which could be explored in depth, I quickly decided to concentrate on visitors' experiences and thus fill a gap in the knowledge. This, of course, has resulted in the silencing of patients and nursing staff and their perspectives.

A second consideration is that of the historic and social contingency of the fieldwork and possible influences on the research participants - both when they visited and when they talked about their experiences. My fieldwork was carried out in 2013 and involved participants who had agreed to talk about their visiting experiences from 2011-2013 when NHS financing was constrained by Government austerity measures. This was also a time of intense media reporting of the Mid Staffordshire Hospital Trust Scandal and the subsequent Francis Reports, which seriously undermined confidence in English NHS hospitals, as I detail in chapter two. The visiting experiences and the research interviews therefore all took place at a time of heightened sensitivity to possible shortcomings within the NHS hospital system. As I have acknowledged throughout the thesis, these factors, coupled with Neoliberal policies of responsibilisation, autonomy and choice might have increased the participants' perceptions of the need to be vigilant on behalf of the patients, undermined their confidence in the NHS and encouraged them to be prepared to encounter and challenge poor care in the hospitals.

Such shortcomings in care featured prominently throughout most of the participants' accounts and have demanded my further use of reflexivity. Although these negative comments could be, again, attributed to adverse media content I also question whether the volunteer

participants were primarily those who, as the participant Gill vocalised, had endured such difficult visiting experiences that they needed and wanted their story to be heard. Although, as I have demonstrated, some participants spoke positively about their experiences, those members of the public who had been more satisfied might have felt less compelled to take part in the research. However, had I been able to recruit from within my workplace environment as a nurse researcher, participants, aware of my profession, might have felt more compelled to speak more highly of their visiting experiences and to refrain from criticisms. In chapter four (section 7.1), for example, I considered whether knowledge of my professional background might have influenced participants' responses and I did not include participants' satisfaction/dissatisfaction as recruitment criteria.

This leads me to consider further my own role in influencing how the participants were telling their stories and what they chose to share or conceal. In the first interviews, especially, when I was making my first forays into semi-structured interviews, my own anxieties sometimes precluded open-ended questions and forced a rapid change of topic, which might have silenced the participants' voices. However, as I became more relaxed with interviewing I was able to sit with pauses and silences.

The next concern was my chosen method for analysing the stories. I disregarded a more technical narrative analysis *per se* for two reasons. First, I felt that it was too restrictive for the broad sweep of my inquiry and second because, by the time I had settled upon the storytelling theme, I had been intuitively handling the data in accordance with the stages of thematic analysis recommended by Braun and Clark (2012) and this seemed to be working well. I also consider that thematic analysis gave me the analytic freedom to explore beyond disciplinary or epistemological boundaries. However, thematic analysis alone produced many codes which were not readily sorted into themes through which to provide a coherent report (Braun and Clark 2012).

This lack of coherence became problematic until, first, I was able to recognise the participants' accounts as stories with a beginning, middle and end. Following from this, I began to assemble the theoretical framework with liminality and the five core themes at the centre. Slowly the structure and focus of the thesis took shape but, as Anfara (2008) and Grbich (2004) warn, the use of liminality precluded other analytic perspectives and traditions such as feminism, phenomenology or discourse analysis, which might have revealed very different research findings. Despite the contextual influences and participants' accounts strongly indicating that hospital visiting is a liminal event, other perspectives and codes (such as 'bringing back matrons', the structure of the NHS and 'luck') that did not cohere with Turner's (1969) characteristics of liminality eventually became redundant.

I also noted in chapters one and three that storytelling is on two levels in this thesis (Bruner 1986). I tell my interpretations of the participants' interpretations of their experiences. My first concern about using participants' stories alone was that much contemporary research now incorporates mixed methods as a means to triangulate the data or shed more light on a phenomenon from differing perspectives. However, as I discussed in chapter four, my options were limited by the policy of the Trust for which I worked in its insistence on retaining intellectual property rights. I could not, therefore, recruit in those hospitals within my nearest reach and neither could I carry out observations on the wards. Research diaries would only have been of use for planned admissions and I wanted to include the richness of emergency admissions in my research. I also considered the use of focus groups but this would have entailed the same recruitment difficulties with the added complication of coordinating a time and place that would be convenient for everyone taking part. I was also concerned that participants in focus groups might be more or less willing than others to share publicly some of the very personal, and sometimes deeply distressing, experiences.

My concerns continued into the writing of the thesis. I did not want to antagonise the participants by incorrectly interpreting and writing about their experiences. But I did aim for as truthful and complete representation of my interpretations as possible. This became particularly difficult when determining occasions of the visitors' (sometimes inadvertent or subconscious) resistance to the social *mores* of the hospitals they visited. For example, I reflected for a long time about whether I could or should legitimately interpret and write about Winnie's illness (chapter 6.3) on the ward or Nina's episode with the drug chart (chapter 5.3) in terms of their resistance to their loss of status when they so obviously worked hard to be 'good visitors'. My intention here was, though, to demonstrate that the hospital environment can be so challenging that, even without obvious intention, it prompts acts of subtle resistance.

Similarly, I attribute the unspoken word 'furniture' to 'not feeling as part of' as Dave describes his needs for information (chapter 5.4). Here I have utilised my familiarity with English language colloquialisms. But this word might not have been Dave's intention or might not have been selected by a researcher for whom English is not a first language. Thus, drawing on Rector-Aranda (2014), I could be understood to be 'giving too much voice' at times in addition to silencing participants' voices as discussed in chapter one.

Towards the end of the thesis, I began to question how my own story of just seventeen differing stories about hospital visiting could be considered a reliable basis for changing policy and education, which would impact on millions of people. To resolve all of these dilemmas, I revisited Taylor's (2003: 319) work (cited in chapter one) in which she, like Yardley (2000) discounts the centrality of establishing causal relationships, and issues of reliability, validity and replicability to qualitative research. Instead, Taylor (2003) proposes that relevance,

usefulness and application are a better way of evaluating qualitative research. Although Taylor (2003) was primarily referring to discourse analysis, her words, I argue, can be readily transferred to all qualitative research.

Therefore qualitative research can never be representative and, as such, not generalisable. However, by using reflexivity as a powerful tool, addressing the activity of hospital visiting, which, to date, has received little interest, by producing new knowledge and by demonstrating how the findings could contribute to future policy making, I would suggest that this thesis has demonstrated its relevance, usefulness and application.

