

**THE PSYCHOLOGICAL IMPACT OF
NOSOCOMIAL INFECTION:
A PHENOMENOLOGICAL INVESTIGATION OF
PATIENTS' EXPERIENCES OF
CLOSTRIDIUM DIFFICILE**

**Thesis submitted for the degree of
Doctorate in Clinical Psychology
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By

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Declaration

The research reported is my own and has not been submitted for
any other academic award.

Nicola Parker

Thesis Abstract

The Psychological Impact of Nosocomial Infection: A Phenomenological Investigation of Patients' Experiences of *Clostridium difficile*.

Nicola Parker

Whilst the genesis and management of healthcare-associated infections (HAIs) is well represented in health literature, less attention has been given to patient experiences. The review of literature is a narrative synthesis of eight qualitative research studies focusing on patients' experiences of healthcare associated infections. Results indicated that psychological needs of patients with iatrogenic infections are often inadequately addressed, and that patients' experiences of iatrogenic infection were characterised by fears, worries, stress and guilt. Furthermore it highlighted inadequate information-giving practices, in some cases due to staff concerns about frightening patients, or because they assumed patients already knew they were infected. This impeded patient adjustment to infection, and may have consequently developed a double iatrogenic effect on those patients.

The research report investigates patients' experiences of hospital acquired *Clostridium difficile* using interpretative phenomenological analysis to interrogate interview data collected from six inpatient participants. Emergent themes were lack of information, psychological distress and concerns over possible future hospitalisation. Patients also reported observing poor adherence to hygiene protocol by hospital staff and anxiety about making complaints due to fear of possible reprisals. Results indicated that poor information sharing practices can inadvertently place an additional burden of anxiety and confusion on iatrogenically infected patients. Systems of staff training need more emphasis on explaining diagnoses and its implications for patients to mitigate some of these avoidable problems. Attention also needs to be paid to HAIs as deterrents of future engagement with health services, potentially putting patients' health at risk.

In reflecting on the process of conducting this research, the critical appraisal addresses several key areas of learning and development that have been pertinent for the author; these being reflections of epistemological and methodological issues throughout, consideration of aspects of researcher safety, a critique of the limitations of the study and proposals for future research.

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Literature Review

Patient experiences of the psychosocial affects of Healthcare Associated

Infections: A narrative synthesis of qualitative research

Nicola Parker

**Patient experiences of the psychosocial affects of Healthcare Associated Infections:
A narrative synthesis of qualitative research**

Abstract

The genesis and management of iatrogenic infection in hospitals is well represented in health literature, but with relatively little attention given to patient experiences. This review examines commonalities in patient experiences of healthcare associated infections (HAIs) in Acute Care settings. A systematic narrative synthesis of qualitative literature was conducted, adopting the principles of transparency and systematicity (Meyrick, 2006). Content analysis was used to elicit key themes. Following synthesis of results, emergent themes were; patient understanding, communication and information; isolation; psychosocial and emotional effects; and alterations in contact with healthcare. Emotions expressed included fear, anger, worry, shock, depression, guilt and shame, anxiety about infecting family members and concerns over loss of role and work prospects. Patients were also concerned about acquiring further infections if they returned to hospital, and were embarrassed about revealing their health status to others. In conclusion, this review demonstrates that the psychosocial impact of healthcare acquired infections cannot be separated from their physical sequelae, and that psychological needs of patients with iatrogenic infections have thus far been inadequately addressed. Increasing patient access to clear, appropriate information and supporting staff through training in information delivery, may both contribute to alleviating the negative psychological impact of HAI diagnosis.

Introduction

Iatrogenic conditions engendered in acute care settings are a common and serious hazard of hospitalisation and are associated with significant adverse patient outcomes. The term iatrogenic, which literally means ‘brought forth by the healer’, is used to denote the damage induced in a patient as an unintended by-product of a medical or therapeutic intervention (Caplan, 2001). The most difficult infections to deal with are Multi Drug-Resistant Organisms such as Methicillin-Resistant *Staphylococcus Aureus* (MRSA) and *Clostridium difficile* (*C.diff*). Acquisition of these infections has been associated with morbidity, extended hospital stay, mortality, and considerable additional costs to the healthcare sector internationally (Abbate & Di Giuseppe, 2008; Expatica, 2008; 2009).

Understandably, in treating physical illness, it is the physician’s role to concentrate on somatic disorder, however the ramifications of nosocomial infection appear not just confined to the physical, and anxiety and depression are frequent concomitants of disease (Snaith, 2003). Negative psychological factors such as stress, pessimism and poor sleep quality are known to affect the body’s vulnerability to acquiring infections (Jensen, Lehman, Antoni, & Pereira, 2007), and are also associated with increased morbidity and mortality (Zachariae, 2009; Frasure-Smith & Lespérance, 2005; 2010). Stress has been shown to increase susceptibility to infection (Pedersen, Boyberg, & Zachariae, 2009), and to significantly slow wound healing (Christian, Graham, Padgett, Glaser, & Kiecolt-Glaser, 2007). In addition, thoughts, beliefs and constructions of infection diagnosis also play a crucial role for patients in the way that they think about their illness (Criddle & Potter, 2006; Coughlan, Sheenan, Bunting, Carr, & Crowe, 2004), and may determine their adjustment to it (Petrie & Weinman, 1997). Illness

perceptions directly influence patients' emotional response to illness as well as coping behaviour such as adherence to treatment (Petrie & Weinman, 2006). Yet psychological implications of iatrogenic infection have been largely overlooked and, despite their importance, patients' views of their illness or symptoms are rarely sought in medical consultations. Given the potentially reciprocal impact between psychological status and infection, optimal clinical outcomes can be enhanced with greater understanding of the psychological aspects of an acquired infection.

To date, an understandable focus on processes established to minimise and manage infection, has precluded understanding the patient's perspective in the illness, a key element of quality care. When adopting the most effective healthcare practices for the treatment of patients with iatrogenic infection, a major resource for hospital staff in handling infection control is the use of isolation rooms (Kiernan, 2009). For infected patients, source isolation has been found to be associated with psychological disturbance, feelings of loneliness and stigmatisation, and increased instances of depression, anxiety, fear and hostility (Abad, Fearday, & Sadfar, 2010), particularly amongst elderly patients (Tarzi, Kennedy, Stone, & Evans, 2001). Resistant organism isolation in particular has been found to have a significantly negative effect on patient mood and causes an increase in anxiety levels (Catalano et al., 2003). One of the challenges for staff working in acute care settings is that caring for infectious patients can in itself be a source of stress (Maunder, 2009), and in addition to anxiety, there are very real constraints on nursing staff of time, resources and the physical environment (Knowles, 1993). This review, however, is confined to an exploration of patient experiences, and how they might be improved.

Key to this review is its focus on the personal experiences of patients living with an iatrogenic infection. Whilst indicators of distress, anxiety and depression can be accessed through standardised inventories such as the Hospital Anxiety and Depression Scale (HAD) (Zigmond & Snaith, 1983) or the Patient Health Questionnaire (PHQ-9) (Kroenke & Williams, 2001), the *reasons for* negative effect, and attributions of blame and responsibility amongst iatrogenically infected patients cannot be captured using these measures. To access this kind of information the most common approach is the qualitative verbal interview. This review thus draws together the most recent qualitative research which seeks to understand better the patient experience of contracting and living with an iatrogenic infection. The benefits of synthesising such findings are that recurrent themes from relatively small data sets from various settings can be explicated, allowing more generalisable conclusions to be drawn. In addition, it becomes possible to address some of the underlying issues relating to how and why these problems occur, and to offer some concrete evidence-based suggestions for shaping better patient care and improving clinical practice.

Aims

To examine the qualitative research to date, which investigates the psychosocial impact on patients acquiring healthcare associated infections (HAIs). This literature explicates more thoroughly than quantitative data the personal experiences of patients themselves, and offers valuable insights into how patients make sense of their condition cognitively and emotionally, and how these meaning-making practices relate back to treatment outcomes and compliance with healthcare regimes.

Methods

A systematic narrative synthesis of qualitative literature exploring patient experiences of HAIs was undertaken. The principles of transparency and systematicity (Meyrick, 2006) were used to analyse the literature, and content analysis was used to elicit key themes.

Analytic Question

How do patients experience healthcare associated infections?

Search Strategy

This first involved identifying key words related to the review topic. A range of search terms were used, relating broadly to the topic under investigation. The subject heading key words ‘isolation/ hospital/ infection/ ward/ nursing/ control/ barrier/ Methicillin resistant/ staphylococcus aureus/ qualitative/ nosocomial/ iatrogenic/ healthcare/ Clostridium difficile/ patient experience’ were used to interrogate the relevant databases, which were PsychINFO (1990-2010), MEDLINE (1990-2010), Scopus (1990-2010), Web of Science (1990-2010). Searches were confined to these dates to capture the most recent qualitative research in this area, and were conducted during August 2010. Limits to search parameters were set to include only journals in English. References from key articles were also interrogated to extend the search more fully. Relevant journal articles accessed in this way were searched for individually in electronic databases, and printed for review.

Inclusion Criteria

The most recent research papers published between 1990 and August 2010 (excluding books, book chapters and dissertations) were included, focusing on studies using qualitative methodology to investigate patient experiences of infections acquired whilst in hospital. The titles and abstracts of 57 papers were initially examined to determine more precisely those which met the inclusion criteria. A total of 22 papers remained and were obtained in full. Of these, six proved to be quantitative and were insufficiently focused on patient experience, and seven comprised either studies of staff experiences or were not specifically about infections acquired in hospital. One was excluded later because it focused on the reactions of families rather than the patients themselves, leaving eight remaining.

Quality Considerations

As the articles under review have been subject to examination of quality of process as well as of content, it is incumbent upon the author to ensure that the process of review itself should also be available to scrutiny. The key values adhered to therefore, have been to promote systematicity - the regularity of data collection and analysis (Meyrick, 2006), and transparency, whereby all relevant research steps are disclosed to the reader (Yardley, 2000).

Reflexivity

The author acknowledges criticisms of narrative synthesis as an approach (Campbell et al., 2003), including potential researcher bias in extrapolating from the data to explicate possible solutions to the problems presented, and the inevitability that the choice of themes emerging from the textual descriptions are at least partly subjective (Rodgers et

al., 2009). However, by occupying the dual roles of both researcher and clinician, the author has intended to offer a balanced and reflective interpretation of the findings of the research reviewed, to satisfy the requirements both of academic rigour and of clinical usefulness.

Identification of Review Methodology

In seeking to elucidate the particular factors which appear to influence patient experiences of iatrogenic infection, a systematic review of qualitative interview-based research was conducted. The object of this review however, has not been to merely offer the reader an aggregated account of the data (Campbell et al., 2003), but to explicitly engage with the intricacies of the relationship between mental and physical health in acute healthcare settings. Thus, narrative synthesis was chosen as the most appropriate method to both summarise the current knowledge of this area, and also to enable the reviewer to move beyond a merely descriptive rendition to develop explanations that may account for the outcomes reported (Popay et al., 2007). A better understanding of process consequently raises more detailed implications for further research (Rodgers et al., 2009). It is acknowledged that this approach requires a level of interpretation of data, and therefore careful attention has been paid to methodological integrity to aid transparency and reproducibility.

The process of narrative synthesis follows four main stages (Popay et al., 2007), beginning with the development of a theoretical model which informs decisions about the review question, identifies what types of studies should be reviewed, and assesses how widely applicable those findings may be. Secondly, a preliminary synthesis of the findings of the studies included in the review is developed to organise patterns across

the studies in terms of size and direction effects. Thirdly, relationships within the data are explored to consider the factors that might explain any differences in direction and size of effect across the included studies. The final stage of analysis is to assess the robustness of the synthesis by drawing conclusions from the data and assessing the generalisability of the findings.

Process

The quality of each paper was assessed on a range of dimensions, and tabulated to enable comprehensive comparisons (Table 1). The clarity of an informing epistemological position, appropriate methodology, recruitment processes, participant demographics, credibility, the grounding of findings in data, systemic analysis and author reflexivity were measured in this process. These dimensions were reviewed to assess the quality and rigour of the research process in each case.

Developing Preliminary Synthesis

Preliminary synthesis was developed using textual descriptions, groupings and clusters, data translation and tabulation (Popay et al., 2006). A table was then constructed to identify common and contrasting themes and outcomes (Table 2). These themes were then further analysed, and common relationships identified and developed as taxonomy of findings (Table 3).

Methodological Overview

The qualitative papers reviewed were authored by professionals from the disciplines of nursing, health sociology, caring sciences, dental health and psychology.

Table 1: Profile of Studies

Study	Burnett, Lee, Rushmer, Noble, & Davey, (2010) UK	Criddle & Potter (2006) UK	Dunne & Quayle (2001) Ireland	Gardner (1998) Australia	Lindberg, Carlsson, Hogman, & Skytt (2009) Sweden	Madeo (2001) UK	Newton, Constable, & Senior (2001) UK	Skyman, Sjostrom, & Hellstrom (2010) Sweden
Epistemology	None offered	Phenomenology.	Not made explicit	Liminality theory.	Not made explicit	Phenomenology.	None offered.	Not mentioned
Methodology	None offered.	Phenomenological approach	IPA.	Interpretative interactionism.	Content Analysis.	Not explicit	Vague	Inter-subjective analysis
Sample	Purposeful and random sampling 18 participants	Purposeful sampling 14 patients. A	Purposeful sampling 32 participants. A G S	Sampling strategy not mentioned. 8 participants G	Purposeful sampling 14 participants A G	Sampling strategy not mentioned 7 patients A G	Sampling strategy not mentioned. 19 patients A G	Theoretical sampling 6 patients A G
Data Collection Methods	In-depth semi-structured interviews; 20-40mins, audio recorded and transcribed, plus field notes. Interview outline provided.	Audio recorded interviews. Transcribed verbatim	5 Focus Groups, 3-9 participants in each. 2 hours, with 15 min break. Audio recorded and transcribed. Discussion guide appended.	Interviews.	Open-ended, semi-structured audio-taped interviews. Interview guide used.	Interview	Semi-structured interviews Key areas provided. Audio recorded and transcribed.	In-depth audio recorded interviews. Probes re. source isolation care. 60-135 mins. Transcribed including emotions.
Ethicality	IC CA	IC CA EA	A IC	Not mentioned	EA C VP T	EA IC	Not mentioned.	EA IC CA
Method of Data Analysis	Thematic.	Interpretative phenomenology.	IPA.	Interpretation of interview data.	Manifest and latent qualitative content analysis.	Colaizzi's (1978) seven-step analysis.	Content analysis.	Inter-subjective analysis.
Transferability/ Limitations	Issues of transferability not directly addressed.	Unique experiences valued. Generic themes suggested that could be extrapolated.	Transferability and limitations not addressed.	Transferability and limitations not addressed.	Mainly women in study. Conducted in Sweden where MRSA rates low. May impact on transferability.	Transferability and limitations not mentioned.	Limits of generalisability, small sample explained in line with custom in qualitative research.	Small sample size given as reason for limited generalisability. 3years had passed since source isolation.
Findings interwoven with relevant literature/theory?	Yes, good links made with relevant literature to support claims.	Yes. e.g. link between the isolation experience and communication.	Yes. e.g. reference made to similar findings with suffers of chronic back pain.	Yes, reference to various literature substantiating evidence for the current thesis.	Yes, links with similar studies in other countries and comparisons made.	Yes, mention made of key studies in relation to similar findings.	Yes, e.g. association of anger, blame and psychological adjustment.	Yes, references used to contrast current study and to compare and validate claims.
Reflexivity	None	Mention of 'bracketing'	None	None	None	None	None	Interview as interaction

Sample: E – Ethnicity, G – Gender, A – Age, S – Socio-economic status reported

Ethicality: CA – Confidentiality and Anonymity, IC – Informed Consent, VP – Voluntary Participation, EA – Ethical Approval, T – Treatment not affected reported

Scope and Purpose

The aims of the articles reviewed were to explore patient experience of iatrogenic infection, to determine their individual ways of making sense of it, and to illustrate the impact of their experiences on their social/emotional/psychological functioning. The research reviewed also sought to discover what improvements could be made within the healthcare system to ensure quality of care for these patients. The majority of the research papers reviewed were investigations of the impact on patients of acquiring iatrogenic MRSA (Methicillin-resistant staphylococcus aureus). Whilst the scope of this review was wider, other nosocomial infections were found to be under-represented in qualitative research, with only one study investigating the impact of iatrogenic Hepatitis C included, the only other HAI represented in this literature.

Epistemological Positions

Of the eight papers reviewed, four offered no coherent epistemological position to frame their research. In consequence, excluding comprehensive assessment of how appropriate the sampling strategy, research method, or data analysis approach was in these studies. Criddle and Potter (2006) and Madeo (2001) both chose to use an explicit phenomenological approach, including their reasons for the value of using this perspective in answering the research question. Dunne and Quayle (2001) used Interpretative Phenomenological Analysis (IPA), but made no reference to the advantages of taking a phenomenological approach. Gardner (1998) appropriately framed his use of Liminality Theory within existential philosophy.