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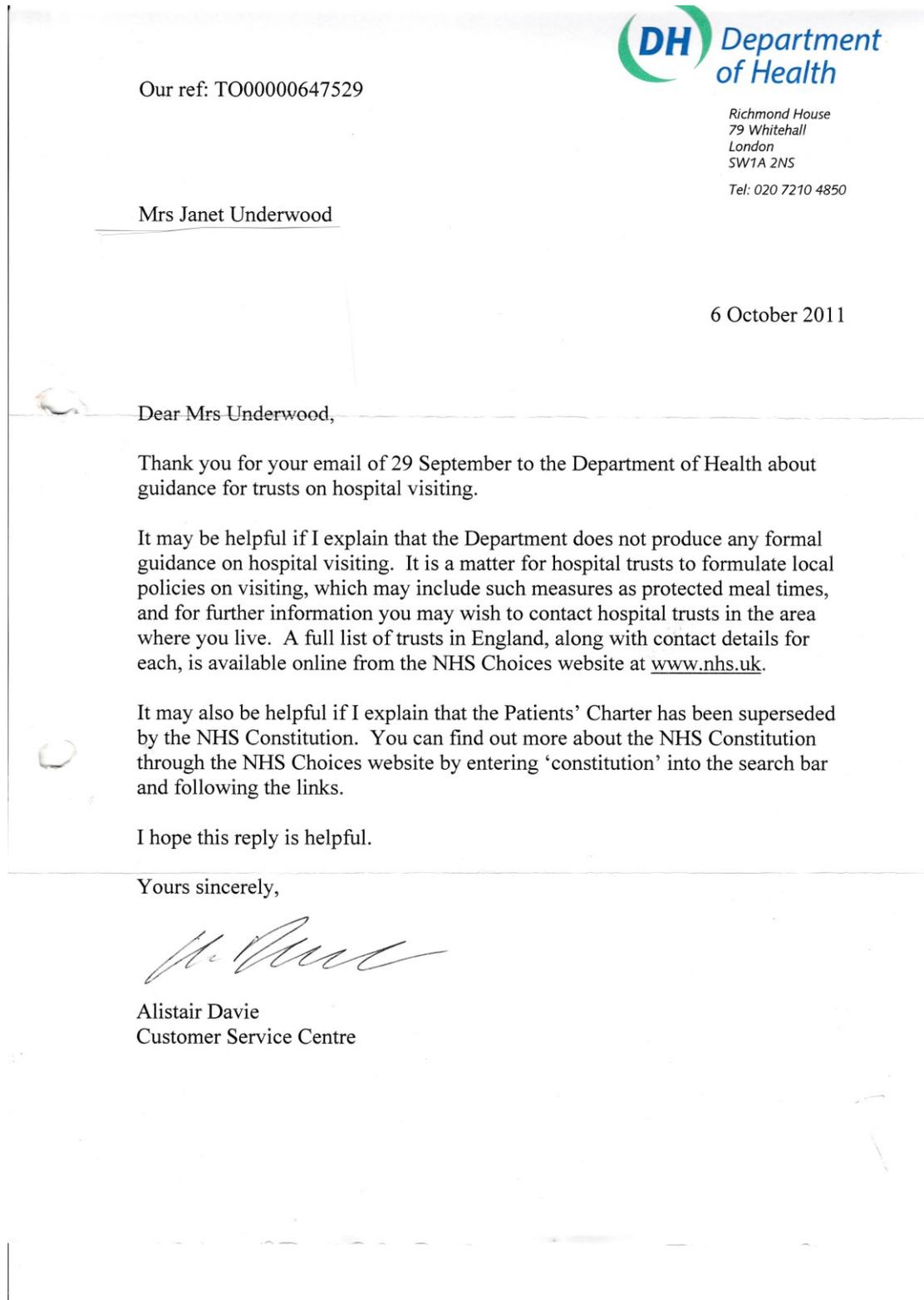
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# Appendices

## Appendix 1. Copy of letter from DoH.



## **Appendix 2. NHS Choices. Visiting someone in hospital.**

The information in this section is a general guide to visiting someone in hospital. Details will vary depending on which hospital you are visiting. Check on the website of the hospital you want to visit for more information.

### Visiting hours

Most hospitals have times at which you can visit your friend or relative. Check with the relevant hospital for information about when you can visit. Bear in mind that different wards often have different visiting times.

If you are unable to attend during visiting hours, talk to the member of staff in charge of the ward to arrange an alternative time to visit.

Hospitals encourage relatives and friends to visit patients. However, patients can get tired very quickly. For this reason, the number of visitors each patient is allowed is usually restricted and it might be necessary to stagger the visitors so they come at different times.

Children can be restricted from visiting a patient in the same way that adults are. In some wards, you need to ask permission for children to visit you, and some wards insist that children under 12 are accompanied by an adult.

### Hand hygiene

When visiting someone in hospital, always clean your hands using soap and water or alcohol hand rubs. Do this when you enter or leave a patient's room or other areas of the hospital. If you are concerned about the hand hygiene of doctors, nurses or anyone else who comes into contact with the patient you are visiting, you are encouraged to ask them whether they have cleaned their hands.

### Illness

If you have a cough, cold, diarrhoea, vomiting or any other infectious condition, contact the ward for advice before visiting.

### Presents for patients

Patients like to receive gifts while in hospital. Most hospitals encourage visitors to bring gifts such as fruit, sweets, books and magazines, but it is important not to clutter the patient's bed area. Check with the ward staff before bringing someone a gift of flowers.

### Smoking

Many hospitals do not permit smoking in any part of their buildings or grounds. If smoking is allowed at the hospital you are visiting, only smoke in the designated outdoor areas.

#### Travel

Parking at hospitals is limited and can be expensive. Where possible, use public transport when visiting someone in hospital.

#### Violence and aggression towards staff

Violence and aggression towards staff, patients or members of the public is not tolerated in any hospital. Assault is a crime, and hospitals will seek the maximum legal penalties for anyone behaving in this way.

#### What not to do when visiting someone in hospital

It's best not to sit on the patient's bed as this can spread germs. Use the chairs provided.

Don't put your feet on the patient's bed.

Don't touch the patient's wounds or any medical equipment they are attached to, such as drips or catheters. This can cause infections.

Don't use the patients' toilets. Ask the ward staff where the nearest public toilets are.

Don't share property, such as toiletries, tissues or items of hospital equipment with the patients.

## **Appendix 3. Peterborough and Stamford Hospitals NHS Foundation Trust Visiting Policy (2014, version 3).**

Retrieved 29/2/2016 from:

[https://www.peterboroughandstamford.nhs.uk/\\_files/policies/31BFAC3E7297D88F5C3AF80745BA86FE.pdf](https://www.peterboroughandstamford.nhs.uk/_files/policies/31BFAC3E7297D88F5C3AF80745BA86FE.pdf)

CAUTION: You must refer to the intranet for the most recent version of this procedural document.

### Key Points

- •  Peterborough and Stamford Hospitals NHS Foundation Trust (PSHFT) actively encourages visiting and the involvement of carers while patients are in hospital.
- •  The statements included in the policy apply to all inpatient areas across the Trust hospital sites.
- •  At all times the Ward Manager or deputy can use their discretion in the best interests of the patients for whom they are caring.
- •  The policy gives staff the authority to manage visiting in a way that provides appropriate access for the patient's family and friends while at the same time protecting confidentiality, security, privacy and rest.
- •  Anyone who is feeling unwell, has a cold or has had any diarrhoea and/or vomiting within the previous 48 hours is asked to refrain from entering the inpatient ward areas.
- •  Infection prevention and control guidance is included in Section 6.

### Patient Visiting Policy

#### 1. Introduction

1. 1.1 The policy for patient visiting at PSHFT aims to balance the therapeutic effect of patients spending time with relatives, carers and friends with the patient's need for rest and the need for clinical staff to manage the ward and care safely and efficiently.
2. 1.2 The Trust are constantly obtaining feedback from our patients and this policy has been written taking into account some of the feedback received around patient visiting.
3. 1.3 PSHFT actively encourages visiting and the involvement of carers while patients are in hospital. There are many ways in which the visitors can help patient care, such as helping patients at mealtimes and visitors should be supported as much as possible, in accordance with the patient's wishes.

## 2. Purpose of the document

1. 2.1 The policy gives staff the authority to manage visiting in a way that provides appropriate access for patients to their families and friends while at the same time protecting confidentiality, security, privacy and rest.
2. 2.2 Clear statements and a common approach are provided so that as patients move between wards and hospital sites consistent information may be given to them and their visitors.

## 3. Scope

3.1 The statements included in the policy apply to all inpatient areas across the Trust. Where special circumstances apply, this is made clear within the policy. At all times, the Ward manager or deputy can use their discretion in the best interests of the patients for whom they are caring.

## 4. Duties and responsibilities

1. 4.1 The Executive Team is responsible to the Trust Board for ensuring Trust wide compliance with the policy.
2. 4.2 General Managers are responsible to the Executive Team for policy implementation.
3. 4.3 Departmental Managers, Lead Nurses, Matrons and Ward Managers are responsible for implementation of the policy and ensuring compliance by clinical staff.
4. 4.4 All Staff providing clinical care are personally and professionally responsible and accountable for complying with this policy.

Patient Visiting Policy

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## 5. Visiting times and guidelines for visitors

1. 5.1 All visitors to patient areas should report to the nurses' station prior to entering the patient bed areas. This is to protect patient privacy and dignity, enhance security in the wards and to improve communication with visitors.
2. 5.2 For the benefit of nearby patients, visitors will be restricted to a maximum of three per patient. Visitors should not visit for long periods – short visits are less tiring for patients.
3. 5.3 Visiting times will be from 2pm to 4pm and 6pm to 8pm on all inpatient wards with the following exceptions:
  1. 5.3.1 The Maternity Unit visiting times are 8am to 8pm for partners and 2pm to 4pm and 6pm to 8pm for all other visitors including siblings. A maximum of 2 well behaved children are allowed to visit at any one time. Please note that these times apply to ward areas only. On the delivery unit and the midwife-led unit, only birth partners are allowed, and they are able to visit at any time.

2. 5.3.2 On NICU, the baby's parents and siblings can visit at any time. No other children under 14 can visit. All other visitors must visit one at a time and be accompanied by the baby's parent. Specific visiting hours apply which are available on the unit as they are too detailed to write here.
3. 5.3.3 Amazon Ward operates an open visiting policy up to 20.00hrs when resident parents /carers only are allowed on the ward.
4. 5.3.4 The Critical Care Services (CCS) visiting times are 12pm to 3pm with a rest period between 3pm and 4.30pm then 4.30pm to 9pm.
4. 5.4 Visitors will be welcome on the wards at other times in discussion with the senior nurse on duty. Consideration will always be given to visitors who are unable to visit during core times because of personal circumstances.
5. 5.5 Visitors are encouraged to be present for specific treatments where they are involved in giving continuing care. If the patient wishes, visitors may be present for consultant/medical rounds by prior arrangement.
6. 5.6 In line with our Carers' Charter we will give you a choice on whether you wish to take on / continue with the role of carer whilst the person is in hospital and ensure that you are given the access and support necessary to enable you to provide care should you so choose.

Waive the restrictions on visiting hours to enable you to support the person you care for at meal times and with their personal hygiene needs, should you wish to. (Carers' Charter - 2320)

Where appropriate visitors will be welcomed at mealtimes to assist and encourage patients with their meals.

7. 5.7 Provision can be made for relatives/carers who wish to stay overnight with critically ill patients. In case of any problems the duty manager may be contacted.
8. 5.8 Cameras (including mobile phone cameras) and camcorders may not to used by visitors in the ward areas. The exception to this is within the Maternity Unit where special procedures are in place.
9. 5.9 Visitors should be reminded that all Trust premises, including the grounds, are no smoking areas.

Patient Visiting Policy

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5.10 The Trust operates a zero tolerance policy relating to any kind of verbal or physical abuse and visitors may be asked to leave if their behaviour causes disturbance to other patients or staff.

## 6. Infection Prevention and Control

1. 6.1 In order to help Trust staff to minimise the risks of healthcare associated infections, the guidance detailed below must be followed.

2. 6.2 Anyone who is feeling unwell, has a cold or has had diarrhoea and/or vomiting within the previous 48 hours is asked to refrain from entering the hospital.
3. 6.3 All visitors are asked to clean their hands before sitting down with the patient they are visiting and on leaving. This can be done using soap and water at the hand washing basins or using the hand hygiene gel located at the entrance to each ward.
4. 6.4 Where patients are being nursed using isolation measures relatives need not wear Personal Protective Equipment (PPE) except if participating in hands on care. Any additional requirements will be explained by the nursing staff.
5. 6.5 Visitors are requested not to sit on the patient's bed but to use the chairs provided.
6. 6.6 Visitors are requested not to use the patient's toilets on the wards.
7. 6.7 Where a ward has an infection outbreak the Ward Manager and Infection Control

Team will have the right to close the ward to all visitors in order to manage and contain the infection as quickly as possible. The Ward Manager will use his/her discretion where there are requests to visit patients during an outbreak situation, for example where patients are receiving palliative care or where the patient has special needs.

8. 6.8 Visitors are requested not to bring flowers in to the ward as they are an infection control risk due to stagnant water.

## 7. Children visiting patients

1. 7.1 There are no specific restrictions on children visiting. However, young children must be supervised by appropriate adults. Staff will ask for children to be removed where this is not the case. It is suggested that visits that include children should be limited to a maximum of 30 minutes. Children are included in the maximum number of visitors for each patient.
2. 7.2 Adolescent visitors may visit without adult supervision.
3. 7.3 In the Maternity Unit a maximum of 2 children may visit at any one time and the

children must remain in the care of the visitor not the patient.

4. 7.4 Ward B1 isolation unit discourages children from visiting. This can be discussed on

an individual basis

## 8. Staff visiting staff

8.1 When members of staff are in-patients, staff wishing to visit them should respect their colleagues' status as a patient and must follow the statements in this policy.

#### **Appendix 4. Email communication with NHS Confederation in attempt to ascertain costs to NHS of handling formal complaints.**

Hi Janet,

Thanks for taking the time to contact me.

Can I just clarify what you are precisely looking for please? Is it the cost to NHS trusts of managing complaints about their services or the costs involved with litigation for cases involving e.g. clinical negligence?

Thanks,

Sam

Sam Hunt  
Knowledge and Research Manager

DDI: 020 7799 8684

Hi Sam

Thank you for getting back to me so quickly.

It is the costs to the NHS trusts in England for managing their complaint - preferably the data for 2014-2015 and, if possible, a contrast year or two to demonstrate how costs are escalating or diminishing

If you have time to let me know the litigation costs that would be great but I know these are available (but, for a non statistician) complex to understand!

Best wishes

Janet

Hi Janet,

Unfortunately I have been unable to locate a central data collection for the costs associated with complaint handling. Sorry that I can't be of more help on this occasion. Page 17 of the NHSLA's annual report provides a helpful visual illustration of the costs involved with both clinical and non-clinical negligence though:

<http://www.nhsla.com/aboutus/Documents/NHS%20LA%20Annual%20Report%20and%20Accounts%202014-15.pdf>

Best wishes,

Sam

Sam Hunt  
Knowledge and Research Manager  
DDI: 020 7799 868

## Appendix 5. Ten types of hospital visitor by Charles Causley.

1.

The first enters wearing the neon armour  
Of virtue  
Ceaselessly firing all-purpose smiles  
At everyone present  
She destroys hope  
In the breasts of the sick,  
Who realise instantly  
That they are incapable of surmounting  
Her ferocious goodwill.  
Such courage she displays  
In the face of human disaster!  
Fortunately she does not stay long.  
After a speedy trip round the ward  
In the manner of a nineteen-thirties destroyer  
Showing the flag in the Mediterranean,  
She returns home for a week  
- With luck, longer -  
Scorched by the heat of her own worthiness

2.

The second appears, a melancholy splurge  
Of theological colours;  
Taps heavily about like a healthy vulture  
Distributing deep-frozen hope.  
The patients gaze at him cautiously.  
Most of them, as yet uncertain of the realities  
Of heaven, hell-fire, or eternal emptiness,  
Play for safety  
By accepting his attentions  
With just-concealed apathy,  
Except one old man, who cries  
With newly sharpened hatred,  
'Shove off! Shove off!  
'Shove...shove...shove...shove  
Off!  
Just you  
Shove!'