Sampling

Four of the studies (Burnett, Lee, Rushmer, Noble, & Davey, 2010; Criddle & Potter, 2006; Dunne & Quayle, 2001; Lindberg, Carlsson, Hogman, & Skytt, 2009) reported using purposeful sampling to recruit participants, and one used theoretical sampling. The rest did not report any specific recruitment strategy. Most indicated the ages of participants, and five of these also reported genders. Ethnicity, age and gender were not reported by Burnett, Lee, Rushmer, Noble, & Davey (2010). Seven of the eight studies stated either their inclusion and/or exclusion criteria with the exception of Gardner (1998). Given the idiographic nature of this study, it is surprising that no reference is made to numbers, age, gender or recruitment of participants. Interview location was mentioned only by Lindberg, Carlsson, Hogman, & Skytt (2009), with participants' choice of interview location at home, work or in the hospital unit. Dunne and Quayle (2001) were the only researchers to describe socio-economic background of the participants.

Data Collection Methods

All but one study used interviews as their chosen data collection method, the exception being Dunne and Quayle (2001), which used focus groups. Whilst it is acknowledged that focus groups can be profitably utilised for conducting IPA research (Palmer, Larkin, De Visser, & Fadden, 2010), it can be argued that as accounts are always situated and subject to context (Edwards, 1997), it cannot be assumed that accounts produced in a focus group would be the same as those proffered in one-to-one interviews. Of the remaining four studies adopting one-to-one interviews, three reported they were 'semi-structured', and one was described as an 'in-depth interview with open questions' (Skyman, Sjostrom, & Hellstrom (2010) et al., 2010). Burnett, Lee, Rushmer,

Noble, & Davey (2010), supplemented their interview data with field notes, although their use is not referred to again in the analysis, nor are they used to inform researcher reflexivity.

Ethical Considerations

Neither Newton, Constable, & Senior (2001) et al. (2001) nor Gardner (1998) make any reference to ethical considerations in their research. Most of the other studies indicate gaining informed consent from participants. With the exception of Burnett, Lee, Rushmer, Noble, & Davey (2010), and Dunne & Quayle (2001) all reported having gained approval from an ethics review board. Confidentiality and anonymity were ensured in five of the studies, with voluntary participation being mentioned in only one study (Lindberg, Carlsson, Hogman, & Skytt, 2009). No study addressed any additional ethical concerns that may have arisen during the course of conducting the research or writing up the analysis.

Table 2: Summary of Thematic Content Analysis

Author (year)	Stated aims	Themes	Conclusions
Burnett, Lee, Rushmer, Noble, & Davey (2010)	To explore patients' narratives of their experiences of HCAI. To emphasise the need for patient involvement within healthcare.	1. Sufficiency of verbal and written information. 2. Patient understanding of infection acquisition. 3. Impact of infection on patients' perceptions of future hospitalisation.	1. Patients should be involved in design and evaluation of systems and patient information. 2. Views of patients should be channelled appropriately within the organisation.
Criddle & Potter (2006)	To explore patients' perspectives of colonisation with MRSA. To suggest information helpful to patients, and improvement of provision.	1. The role of staff knowledge affecting patients' experiences. 2. Patient's experience described on a continuum, and varies at different temporal points.	1. Infection control education must also cover the provision of practical information. 2. Clear guidelines on information for patients should be given in bullet point form
Dunne &	To capture the	1. Anger and depression	1. Compromised health

Quayle (2001)	individual experiences of women with iatrogenic Hepatitis C. To inform practice in managing the day-to-day impact of Hepatitis C.	common emotional reactions. 2. Role erosion, loss of control. Deterioration of relationships, and feelings of guilt. 3. Other people's difficulty understanding illness.	had a major impact on their sense of identity. 2. Participants' lack of understanding about their level of disability, and a wish to shield others from worry.
Gardner (1998)	To explore the experiential dimension of nosocomial wound infection using a sociological interpretative approach.	1. Nosocomial wound infections do not easily fit within the current systems of classification 2. Liminality experienced – a feeling of living 'in between health and illness'.	1. Nosocomial wound infection requires a healthcare approach attending to both existential and corporeal features of this illness experience.
Lindberg, Carlsson, Hogman, & Skytt, (2009)	To explore MRSA colonised patients' experiences and understanding To inform the development of patient care through descriptions of patient perceptions of living with MRSA	1. Life difficult, feeling unclean. 2. Uncertainty and blame about how it was contracted. 3. Feelings of guilt & shame, not wanting to infect others. 4. Fear of others' reactions and losing work role. 5. Worry about telling others.	1. Healthcare sector should assume responsibility for managing MRSA. 2. Healthcare workers must improve their information skills to better meet patient needs.
Madeo (2001)	To describe the experiences of patients with MRSA being nursed in isolation. To use this information to identify strategies to improve patients' time in hospital.	1. Understanding and impact on visitors. 2. Hotel or prison, hospital room. 3. Stigma – effect of diagnosis. 4. Treatment of condition – eradication.	1. Effective communication, including information on treatment, unrestricted visiting and staff being accessible to patients and visitors.
Newton, Constable, & Senior (2001)	To investigate affected patients' perceptions of MRSA and source isolation. To assist the effective functioning of infection control procedures.	1. Patient understanding of the likely duration, cause and seriousness of the infection. 2. Patient understanding of the purpose and need for source isolation, and their reactions to it.	1. Improvement needed in patient understanding about the reasons for and efficacy of topical treatments for MRSA and barrier nursing procedures so that they can play a more active role in infection control.
Skyman, Sjostrom, & Hellstrom,	To gain knowledge of patients' experiences of	1. Source isolation limitations. 2. Information lacking.	1. Increased staff knowledge about transmission needed.

(2010)	contracting MRSA in hospital and subsequent source isolation.	3. Deteriorated initial condition. 4. Stigmatisation, guilt, shame. 5. Uncertain sick or healthy?	2. Staff ought to take personal responsibility for compliance with basic hygiene practices.
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Methods of Analysis

Thematic or content analyses were used by three researcher teams. Confusingly, Burnett, Lee, Rushmer, Noble, & Davey (2010) use the term ‘saturation’ borrowed from Grounded Theory (Morse, Stern, Bowers, Charmaz, 2009) to justify participant numbers, but given they fail to state their epistemological position or methodology its use appears naive. Similarly, although Newton, Constable, & Senior (2001) give a brief explanation of research process, they appear to possess only a limited grasp of methodological and epistemological integrity in their use of content analysis. The studies by Lindberg, Carlsson, Hogman, & Skytt (2009) and Skyman, Sjostrom, & Hellstrom (2010) displayed similar limitations. Criddle and Potter (2006) were thorough in outlining their choice of IPA, explicitly locating it within a phenomenological epistemology. Dunne and Quayle (2001) also explain their use of IPA and detail their processes, although they fail to make appropriate links to phenomenology. Fleetingly, Madeo (2001) explains the use of Colaizzi’s (1978) seven-step process analysis including the steps used within the constrained word limit for this article. The theme of ‘liminality’, a state of remaining between health and illness, is used effectively by Gardner (1998) to give a detailed narrative of the impact of living with a nosocomial infection.

Reflexivity

It was disappointing to note that the majority of authors made no mention of reflexivity in their papers (six of the eight articles). Surprisingly, with such a personal account of individual experiences of living with a non-healing wound, the opportunity for reflexivity by Gardner (1998) was missed. Of the two that were minimally reflexive, Criddle and Potter (2006) applied the notion of ‘bracketing’ to demonstrate an awareness of separating the role of nurse from that of researcher, and Skyman, Sjostrom, & Hellstrom (2010), made reference to the interview process as a personal interaction.

Limitations and Transferability

Half of studies reviewed offered no suggestions regarding the limitations or transferability of their study. Of those that did, limited sample size was quoted in three of the remaining four. One study (Lindberg, Carlsson, Hogman, & Skytt, 2009) mentioned that there were more women in the study than men, and its conduct in Sweden, where MRSA rates are relatively low, might affect generalisability of results. Criddle and Potter (2006) maintained a phenomenological stance when stating that “although generic themes can be extrapolated from the data, a uniform narrative cannot be described, each patient having a unique experience” (Criddle & Potter, 2006, p25).

Validity and Implications of Findings

The continuity assumption (Shaughnessy & Zechmeister, 1994), states that behaviour is continuous across time, subject and settings unless there is reason to believe otherwise. In relation to this, it is assumed that patients might reasonably be expected to behave differently in different healthcare settings, and at different times during their treatment pathway. However, the findings of these studies retain ecological validity in that they

are likely to be transferable to similar acute hospital settings geographically, as there are sufficient similarities between these settings to warrant reasonable claims to transferability. Whilst acknowledging that prevention and treatment of the physical symptoms of HAIs is vital, this review also demonstrates that attention to the emotional and psychological wellbeing of patients is crucial, not just for patient satisfaction, but to facilitate recovery, increase adherence to treatment regimes, and to facilitate future engagement with healthcare professionals. In short, if patients are less distressed, they may recover more speedily with fewer long term ill effects, thus releasing resources earlier to treat other patients.

Table 3: Taxonomy of Findings

UNDERSTANDING
<p>Causes – poor personal hygiene/cleanliness, lack of cleaning and nursing staff, lack of toilet and shower facilities, bad luck, result of hospital stay Risk reduction – isolation, screening staff Management and treatment – acceptance of need for screening, understood purpose. Concern over treatment regime.</p>
COMMUNICATION & INFORMATION
<p>Lack – for patients and families. Colonisation, organism, its significance, isolation, test results, infection status, treatment, efficacy, expected duration of infection. More information required about the bacteria not just about practical management. Conflicting - prevalence, contagiousness, seriousness, mixed messages. Use of pseudonyms (e.g. ‘super-bug’). Media influence – scare mongering. Delivery – Important for patient perceptions. Little or none verbal or written. Lack of information connected to staff ignorance.</p>
ISOLATION
<p>Onset - a significant event, particularly where patients were moved with little or no warning or explanation. A traumatic experience when diagnosis was unexpected. Patients surprised how quickly they were cut off from everyone Positive – more freedom, greater privacy, solitude, quietness, facilities, care not impeded, undisturbed sleep. Negative – lack of attention from staff, loneliness, imprisoned, stigmatised, excluded, limited, violated, confined, bored, and frustrated. Perceptions - To prevent contagion, no idea, barrier nursing not effective.</p>
PSYCHOLOGICAL IMPACT
<p>Emotions - Anger, fear, dread, worry, concern, anxiety, frustration, disappointment, depression, shock, upset, bitterness, loss and injustice, guilt, shame Lived Experience – Being contagious and fear of infecting others, unclean, scared, and uncertain, unwelcome Stigma - Feeling unclean/dirty, isolation sign on the door seen as breach of</p>

confidentiality. Uncertainty and loss of social identity.
<p style="text-align: center;">HEALTHY OR SICK?</p> <p>Transition - social transition, ambiguous, indeterminate state between health and illness. Waiting. Absence of resolution, not knowing when it will end. Embodiment - Bodily discharge, disruption of body boundary, attempts to distance self from body. ‘Falling apart’, vulnerability, malodour, checking.</p> <p>Consequences - Deterioration of primary condition, prolonged stay in hospital, infection may reoccur</p>
<p style="text-align: center;">SOCIAL IMPACT</p> <p>Negative impact on relationships with family, friends, partner. Fear of infecting others. Feeling loss of control, forward planning affected. Uncertainty about whether to disclose health status to others. Loss of work role</p>
<p style="text-align: center;">ALTERATIONS IN CONTACT WITH HEALTHCARE</p> <p>Restrictions – unwanted responsibility to declare infection status, healthcare staff wearing protective clothing, inadequate follow-up.</p> <p>Concern about acquiring another infection if they returned to hospital.</p>

Discussion

In drawing together the themes synthesised from the research reviewed here, there are a number of recurrent topics which deserve particular attention in relation to this enquiry about how patients experience healthcare-acquired infections. These are communication and understanding, inclusion and involvement, individual differences, continued staff training and considerations pre- and post- discharge. These will be addressed in turn.

Communication and Understanding

In all the studies reviewed, the importance of communication of information about an HAI was indicated as a priority. What is communicated at an early stage in infection, and how this is done can affect how patients cope with isolation, and with their longer term psychological and social functioning post-discharge (Lindberg, Carlsson, Hogman, & Skytt, 2009; Newton, Constable, & Senior, 2001). Emotional preparation may be an important protective factor in ‘immunising’ the patient against later anxiety (Catalano et al., 2003), and ideally should consist of explanations about the infection the patient has contracted, why there may be need for isolation, and what to expect. Appropriately

communicated information can positively affect patients' adjustment to their diagnosis, helping them to be more relaxed and also more compliant with infection control regimes (Newton, Constable, & Senior, 2001; Madeo, 2001; Petrie & Weinman, 1997). This review has highlighted the need for written as well as verbal information about daily routines and treatments (Burnett, Lee, Rushmer, Noble, & Davey, 2010), isolation (Zerbe, Parkerson, & Spitzer, 1994), and about what happens after discharge from hospital (Lymer & Richt, 2005). This should be in addition to regular verbal updates on progress and procedures throughout a hospital stay (Rees, Davies, Birchall, & Price, 2000).

Inclusion and Involvement

For many patients contracting an infection in hospital, source isolation is a concurrent experience, often accompanied by feelings of dread, anxiety and apprehension as they experience themselves as being 'cut-off' from the main ward (Madeo, 2001; Skyman, Sjostrom, & Hellstrom (2010). For example, Madeo (2001) reports that patients were surprised by the speed they were cut off from everyone, and for those for whom the diagnosis was unexpected, it was a traumatic experience. The human need for physical closeness has been shown to increase during times of ill-health, and it is at these times that positive non-verbal behaviour such as smiling, a positive manner and showing consideration can be an important adjunct to physical medical care, promoting staff/patient relations, and elevating patient mood (Lymer & Richt, 2005). Patients who are not passive but have some involvement in what happens during and after their hospital stay, have been found to recover more quickly (Lymer & Richt, 2005).

Individual Differences

To varying extents, this review revealed there are individual differences in patients' reactions to infection diagnosis (Criddle & Potter, 2006). The link between cognitive processing and physical symptomology has been noted in previous health research, for example, Coughlan et al. (2004) indicate that individuals who had been largely asymptomatic prior to diagnosis subsequently developed disease-consistent symptoms after diagnosis. Illness perception also varies between patients; a simple and quick measure such as the Brief Illness Perception Questionnaire (Brief IPQ) can provide a rapid assessment of patient perceptions of their cognitive and emotional representations of illness (Broadbent, Petrie, Maina, & Weinman, 2006). Of particular salience to the problems of iatrogenically acquired infection is blame allocation and individual variability in perceived culpability. Blaming others for one's misfortune has been found to be associated with impairments in emotional well-being and physical health, shattering "one's belief in a benign world and the reliability of others" (Tennen & Affleck, 1990, p. 226). Thus, the sense that individual patients make of their situation, their understanding of its etiology and prognosis, and their experience of barrier nursing and treatment, can all affect how patients construe their HAI (Dunne & Quayle, 2001; Skyman, Sjostrom, & Hellstrom (2010); Gardner, 1998). In the absence of calm, clear insightful and informed explanations, patients rely on drawing their own conclusions from the situation in which they find themselves and ad hoc or sensationalised media reports (Burnett, Lee, Rushmer, Noble, & Davey, 2010). It is recommended therefore, that individual differences and personal experiences be taken into account when offering explanations to patients about their infection (Criddle & Potter, 2006; Madeo, 2001).

Continued Staff Training

Patient reports suggest that negative experiences arising from iatrogenic infection were compounded by perceived lack of staff professionalism and lack of knowledge (Skyman, Sjostrom, & Hellstrom (2010); Criddle & Potter, 2006). Factors found to adversely influence nurse and healthcare assistants' capacity to understand and implement infection control recommendations are a lack of expertise in HAIs, irrational staff beliefs, and inaccurate perceptions of risk (Prieto, 2005). In other areas of infection control, such as hand hygiene, sustained improvement in compliance is concomitant with an equally sustained intervention (Pittet et al., 2000). Thus, structured, continuing education for all grades of hospital staff involved in the care of patients in source isolation is recommended (Cassidy, 2006), including the consistent use of verbal and written information (Rees, Davies, Birchall, & Price, 2000). Whilst it is acknowledged that the goals of quality care may be constrained by time and the physical environment (Knowles, 1993), regular continuing professional development in the form of teaching on disease aetiology and prognosis, and communicating effectively with patients should be prioritised in line with training on practical aspects of infection management. Behaviour change is notoriously difficult to maintain within health promotion, and requires interventions at different levels, including individual, group and environment (Michie, 2008).