3.

The third skilfully deflates his weakly smiling victim  
By telling him  
How the lobelias are doing.  
How many kittens the cat had,  
How the slate came off the scullery roof,  
And how no one has visited the patient for a fortnight  
Because everybody  
Had colds and feared to bring the jumpy germ  
Into hospital  
The patient's eyes  
Ice over. He is uninterested  
In lobelias, the cat, the slate, the germ.  
Flat on his back, drip-fed, his face  
The shade of a newly dug-up Pharaoh,  
Wearing his skeleton outside his skin,  
Yet his wits as bright as a lighted candle,  
He is concerned only with the here, the now,  
And requires to speak  
Of nothing but his present predicament.  
It is not permitted.

4.

The fourth attempts to cheer  
His aged mother with light jokes  
Menacing as shell-splinters.  
'They'll soon have you jumping round  
Like a gazelle,' he says.  
'Playing in the football team.'  
Quite undeterred by the sight of kilos  
Of plaster, chains, lifting-gear,

A pair of lethally-designed crutches,  
'You'll be leap-frogging soon,' he says  
'Swimming ten lengths of the baths.'  
At these unlikely prophecies  
The old lady stares fearfully  
At her sick, sick offspring  
Thinking he has lost his reason-  
Which, alas, seems to be the case

5.

The fifth, a giant from the fields  
With suit smelling of milk and hay,  
Shifts uneasily from one bullock foot  
To the other, as though to avoid  
Settling permanently in the antiseptic landscape.  
Occasionally he looses a scared glance  
Sideways, as though fearful of what intimacy  
He may blunder on, or that the walls  
Might suddenly close in on him.  
He carries flowers, held lightly in fingers  
The size and shape of plantains,  
Tenderly kisses his wife's cheek  
- The brush of a child's lips -  
Then balances, motionless, for thirty minutes  
On the thin chair.  
At the end of visiting time  
He emerges breathless,  
Blinking with relief, into the safe light.  
He does not appear to notice  
The dusk.

6.

The sixth visitor says little,  
Breathes reassurance,  
Smiles securely.  
Carries no black passport of grapes  
And visa of chocolate. Has a clutch  
Of clean washing.  
Unobtrusively stows it  
In the locker; searches out more.  
Talks quietly to the Sister  
Out of sight, out of earshot, of the patient.  
Arrives punctually as a tide.  
Does not stay the whole hour.  
Even when she has gone  
The patient seems to sense her there:  
An upholding  
Presence.

7.

The seventh visitor  
Smells of bar-room after-shave.  
Often finds his friend  
Sound asleep: whether real or feigned  
Is never determined.  
He does not mind; prowls the ward  
In search of second-class, lost-face patients  
With no visitors  
And who are pretending to doze  
Or read paperbacks.  
He probes relentlessly the nature  
Of each complaint, and is swift with such  
Dilutions of confidence as,  
'ah! You'll be worse  
Before you're better.'  
Five minutes before the bell punctuates  
Visiting time, his friend opens an alarm clock eye.  
The visitor checks his watch.  
Market day. The Duck and Pheasant will be still open.

Courage must be refuelled.

8.

The eighth visitor looks infinitely  
More decayed, ill and infirm than any patient.  
His face is an expensive grey.  
He peers about with antediluvian eyes  
As though from the other end  
Of time.

He appears to have risen from the grave  
To make this appearance.  
There is a whiff of white flowers about him;  
The crumpled look of a slightly used shroud.  
Slowly he passes the patient  
A bag of bullet-proof  
Home-made biscuits,  
And strong death-dealing cake –  
'to have with your tea,'  
Or a bowl of fruit so weighty  
It threatens to break  
His glass fingers.  
The patient, encouraged beyond measure,  
Thanks him with enthusiasm, not for  
The oranges, the biscuits, the cake,  
But for the healing sight  
Of someone patently worse  
Than himself. He rounds the crisis-corner;  
Begins a recovery.

9.

The ninth visitor is life.

10.

The tenth visitor  
Is not usually named.

## Appendix 6. Human Research Ethics Committee approval



The Open University

From Dr Duncan Banks  
Chair, The Open University Human Research Ethics Committee  
Email [duncan.banks@open.ac.uk](mailto:duncan.banks@open.ac.uk)<sup>[1]</sup>  
Extension 59198

To Janet Underwood, Faculty of Social Sciences

Subject *"Just a bunch of grapes? An exploration of the needs and experiences of adult visitors to NHS acute medical and surgical wards in England."*

Ref HREC/2012/1316/Underwood/1

Red form

Submitted 23 November 2012

Date 24 November 2012

### Memorandum

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This memorandum is to confirm that the research protocol for the above-named research project, as submitted for ethics review, is **approved** by the Open University Human Research Ethics Committee.

Please make sure that any question(s) relating to your application and approval are sent to [Research-REC-Review@open.ac.uk](mailto:Research-REC-Review@open.ac.uk) quoting the HREC reference number above. We will endeavour to respond as quickly as possible so that your research is not delayed in any way.

At the conclusion of your project, by the date that you stated in your application, the Committee would like to receive a summary report on the progress of this project, any ethical issues that have arisen and how they have been dealt with.

Regards,



Dr Duncan Banks  
Chair OU HREC

<sup>[1]</sup> please note the change in email address

The Open University is incorporated by Royal Charter (number RC 000391), an exempt charity in England & Wales and a

**Appendix 7. Participants' consent form.**

**HREC ref: 1316**

**Faculty of Social Sciences**

**Just a bunch of grapes? What are the experiences of adult visitors to NHS acute medical and surgical wards in England.**

**Agreement to Participate**

I,  (print name)

Agree to take part in this research project.

I have had the purposes of the research explained to me.

I have been informed that I can refuse to participate at any point by simply saying so\*.

I have been assured that my confidentiality will be protected as specified in the leaflet.

I agree that the information I provide can be used for educational or research purposes, including publication and can be stored until 2022.

I understand that if I have any difficulties or concerns I can contact:

Janet Underwood at  [ju39@my.open.ac.uk](mailto:ju39@my.open.ac.uk)

If I want to talk to someone else about the project, I can contact

Dr Janet Fink - [j.fink@open.ac.uk](mailto:j.fink@open.ac.uk) tel 01908 654534

Dr Jean Carabine - [j.j.carabine@open.ac.uk](mailto:j.j.carabine@open.ac.uk) tel 01908 654534

I assign the copyright for my contribution to the Faculty for use in education, research and publication.



Signed.....  
.....Date.....

## **Additional information**

### **\*Withdrawing from the research.**

Consent can be withdrawn at any time up until the commencement of data analysis by:

- simply saying so **or** emailing me at - [ju39@my.open.ac.uk](mailto:ju39@my.open.ac.uk)

Following a request to withdraw from the research any data previously collected and information held about participants will be destroyed within one month of the request.

### **Data Protection and Confidentiality**

The research project has been lodged with the Faculty of Social Sciences Data Protection Officer (Carole Moyle) for registration under the Data Protection Act . All data will be stored in secure facilities both on and off campus. Encryption arrangements for storage of data on portable equipment whilst the research is being undertaken will be made. All data will be fully anonymised and treated as confidential. Data will not be shared between participants except for their own personal transcripts. No personal details or data will be passed for use by a third party.