Additional Considerations Post Discharge

In all the studies reviewed without exception, contracting an iatrogenic infection and subsequent source isolation was found to have a significantly detrimental impact on the psychological wellbeing of patients. Not only did infections increase the length of hospital stay and interfere with treatment of the original condition (Skyman, Sjostrom, & Hellstrom (2010), but patients were frequently left uncertain about their infection

status long after discharge (Lindberg, Carlsson, Hogman, & Skytt, 2009; Burnett, Lee, Rushmer, Noble, & Davey, 2010; Gardner, 1998). The focus on the psychological impact of source isolation in the studies reviewed may have precluded analysis of more generic features of infection attribution and effect. It is proposed that upon discharge, when the immediacy of isolation is no longer dominant, patients may re-appraise their experience in its entirety, and be left with lingering doubts, fears and questions about their health status. In a study of post-gastroscopy health anxiety, medical reassurance was shown to be short term, with some patients showing a significant resurgence in anxiety levels up to one year later (Lucock et al., 1997). It is therefore incumbent upon primary and community healthcare providers to be aware of the continuing impact on outpatients with slow healing wounds and other infection symptoms, that they are likely to continue to be vulnerable to states of stress, anxiety, guilt and depression long after discharge.

Conclusion

Quality of care for patients in acute settings involves not merely attention to physical needs; what this review demonstrates is that the emotional, social and psychological needs of patients with iatrogenic infections are often overlooked or inadequately addressed. The results of this synthesis demonstrate recurrently that patients' experiences of iatrogenic infection were characterised by fears, worries, stress and guilt. These strong negative emotions have a detrimental impact on physical recovery, and perception of contagion is often also associated with a deterioration of the primary condition (Skyman, Sjostrom, & Hellstrom (2010). Each patient holds idiosyncratic views on the identity, cause, time-line, and consequences of their illness, in addition to the cure and controllability of their condition (Weinman, Petrie, Moss-Morris, & Horne,

1996). There remains a clear need to operate in a more preventative way to mitigate psychological distress. It is recommended therefore that there be a more thorough assessment of patients' understanding of their disease in order to reduce future consultation. The longer term implications of more thorough information giving and understanding have been reviewed for other infections such as Hepatitis C and HIV (Briongos, Bachiller, Palacios, Gonzalez, & Eiros, 2011), but as yet have not been assessed in the context of hospital acquired infections.

The specifically iatrogenic nature of contracting a multi drug-resistant infection was not overtly addressed in reviewed studies, and deserves further attention. Patients may feel angry and betrayed having caught an infection whilst in hospital (Gelbart, 2006). Self-blame has been consistently linked to poor mental health outcomes (Else-Quest, LoConte, Schiller, & Hyded, 2009) and attribution of culpability researched in other medical fields, such as in cancer patients, revealed that knowledge of its preventability seemed to be associated with perceived responsibility (Marlow, Waller, & Wardle, 2010). The relationship between personal culpability and responsibility are particularly pertinent to iatrogenic infection, and these factors deserve further investigation in terms of understanding patient perceptions about their behaviour and power to change clinical process in relation to agency in infection acquisition.

Patient involvement in their recovery was central to the studies reviewed, and further work could be carried out to consider the relationship between patient passivity versus activity in relation both to treatment regime adherence, but also more importantly in terms of their perceptions of responsibility for infection control, such as adequate hygiene procedures. Variation in how patients ascribe blame may affect psychological

adjustment to diagnosis and to their subsequent well-being and recovery. In addition, more attention should be paid to patient well-being post-discharge with more effective partnerships between inpatient and community healthcare, particularly where there is likelihood of patients needing to be re-admitted for further treatment. Following distressing inpatient experiences some patients have been shown to display anticipatory or conditioned side-effects connected with the hospital environment, and the tastes and odours associated with the treatment (Zachariae et al., 2007).

Lack of information-giving impedes patient adjustment to iatrogenic infection. In some cases this did not happen because staff thought they might frighten patients, or assumed they already knew that infection had occurred (Burnett, Lee, Rushmer, Noble, & Davey, 2010). However, a problematic implication of lack of understanding in patients is not just non-adherence with treatment regimes, but also additional anxiety and distress caused by missing or misinformation. There may develop a double iatrogenic effect on patients unfortunate enough to contract an infection whilst hospitalised, in that the inadequacy and inappropriateness of information given by staff following a positive diagnosis of a HAI causes additional psychological and emotional turmoil for already physically beleaguered patients. Where uncertainty and confusion reign, so too do anxieties, fear and depression. What is needed is effective change within inpatient systems for information communication regarding patient care, not just for individual staff. There is therefore a need to develop effective methods for eliciting and addressing erroneous or unhelpful illness beliefs at an early stage (Petrie & Weinman, 2006), in order to facilitate clinical improvements in physical outcomes and to reduce inappropriate healthcare utilisation post-discharge (Robertson, 2010). Active collaboration with patients and working together towards recovery require effective and

appropriate explanations about the infection and its treatment (Madeo, 2001).

Attending systematically to relatively simple changes in improving information sharing practices may go a long way towards redressing some of these problems: As one patient remarked, “I didn’t require more than just understanding it” (Lindberg et al., 2009, p275).

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Research Report

The psychological impact of hospital acquired *Clostridium difficile*:

A phenomenological investigation of patients' experiences

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The psychological impact of hospital acquired *Clostridium difficile*:

A phenomenological investigation of patients' experiences

Abstract

Background: The genesis and management of hospital-acquired infection in hospitals is well represented in medical and health literature. However, relatively little attention to date has been given to patient experiences, and most has focused on patients with MRSA. In order to understand the psychological effect of iatrogenic infection, and to consider the longer-term implications for patients returning for further hospital treatment, a qualitative interview investigation was conducted.

Methods: Patients testing positive with *Clostridium difficile* were recruited as inpatients, forming a homogeneous sample of individuals with similar symptoms. Six patients' experiences of contracting *C.diff* whilst in hospital were then analysed using Interpretative Phenomenological Analysis.

Findings: Emergent themes were lack of information about infection status and treatment; psychological distress including anger, worry, and anxiety; and concerns over possible future hospitalisation. Patients also reported observing poor adherence to hygiene protocol by hospital staff and anxiety about making complaints due to fear of possible reprisals.

Discussion: The results of this study indicate that an additional burden of anxiety, stress, anger and confusion is inadvertently placed on iatrogenically infected hospital patients, largely due to poor information sharing practices. It is recommended that systems of staff training be updated to include more emphasis on explaining diagnoses and its implications to patients to help mitigate some of these avoidable problems. Furthermore, that increased attention is paid to the long-term impact of hospital-acquired infection, especially in regard to its role as a deterrent to future engagement with health services, potentially putting patients' health at risk.

Introduction

Nosocomial complications are those that occur in the course of medical and healthcare, including Hospital Acquired Infections (HAIs) (Francis, 2008). One of the ways that unintentional iatrogenic harm can be caused incidentally in the course of medical intervention is through inadequate procedures for the control and spread of infections (Caplan, 2001). Iatrogenic infections are common amongst hospitalised patients, and are associated with morbidity, extended hospital stay, mortality, and increased incurred costs to the healthcare sector (Abbate & Di Giuseppe, 2008; Sheng, Wang, Lu, Chie, & Chang, 2005; Stone, Braccia, & Larson, 2005). In the UK, it is estimated that healthcare infections such as Methicillin-resistant *Staphylococcus aureus* (MRSA) and *Clostridium difficile* (*C.diff*) cost the NHS around £1 billion per year (Department of Health, 2007). *C.diff* is a major nosocomial infection, its manifestations ranging from mild diarrhoea through to severe disease in the form of pseudomembranous colitis, and toxic megacolon which can lead to death. Patients often report ongoing irritation of the bowel even up to a year after an infection, including stomach cramps, nausea, backache, and loss of appetite (Poppysmum, 2009).

In 2006 an independent report stated that of a total population of 53,729,000 in England and Wales, *C. diff* caused or was associated with 6480 deaths (Bandolier, 2006). The Department of Health estimated that in 2010 there were approximately 30,000 cases of *C.diff* being reported annually, and pledged to promote its objective to “embed a zero tolerance approach to preventable infections” (Department of Health, 2010, p. 1). The risk of infection is higher in healthcare settings due to a combination of factors including susceptible older populations, antibiotic use, and the possibility for

cross-infection (Department of Health, 2010). There is increasing concern about the widespread use of antibiotics, in particular the fact that it continues to precede nearly all cases of *Clostridium difficile* colitis (Morris, Jobe, Stoney, Sheppard, Deveney, & Deveney, 2002). The risk of colonisation with *C. diff* whilst in hospital appears to increase in direct proportion to length of stay suggesting that ongoing exposure to *C. diff* occurs throughout a hospital admission (Johnson et al., 1990).

Circumscribed research has suggested some psychologically detrimental effects for patients acquiring nosocomial infections, including feeling stigmatised (Madeo, 2001), unclean, guilty, and ashamed (Lindberg, Carlsson, Hogman, & Skytt, 2009; Skyman, Sjostrom, & Hellstrom, 2010). Patients also feel uncertain and confused about the likely duration, cause and seriousness of the infection (Newton, Constable, & Senior, 2001). Additional difficulties for patients are also incurred as a result of source isolation, which is the primary infection control resource for hospital staff (Kiernan, 2009). Guidelines for the safe management of *C.diff* in hospitals instruct that wherever possible affected patients, including those who have diarrhoea but have not yet been confirmed as *C.diff* positive, should be transferred and managed in single rooms (Department of Health: Health Protection Agency, 2009). However, some of the problems with source isolation are that isolated patients are both more likely to experience a preventable adverse event (Stelfox, Bates, & Redelmeier, 2003), to experience social isolation, lack of stimulation, loss of control and to express dissatisfaction with their care (Lewis, Gammon, & Hosien, 1999; Madeo, 2003). Isolation has a significantly negative effect on mood for resistant-organism infected patients (Catalano et al., 2003), and causes increased anxiety levels as patients

experience loneliness, feel concerned that they may be a threat to their families and are anxious that their rehabilitation may be prolonged. Psychological deterioration associated with isolation occurs in the form of increased instances of depression, anxiety, fear and hostility (Abad, Fearday, & Sadfar, 2010), particularly amongst elderly patients (Tarzi, Kennedy, Stone, & Evans (2001).

Although stress has been shown to be a significant contributor in slowing wound healing (Christian et al., 2007), the psychological impact of iatrogenic infection and isolation have been largely overlooked. Limited research investigating the experiences of patients infected with MRSA has begun to demonstrate the importance of this area of research, although no studies to date have investigated the experiences of patients infected with hospital acquired *Clostridium difficile*. Numerically there are more cases of *C.diff* reported in UK hospitals than there are cases of MRSA, and therefore it has a more wide-reaching impact on the general population. This makes the examination of hospital acquired *C.diff* of particular clinical and public interest. In addition, patient perceptions of the specifically iatrogenic nature of HAIs, have as yet not been examined, and empirical analysis is therefore needed to explore patients' reactions in relation to having caught an infection whilst in hospital (Gelbart, 2006).

The thoughts and beliefs that patients hold about an infection diagnosis are crucial determinants of how they think about, relate to (Criddle & Potter, 2006; Coughlan et al., 2004), and adjust to their illness (Petrie & Weinman, 1997). Perceptions not only influence patients' emotional responses but also have an effect on coping strategies including adherence to treatment regimes (Petrie & Weinman, 2006). It is therefore

important to not only seek to understand to what extent patients are adversely affected by HAIs, but also in what ways infection diagnosis is understood, experienced and made sense of.

Method

Design

The primary aim of the study was to gather qualitative data from patients who had acquired *C. diff* whilst in hospital in the UK, and to investigate what effect the experience of contracting an iatrogenic infection had on their psychological well-being. *C.diff* was chosen as the focus of this study in part due to the lack of research amongst this population to date, and also because of the possibility to access a more homogenous sample of infected patients than with some other hospital acquired infections. Symptomatic hospitalised patients' stool samples are laboratory tested, and positive infection identified. It is therefore possible to determine those *C.diff* positive patients who have acquired an infection whilst in hospital, and using a selective sampling strategy to then target those patients as potential participants.

An additional aim of this study was to assess the ways and extent to which patient's attitudes towards future possible hospitalisation and treatment might be affected by their experiences.

Methodological Framework

Perceptions of illness have been shown to be determinants of how patients adjust and cope with a diagnosis; therefore a phenomenologically-informed, inductive methodology was selected as the most appropriate approach in eliciting depth data of individual experiences. Within the arena of possible approaches to use, interpretative phenomenological analysis (IPA) (Smith & Osborn, 2003) was considered to be best suited to this particular investigation as it facilitates the examination of how people make sense of their major life experiences (Smith, Flowers & Larkin, 2009). A theory-building approach such as grounded theory (Thorne, 2000), was not felt to be appropriate for the research question, as the question indicates a technique which allows greater exploration of individual experiences of iatrogenic infection and their attitudes towards future re-engagement with health services. Other analytic approaches such as discourse analysis, particularly those which favour naturally occurring data, were felt to be less appropriate, as the most practical solution to gathering data was to interview participants. This study builds on general trends signified in prior research into the effects on patients with other kinds of iatrogenic infection, and explores whether these might similarly be indicated amongst a population of patients with hospital acquired *C.diff*.

Phenomenology has already been used to explore various aspects of human experience in health and illness, such as post-natal depression (Beck, 1992), the experience of AIDS sufferers (MacLacklan, 1992), and mental health and stigma (Mullen, Rozell, & Johnson, 1996). This increase in the use of IPA within health psychology research reflects the way that the constructed nature of illness has become

more widely recognised (Brocki & Wearden, 2006). It therefore has good validity as an established research methodology within the field of health research, making it eminently appropriate in investigating the very personal meanings that each patient derives from their hospital stay. Using an idiographic approach it was possible to capture personal nuances between patients in terms of age, gender and culture, as well as being able to explore possible trends and patterns between participants. This enabled a focus on individual patients' experiences, and their personal psychological mechanisms for attributing causality and making sense of their experiences. To this end, homogeneity in terms of diagnosis of participants whilst in hospital was planned in the sampling strategy. In keeping with the idiographic commitment that is inherent within IPA, each case is examined in detail in its own right before moving to more general claims in the narrative account in which extracts from all participants are used (Osborn & Smith, 2008).

A particular feature of IPA which is relevant to this study is the place that anticipation plays in shaping the significance of people's day-to-day experiences. In relation to the current study which aims to explore how patients view subsequent treatment, hospitalisation and their relationship with health professionals, the issue of anticipation and possible new significance and meaning that may have been created in the patient becomes relevant to the topic. In this respect IPA provides an excellent 'fit' between research question and chosen methodology.

The second major theoretical axis of IPA is that it is also an interpretative endeavour. As such it is informed by hermeneutics, the theory of interpretation. IPA is based on

the view that as sense-making beings, the accounts that participants give will be reflections of their attempts to make sense of their experiences. However, access to these sense-making processes is limited to what participants actually say during the interview. It therefore becomes necessary to engage in a process of sensitive, ethno-methodologically congruous interpretation. By this, what is meant is that the researcher's methodology is harnessed to the 'members own methods' of making sense of their lived experiences so that the interpretations retain the source integrity of the participants themselves, rather than being suffused with the researcher's own bias. It is acknowledged however, that in moving beyond thematic description to interpretation, some assumptions are made by the researcher about access to participant cognitions, and that this may be regarded in some discourse-based qualitative traditions as going beyond what is indicated by the data (Potter & Hepburn, 2005; Smith, 2005). This concern is respected, and within the bounds of retaining methodological integrity to IPA, every effort has been made to consider the context-dependent nature of the interview interaction, and to regard the data produced as situated and occasioned. To this end, wherever possible, data extracts include interviewer questions as well as participant responses, and priority has been given to reflexivity and transparency throughout.

Ethical Considerations

Prior to data collection, the research project was reviewed and given approval by NHS Research Ethics Committee and by the Research and Development Department of the hospitals included in the project (Appendix F). Care was taken throughout data collection to ensure informed consent was given and that participant details were

anonymised and dealt with confidentially. Participants were given the option to withdraw from the study during or after interview without giving any reason (Appendix E). During interviews there were occasions when participants sought clarity of information about their infection from the interviewer, and at times sought advice about how to make complaints. The position adopted by the interviewer was to act as a signpost to the hospitals' specialist infection control team for further information, via ward staff as appropriate, thus bracketing her role as independent researcher from any perceived role as a medical expert.