The data will be used as part of doctoral program that will hopefully be completed by 2017. It is expected that the earliest date for destruction of the data could potentially be 2027. All the data will be securely stored on-campus. All participants will be asked if the data relating to them can be kept until 2022.

Participants will be invited to read and comment on their own data transcripts, and add or delete material if they so wish

## Appendix 8. Information leaflet side 1

<p><b>What are the benefits of taking part?</b></p>	<p>People often find it both interesting and helpful to talk about their experiences.</p> <p>What you say will help complete my research project.</p> <p>The research findings might be helpful to others in the future</p>	
<p><b>Contact Details</b></p>	<p>Should you have any queries or concerns, please contact me or my supervisors at the Open University, Dr J Fink and Dr J Carabine (tel 01908 654534)</p>	<p><b>Email addresses</b></p> <p>Dr Janet Fink - <a href="mailto:j.fink@open.ac.uk">j.fink@open.ac.uk</a></p> <p>Dr Jean Carabine <a href="mailto:j.j.carabine@open.ac.uk">j.j.carabine@open.ac.uk</a></p> <p>Janet Underwood—<a href="mailto:ju39@my.open.ac.uk">ju39@my.open.ac.uk</a></p>
<p><b>Just a bunch of grapes? What are the experiences of the hospital visitor</b></p>		<p><b>Janet Underwood</b></p> <p>A PhD Research project</p>

## Appendix 9. Information leaflet side 2

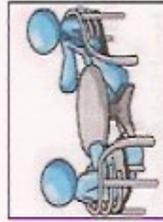
### **What does it feel like to be a hospital visitor?**



Although people have been visiting loved ones in hospital for years, very little is known about their needs and experiences. For my PhD research, I want to find out what really happens for people when they become hospital visitors.

### **What is involved in taking part?**

I would like to record a discussion with you lasting 30-60 minutes. I am interested in hearing about your experiences as a hospital visitor.



Everything you say will be treated as confidential. I will use a false name for you throughout the research so you cannot be identified

### **What if I change my mind?**

You will be free to stop the recording at any time. You will also be able to 'take back' anything you say which you feel unsure about. You can also withdraw from the research at any time.



## **Appendix 10. Interview schedule.**

### Interview Schedule

1. Ice breaking – establishing a rapport
2. Going through leaflet, explaining research and obtaining informed consent and informing of right to stop the recording at any time
3. Testing recording equipment
4. Starting interview:

### Main Interview question

I wonder if you could tell me a bit about yourself and your recent experiences of being a hospital visitor.

### Topics to be introduced as interview progresses and to be worded as appropriate

1. How expectations or prior knowledge/experience may have shaped the recent experience
2. The hospital environment eg car park, signage, ward, privacy, information
3. How the rules and regulations impacted
4. Interactions with other people
5. Feelings and emotions (? aroused by sight, sound and smell)
  - Responsibility
  - Anxiety
  - Guilt
  - Empathy etc

### Concluding questions

Could you describe for me a bit about how you felt when you were leaving the ward/hospital?

Can you think of things that might have made the situation any better/easier for you?

### Debriefing

Permit time for discussion of interview process, feedback etc.

Make sure participant is ok before leaving, thank them and point out contact details again.

Appendix 11. Analysis: working paper

679 actually engage eye contact with one of  
 680 those people. Now they were, they must  
 681 have been aware of my presence because  
 682 I don't travel into hospital unless I am  
 683 dressed for importance. I go in heels. I  
 684 go in a jacket and I go as if I mean  
 685 business because otherwise you have no  
 686 chance. You have to make the power  
 687 statement. You have to be, 'I will know  
 688 and you will engage with me. So you  
 689 stand at that desk for six and a half  
 690 minutes until somebody actually looks at  
 691 you and you say, 'I'm sorry to disturb  
 692 you but I need some information.' 'And  
 693 who are you?' 'I'm Gill Brown, <sup>the patient</sup>  
 694 ~~But~~ is my husband. I'm his carer and  
 695 advocate. I need to know what is going  
 696 on with his care.' Then there is a certain  
 697 amount of 'Uhh, do we really have to g-,  
 698 do we really have to do this?' 'Well,  
 699 I'm act-, you may be quite busy and I'm  
 700 sure it's all important but I'm also busy.  
 701 I have to manage everything that goes  
 702 with our life and that's include ~~his~~  
 703 care whilst he's in your care because I'm  
 704 his advocate'  
 705 **Janet.** Do you trust them?  
 706 **Gill.** Er, I don't trust them to know  
 707 what's going on because I've found too  
 708 many occasions when there has been  
 709 holes in the information which has been  
 710 handed over. Which is not. It's either, it  
 711 may well be recorded. I won't say that  
 712 it's not recorded because I think so much

relevance of eye contact? being ignored?

counteracting staffs attempt to make her feel unimportant? no chance? at what? being acknowledged?

sarcasm? irony? or real apology?

clearly identifying herself as primarily Gill before elaborating her role

she is not possessed by ~~him~~ but possessed by him? relationships?

time pressures

assertiveness

desk as a barrier - use them?

were they for (invisible)?

INTERACTIONS  
waiting to engage, be acknowledged

PRESENTATION OF SELF  
power dressing, power statement, means business, assertiveness in control

IMPORTANCE OF SELF  
1) is she rebelling against ~~her~~ husband importance & asking for acknowledgement of herself & her needs (eg info)  
2) Does being wife, carer, advocate add to self importance?

TIME  
she is as busy as they are

'YOUR CARE'  
1) she has lost role  
2) ? Resent of their care  
3) she can't hand over full responsibility  
4) she reminds them of her importance of her importance? psychological ownership

TRUST/INFO  
lost trust due to poor communication

## Appendix 12. Potential working codes

Support	Complaining	Trust
Time – pressures, waiting, value of time, regulation and control of time	Knowledge/information	Risk
Family	Luck	Dehumanisation
Being ignored	Car park	The visitors' role
Material aspects of hospital environment	Patient's basic human rights (to adequate care)	Metaphor and other linguistic strategies
Care (for and about)	Matrons	Own embodiment
See themselves as consumers	Language	Patient's embodiment
Waiting/visitors room	Privacy	Responsibility
Emotions	Territoriality	Lack of communication
Uncertainty	Past experiences	Cup of tea/coffee
Anxiety and stress	Hierarchies	Matrons
Coping strategies	Losses/gains	How the NHS is organised
Roles and identities	Getting lost	Chairs and comfort
Not the 'everyday'	Media	Changes (lifestyle etc)
Coping with continuing work and domestic tasks	'Prime' visitor	Next of kin
Being a good family	Being a good visitor	Patient confidentiality
Compliance and power	Assertiveness/resistance	Mismatch of perceptions and expectations
Nurses station	Empathy	Removal from everyday
Interactions with others outside hospital	Interactions with other patients and visitors	Interactions with staff
Psychological ownership	Us and them	Consistent information
Media reports of poor care	Regulation and control of time	Observing and being observed
Recognising boundaries	Complaining	Hand gel