Participants

The purpose of qualitative research is not to enumerate opinions but to explore the range of different representations of an issue (Gaskell, 2000). In light of this, the main criteria for an optimum sample size is that sufficient depth of information can be gathered to fully appreciate the phenomenon (Fossey et al., 2002). A frequently used measure of sample size sufficiency is the notion of saturation, which is usually understood to mean that sampling should continue until the themes emerging from the research are fully developed and all diverse instances have been explored (Kuzel, 1992). However, the concept of saturation within IPA is problematic due to the cyclical, iterative nature of analysis in which passages are analysed repeatedly in the light of insights obtained from other sources. Thus, the process could theoretically continue ad infinitum (Brocki & Wearden, 2006; Smith, Jarman, & Osborn, 1999). It is acknowledged therefore that adequacy of sample sizes (Bowen, 2008) in qualitative research should be assessed in relation to the requirements of the particular qualitative approach chosen. For this project, seven participants were recruited, in line

with the recommendations for a study of this type using Interpretative Phenomenological Analysis (Smith , 2008, p. 57). The interview data from one participant was omitted from the final analysis after discovering that she had acquired the *C.diff* infection prior to coming into hospital and therefore did not meet the sampling criterion that the infection be acquired whilst in hospital. The remaining participants were all White British, ranging in age from the youngest participant who was in his 20s to the eldest who was in his 80s (Table 4). Patients had varying primary medical needs that had necessitated their initial admission to hospital. Participants' names and the names of the hospitals that they were in have been changed to protect their identities.

Recruitment of participants was conducted in close consultation with the specialist *C.diff* infection management team. A record of patients located across three hospitals within the same Trust with a diagnosis of *C.diff* was held by this team, and suitable participants were identified from this list by a senior specialist nurse after meeting with the patients. The majority of *C.diff* infected patients were being treated in isolation rooms connected to the main hospital wards. In terms of the research criteria, a homogenous sample of patients who had acquired *C.diff* whilst in hospital was purposefully sampled. Participants were excluded if they had acquired the infection whilst in the community before being admitted to hospital. This was in order to adhere to the research question which aimed to explore the impact of iatrogenic hospital acquired infection. Decisions about the capacity of patients to engage in the research were taken by the senior specialist nurse, who used her clinical judgement to assess whether patients were well enough to be interviewed. All participants were

adults. Those in Intensive Care or for other reasons unable to communicate verbally were excluded from the sample based on their incapacity to understand and engage in the research process.

Table 4: Anonymised List of participants

Pseudonym	Gender	Age Group
Beryl	Female	70-80
Joan	Female	50-60
Dennis	Male	50-60
Barbara	Female	50-60
John	Male	20-30
Raymond	Male	80-90

Procedure

This study employed the use of semi-structured interviews as a data collection method which was planned in accordance with the research questions, and was designed to facilitate the participant's ability to answer as freely as possible. A semi-structured interview schedule was used to guide the researcher, and is displayed in Table 5. The interviews were semi-structured in that the researcher was informed by the schedule, but where there were particular topics of concern raised by participants, they were allowed to express their feelings freely and to talk in more detail about those particular areas. This is a method congruent with the underlying assumptions of IPA (Wimpenny & Gass, 2000), which indicates that minimal probes be used throughout,

and that respondents ideally be allowed “a strong role in how the interview proceeds” (Smith & Osborne, 2003, p. 63).

Table 5: Semi-structured Interview Schedule

1.	Can you just start by telling me about how you came to have <i>C.diff</i> ?
2.	How would you describe the kind of person you were before you came into hospital? - How were you after you contracted <i>C. diff</i> ? - Tell me about how you handled it
3.	How, if at all, have your thoughts/feelings been affected since you first found out you had <i>C.diff</i> ?
4.	How, if at all, have your views of the healthcare system changed as a result of your experience?
5.	Is there anything you would have done differently if you had your time again?
6.	How has your experience affected how you feel about going into hospital in the future?
7.	What would you like to say to healthcare professionals to help them understand what your experience has been like? - Is there anything else you think I should know to understand your experience better?

It is acknowledged that interviews are not neutral data collection tools but active interactions (Fontana & Frey, 2003) and as such the researcher’s place in the production of the data has been considered (Potter, 2002). Interviews lasted between 30 and 60 minutes, and were audio-recorded on both tape and digital devices to ensure adequate recording quality. Due to the infectious nature of *C.diff*, the researcher followed the usual hospital protocol of wearing an apron and gloves when interviewing patients, and followed careful hand-washing guidelines before and after

contact with patients. Furthermore, recording equipment was placed on a disposable towel during interviews to ensure that the equipment did not become a source of transfer of infection around the hospital. Most participants were interviewed in Isolation Rooms within the hospitals, one in a room shared with another patient, and one was interviewed at home one week post-discharge. It is acknowledged that the context of the interview in terms of location, and timing will have a bearing on disclosure in terms of what aspects of their illness, and in the way that they chose to talk about it.

Three interviews were transcribed in full by the researcher, however due to time constraints, a professional transcriptionist was employed for the remainder. The transcriptionist was encouraged to reflect on the process and the data contained so that she was able to de-brief fully from the experience with the researcher. All recordings and transcripts were re-checked by the researcher to ensure accuracy and to enable the researcher to gain familiarity with the data. It is acknowledged that choices about transcription convention and style reflect the theoretical position held by the researcher and are a particular representation of the data (Lapadat & Lindsay, 1999). In this case, only pauses, laughter and other major paralinguistic elements were included in keeping with the mainly thematic nature of the analytic convention adopted.

The data were analysed using Interpretative Phenomenological Analysis (IPA), following the four stage model recommended by Smith and Osborn (2003). During the first phase, the data management software NVivo was used to aid the researcher in

annotating transcripts during the initial close interpretative reading. The software was then used to order initial themes emergent from transcripts as it provides a convenient and logical paperless system for coding and clustering extracts. The data at this stage were then manually interrogated to investigate the connections between themes, and a table of super-ordinate and subordinate themes was developed. Data extracts exemplifying these themes were then edited for brevity and conciseness when used within the analytic narrative.

Reflexivity and Transparency

As a measure of quality, the principle of transparency (whereby the researcher gives a clear account of how the research was conducted so that the reader is able to see how the findings were derived (Spencer et al., 2003)) was prioritised throughout. This is an especially important process for qualitative researchers because of the need for reflexivity (Finlay & Gough, 2003). Reflexivity, which refers to the sensitivity of the researcher to the ways in which s/he influences and shapes the research process (Mays & Pope, 2000), is one of the key mechanisms through which transparency is achieved. To this end, the researcher maintained a reflective journal which informed understanding about process decisions (Freeman & Tyrer, 2006). In addition, wherever possible, interviewer questions have been included in data extracts quoted to facilitate transparency, and to exhibit context. Some additional notes relating to the quality and rigour of the investigation are also appended (Appendix C). Whilst reflexivity is valued in all qualitative research, there is a particular meaning within IPA which explicitly recognises the interpretative facet of the approach. In this regard, there is less focus on individual researcher characteristics, and more emphasis on appropriate reflection

on the dynamic process of analysis and its impact on the final narrative (Brocki & Wearden, 2006).

My personal position as a researcher in this project was as a trainee Clinical Psychologist conducting the investigation as part of the training requirements. As such I had no prior experience of working within a health setting, and had chosen the subject area as an opportunity for personal development. My previous research experience had been confined to an academic rather than applied focus, and although I am experienced and interested in qualitative approaches generally, had not used IPA as a mode of enquiry and analysis prior to this project. The impact of this firstly, is that I approached the data collection as someone relatively naïve about the clinical processes involved in physical health care, and as such did not bring to the study any prior assumptions or background knowledge about healthcare associated infections. This may have the advantage of a relatively unbiased perspective, and yet at the same time, may have impacted on my capacity to fully engage with the wider issues relating to health psychology as they relate to patients sense-making practices, and to my analytic interpretations of them.

In addition, my background in micro-analysis of transcripts of interaction through conversation analysis meant that it was a discipline to maintain a wider interpretative stance during the data analysis and discussion stages. Furthermore, my own ontological position is primarily constructivist, and therefore I have needed to 'bracket' some of my learned preferences about the nature of, and potential for access to the

‘truth’ about what participants may be thinking about their experiences in order to fully engage with the process of Interpretative Phenomenological Analysis.

Results

The systematic analysis of interview transcripts elicited a number of themes which have been tabulated below (Table 6) for ease of reference. The data relating to each area was interrogated further and more detailed findings explicated in the descriptive narratives that follow.

Table 6: Taxonomy of Findings

Searching for the Cause of <i>C. diff</i>
<ul style="list-style-type: none"> • Attempts to locate causality within their own or other people’s behaviour • Concern over prevention to avoid future contraction and contamination • Accounts relating to inadequate ward cleanliness • Blame and responsibility attributions to hospital systems
The Effects of Contracting <i>C. diff</i>
<ul style="list-style-type: none"> • Physical symptoms including diarrhoea, loss of appetite, sickness, dehydration, back pain and immobility • Expressed emotional distress including tearfulness, confusion, frustration and anxiety in both patients and their families. • Attitudes towards isolation and barrier nursing.
Diagnosis and Reactions to Diagnosis
<ul style="list-style-type: none"> • Diagnoses received directly from staff or inferred from treatment regimes changing • Initial reactions included upset, surprise, desire to fight
Communication and Information-giving
<ul style="list-style-type: none"> • Patients reported a lack of verbal and written information • Feelings of anxiety about unanswered questions • Expressions of not being listened to • Concerns about not being treated holistically, leaving patients feeling frustrated or neglected.
Complaining and Inhibition
<ul style="list-style-type: none"> • Reluctance to complain about hygiene protocol and ward cleanliness for fear of

<p>upsetting staff or causing trouble</p> <ul style="list-style-type: none"> • Pessimism that complaints are not acted upon
<p style="text-align: center;">Recovery and Attitudes to Re-engagement</p> <ul style="list-style-type: none"> • Desire to try to get back to normal and relief to be out of hospital • Fear of infection returning and lasting intrusive memories • Worries about loss of income resultant from extended hospital stay • Avoidance of re-engagement with hospital care in future

Searching for the Cause of C. diff

All participants showed a motivation to locate the cause of their infection in relation to either their own, or other people's behaviour. This was felt by patients to be important so that preventative measures could be taken to avoid it happening again in the future. In all data extracts 'P' refers to the Patient, and 'I' to the Interviewer.

Extract 1

- 1 P: I'm just wondering how did I get it in the first place,
2 I: mm
3 P: ... ((sigh)) it's a worry that cos you don't know how you got it therefore you
4 can't avoid it next time (Dennis)

Extract 2

- 1 P: I've asked different people where they think I've got it from and they've not
2 really looked into it I don't think.
3 I: mm
4 P: so if they looked into it and they found out it is the cleanliness what's spreading
5 the germs then they can do sommat about it can't they?
6 I: yeah
7 P: I mean it don't look like they're tryin' to find out where I've caught it from.
8 That's one of the most frustrating things I think (John)

Dennis and John both expressed concern and frustration that hospital staff did not appear to take seriously enough the causal factors in their contagion: “it don’t look like they’re tryin’ to find out where I’ve caught it from” (Ext. 2, Line 7) and as a result, measures to avoid future infection could not be implemented, “you don’t know how you got it therefore you can’t avoid it next time” (Ext 1, lines 3-4).

Joan explained how she and her family were careful to participate in infection control by following proper hand hygiene procedures, but expressed a sense of futility that there were limits to how much they could do individually to prevent contagion.

Extract 3

- 1 P: I make sure everybody washes their hands and that sort of thing but you can’t
2 do a great deal, can you? (Joan)

Deficiencies in the cleanliness of the hospital ward were reported as an over-riding feature of patient accounts. Cleanliness accounts were typically situated within longer sequences of talk focusing on the issue of how or from where the infection was contracted.

Extract 4

- 1 P: I tell you what the toilet in the ward was absolutely filthy, and we told em one
2 day and they cleaned it but you could still see mess on the floor, they hadn’t
3 cleaned it away so people are going to walk in that and tread it round in’t they?
(Barbara)

Extract 5

- 1 P: there was a whole trail of poo going down t- down the corridor, ...I don't know
2 how that had happened but () erm y'know had they touched the handles and
3 stuff like that? (Dennis)

In these extracts, two patients refer to how inadequate hospital cleaning may potentially lead to germs being carried on people's feet or hands to other parts of the ward, "people are going to walk in that and tread it round in't they?" (Ext. 4, line 3), "had they touched the handles and stuff like that?" (Ext. 5, lines 2-3).

Other patient contagion theories supposed that *C.diff* may have been contracted as a result of hospital staff insufficiently attending to hygiene protocol such as washing hands or changing gloves between attending to individual patients.

Extract 6

- 1 P: I've seen them go from one patient to another with the same pair of gloves on,
2 or no gloves on. If I caught it, that's probably where I caught it (Joan)

Extract 7

- 1 P: there was also a nurse that went around and never washed her hands and ...did
2 things from patient to patient ... so it's no wonder we get things (Barbara)

Joan and Barbara in the extracts above, both referred to observing nurses going from "patient to patient" (Ext. 7, line 2) and either "never washed her hands" (Ext. 7, line 1) or with "the same pair of gloves on" (Ext. 6, line1). These patients were clearly vigilant to the activities of nursing staff in relation to hand hygiene, and attributed potential

iatrogenic spread of infection to these oversights in procedure: “it’s no wonder we get things” (Ext. 7, line 2).

Causal attribution was also a theme in the narrative provided by John, who in addition to describing apparently very lax cleaning standards, also suggested the transfer of a patient from another hospital into the bed next to him as a possible source of infection. The patient who had been transferred was already infected with a ‘bug’, but after remaining for only a day on the ward had been sent back to the hospital he had come from.

Extract 8

- 1 P: the same day he got transferred to () this hospital he got transferred back to
2 that hospital because they didn’t want the bug spreading any further. But the
3 bug’s already got out
4 I: they’d already brought him here then sent him back again?
5 P: yeah, yeah. Which in my eyes is just a () a () terrible thing to do that is.
6 I: yeah
7 P: totally out of order. They shouldn’t be, if they know somebody’s got a germ
8 they shouldn’t be spreading it around different hospitals. (John)

This patient was clearly very agitated and aggrieved by what had happened, describing it as “a terrible thing to do” (Ext. 8, line 5) and “totally out of order” (*ibid*, line 7). John was a young man who worked in the catering industry. He was trained in procedures relating to food hygiene, and as such particularly appalled by what he felt was a seriously inadequate adherence by hospital staff to appropriate hygiene procedures on the ward.

Enmeshed in the process of identifying causality, most patients indicated that their understanding of who was responsible for their *C.diff* infection was that the hospital was culpable for the fact that they had caught it whilst they were there.

Extract 9

- 1 P: so it's gotta be () the hospital's responsibility in my eyes that I've got it.
2 I: mm () how do you feel about that then?
3 P: well () a bit peed off to be fair. But there's not really much I can do (John)

After reflecting on how he had not been symptomatic prior to admission, John expressed that he was "peed off" (Ext.9, line 3) that it was the hospital's responsibility he had caught the infection, but also resigned to being unable to do anything about it: "there's not really much I can do" (Ext. 9, line 3). Similarly, Beryl and Barbara both complained that it was the hospital's fault that they had caught it whilst there.

Extract 10

- 1 P: I suppose it is their fault really. I said to the doctor ... of course, you gave me
2 *C.diff*. She said well we didn't mean to, and I said I know you didn't but you still
3 gave it to me. (Beryl)

Although the doctor protests that it was not intended that she had contracted an infection, the patient reports irritably that whether it was intended or not, it was still the hospital's fault that they "gave it to me" (Ext. 10, line 3). Barbara, who was interviewed at home a week after discharge alluded to the fact that she felt aggrieved at the lack of acceptance of responsibility for iatrogenesis. This was indicated in her

narrative that she was still symptomatic on discharge, and that no-one had contacted her to “check up and see how things are going” (Ext. 11, line 2).

Extract 11

- 1 P: y’know seeing as it’s something that you’ve got through their fault they could
2 just () y’know () check up and see how things are going or ask the doctor to
3 give you a ring (Barbara)

The issue of blame was particularly pertinent for Barbara, who prior to being infected with *C.diff* in hospital had also suffered several other nosocomial complications from hospital procedures that had been incorrectly performed (Ext. 12, lines 5-6). After the interview, Barbara made a formal complaint to the hospital about what she felt had been serious negligence of care.

Extract 12

- 1 I: (pause) so who’s fault do you think it is that you got the *C.diff*?
2 P: it’s o- it’s their’s. Through () well through just not doing things right in’t it?
3 I: mm mm. How does that make you feel?
4 P: well you feel that if you went again you’d a- I wouldn’t be surprised if you got
5 something I like I ‘ve had ten operations () but () in all the times there’s sort
6 of always been some sort of problem. (Barbara)

The Effects of Contracting C. diff

In addition to severe diarrhoea, the main symptom of *C. diff*, patients experienced a range of physical symptoms including loss of appetite, sickness, dehydration, back pain and immobility.