**Appendix 13. Features of liminality (Turner 1974 pp92-93) corresponding to analysis themes**

<u>Turner's liminal features</u>	<u>Corresponding features in data</u>
Transition	Transition – caused by patients' altered physical state and possible future lifestyle changes
Communitas in opposition to structure	Communitas as in 'all being in it together' – within kinship group members and close friends but not with other patients or visitors as expected. BUT. Hospitals are a highly structured environment.
Absence of status and rank	Own 'everyday' roles, identities and routines often suspended as visitor role and identity assumed.
Homogeneity, equality, absence of property	All have the same status as hospital visitor irrespective of status outside of hospital but nb one person becomes 'the prime visitor'. Visitors do not own anything in the hospital - not even the bedside space.
Nakedness or uniform clothing	Most people in hospitals are patients in nightclothes or staff wearing name badges and often in uniform. Visitors amongst minority wearing own day clothing and no identity badge.
Humility, total obedience, silence, heteronomy, master of ceremonies	Many attempts to be a 'good visitor' and comply with regulations, directions etc (but not all). Subject to hospital rules and regulations. (This raises issues of power, compliance, resistance, assertiveness – more so due to policies of responsabilisation and a better informed society)
Anonymity	Participants report being 'invisible', ignored, not seen, not acknowledged (especially at the nurses station)
Disregard for personal appearance, unselfishness, acceptance of pain etc	Visitors made the patients' well-being their prime concern. Their own needs were secondary.
Suspension of kinship rights and obligations	Obligations and responsibilities continue and often enhanced but issues of psychological ownership demonstrate acknowledgement of hospitals' assumptions of some of these rights and obligations

Simplicity, foolishness, sacred instruction	Visitors are subject to discourses of medical knowledge, which accentuates their own lack of knowledge. They seek information to redress this.
Sexual continence	This is a tacit social norm within hospitals
Minimisation of gender distinctions	More female volunteers for taking part in the research. Women seemed more engaged with the patient's position, care etc. but participants did not explicitly refer to the gendered influences on visiting experience.
Distinctions of wealth downplayed	Financial capital -influential in facilitating the journeys to and from hospital (ie car ownership). Social and cultural capital influential.
Continuous reference to mystical powers	Some references to fate or luck (more as colloquialisms), one reference to a Deity and one reference to spirituality

Name	Admission	Good experience of structure	Close bond with patient	Weak bond with patient	Poor structure	Strong communitas	Weak communitas	Safe exit from liminality	Prolonged liminality
Gill	emergency		X		X		X		X
Jane	emergency		X		X		X		X
Liz	emergency	X	X			X		X	
Ed (sister)	emergency	X	X				X	X	
Ed (friend)	emergency			X	X		X	X	
Winston	planned	X	X				X	X	
Danny	emergency	X	X			X		X	
Meg	emergency	X	X			X		X	
Dave	emergency	X	X			X		X	
Ruth	planned	X	X			X		X	
Amanda	planned	X	X				X	X	
James	planned	X	X			X		X	
Winnie	planned	X	X				X	X	
Jim	planned	X	X				X	X	
Nina	both		X		X	X		X	
Sue	both	X	X			X		X	
Molly	emergency	X	X			X		X	
Sally (mother)	emergency		X		X		X		X
Sally (husband)	planned	X	X			X		X	

Appendix 14. Table 4. Participants' experiences of structure, communitas and exiting liminality

## **Appendix 15. Forthcoming paper. Nursing Standard (2016)**

### **On the other side: hospital visitors' experiences at the nurses' station.**

#### Abstract

The experiences of visiting hospitalised friends and family members in English NHS general wards is under-researched. In the research interviews, the participants all seemed to describe their experiences as hospital visitors as a rupture from their everyday and a sense that 'things' might never be the same again. In effect, they were describing liminality or that state of being between one way of life and another way, yet to be determined. Using liminality as an analytic lens, permitted recognition of the lack of status, challenges, ambiguity, invisibility and uncertainty hospital visitors' experience. Nurses' heavy workloads often result in missed meal breaks, meaning they seek some 'down time' behind the nurses' station. This research suggests that nurses consider the area behind the nurses' station as 'backstage' (Goffman 1971) whilst visitors understand it as continuation of the ward 'front stage'. Waiting at the nurses' station to be acknowledged whilst ward staff continued personal conversations exacerbated hospital visitors' discomfort and frustration and their sense of the structural invisibility of liminality.

Key words: hospital visitors, nurses' stations, liminality

#### **Introduction**

This paper arises from a wider qualitative PhD study (Underwood, 2016 thesis in progress) of the under-researched experiences of visitors to their hospitalised friends and family members in National Health Service (NHS) acute general wards in England. There were 120,778 written complaints about poor care in NHS hospitals in England for the year 2014 -2015<sup>94</sup> with no account of those problems diffused verbally on the wards. A better-informed awareness of hospital visitors' perceptions might lead to less complaints and permit costly resources to be directed towards better care.

Hospital visitors in this research described their experiences as a removal from the humdrum of their everyday, a memorable event, a time of great uncertainty with fears about the illness trajectory of their significant other and what changes in lifestyle might be required. In his anthropological study, van Gennep (1960) coins the term, 'liminality' to represent this interim, or threshold, stage of a tripartite progression from one status to another. Liminality is

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<sup>94</sup> Retrieved 30/09/2015 from [www.hscis.gov.uk](http://www.hscis.gov.uk)

preceded by the first stage of removal from society and followed by reincorporation back into society but with altered status.

Turner (1974) extends this work and suggests several features and characteristics of liminality. Liminal personae may be considered as ambiguously 'betwixt and between' two social structures, or ways of being. They endure character-building challenges, which will increase their contribution to society after reintegration. They lack status, their total obedience is obligatory and they often bond together in 'communitas', which is the sense of all being in the same situation together. Liminality is accompanied by uncertainty and structural invisibility and liminal personae are considered as disruptive threats. Structural invisibility is not a physical invisibility but arises from the human need to categorise in order to make sense of the world (Douglas 1966). The ambiguity of liminality means that those charged with maintaining structure in a society are unable to effectively categorise the liminal personae and therefore 'overlook' them.

Liminal personae are also expected to demonstrate total obedience to those charged, as 'masters of ceremony', with overseeing their safe passage through liminality (Turner 1974). Whilst not generally a phenomenon of hospital visiting in all its totality, this was implicitly demonstrated in a lesser form throughout the participants' accounts by their attempts to be seen, by others in the hospital, as 'good visitors'. This is reminiscent of Lorber's (1975) seminal work in which she suggests that hospital patients who are compliant and do not complain are seen by nurses as 'good patients'. 'Problem patients' are those who loudly complain, often unnecessarily, and vocalise many demands. Similarly, 'good visitors' must obey the rules and not complain. As Turner (1974) states:

[Liminal personae] elude or slip through the network of classifications that normally locate states and positions in cultural space. Liminal entities are neither here nor there; they are betwixt and between the positions assigned and arrayed by law, custom, convention and ceremonial [...] Secular distinctions of rank and status disappear or are homogenized' (p81) [...]

[T]hey are persons or principles that (1) fall in the interstices of social structures, (2) are on its margins, or (3) occupy its lowest rungs (p112)

Hospital visitors can be grouped into one or more of four categories: 'patients' visitors' who are friends and family; 'public visitors' include the clergy, entertainers, sports personalities who have no direct involvement with the hospital; 'house visitors' who are associated with the hospital, for example, management or financial benefactors; and 'official visitors' such as government inspectors (Mooney and Reinartz 2009 p8). Utilising liminality as an analytic

lens, this research concentrates on the first category of 'patients' visitors' and focuses on their experiences whilst seeking attention at nurses' stations as a specific place on hospital wards.

### **Literature review**

The limited research into hospital visitors' experiences in England has been predominantly quantitative and concentrates mostly on visitor rules and time restrictions (Bates 2002, Hoban 2004, Tanner 2005, Taylor 2008). Webb (2007) seeks hospital visitors' perspectives on other practicalities, such as ward cleanliness. However, she considers visitors' opinions as cohering with those of the patients. A more recent qualitative study has involved researching, specifically, older patients' and visitors' experiences of hospital visiting (Green et al 2012).

More critically and of salience for this paper, there have been complaints of excessive waiting at the o (Carpenter 1997) and places where nurses socialise inappropriately and keep away from the patients (Rayner 2008). This central feature has also been criticized for being a site of too much noise (Pope 2010). Jarrel and Shattell (2010) debate whether this work place should be called 'nurses' station' or 'nursing station', with the former implying possession and in/exclusion and the latter a place where nurses work.

NHS hospital ward designs vary but a common feature is the nurses' station which are multi-purpose: a place for multi-team collaboration (Gum et al 2012); a site of rites of passage for those entering the ward and, so, a barrier between public and private ward processes and a site of power and control (Wakefield 2002); and places on the wards where nurses spend the greatest part of their time (Hendrich et al 2008). In the context of design, nurses stations have also been described as 'hubs of activity where nurses gather to work individually, collaborate or socialize' [sic] (Chiang 2010: 1), or a place where team spirit and collaboration could be adversely affected by their decentralisation (Zoborowsky et al 2010). An extensive literature search has failed to reveal any more detail of how hospital visitors might experience the nurses' stations as specific places on wards.

### **The research design**

The research is a qualitative study and, as such, aims for rich interpretations and the deeper meanings of the experiences of those who went to visit their hospitalised, adult family member or friend. Due to the constraints in the local NHS hospital trust's policy for researchers it does not employ, the participants were all recruited within the wider community. They had all been hospital visitors on the more general wards within the preceding two years and were adults of varying ages (20 – 80+ years). Other social determinants, such as employment or marital status, were equally varied and hospitals visited included two in London, several in the Midlands and one in northern England. Although both men and

women took part, there were more female volunteers (n = 12) than male (n = 5). British Sociological Association (2002) ethical principles were followed. Ethical approval was obtained from The Open University Human Research Ethics Committee with the condition that 10% of the participants should come from a developing country and/or should not have English as their first language. A small pilot study was completed prior to the main fieldwork. All participants and the patients they visited have been accorded pseudonyms, with full confidentiality assured. Information leaflets were supplied to the participants and their written consent was obtained prior to the interviews. The participants were advised of their rights to halt the interviews or withdraw from the research. 17 semi-structured interviews, lasting between one and two hours, were carried out in 2013 and recorded. A schedule of open-ended questions was compiled as an aide-memoire but participants were also encouraged to talk freely about their experiences, with emerging themes being further explored as the research progressed. The interviews were transcribed verbatim and subjected to a thematic analysis (Boyzatis 1998, Braun and Clark 2012) with liminality employed as an analytic lens.

## Results

The characteristics of liminality prevailed throughout the participants' accounts as they unanimously described their time as hospital visitors as a suspension of the humdrum of their 'everyday'. For many there were major life transitions as they contemplated uncertain futures. Examples of the transitions included bereavement, a house move due to on-going illness or the demands of undertaking a greater caring role. There were also positive transitions to include a better quality of life following surgery for arthritic joints or a troublesome hernia, for example.

Within the hospitals, the participants' everyday roles were suspended, but they were often unaware of the more implicit rules associated with their new roles. This sometimes led to an involuntary, but disruptive, infringement of the rules with, sometimes unwelcome, results. The participants' 'outside hospital' status became irrelevant. They did not wear the identity badges or uniforms of staff or patients (nightclothes) and so were not readily categorised. This resulted in structural invisibility (Turner 1974). Participants often felt marginalised and not part of the main event, which was the patient's illness and care.

The participants described differing experiences of entry onto the ward. Although two participants said they were welcomed and taken to the patient's bed, Sue describes her entry:

**Sue:** And very convoluted way of getting to that particular ward, which was signposted eventually, but when you came on to the ward, very hard to locate my father. It was a little bit like a rabbit warren. Corridors off onto other corridors. And nobody at the nurses station when you first get there, and having to hang

around for a few minutes. And then when somebody did come to the nurses station, they asked, obviously asked for his name and then they just pointed in a general direction. So I ended up going twice round the loop trying to find it. I thought perhaps the nurse would take me round and actually show me where he was physically. So to actually find him was just a little bit more tricky.

Sue demonstrates the frequently reported challenge of successful navigation around the hospital. At the ward entrance she did not receive the welcome, comfort or refreshment, which are the qualities of hospitality norms (Lashley 2000). 'Hanging around at the nurses station' was a common experience for participants. This was sometimes because nurses were absent from the nurses' station and engaged in delivering patient care, but was often due to other circumstances as Gill described:

**Gill:** I feel I'm invisible, I'm a nuisance, I'm detracting them from their work and I really should know better than to interfere.[...] I certainly had this on one occasion, five members of staff all seated in front of computer screens and I stood at that desk for six and a half minutes before I could actually engage eye contact with one of those people. Now they must have been aware of my presence because I don't travel into hospital unless I am dressed for importance. I go in heels. I go in a jacket and I go as if I mean business because otherwise you have no chance. You have to make the power statement. You have to be, 'I will know and you will engage with me'. So you stand at that desk for six and a half minutes until somebody actually looks at you and you say, 'I'm sorry to disturb you but I need some information.'

For Gill, being 'dressed for importance' was of little consequence when trying to get attention at the nurses' station. Like other participants, she encountered a bewildering difference in hospital hospitality rules from those that prevail in either the domestic sphere or the commercial arena (Brotherton 1999, King 1995, Lashley 2008). Hospital hospitality, as a concept, sits ambiguously between both categories. The barrier between professional and lay, included and excluded and private and public was physically emphasised by the desk between Gill and the nurses. Furthermore, due to the implicit need to be seen as a good visitor, Gill was unable to make her request without first engaging eye contact with the nurses. Her words, 'I'm sorry to disturb you' can be interpreted in two ways. She could have been employing sarcasm to signify that she had been kept waiting. She could also have been ultimately so discomforted, that her first words are those of an apology as she tries to be a good visitor.

Several of the participants reported similar experiences. Although, Gill's account suggests that the nurses were preoccupied with their work on computers, several also mentioned that

the nurses were engaged in personal conversations, as Jane's following description demonstrates:

**Jane:** They were chit-chatting at the nurses station and there was quite a group of them as well and they weren't just nurses, there were doctors as well. There was quite a group of them, there must have been eight or nine of them. And I was stood there, the other side of the counter, for a good few minutes before anybody - . They knew I was there 'cos they couldn't possibly not know I was there but before anybody dare give me eye contact, I was stood there.

Like Gill, Jane waited for eye contact before expressing her request. Similarly she was one side of the desk with the staff the other. A direct gaze and eye contact signals inclusion and being valued, with a consequent increase in self-esteem and sense of control and belonging (Wirth et al 2010). Without eye contact, Gill and Jane both experienced the characteristics of liminality: exclusion; invisibility; a loss of self-esteem and status; and a perception that they do not have permission to speak. To interrupt the staff and their computer work or 'chit-chatting' in order to verbalise their requests would also mean becoming a problem visitors (Lorber 1975).

Ed is from the Philippines and described his visiting experiences from the perspective of also being a visitor to England. Arriving on the ward, Ed presented himself at the nurses' station. Here, Ed was invited to wait at a nearby bedside to await his friend's transfer from Accident and Emergency. He described his experience:

**Ed:** Being also a visitor, you get an awareness to what's happening. I think certain places where people that stand, especially if you're staff or hospital, you shouldn't be joking, making noises and laughing. There could be somebody really ill [...] There's a code of conduct that you have to be more respectful.