Extract 13

P: I was being violently sick, really, really sick and it was all black acidic stuff
(Beryl)

Extract 14

P: it were terrible to be in that agony (Barbara)

Extract 15

1 P: I've seen the loss of appetite ...severe diarrhoea ...dehydrated ...a bad back for
2 the last few weeks as well (Dennis)

Extract 16

1 P: As I say, I was all right after the operation, until I got this *C.diff* and that did, it
2 literally just took me off me feet, I couldn't stand up, couldn't do anything, it
3 just flattened me. (Beryl)

Although not fully represented in these extracts, patients tended to speak at length about their physical symptoms, particularly the diarrhoea. Some patients spoke about their 'stools chart', a pictorial chart kept at the end of the patient's bed to record stool consistency. There was also vigilance to monitoring symptomatology amongst patients, which appeared to indicate a desire or attempt to predict a recovery trajectory. The degree to which patients were affected by diarrhoea varied, for some it was an inconvenience, but for others it was seriously debilitating and humiliating. Beryl was unable to walk or to move from her bed (Ext. 16), and Barbara was so anxious and frightened about not being able to control the diarrhoea that she couldn't sleep in case she made a "mess the bed in the night" (Ext.19, line 3)

In addition to the very unpleasant physical symptoms reported, patients also expressed their own emotional distress, frustration and anxiety and that of their families.

Extract 17

P: it's just frustrating you can't do nothing (John)

Extract 18

P: a bit peed off () big time that they didn't do anything sooner (Dennis)

Extract 19

1 P: I lived on my nerves waiting for somebody to come and empty the commode
2 ...
3 P: - I couldn't go sleep cos I were so frightened that I'd mess the bed in the night
4 cos that's how it was y' just had to go y'know (Barbara)

The three extracts above address different areas of patient's concern; emptying a commode (Ext. 19), delayed treatment (Ext. 18), and a sense of being helpless (Ext. 17). Resulting from these practical constraints and concerns, patients expressed frustration (Beryl), annoyance (Dennis) and anxiety (Barbara).

In addition patients referred to the impact that their illness was having on their families, an example of which is illustrated below when Beryl spoke of how her family were "very upset" (Ext. 20, line 1) and "grieved" (*ibid*, line 2) to see her suffering with the impact that the *C.diff* infection had on her.

Extract 20

- 1 P: And, um, of course the family were all very upset about it ((pause)) because it
2 was affecting me so badly. They were just grieved to see me in such a state,
3 really. (Beryl)

Extract 21

- 1 P: at the beginning the kids were having to tell me, come on mum, you've got to
2 fight it, you've got to fight it. ((starts crying)) ... and, um, I just didn't feel then
3 as though I could fight it, I was just lain so low that I didn't feel that I'd ever get
4 back up again. (Beryl)

Beryl had been admitted with pneumonia and had survived being acutely ill in the Intensive Care Unit. On recovering sufficiently to be moved to a general ward, she subsequently contracted *C.diff*. This extract demonstrates not only how low she felt, but how important at that time her family had been in encouraging her to keep fighting to get better. Beryl was tearful as she reported her experiences to the researcher, and reflected on how she “didn't feel that I'd ever get back up again” (Ext. 21, lines 3-4). It is difficult to represent the level of distress expressed by patients about their experiences, but this is indicated to some extent in this extract by the fact that even on an open ward with a researcher who she had never met before, this lady was so overcome with her distress at what had happened to her that she openly cried as she spoke of her experiences.

Diagnosis and Reactions to Diagnosis

In relation to receiving a diagnosis most patients reported that they had been informed that the results of their test for *C. diff* had come back positive. The following two extracts exemplify how two patients were informed quite directly, if not a little curtly, that they had contracted *C.diff*.

Extract 22

- 1 I: how did you find out?
2 P: erm just from one of the nurses she just came up and said it's come back
3 positive with *C.diff*. (John)

Extract 23

- 1 P: somebody just told me, didn't beat about the bush, they just said, you know,
2 I'm afraid you've got *C.diff*. (Beryl)

Whilst, in these examples, explanations and reassurances following diagnosis were not necessarily forthcoming, Joan had the additional unfortunate experience of indirectly finding out that she had a contagious infection only when she was placed in an isolation room with a sign on the door (Ext. 24).

Extract 24

- P: I think it was kept quiet ... I mean nobody said anything until they put a notice
on the door (Joan)

This patient's way of making sense of this action was that she formed the impression that the motives staff may hold for not informing her directly about having *C.diff* were that they were making attempts for it to be "kept quiet" (Ext. 24, line 1), implying perhaps that there was an unwillingness to acknowledge or take responsibility for the infection.

It should be noted again that the patients included in the sample were those who were well enough to manage a short interview. Other *C.diff* positive patients who were being treated in the Intensive Care Unit or who were too ill to be interviewed were excluded from the sample. The patients in the sample tended to be those who were recovering from the operation or medical intervention that had necessitated their initial admittance to hospital, and who had then contracted *C.diff* during this stage. As they were no longer in an acute stage when they were infected, they were conscious and well enough to understand any diagnostic information that was provided. Initial reactions to diagnosis for these patients tended to be quite negative.

Extract 25

- 1 P: I think my first thought was I've got to get out of here.
2 I: That was your first thought?
3 P: Yeah, I think so, before I catch anything else. (Joan)

Extract 26

- 1 P: when they told me I'd got *C. diff* I just cried ... y'know it's really upsettin' ... cos
2 well you feel like you're dirty don't ya' y'know cos you've got something awful.
(Barbara)

For Barbara, to be told that she had caught an infection in hospital was particularly distressing. She was a lady who took a lot of pride in her appearance, and in her cleanliness. She reported that her initial reaction to the diagnosis was that she “just cried” (Ext. 26, line 1). In terms of what this meant to her personally, we can glean an indication of this when she reports “you feel like you’re dirty” (*ibid*, line 2), something particularly abhorrent to her.

In contrast, Raymond an elderly gentleman in his eighties, when asked what his reaction to the diagnosis was, had a more philosophical view, reflecting on this illness in the context of a life well lived and that he was content with, “I’ve had a reasonable life ... I think I’ve done alright” (Ext.27, lines 4-5).

Extract 27

- 1 P: I’ve had all my life so why should I worry about the few minutes, days, weeks
2 I’ve got to live ... I’m beginning to think of the end of my day.
3 ((several lines omitted))
4 P: Well, you know overall it, I don’t know, I’ve had three children. I’ve had a
5 reasonable life. ... I think I’ve done alright. (Raymond)

This highlights the importance of thinking phenomenologically about patients’ experiences. The people interviewed for this study were at different life-stages when they contracted *C.diff*, and, whilst there are clearly some generic similarities in their experiences in hospital, they also demonstrated different ways of making sense of those experiences in the context of other things in their lives. For example, for Raymond as an elderly retired gentleman living alone, and reflecting on having had

good life, perhaps felt that he had less to lose than some other participants. Both John and Dennis however, who were both of working age, expressed concern over lost earnings, indicating that the meaning of acquiring an iatrogenic infection for them was also connected to the enforced extension of their hospitalisation as well as their health concerns. For Dennis, who was in a hospital many miles away from his family, the loneliness of the isolation ward and the lack of contact with his family were reported by him to also be factors which magnified his distress experienced.

Communication and Information-giving

A major theme, alluded to by all patients was that of communication and information giving. On the whole, patients reported that they felt they had received insufficient information from the hospital about *C.diff*. Typically they had received a diagnosis, but had not been given further information about what *C.diff* is, how they may have contracted it, or what they might do to avoid infecting others. There was also no preparatory information about the need and purpose of isolation, which was largely inferred by patients.

Extract 28

- 1 P: They said I've got it but they don't tell me how I got it or anything about it ...
2 *C.diff*s er been mentioned perhaps sometimes by various people in the medical
3 profession, but they've never given me any explanation what it is ... I would like
4 to fully know what it is (Raymond)

Extract 29

- 1 P: I'd want to know how easy it was to catch it, for other people to get it. Yeah.
2 'Cos I don't know that, how do you catch it? I still don't really know. Nobody's
3 ever explained how you catch it. Is it air borne or? (Joan)

Extract 30

- 1 P: and they should really give you an explanation why you've got it ... I don't know
2 how long it lives in our body for or owt like that. So I don't know the main
3 things about it, I just know it's a bug that's contagious between people. (John)

These extracts demonstrate that patients have questions and concerns about their diagnosis that might fairly easily be addressed, regarding infection transmission, how long they may be contagious, and why they may have been susceptible to catch it. The inadequacy of explanations “they’ve never given me any explanation” (Ext. 28, line 3), “nobody’s ever explained” (Ext. 29, line 2), left patients with many unanswered questions. Furthermore, John implies through his use of the word “should” in his comments in Extract 30 (line 1) that there is some kind of moral obligation for hospital staff to provide an explanation about the infection to patients beyond just diagnosis confirmation. For John, part of his sense-making of what has happened seemed to be that he had clear expectations about what he thought should happen procedurally in hospitals. The fact that these things did not happen caused him to feel particularly angry and aggrieved as these expectations were not met.

In the absence of reliable explanations from hospital staff, patients were often left trying to integrate information gathered from the media or the internet. In the following extract (Ext. 31) Raymond refers to information he has read in the “national

press” (line 1), which has led him to believe that “no-one knows the reason why they do get it” (line 2).

Extract 31

- 1 P: in recent times what’s been in the national press, that people get these
2 infections in hospital and then no-one knows the reason why they do get it
(Raymond)

Similarly Dennis explained that he would have preferred to have been given reliable information from the hospital at the time of diagnosis rather than searching the internet and getting “misinformation” (Ext. 32).

Extract 32

- P: it’d stop you looking on the internet and getting misinformation wouldn’t it?
(Dennis)

Dennis was the only participant interviewed who had received a short leaflet from the hospital about *C.diff* which he had found helpful. Raymond however said that he would prefer to talk to someone than have the information in written form “I’d prefer somebody to come along and I’d chat with them” (Ext. 33, line 3).

Extract 33

- 1 P: I don’t think a leaflet would tell me everything so if that was necessary
2 I: Mm
3 P: I’d prefer somebody to come along and I’d chat with them as I’m chatting with
4 you. (Raymond)

This again shows that it is important to attend to the different needs of individual patients in terms of how and when information is communicated, taking into account age, physical health, and personal preferences. In addition, the physical presence of a member of staff in talking with a patient has a function in containing anxiety. Human interaction is something that research shows is more limited for patients in isolation (Cassidy, 2006), due to a heightened anxiety of staff about the risk from exposure to infection (Prieto, 2005). However, the healing benefits of personal communication ought not to be underestimated (Holland, et al., 1977), and patients in this study all commented that they would have preferred someone to explain to them more fully what their diagnosis meant.

Although there may be personal preferences for patients relating to how information is presented, the unanimous opinion of all patients was that more information, both written and verbal was required. They suggested that if they had received explanations at the point of diagnosis, this would have helped to mitigate anxieties fuelled by imagining the worst or trying to work out the implications themselves. Joan explains in the following extract how in the absence of clear information about *C.diff* from the hospital, her imagination “would go to the worse thing” (Ext. 34, line 3). This potential risk of catastrophising could be averted by offering some simple explanations.

Extract 34

- 1 I: And what did they tell you about it?

2 P: Nothing really. I always want more information, 'cos I can deal with things if I
3 know what's happening, because I think my imagination would go to the worse
4 thing. (Joan)

A reciprocal process of communication was felt to be lacking both in information giving and for some patients also in not feeling that they had been listened to, resulting in feeling frustrated.

Extract 35

1 P: there's a few of us that have been on the wards with me at the same time and
2 we don't feel like we have been listened to. (Dennis)

Extract 36

1 P: it's just frustrating ... you can't do nothing about it, you voice your opinion and
2 it doesn't seem like no-one listens. (John)

Two of the three men in the study, Dennis and John, both complained that they felt hospital staff had not listened to them. Dennis, who had been in hospital longer following a kidney transplant, added weight to his grievance by claiming that several other patients on the ward felt the same way "there's a few of us" (Ext. 35, line 1). By including others, Dennis seems keen to avert any possible inference that his complaints are just personal. Also, his sense of camaraderie with other men in the ward is apparent, and helps to understand how acutely he feels the loneliness of his enforced isolation.

There was also a sense that doctors were not concerned about them holistically as people, not just malfunctioning body parts or diseases, leaving them feeling frustrated or neglected.

Extract 37

- 1 P: they forget that th- other things can cause you issues..... What I'm trying to say
2 is that they look at you as a kidney not as a whole person (Dennis)

Dennis in this extract expressed that in endeavouring to treat the problem body part, in his case his kidney, he felt that other aspects of him as a person had been overlooked, "they look at you as a kidney not as a whole person" (Ext. 37, line 2). Similarly, Barbara explains that "you sort of respect doctors" (Ext. 38, line 1), but that in return they don't "bother about us like they should" (*ibid*, lines 3-4).

Extract 38

- 1 P: cos you sort of respect doctors and that don't you () but sometimes I don't
2 think they think much of () patients at all ...y'know we're not rude to them and
3 we respect 'em an () that but I don't think sometimes they bother about us like
4 they should. (Barbara)

After explaining that she had only had her hair washed twice in eleven weeks, Joan elaborated the significance of this to her by contrasting it with her usual self-care at home involving washing her hair every day (Ext. 39).

Extract 39

- 1 P: 'Cos I thought, eleven weeks, my hair's only been washed twice and when you
2 wash it every day you think, phaw, what do I look like? (Joan)

Similarly, Beryl (Ext. 40) having just had a shower and her hair washed after seven weeks also felt that staff didn't seem to have time to attend to patients' needs, which had made her feel neglected.

Extract 40

- 1 P: But they just don't seem to have time for anything, you know what I mean?
2 I: How does that make you feel?
3 P: Neglected? (Beryl)

Complaints of this kind about how patients felt that their personal cleanliness had been overlooked by staff in the absence of their own capacity to wash and care for their bodies as they would normally do are understandable. However, given the nature of the infection that they have acquired in hospital and their basic knowledge of its spread being connected with cleanliness and hygiene, their worries over personal washing appear heightened. As Barbara said when she first heard about her diagnosis, she immediately felt 'dirty' (Ext. 26).

Complaint and Inhibition

Although patients felt that the hospital was responsible for the fact that they had acquired an infection whilst in its care, they were often reluctant to complain about deficiencies in cleanliness, or staff not adhering to hand-washing protocol because of fears about not wanting to "upset them" (Ext. 41) or "cause trouble" (Ext. 42).

Extract 41

- 1 P: you're left with these people who are looking after you, and if you've upset
2 them. (Joan)

Extract 42

- P: why I never complained is I don't want to upset anybody or cause trouble
(Barbara)

Patients expressed their complaints to family members, but for these reasons seemed less able to verbalise complains to staff or to the organisation. Those who did feel confident enough to challenge staff or to make complaints were pessimistic about how those complaints would be followed up or dealt with. John who was a male, and the youngest in the sample aged in his 20s, explained that other people besides himself had also complained about the cleanliness of the ward, but that it appeared nothing had been done, "obviously nothing's been done from them complaints" (Ext. 43, lines 4-5).

Extract 43

- 1 P: It's how far that complaint goes, it's perhaps not very far in my eyes
2 I: you don't think they'll do much about it?
3 P: not really... I'm not the only one that's complained about it. They've already
4 told me they've had a few complaints in the last month and obviously nothing's
5 been done from them complaints. (John)

Recovery and Attitudes to Re-engagement

One of the main aims of this research project was to assess the ways and extent to which patients' attitudes towards future possible hospitalisation and treatment may be affected by their experiences. In light of this, one of the questions on the interview schedule asked: 'How has your experience affected how you feel about going into hospital in the future?'

Extract 44

- 1 P: I wouldn't want to come back, no. Not if it could be avoided ...it's not been a
2 good experience. (Beryl)

Extract 45

- 1 P: obviously they can't make you come into hospital can they? And er () I would
2 have tried me hardest to er ... I would have gave it a bit more longer at home
(John)

Patients expressed that they would try to avoid coming back into hospital again in the future (Ext. 44), even suggesting staying at home as long as possible (Ext. 45). John had Crohn's Disease, and had needed to be admitted to be treated intravenously with steroids. About 80% of people with Crohn's disease will require surgery to relieve their symptoms, repair damage to their digestive system and treat complications of the condition (NHS, 2009). Reluctance to come back to hospital for necessary medical attention because of anxieties about possible iatrogenic infection may therefore potentially put patients' health at risk.

Joan had been on the verge of collapse as she described it, when she was admitted to the Intensive Care Unit with pneumonia and septicaemia. Consequently, although she would not wish to come back to hospital, she rather resignedly stated that “if you’ve got to come in, you’ve got to come in” (Ext. 46, line 1), but that if she did, she would be more alert to “things not being done right” (*ibid*, line 4), and take precautions to protect herself from infection where possible.

Extract 46

- 1 P: If you’ve got to come, you’ve got to come haven’t you? Probably I might be a
2 bit more alert next time.
- 3 I: What would you be alert to?
- 4 P: Things not being done right. So that, you know, I could perhaps take a few
5 more precautions. (Joan)

Barbara, who was interviewed one week post-discharge at her home, was still affected by intrusive memories from what she experienced as quite a traumatic time in isolation, where she struggled with constant diarrhoea and a commode which was frequently dirty and smelly in her room.

Extract 47

- 1 P: just terrible y’know and I’ll never forget that room if I wake up now at night I
2 think of being in that room (Barbara)

Barbara also experienced continuing fear that the *C.diff* might “come back” (Ext. 48).

Extract 48

P: I'm frightened to death that the *C.diff* II- come- were coming back

(Barbara)

Whilst the majority of patients interviewed were retired, those that were still of working age were additionally concerned about the loss of income that was anticipated as a result of an extended hospital stay because of contracting *C.diff*.

Extract 49

- 1 P: so I'm assuming I've stayed in hospital longer because I've got *C. diff* which
2 means obviously I'm losing more money from wages ... 'cos I can't go back to
3 work till I get the all clear off the hospital. Erm so obviously if that's going to be
4 another week that's another week's lost wages. Just 'cos I've caught a bug from
5 something that's not been done right in hospital. (John)

The frustration felt by John because of his loss of wages from an extended hospital stay is evident, and is further exacerbated by the knowledge that his loss was due to hospital negligence in infection control processes "just 'cos I've caught a bug from something that's not been done right in hospital" (Ext.49, lines 4-5) .

Discussion

The aims of this study have been to understand the psychological effect of iatrogenic infection, and to consider the longer-term implications for patients returning to hospital. Although there has been some circumscribed research conducted within the field of hospital infections, relatively little attention to date has been given to understanding patient experiences. The few qualitative studies to date have mainly

focused on patients with MRSA and have been particularly interested in the impact of isolation. Whilst isolation has been an issue that has been raised by participants in this study, its scope has been wider, and has looked forward to thinking about the clinical implications of HAIs and in particular, the ways in which care for iatrogenically-infected patients may be understood and improved. Hospitalised patients with *Clostridium difficile* were interviewed about their experiences, and the data were analysed using Interpretative Phenomenological Analysis. Key findings revealed that patients felt that there was a lack of information about their infection status and treatment. They expressed distress, anger and anxiety, about their current diagnosis, and were concerned about possible future hospitalisation. Patients also reported observing poor adherence to hygiene protocol by hospital staff and anxiety about making complaints due to fear of reprisals.

The Department of Health are clear that doctors should consider *C.diff* “as a diagnosis in its own right, grading each confirmed case for severity, treating accordingly and reviewing each patient daily” (Department of Health: Health Protection Agency, 2009, p. 9). Unfortunately, infected patients who are subsequently source isolated tend to be less likely than non-isolated patients to have their daily signs accurately recorded, and to have daily physician progress notes documented (Stelfox, Bates, & Redelmeier, 2003). From the reports that patients in this study gave, it appears that to some extent *C.diff* was treated as a diagnosis in its own right. Symptomatic patients were tested and where test results proved positive, were all moved to isolation rooms and their progress monitored. What appears to have been less thorough was *the manner* in which patients were transferred to isolation, informed of their diagnosis and given

opportunity to ask questions about their diagnosis. Patients reported feeling neglected and not listened to. The way that patients understood this was to attribute uncaring qualities to staff, to justify their actions by reasoning that they were very busy, or to imply that the fault was at a more systemic level. None of the patients interviewed made internal attributions about the cause of their infections or implied that it might have been their fault; all assumed that the responsibility lay with the hospital. Attributions were concentrated primarily towards the immediate ward staff. Given that patients were interviewed whilst still on the ward, and that their perceptions of causality and blame may have been influenced by their proximity, it is suggested that a follow-up study conducted with patients post-discharge in an environment away from the hospital may evoke different kinds of responses and attributions, perhaps encompassing wider social and governmental systems.

One of the challenges to improving patient outcomes is that adverse consequences are not always easily detected. As Stelfox et al. note, “because most medical interventions are well intentioned, faulty systems often arise when a focus on one priority detracts from other unrelated clinical concerns” (Stelfox, Bates, & Redelmeier, 2003, p. 1904). It appears that where there is a focus on one priority, such as the success of a kidney transplant (Ext. 37), the impact of an additional iatrogenic infection diagnosis may not be attended to as fully. What this study shows therefore, is that care needs to be taken to ensure that iatrogenic infection does not become a ‘diagnosis of exclusion’, where patients are isolated and excluded and additional health risks are created through inattention to patient needs. Patients require that they be informed, monitored and treated as conscientiously for their *C.diff* diagnosis as they are for any other clinical

needs that they present with. In this study, the issue that was foremost for all participants was their need for more information. It is proposed that the needs of patients as they perceive them will be different at different times and stages of their illness. For patients who are still infected, immediate concerns about treatment, recovery and transmission are prominent. It is proposed that those who are at a less acute stage may have different priorities of needs. What this study does demonstrate quite clearly is that patients who are currently infected with *C.diff* express distress, uncertainty and anxiety about their health status, feel aggrieved that it has been iatrogenically acquired and frustrated by poor communication and inadequate cleanliness.

A key issue highlighted by this study, and not evidenced in previous research into patient perceptions of iatrogenic infection, is the concerns that patients have about making complaints to staff about adherence to hygiene protocol for fear that their care may be compromised. Despite concerns about contracting an infection, a large proportion of patients do not say anything when a healthcare worker does not wear gloves when touching blood or body fluids (Abbate & Di Giuseppe, 2008). This finding has been confirmed in the current study which showed that there was reluctance amongst participants to make complaints about lax hand hygiene observed amongst hospital staff. Some participants reported that they didn't want to "cause trouble" (Barbara, Ext.42) or "upset them" (Joan, Ext. 41), which indicates that just because patients are not complaining does not necessarily mean that they are happy.

Explication of what patients are actually thinking by means of qualitative interviews that value idiographic data have been shown to be extremely valuable in accessing

these silent perceptions and concerns. Empowering patients to take a more active role in their care by feeling confident about pointing out these lapses to staff, and to feel confident that any complaints they make will be taken seriously and acted upon would go a long way to improving this institutional culture of suffering in silence.

Research shows that an individual will typically react to and make sense of their illness on two levels, emotionally and cognitively. Cognitively, a patient relates to their diagnosis in these ways: the label and its meaning, the expected outcome, ideas about cause, expected length of illness, belief in recovery or control, and the degree to which they feel they understand their condition (Kaptein & Broadbent, 2007). Emotional reactions such as fear, anger, and distress are connected to these cognitions (Lau & Hartman, 1983). The findings of this study support and explicate these previously well known dimensions of illness perception. Through analysis of patient narratives, it has been shown that the same concerns are present in iatrogenic *C.diff* diagnosis as they are in other health problems. Patients were found to be concerned with the outcome and consequences for themselves and others (Ext. 30), with causality (Ext. 1), recovery (Ext. 21) and in particular, their understanding of the condition (Ext. 28). However, the interesting parallel with other illness perception research is that it is usually people who have not yet received a diagnosis for their symptoms that report the lowest understanding, lowest treatment control beliefs, and highest emotional response (Broadbent et al., 2006, p. 636). This study shows that very similar patterns of response exist between symptomatic patients without a diagnosis, and patients who have received a diagnosis but remain unclear about what that diagnosis means. This indicates that explanation-giving about the implications of a diagnosis not just offering

a diagnostic label, are crucial to illness perception and in turn to illness adjustment and recovery.

Some of the ways that illness perceptions can be shaped adaptively are by offering explanations of the illness and its associated symptoms, exploring ideas and addressing myths about causality, and discussion about medications (Broadbent, Ellis, Thomas, Gamble, & Petrie, 2009). Using these methods with patients with myocardial infarction has been shown to improve recovery (Petrie, Cameron, Ellis, Buick, & Weinman, 2002). It is argued therefore that by improving illness perceptions of patients with *C.diff* through better information giving practices, that this in turn will have a positive effect on patient satisfaction and recovery. To have optimum effect, information should be provided both verbally and in written form, and should include explanations about cause and contagion, as well as information about daily routines and treatments (Burnett, Lee, Rushmer, Noble, Davey, 2010), isolation (Zerbe, Parkerson, & Spitzer, 1994), updates on progress and procedures throughout a hospital stay (Rees, Davies, Birchall, & Price, 2000). It should also explain what is likely to happen after discharge from hospital (Lymer & Richt, 2005). As individual patients are active processors in information receiving, there should also be some focus on the monitoring of understanding and perceptions.

In relation to hospital acquired infections, although patient knowledge has been found to significantly influence risk perception, worried individuals are not necessarily more likely to seek information as one might expect (Abbate & Di Giuseppe, 2008).

Transparency of information giving has also been found to be problematic with other

iatrogenic infections such as HIV, where studies have found that physicians minimised or even denied the possibility that a patient was HIV positive. As with the patients in this study, iatrogenically-infected HIV patients in Japan felt frustrated that they were not offered proper explanations or information about the infection (Seki, Yamazaki, Mizota, & Inoue, 2009). The issue for patients in this study seems to be that as a preventable disease, the hospital has a responsibility to ensure that adequate measures are taken to prevent contagion. Where these systems fail, patients feel that the reasons for those failures should be investigated (Ext. 44), culpability accepted by the hospital (Ext.13), and measures taken to improve systems so that iatrogenic infections are less likely to occur in the future. Thus, it is necessary for hospitals to take responsibility for putting in place good information dissemination systems on behalf of patients, so that they will have a more thorough understanding of the meaning, causes, likely outcome and recovery prognosis of their *C.diff* diagnosis. This may also additionally benefit primary care services that subsequently carry the burden for care post-discharge.

Another issue raised by participants was the inconsistency in nurses' adherence to hygiene protocol in wearing gloves and hand-washing. The problem of poor adherence to hand-hygiene practice is well recognised in the literature (Pittet et al., 2000), and can in part be explained by a misunderstanding of the need for infection-control practice to be focused on all patients not just those with recognised infectious conditions. This is in part due to a degree of confusion about the rationales for infection-control practice stemming from a lack of knowledge of basic microbiology and infection control principles (Prieto, 2005; Courtenay, 1998). Inaccurate knowledge

of hospital-acquired infections for both staff and patients can lead to stigmatisation of individuals who have contracted a disease (Mozillo, Ortiz, & Miller, 2010). For one lady in this study who had severe diarrhoea and was limited to the use of a commode in her room, the fact that she frequently had to wait for it to be emptied by a member of staff meant that she was often left sitting in a room with her own dirty smelly faeces. This experience left her traumatised to the extent that she continued to have intrusive memories and images of the room that she carried with her even at home after discharge.

In the hospitals that participated in this study, as with many others in the UK, cleaning is outsourced to contract agencies, and as such cleaners are not direct hospital employees. This can create the perception that cleaning is not a core function of hospitals and can erode the status of hospital cleaners. A recent focus group study of cleaners in Irish hospitals, Clynes et al. (2010) found that communication between cleaners and other healthcare professionals was a significant problem. For example, nursing staff were often unsure whether it was appropriate to tell cleaners about the exact nature of a patient's infection. There was also inconsistency in the regularity of meetings between nursing staff and cleaners where cleaning responsibilities could be discussed. It was also found that there was a greater need to define the cleaning roles between cleaners and healthcare assistants. It has been suggested that one way to address this problem is to find ways for greater integration of cleaning staff and services within the NHS, and that an acceptance of the value of the cleaner within the team will promote improved communication and thus higher standards of hospital environmental cleanliness (Davies, 2009, p. 9). In addition, simple educational

interventions for cleaning teams in the use of appropriate bleach disinfection have also been shown to dramatically reduce environmental contamination with *C.diff* (Eckstein, et al., 2007, p. 72). The current study revealed that the way that cleaning practices within the hospitals participating in this research were managed was not of a standard that patients expected. It is anticipated however that this is not an issue peculiar to these hospitals. Several patients also referred to having cleaned toilets themselves because they were too dirty to use, and reporting finding body fluids which had not been cleaned away in corridors and bathrooms. The fact that participants initiated talk about these incidents during interviews indicates that patients have particular expectations about what they believe is an appropriate standard of cleanliness for a hospital. None of the participants interviewed mentioned the comfort or décor of the hospital, which suggests that they did not have any prior expectations that hospitals should necessarily be aesthetically pleasing and physically comfortable, but that they should be clean.

Limitations

It is worth noting that at the time of interview, patients were still infected with *C.diff*, and consequently still feeling physically and emotionally vulnerable. Furthermore, they were still within the proximity of their perceived source of infection, which it is anticipated would also affect their feelings of anxiety about their situation. A retrospective study conducted several months after patients were discharged from hospital may generate different expressions of affect, as situational factors would be quite different, and subsequently their thoughts and feelings about their experience

may be mediated by proximal and temporal distance. It may also tap into any continuing concerns that currently affect their health and care in the community.

Furthermore, it is acknowledged that an additional limitation of the study may be that patients were not asked as part of the background demographic information gathering, nor in the course of the interview, about the medical conditions which had led to them being hospitalised initially. In sympathy with the broadly inductive epistemology of the IPA approach to this study, the position taken was to minimise the level of directedness of the interview questioning, so as to allow topics of personal importance to be raised by participants themselves. However, the limitations of this approach become apparent at the stage of analysis where interpretations are sought to be inferred from patient responses. It is at this stage, that the sense-making practices and the possible meanings imbued by patients to their situation and experience cannot be fully contextualised within the broader picture of their initial or primary diagnosis. It is speculated that those patients with conditions which are more likely to require continued re-hospitalisation may have different expectations about their future re-engagement than those who were admitted for acute and potentially discrete medical incidents. Additionally, those patients who suffered severe or life-threatening initial diagnoses may have a different perspective of their additional iatrogenic infection than those patients who had been admitted for less severe conditions.

Conclusion

It is anticipated that lessons learned from this study will help to inform healthcare professionals who work with patients who contract *C. diff* whilst in hospital in a way that will enhance care quality. In addition, this study raises awareness of the serious anxieties that many patients have in relation to re-engaging with subsequent hospital treatment. It is acknowledged that staff working within healthcare settings are trained predominantly to deal with the physical presentations of symptoms of illness and disease, however it is hoped that working professionally in a mutually respectful partnership, nurses, doctors, psychiatrists and psychologists together with other healthcare professionals, can ensure that an excellent service is provided to patients that addresses both their physical and psychological needs.

In circumstances where patients have choice over which hospital they can go to, general cleanliness, low nosocomial infection rates, and friendly staff tend to be the most important considerations (Vonberg, Sander, & Gastmeier, 2008). It seems that kindness and basic hygiene measures, both quite inexpensive factors, are key issues for patients. What this study demonstrates is that patients with iatrogenic *C.diff* infection tend to suffer an additional emotional burden engendered by a lack of information and explanation about their condition. Ideally this should consist of explanations about the infection the patient has contracted, why there may be need for isolation, and what to expect (Catalano, et al., 2003). Appropriately communicated information can positively affect patients' adjustment to their diagnosis, helping them to be more relaxed and also more compliant with infection control regimes (Newton, Constable, & Senior, 2001; Madeo, 2001; Petrie & Weinman, 1997). It is argued that

increasing patient access to clear, appropriate information and supporting staff through training in information delivery, may contribute to alleviating the negative psychological impact of a diagnosis of Hospital Acquired Infection .

Clinical Implications

It is appropriate that nursing and medical staff working in hospital settings are trained predominantly to deal with the physical symptoms of illness and disease. However, quality of care for patients involves not merely giving attention to patients' physical needs, but also to their emotional, social and psychological needs. In hospital settings clinical psychologists often work with clients who have psychological difficulties that relate directly to their physical health problems. This study highlights one particular area where the psychological issues faced by patients with iatrogenic infections could be more adequately addressed, by showing that limitations in information-giving practices impede patient adjustment to iatrogenic infection, and add further unnecessary psychological confusion and distress to patients. One of the problematic implications of lack of understanding in patients is not just non-adherence with treatment regimes, but also additional anxiety and distress caused by missing or misinformation, which may thus create a double iatrogenic effect on patients unfortunate enough to contract an infection whilst hospitalised.

This study, relates to the role of psychologists within physical health settings by highlighting and addressing these issues, and by making recommendations about improvements to clinical practice. These recommendations are indicated by the need to operate in a more preventative way in relation to improving post-diagnosis

information-giving practices. Ideally this should consist of explanations about the infection the patient has contracted, why there may be need for isolation, and what to expect (Catalano, et al., 2003). Appropriately communicated information can positively affect patients' adjustment to their diagnosis, helping them to be more relaxed and also more compliant with infection control regimes (Newton, Constable, & Senior, 2001; Madeo, 2001; Petrie & Weinman, 1997). It is argued therefore that increasing patient access to clear, appropriate information and supporting staff through training in information delivery, may contribute to alleviating the negative psychological impact of a diagnosis of Hospital Acquired Infection .