**Janet:** When they're laughing and joking, how do you feel?

**Ed:** One of the things they were laughing about, was, there was this woman. I never saw her, but in another room.

**Janet:** Do you think it was right that you were party to that discussion?

**Ed:** Well. It depends. I could hear them. Whether I wanna ignore them or not, I can hear them. And the fact that they were very animated in how they're saying things, you cannot help.

Once seated, Ed recognised the tacit rules, which meant his movements around the ward were restricted. He therefore became an unwilling witness to the nurses' laughter, at the nurses' station, about another patient. As Klages and Wirth (2014) suggest, witnessing

general laughter, but being excluded from the amusement was, for Ed, alienating and self-demeaning.

Alternatively, Meg and Winston received cups of tea and light refreshments when they visited. This hospitality appears to have positively influenced their perceptions of hospital care as their words demonstrate:

**Meg:** They used to bring us a drink. They were just wonderful. It was sad that Mum was dying. She got the best care, I think. It would have made no difference had we paid for it, we wouldn't have got better care. I thought they were great.

**Winston:** I find it was very pleasant inside there. When they were going round doing, like, tea break, having a refreshment time, they'll come with tea and fancy cakes or even a sandwich for the patients. And the visitors, they were offered a cup of tea. I find that was very, very good. Very generous. A lot of generosity and kindness.

## **Discussion**

The analytic lens of liminality permits recognition of the participants' expressed feelings of marginalisation, uncertainty and discomfort and their awareness of tacit, socially proscribed rules of behaviour to remain 'good visitors'. The participants' need to be good visitors is further explained by the wish to be liked, which arouses positive self-evaluations (Srivastava and Beer 2005) and fulfils the basic human need to belong (Baumeister and Leary 1995). 'Being liked' also makes us happier because an enemy, who likes in some small way, is less likely to harm and a friend who likes will do more for us (Blumberg 1969). Williams and Nida (2011) add support to this with their work on ostracism, or being ignored and excluded. This, they argue, initiates both a 'social pain' (p71) and reflections on the meaning for it, with strategies for avoiding it including conforming, obedience and lack of resistance. Therefore the need to belong and be judged positively is a powerful driver of pro-social behaviour (Baumeister and Leary 1995).

With ubiquitous hospital signage warning against aggression and abuse and the universal use of closed circuit television, the most obvious approach for the participants was to acknowledge and adapt to their liminal position, be compliant and conform to the requisites of being a 'good visitor'. Voicing demands and complaints meant they were risking the uncomfortable position of being labelled problem visitors and the associated risks of not being liked. Some were also fearful that their own label of problem visitor might be reflected in compromised care for 'their' patient.

However, this only partially explains this sense of exclusion and 'invisibility'. The integration of Goffman's (1971) dramaturgical theory and Hochschild's (1983) concepts of emotional labour and burn out provide further possible explanations of behaviour and experiences at the nurses' station. Goffman (1971) suggests that human self-presentation is a performance in accordance with rules applicable to either front or back regions:

The performance of an individual in a front region may be seen as an effort to give the appearance that his (sic) activity in the region maintains and embodies certain standards (p110)... A back region or backstage may be defined as a place, relative to a given performance, where the impression fostered by the performance is knowingly contradicted as a matter of course (p114)... Here the performer can relax; he can drop his front, forgo speaking his lines, and step out of character (p115).

Goffman (1971) further suggests that standards of behaviour are idealised. The 'actors', despite their own moods, circumstances or personal characteristics, must at all times commit to delivering these standards.

Hochschild (1983) coined the term 'emotional labour' which, I suggest, can be applied to nursing. Emotional labour involves workers having to suppress their own feelings in order to 'sustain the outward countenance that produces the proper state of mind in others' (Hochschild 1983 p7). However, this emotional labour carries its own costs. The continual demands of acting in an emotionally sensitive manner and, if necessary, distancing the self (or depersonalising) as the target of inappropriate abuse and aggression can lead to a prolonged numbing of feeling. This eventually leads to 'burn out' and the inability to correctly assess the social world. Self-protection strategies include a refusal to depersonalise and/or act (Hochschild 1983).

The visiting experiences described by the participants all took place at a time of the 2010-2015 Coalition Government austerity measures when NHS funding was under pressure. This inevitably led to staff reductions and increased workloads. The participants all acknowledged the nurses' heavy workloads and attributed failings in care to the pressure of work. The nursing literature cites long shifts, inadequate staffing and/or missed meal breaks as causes of nurses' stress (for example Duffin 2005, Bates 2010, Dean, 2011, Kendall-Raynor 2012, Happell et al 2013). Nurses therefore have no break from the incessant demands of emotional labour and so risk being unable to fully 'feel' the emotion and pain of others (Hochschild 1983).

I therefore hypothesise that staff, missing their 'down time' of meal breaks, are considering that the professional space behind the nurses station is their 'back stage' space (Goffman 1971). Conversely, the hospital visitors perceive this space as part of the ward, where professional 'front stage' behaviour should be displayed. Hospital visitors not only feel excluded, they also perceive nurses' socialising as 'out of place', inappropriate or not adhering to implicit social rules (Goffman 1971, Heritage 1984, Layder 1994, Cresswell 2008.). As Heritage (1984) emphasises, rule-governed behaviour depends on both parties identifying and understanding a specific situation in the same way. With differing perceptions of front and back stage, a sense of disorder, exclusion and disempowerment prevailed for the participants.

This hypothesis was also informed by my own professional experiences and the account provided by one of the participants, who was also a registered nurse. Future research could therefore further explore nurses' perceptions and understandings of hospital visiting times. Another limitation of the research is the inability to generalise from just seventeen interviews. However, as Taylor (2003) notes, qualitative research, underpinned by an interpretative epistemology can only ever be partial, situated [the research context] and relative [to the researchers' subjectivity]' (p12) with greater emphasis on 'relevance, usefulness and application' (p319).

## **Conclusion**

Nurses on NHS wards are continually placed under pressure with heavy workloads and understaffing a contributing factor. This, in turn, means that 'down time' for socialising and team building is often at a premium. Efforts to limit stress, improve communication and complete paperwork consequently take place at the nurses' station. Nurses might perceive this area more as a 'backstage' (Goffman 1971) area where they can step down from the ideal, rule- and role-governed behaviour demanded of them on the wards.

However, the research participants identified and understood (Heritage 1984) this area as 'front stage' and a continuation of the ward space where nurses should self-present within professional ideals (Goffman 1971). When visitors, already feeling discomforted in their liminal status, encounter the nurses' 'backstage behaviour' at the nurses' station, their feelings of marginalisation, exclusion and mistrust become exaggerated. This leads to judgements of lack of professionalism and care, which may then be translated into complaints.

Complete redesign of all hospital wards is not a cost-effective solution. Nurses will continue to have heavy and stressful workloads with frequently missed meal breaks. The solution is to bring this research to their attention so they may realise that 'chit-chat', inappropriate

discussions and laughter and preoccupation with computers and paperwork results in extra discomfort for hospital visitors. Also the offer of a simple cup of tea to visitors increased their satisfaction with hospital hospitality and care provision and reduced feelings of marginalisation and exclusion. If visitors were included in patients' tea rounds, the number of costly complaints might be substantially reduced.

#### Bullet points

- Hospital visiting can be seen as a liminal experience.
- Visitors, as liminal personae, might be structurally invisible and overlooked.
- Nurses often miss meal breaks and, instead, use 'backstage' (Goffman 1971) space behind the nurses' station for 'down time'.
- Visitors see this space as continuation of 'front stage' (Goffman 1971).
- Witnessing 'back stage' behaviour in 'front stage' areas causes visitors to judge it as unprofessional.
- Visitor consequently feel ignored, demeaned and dissatisfied and more inclined to complain.

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