The implications of the results of this study within the field of psychology are that it will add to a currently very small evidence base which investigates the lived personal experiences of individuals who have experienced an iatrogenic infection. To date, a very limited qualitative literature has identified some of the psychological implications of healthcare associated MRSA infections, and this research is the first of its kind to investigate the experiences of patients acquiring *Clostridium difficile* infections whilst in hospital. Research clearly shows a link between anxiety and stress and physical susceptibility to disease. In the instance of patients needing to be re-admitted to hospital for further treatment following a prior episode of a HAI, it is suggested that anxiety about becoming re-infected with a HAI may actually increase risk. Previous research has shown that following distressing inpatient experiences some patients have been shown to display anticipatory side-effects connected with the hospital environment (Zachariae et al., 2007). This research therefore adds incrementally to previous work in this area, and hopefully provides the basis for future work of this

kind. It is anticipated that lessons learned from this study will help to inform healthcare professionals who work with patients who contract *C. diff* whilst in hospital in a way that will enhance care quality.

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Critical Appraisal

Overview of Research Process

Initially this project was planned as an investigation of iatrogenic infection more widely, encompassing both MRSA and *C.diff*. Ethical permission was granted to interview participants in both of these groups. MRSA participants were to be drawn from a community support group, and their experiences were to be compared with the *C.diff* sample. However there were two important events that necessitated that the MRSA aspect of the project be postponed and revisited as a separate research project after completion of this thesis. The first was that a serious incident relating to an MRSA participant that I interviewed meant that I then suspended conducting further interviews due to my own need to take time to reflect on and recover from my experience, and secondly that access to more participants could not be followed up as this participant was the gatekeeper to other participants. This incident is reported more fully in this appraisal in the 'researcher safety' section. The second reason for not continuing at that stage with collection of MRSA infected participant data was that I myself was colonised with a Staphylococcal infection, and, under medical advice was strongly urged not to put myself in contact with anyone with MRSA as it would very likely jeopardise my own health. This thesis has thus undergone a transition to a more focused study on the experiences of patients colonised with *C.diff* whilst in hospital. It is acknowledged that in making this choice the findings of the research are more limited in transferability, and that an additional investigation of MRSA patient experiences would provide a wider evidence base for the impact of iatrogenic infection. I intend to continue this element of the research following submission of this

thesis in order to honour the original research proposal as it was initially submitted and accepted by the ethics review panel. Access to MRSA infected participants will be organised via a different route than the one originally planned.

The choice of topic for this study was reached through a series of discussions with academic tutors at the University. My consideration during this process was whether to choose a topic area close to other research that I had conducted in the past, and had familiarity with, or to take a more adventurous path into a field that at that point was quite unfamiliar to me. My decision was finally taken on the basis that I regard my training on the Clinical Psychology Doctoral course as an opportunity to stretch myself in areas that I would not normally gravitate towards. The area of health psychology is one such area. My reasoning being, that this would add a breadth and depth of knowledge and understanding to my existing skill base, so that I might become a more holistically competent clinician. I was also keen to work alongside Dr Noelle Robertson, who kindly agreed to supervise this project, and I was happy to work on an area of interest that also had some resonance for her in terms of her existing research experience. On reflection, I am very pleased that I made this decision. Although charting territory that has been completely new to me has at times been quite a challenge and a steep learning curve, I feel that I have learned so much more as a result of putting myself in this position. One of the things that I have been most surprised about has been the huge overlap and interrelationship between physical and mental health. This I believe is going to be an invaluable lesson to have learned whichever field I specialise in when I am qualified. The other fascinating discovery for me has been the cognitive and emotional impact of a physical health diagnosis on

patients, and I can see significant parallels between this and the potential impact of mental health diagnoses on clients. This is an area that I believe warrants further attention, and something I would be interested to consider looking at more closely in the future.

Epistemological Journey

Having been steeped in a discourse and conversation analytic tradition prior to commencing this course, it was quite a transition for me to move towards embracing Interpretative Phenomenological Analysis (IPA) as a methodological approach for this research project. However, I was glad to take the opportunity to broaden my methodological understanding and experience by challenging myself to learn a new approach. In seeking to learn all that I could about IPA, I was fortunate enough to be selected for a special Summer School for Health Psychologists in Italy during the summer of my second year. The content of this school was the practice and application of two qualitative approaches which had up to that point remained fairly unfamiliar to me: grounded theory (led by Jan Moore) and IPA (led by Michael Larkin). It was through discussions with Michael Larkin and the reading that he recommended (Smith, 2005; Smith & Osborn, 2003; Smith, Jarman, & Osborn, 1999) that I was able to work through my own thinking relating to the valuable place that IPA holds in qualitative health research. At this stage it was important for me personally to wrestle with my own position on ontology and the place of knowledge, as I had at that point (and still do), a very strongly held social constructionist viewpoint. My struggle was that the epistemological position of IPA is one that did not quite fit for me in terms of my personal understanding of the basis of knowledge and the place of interviewing as a

valid data collection method. However, I have come to appreciate and value the role that the interview plays in various methodological approaches including IPA. As a result of this process, I feel that I have reached a position where I no longer regard interviewing as a rather blunt generic tool for collecting qualitative data, but have a more coherent appreciation of the different ways that interviews are conducted and analysed as they are differentially influenced by the particular epistemological position informing that methodology.

Methodological Journey

Saturation and Sample Sufficiency

During the course of completing this thesis I have found myself thinking again about how qualitative research is evaluated in terms of its rigour and validity. One key issue that was brought to my awareness during this process was the concept of saturation. Many reviewers of qualitative papers submitted to journals now use the concept of saturation as a criterion of sufficiency of data. There has also been a debate within the world of IPA and within qualitative research more widely about what constitutes a sufficient data sample. For example, Smith and Osborne suggest that whilst Interpretative Phenomenological Analysis can be used for up to 15 or more interviews, students new to qualitative work and IPA in particular should regard 3 participants as a more appropriate data set (Smith & Osborn, 2003, p. 57). In terms of the concept of saturation, Smith et al. (1999) write that it is problematic due to the “cyclical or iterative nature of analysis, in which passages are analysed repeatedly in the light of insights obtained from other sources. This is a process which could theoretically continue ad infinitum.” (p95). Having come from a background of Conversation

Analysis, this concept was never an issue, so it has been an interesting journey of reflection to consider the arguments about sufficiency and saturation. It is argued that the concept of saturation is something that although routinely reported in research, is questionably ever actually reached (Green & Thorogood, 2004). The position that I have found myself coming to in this regard, has been that it is a valuable heuristic to use within certain qualitative traditions, most notably within grounded theory where it originated, but ought not to be a measure of sufficiency that is applied universally across all qualitative disciplines.

Bracketing and Reflexivity

The concept of bracketing, which means to suspend prior assumptions and knowledge, is one that originates in phenomenological research (Husserl, 1970). The basic premise is that one should 'bracket' off aspects of the self or one's specialist knowledge so as not to interfere with and adversely influence the data collected. A simple example might be that a nurse who is also collecting interview data ought to 'bracket' off her prior medical knowledge in her nurse role in order to effectively and neutrally engage with the participant in her role as researcher. In relation to my research for this thesis, the issue of bracketing is not one that I have reflected on extensively in a general sense, but have had occasion to consider my own position reflexively in the interview dyad. Prior to conducting the interviews I had considered my own distinctive personal characteristics such as gender, race and class, and their potential impact on the research relationship (Nunokoosing, 2005). I had also considered how to introduce myself to the participants, and the impact this might have. In line with ethical protocol, I had introduced myself to participants as a trainee clinical psychologist from Leicester

University, conducting this research as part of my Doctoral thesis. It became relevant at the point when I initially met with participants to further explain that I was not a medical doctor, and was not connected to the hospital, so as to assure patients of their anonymity and that I had no access to their medical records, and had no influence over their medical care.

A further issue that became apparent in relation to the notion of bracketing was that I was confronted with situations where participants asked me directly for information and/or advice about aspects of their diagnosis and treatment. At this point I felt that I had to make a decision about whether to share the knowledge that I had gained about *C.diff*. What I decided to do was to adhere to the principle of bracketing at this point and to separate this aspect of specialist knowledge from the interaction, and to direct patients towards staff on the ward to answer their questions about their infection. In making this choice, I was aware that it was in part an ethical dilemma, as I was not completely confident that patients would have their questions fully or appropriately answered. However, I felt that my role was as an interested observer recording what I saw, rather than as someone who had a role or obligation to intervene.

A similar dilemma also arose when talking to patients who wished to make complaints to the hospital. For some there was a desire or expectation that I would take what they had said and report their complaints for them to the hospital managers. At this point, I chose to reiterate the boundaries of my role by explaining that the anonymised data would be publicly disseminated in the form of a journal article, but that I was not in a position to act as a mediator of personal complaints. One patient requested the

transcript of our interview so that she could use it to inform her complaint. Provision of copies of transcripts to participants was already part of the research protocol, and I duly agreed to this on the proviso that the limit of my involvement would be to provide the transcript, but not to comment further on my opinion about her complaints and their validity.

The Role of the Transcriptionist

An issue that came to my attention during the process of data collection was the role of the transcriptionist in the research process. Having had the experience where one of my interview tapes contained some potentially upsetting material, I took time to speak with my transcriptionist about it, and her reactions and feelings in response to its content. This experience made me realise that often transcriptionists are overlooked in the sense that the impact of the data on them is not acknowledged. This prompted me to commence a small scale project which I am still conducting, to interview transcriptionists about their experiences and their ways of handling distressing material that they are exposed to. One of my preliminary findings is that transcriptionists often feel that it is difficult to find someone to share these feelings and reactions with as due to the constraints of confidentiality they are bound not to discuss their work with anyone outside the research team. What I have learned from this therefore is that transcriptionists should be acknowledged as being more central to the research team and not just neutral mechanical agents, and afforded the opportunity to reflect and debrief with the researcher who conducted the interview.

Researcher Safety

Early in the process of collection data, I conducted an interview in an MRSA participant's home. Several issues relating to researcher safety arose during this interview which it is pertinent to elaborate on in this reflective space. However, due to the necessity of protecting the participant's identity it is incumbent upon me to be very circumspect in describing this encounter. The participant had been recommended to me from a supposedly reliable source, and I had made email contact prior to the interview to make practical arrangements. After discussion with colleagues, an appointment was made to meet at the participant's home where the interview would not be interrupted and so that the recording quality could be optimised. The protocol for lone working was followed, including informing a research associate of the location and time of the interview, and expected length of time that it would take. An agreed 'check in' phone-call was arranged at a specified time. There were no prior indications that there might be any cause for concern relating to my safety beyond consideration of the fact that the participant might be carrying an infection. Proper procedures were observed for ensuring my own health was protected including using recommended barrier hand creams and avoiding physical contact with the participant.

It became apparent early in the interview that the participant was under the care of a psychiatrist, and his behaviour became belligerent, aggressive and threatening. I was also offered a weapon by the participant to protect myself should I feel that I was unsafe during the course of the interview. The weapon had been concealed under my chair prior to my arrival, and its use was carefully demonstrated to me by the participant. The situation was one which I handled by remaining as calm as possible,

and although the participant was very resistant to my leaving, I was eventually able to make a retreat. I was able to briefly text my research associate during the interview to alert her to the possible danger I was in, and I telephoned her as soon as I was safely away from the participant's home. The experience had left me quite shaken. I was fortunately able to share this experience with my research supervisor, serving the dual purpose of enabling me to resolve my own emotions, and to also think carefully about what course of action would be required. We agreed that I should contact the participant's psychiatrist, as this had already been indicated by the participant during the interview. This I did, explaining the situation, and leaving the duty of care and any further necessary legal implications with him. I was obliged also to commission the interview to be transcribed so that I could send a copy of the transcript to the participant as had been agreed according to the ethical guidelines that were followed for this project. This raised a further issue in that the transcriptionist whom I employed found that listening to the tape increased her own anxiety and concern about my safety which I have already commented on earlier.

An important lesson learned from this experience are that even when guidelines and protocol for safe working are followed, this does not necessarily afford physical protection to the researcher should a participant become threatening or aggressive. Where interviews in participants' homes cannot be avoided, I would therefore recommend that the researcher take a colleague with them, and not conduct data collection alone.

Lessons Learned During Analysis and Writing Up

NVivo

I made the decision during the early stages of analysis to use the software NVivo to assist in grouping and coding extracts of data. My primary reason for this was that I have not used the software before, and I felt that it would be a beneficial learning experience for me to use it for this project. I was fully aware that it is not appropriate as an analytic tool, but simply a helpful way of managing large amounts of data. My preference previously has been to work with printed copies of data and to code them manually by hand, however I was pleasantly surprised to discover how useful NVivo was in the initial coding phase, as I was not only able to use it for making notes on interview transcripts, but also to allocate extracts to preliminary themes and 'nodes'. This eliminated the problem of having to manage large amounts of paper and handwritten notes. During the second phase of analysis, I copied the themes and notes from NVivo into Word files to examine them more closely once my ideas were beginning to come together in a more coherent narrative. Although this paperless system felt like quite a discipline during the process as it was new and unfamiliar to me, I found it useful in helping me to keep all of my notes in one place, and I am glad that I made the effort to experiment with it as a research tool.

Labelling

When anonymising my participants I had initially labelled them as 'C.diff 1', 'C.diff 2' etc. on data transcripts and audio files. However, when I came to label extracts of their talk in the body of the thesis results section, I decided to label them as 'patient 1', 'patient 2' etc. in preference to 'participant 1/ 2'. I made this decision on the basis that

it seemed more reflective of their status as a person with an infection within a hospital context to refer to them as 'patient' rather than 'participant'. I used this approach throughout the write-up of this section until I re-read another IPA paper which I was referencing. At this point I noted that participant extracts were labelled by name (pseudonym), and this caused me to reconsider why I had made the labelling choices that I had. For me it was quite significant at this point to realise that the project I was engaged in was primarily phenomenological, and that what I valued in this approach was that it was essentially idiosyncratic. As such it draws upon the particularly individual characteristics and personal sense-making practices of each participant. It occurred to me that my labelling practice of using the referent 'patient' did not appropriately reflect this idiosyncratic position, and in fact perhaps worked against it in a way that reduced participants again to a generic status of 'patient'. I resolved therefore to adopt a labelling system that attributed pseudonyms to participants so as to retain a better degree of methodological integrity and to more appropriately represent the participants as individual people.

Critique of Methodology

The research questions for this investigation were developed in parallel with the choice of perspective, as different types of research questions are grounded in different epistemological assumptions (Honan, Knobel, Baker, & Davies, 2000). These questions provide a point of orientation, and were used to inform decisions about design and methods (Bryman, 2007). Interpretive Phenomenological Analysis (IPA) was chosen as the most appropriate methodology to address the research questions. It is a research method and analytic approach that combines phenomenology and

hermeneutics (Smith & Osborn, 2003). Phenomenology is the study of human experience (Field & Morse, 1996) and is concerned with interpreting the meanings that individuals attach to their experiences in order to make sense of them. Hermeneutics is a branch of phenomenology which takes an interpretive approach to understanding an individual's life world (Heiddeger, 1962; Diekelmann, 1992). IPA was chosen for this project, partly in an attempt to re-humanise healthcare, to bring it back into the domain of treating whole people, not just bodies and diseases, but people with thoughts and feelings, fears and hopes, people who need to be considered for who they are and not just what illness they have.

Advocates of IPA as an approach would argue that its advantage over methodologies such as discourse analysis is that it allows the flexibility to make interpretations of the data which infer cognition (Smith, Jarman, & Osborn, 1999) which is the mechanism by which participants make sense of their experiences. Inferences made by the researcher about cognition in this approach are heralded as a strength. However, a weakness of this thinking as it is promoted is that all inferences made by a researcher can only be a subjective interpretation of what the participant had said. The danger therefore is that inferences or interpretations may actually go beyond what the participant has intended. That being the case therefore, it is questionable if it is tenable to make the assumption that cognition and intent can or should be inferred from what a person says. From a discourse analytic perspective, this fundamental assumption about direct access to cognition through discourse would be untenable, and analysis would be strictly limited to the content of the text.

Furthermore, IPA does not fully take into account the situated and contextual production of talk. By this I mean that all talk is occasioned, and designed for the particular situation and context in which it is produced. In the case of an interview study, the kinds of responses and descriptions proffered by a participant are designed for that particular interaction, in its context as an interview, in response to particular questions, put forward by a particular individual. As such what participants say ought to be 'heard' as statements which occur within an interview, and ought not to be taken as objective representations of what that person 'actually' thinks in any kind of positivistic way. Given this proviso, I have attempted within this thesis to be as transparent as possible about the situated nature of the responses provided by participants, and have sought wherever possible to include the interview question in data extracts as well as the participant's response.

Limitations and Consideration of Future Research

As indicated in the introduction to this critical appraisal, this particular piece of research was limited to the investigation of patients' experiences of contracting *C.diff* whilst in hospital. The larger original project was intended to have a broader scope which would have also incorporated the experiences of patients with MRSA. It is acknowledged therefore that one of the limitations of this thesis is that it is confined to the experiences of patients with *C.diff*, and that further research could usefully be focused on patients with other iatrogenic infections including MRSA. Furthermore it is acknowledged that the sample, whilst appropriate for a qualitative study of this kind, may not fully represent the views of a wider cohort, and that a larger scale project may

elicit more general trends, albeit perhaps at the expense of a depth of understanding of individual experiences.

The participants in this study, with the exception of one, were interviewed whilst still in isolation on the hospital ward. This also is considered to have been a contributing factor on the responses that participants gave. It is proposed that if participants were interviewed in a different setting or at a different time, their responses may have been different. Whilst still in a situation where they are potentially still exposed to the threat of infection, a primary concern seemed to be that of understanding diagnosis and how the infection might be caught or passed on. However, it is speculated that if patients were interviewed post-discharge when they were no longer affected by the infection, their concerns might be less about those immediate issues that had pre-occupied their thinking whilst on the ward, and perhaps more future oriented.

In addition, participants made frequent reference to lack of control and lack of cleanliness of the ward environment. These factors may also be contributing variable to an individual's sense-making practices and cognitions about their health status. As participants also stated, they were at times, anxious about making complaints to staff whilst they were still under their care. This inhibition may be lessened once patients are in a different environment where they may feel more at liberty to make those complaints without the additional anxiety that their personal care may be compromised. It is anticipated that the passage of time and some physical distance from the hospital environment may result in participants' perspective on the nature of their infection altering. I do not feel that I could make any hypothesis about the ways

in which their views may change given temporal and physical distance from the precipitating event beyond a sense that in other research it has been shown that people's perceptions of events change over time and in retrospect. To this end, I suggest that further research also be interested in the dynamic of how individual perceptions may change between the time they are resident as an inpatient, and at a later point post discharge.

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Appendices

A. Statement of epistemological position

Much health research has historically been situated within the positivist paradigm, but there are clear benefits to approaching the world of healthcare from a more constructivist viewpoint. This enables the researcher to explore ways in which individuals make sense of their (ill) health, how they cope or don't cope, and what it means to them personally given the myriad of experiences, expectations and encounters that influence the way that they construe their current situation. The epistemological position of this research project takes the stance that the research exercise is a dynamic process, and that access to the participant's inner world cannot be achieved fully and directly. However, unlike discourse analysis, IPA allows the flexibility to make interpretations of the data which infer cognition, and thus the mechanism by which participants make sense of their experiences (Smith, Jarman, & Osborn, 1999).

An inductive approach was adopted using IPA to explore the personal experiences of patients with *C.diff*. Findings were allowed to emerge from the data rather than themes having been previously identified. However, it could be argued that IPA is actually a hybrid of deductive and inductive reasoning, whereby there is to some extent a focus on some particular phenomena that the researcher has a prior knowledge of. For example, in this study, it was in part an exploration of whether general trends signified in prior research into the effects of iatrogenic infection on patients with MRSA might be similarly to indicated amongst this particular

population of patients with hospital acquired *C.diff*. Clearly it is not inductive in the way that conversation analysis or grounded theory is, but it does present elements of both. (See Fereday & Muir-Cochrane, 2006 for a discussion of a hybrid approach to thematic analysis).

I acknowledge that there is an inevitable subjectivity in research, coloured and shaped as it is by the culture, experience, history, background, beliefs and expectations of the researcher. In this project, the researcher has thus taken a reflexive stance to collecting 'facts', believing that whatever information is gleaned will always be occasioned and context dependent (Edwards, 1997). Given that this is the ontological position taken, the methodology of IPA is epistemologically congruent. The central tenet of interpretative phenomenological inquiry is that human 'truths' can only be accessed through the exploration of inner subjectivity (Burch, 1989), which presupposes a particular understanding of the way that knowledge exists and can be accessed. The view held in this approach is that any piece of reported information does not exist outside of the meaning that an individual attributes to it.

Taking an idiographic approach it was possible to capture differing personal nuances between patients in terms of age, gender and culture, as well as being able to explore possible trends and patterns between participants. It is generally acknowledged that a degree of rapport between the researcher and the participant is an essential starting point for the qualitative research relationship (Coles & Mudaly, 2010), and is important in helping the participant feel comfortable during the interview and able to express themselves freely (Corbin & Morse, 2003). In keeping with the position that all talk and

descriptions are context sensitive, the impact of the person of the interviewer as the mechanism by which data were collected was also taken into account (Sorrell & Redmond, 1995). It was however, borne in mind that the position advocated by some phenomenological researches is that one should 'bracket' off aspects of the self in order to suspending prior assumptions and knowledge (Husserl, 1970). To this end, the researcher was clear in informing participants that she was not a member of the medical profession and was solely collecting their opinions about their condition and not able to offer medical advice. In effect this amounted to 'bracketing' any expertise in the area of *C.diff* that had been acquired through the process of this research project.

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B. Chronology of research process

October 2008	Research diary started and initial discussions with academic tutors about research topic
November 2008	Discussions with staff and colleagues about research methodology
December 2008	Agreed research topic area and supervisor
January 2009	Started literature review
April 2009	Discussions with potential external supervisor about using discourse analysis
November 2009	Decision to use IPA
January 2010	Researching reflexivity for critical appraisal
February 2010	Field supervisor agreed
March 2010	NHS Ethics Research Committee approval granted
June 2010	Started community MRSA interviews
July 2010	Attended workshop in IPA and Grounded Theory for Health Psychologists
September 2010	Abandoned MRSA interviews and changed thesis to focus just on <i>C.diff</i>
October 2010	UHL R & D Committee approval granted
November 2010	Started inpatient <i>C.diff</i> interviews and transcripts
January 2011	Completed literature review
February 2011	Started transcript analysis
March 2011	Completed <i>C.diff</i> interviews and transcripts
April 2011	Completed analysis
May 2011	Completed writing up

C. Additional supporting information relating to qualitative rigour

Additional Report of Key Areas of the Project Based on the 'Consolidated Criteria for Reporting Qualitative Studies (COREQ): 32 – item checklist' (Tong, Sainsbury, & Craig, 2007)

Research Team and Reflexivity

Personal Characteristics

The author of this thesis is a female postgraduate researcher and was the person who also conducted all the interviews. At the time when the data was collected the researcher was a third year Trainee Clinical Psychologist with a previous PhD in psychology. The researcher had previous experience in conducting interviews and focus groups for research purposes, and of qualitative analysis.

Relationship with Participants

Participants were not known to the researcher prior to the study, and the first and only meeting was at the time of the interview. Participants were informed in writing and verbally that the researcher was a trainee Clinical Psychologist from the University of Leicester engaging in research at the hospitals where they were interviewed, and that the data would be a constituent part of the doctoral thesis. They were clearly informed that the researcher was not a medical doctor and that as such was completely independent of their hospital care and treatment. Participants were informed that the reasons for the research were to explore what the psychological effect of hospital acquired *C. diff* might be for them personally. The researcher had no prior experience of research within health psychology, but having completed a literature review of

qualitative research relating to the impact of iatrogenic infection on patients, was aware of some of the dominant themes that had been reported by other patients in similar situations.

Study Design

Theoretical Framework

The methodological orientation underpinning this study was phenomenological in that its purpose was to describe the meaning and significance of participants' experiences.

Participant Selection

Purposive sampling was used to access patients who had contracted *C.diff* whilst in hospital. Names of all *C.diff* patients within the 3 hospital sites from which the sample population were drawn were kept by the specialist *C.diff* nurse. She was contacted by telephone by the researcher weekly to discuss which patients might be suitable to approach for interview. Patients were excluded if they were in ICU or had other physical impairments or language difficulties that would mean that they were not able to participate in a short interview. These decisions were made at the discretion of the specialist nurse who had seen each patient personally and assessed their suitability based on her clinical opinion. The specialist nurse gave the names and ward details to the researcher who then contacted ward staff via telephone to ask whether the patient would be willing for the researcher to visit them. Nursing staff on the wards spoke to patients explaining briefly that a researcher from Leicester University would like to interview them about their *C.diff* condition and to ask whether they would be willing to meet with the researcher. Only one patient that was approached declined, as

he did not feel well enough. A time was arranged via the ward nurse for the researcher to visit the patient. Verbal and written explanations about the study were given to patients by the researcher at this visit and patients were given the choice to go ahead with the interview at that time, or to arrange another visit. All patients chose to go ahead with the interview at that time. Seven participants were interviewed, but one interview was later discounted as it transpired that she already had *C.diff* on admission to hospital therefore it did not meet the criteria of the study that the infection was hospital acquired.

Setting

All but one of the interviews were conducted on the hospital wards of the three hospitals involved in the project. One was conducted at a patient's home one week post-discharge as a suitable time to interview her on the ward could not be arranged before she was discharged. She was interviewed alone. Of the six that were conducted in hospital, five were conducted in the isolation rooms where the patients were staying and no-one else was present. One interview was conducted on a sideward where the patient was staying and there was one other patient present on the other side of the room. The participant was asked by the researcher whether she was comfortable to talk in this setting and she agreed that she was, and also asked the other patient if she had any objection, which she didn't. There were three men and three women in the final sample, all White British. The youngest was in his 20s and the eldest was in his 80s. Interviews were conducted between September 2010 and March 2011.

Data Collection

The researcher used a semi-structured interview schedule, but also allowed participants to talk freely about topics related to the research agenda that they brought up of their own initiative. No repeat interviews were conducted. All interviews were audio recorded using both tape and digital recording devices to ensure that sound and recording quality were optimised. Field notes were audio recorded by the researcher following each interview and used to inform the analysis. Interviews varied in length between 30-60 minutes. Longer interviews were due to participants wanting to talk in greater detail about their experiences. The number and length of interviews conducted was in accord with guidance given for studies of this kind using Interpretative Phenomenological Analysis. Data saturation was not used as a criterion for sufficiency in this approach as it is primarily phenomenological. One participant accepted the offer to have a copy of the transcript of the interview, which was sent to her in an anonymised format as requested.

Analysis and Findings

Data Analysis

The primary researcher coded the data using NVivo software in the first instance to create a coding tree where primary themes and subsidiary 'nodes' were identified. Beyond this initial stage, where large bodies of text were managed and organised with the help of the software, subsequent levels of analysis were conducted manually. The initial data coding was then subject to a second phase of analysis whereby themes and links between themes were annotated via a more thorough and sophisticated review. Larger extracts of exemplary data were at this stage refined and edited to better

represent the key themes that they represented. All major and subsidiary themes were identified through analysis of each transcript individually before any overarching links or commonalities were extracted. Thematic extraction was thus inherently data driven rather than being identified prior to analysis. Participants were not involved in commenting or feeding back on the analysis, and were only involved at the point of interview.

Reporting

Quotations from patient interviews have been used throughout to illustrate findings and to exemplify themes. These are identified by participant pseudonyms and by extract numbers. The findings have been very closely linked to the data at all times to ensure transparency about claims and interpretations and to increase internal validity. Major themes have been tabulated for ease of reference, along with concomitant subsidiary themes, which are later explicated in the results section in narrative form. Minor themes and divergent cases are also noted, in accord with the idiomatic value base inherent in the phenomenological approach of the research.

D. Guidelines to authors for journals targeted

Literature Review

Target Journal - Psychology and Health

FORMAT OF MANUSCRIPTS

Manuscripts should be typed according to the guidelines in the Publication Manual of the American Psychological Association (5th edition, 2001). Manuscripts should be double-spaced throughout (including tables and references), and each page should be numbered consecutively. Manuscripts should not exceed 30 pages (including references, tables, and figures), with a font size of 12 in New Times Roman, and all margins should be at least 2.5cm.

Title page: This should contain the title of the paper, a short running title, the name and full postal address of each author and an indication of which author will be responsible for correspondence, reprints and proofs. Abbreviations in the title should be avoided.

Abstract: This should not exceed 200 words and should be presented on a separate page.

Key words: Abstracts should be accompanied by between three and six key words or phrases. These will be used for indexing and data retrieval, and so where appropriate we recommend using standard MeSH terms (the terms used for indexing articles for MEDLINE)..

Style guidelines

The primary headings should be: Objective, Design, Main Outcome Measures, Results, Conclusion.

Description of the Journal's [article style](#)

Description of the Journal's [reference style](#), [Quick guide](#)

Please use British spelling (e.g. colour, organise) and punctuation. Use single quotation marks with double within if needed.

If you have any questions about references or formatting your article, please contact authorqueries@tandf.co.uk (please mention the journal title in your email).

Word templates

[Word templates](#) are available for this journal. If you are not able to use the template via the links or if you have any other template queries, please contact authortemplate@tandf.co.uk

FIGURES

All figures should be numbered with consecutive arabic numerals, have descriptive captions and be mentioned in the text. Figures should be kept separate from the text but an approximate position for each should be indicated in the text. It is the author's responsibility to obtain permission for any reproduction from other sources.

E. Patient information sheets

Date:

Dear (Name of prospective Participant)

Re: Research Opportunity

What is the Psychological Impact on Patients Infected with MRSA or C.Diff whilst in Hospital?

As part of my training at Leicester University to become a Clinical Psychologist, I am conducting some research into the experiences of people who have contracted an infection whilst they were in hospital. I am investigating people who have acquired MRSA or C.Diff.

Your involvement in the research, should you agree, will be to take part in an interview with myself which will last about 1 hour. In the interview I will ask you questions about what it has been like for you, and how you feel about the possibility of going back into hospital in the future. I am interested in your own experience, and particularly how the infection you contracted affected you psychologically.

Please read the enclosed Information Sheet which provides further details. I will be in contact with you shortly to find out what you have decided about whether you would like to take part or not; and if you are happy to go ahead, to arrange a suitable time for the interview.

Participation is entirely voluntary, and you will be able to withdraw from the study at any time if you change your mind without having to give an explanation.

Thank you

Yours Sincerely

Dr Nicola Parker
School of Psychology – Clinical Section
University of Leicester
104 Regent Road
Leicester LE1 7LT

Email: nsp7@mail.cfs.le.ac.uk

Tel: 0116 2231639 (this is a university number where messages can be left for me)

PARTICIPANT INFORMATION SHEET

What is the Psychological Impact on Patients Infected with MRSA or CDiff whilst in Hospital?

You are being invited to take part in a research study about people who have contracted either MRSA or CDiff whilst in hospital. This Information Sheet explains what the research will involve. Please read through the following information carefully, to help you decide whether you would like to take part in the study. If you require more information please contact me using the details below. Participation is entirely voluntary and you are free to change your mind at any time and withdraw from the study without giving an explanation.

Who is conducting the research?

My name is Nicola Parker. I am a trainee Clinical Psychologist at the University of Leicester, and employed by the Leicestershire NHS Partnership Trust. The research will form part of my Doctorate in Clinical Psychology. My contact details are:

Dr Nicola Parker
School of Psychology – Clinical Section
University of Leicester
104 Regent Road
Leicester
LE1 7LT

Email: nsp7@mail.cfs.le.ac.uk

Tel: 0116 2231639 (this is a university number where messages can be left for me)

What is the purpose of the research?

The purpose of the research is to find out what the psychological affects are on patients who contract either MRSA or CDiff whilst in hospital. You have been selected as a potential Participant because of your experience of one of these infections. Although there has been a lot of research about how people get infected and how to protect patients from infection, there has not been any research so far about how these physical symptoms affect patients psychologically. I would like to find out from you what it has been like, and how you feel about possibly having to go back into hospital again in the future. I am very interested in your own personal experience, and what it has meant to you.

Will information obtained be confidential?

Throughout the research process, your identity will remain anonymous. The interview will be audio recorded using a digital Dictaphone, and the recording will be saved onto an encrypted Memory Stick. The recording will be downloaded onto a password protected computer so that it can be transcribed, after which it will be deleted from the computer. When the interview is transcribed, your name, the names of other people you mention, and any other identifiable information will be anonymised, and pseudonyms will be used instead of real names. Transcripts and audio files will be labelled 'Interview One, Interview Two' etc. and will not be identified by name. The encrypted Memory Stick, consent form, transcripts and any other information will be kept in a locked cupboard at Leicester University when not in use.

What happens if I do not want to participate I change my mind?

Involvement in this research is completely voluntary. If you do not wish to take part in the study please let me know and I will not contact you again. If you are currently undergoing any treatment, this will not be affected in anyway by your choice. If you decide to take part, but later change your mind, then I will not use any information collected up to that point, and that information will be destroyed. You are free to withdraw from the study at any point up to the time that the research is completed, and do not need to give a reason.

What are the possible disadvantages and risks of taking part?

In the interview I will be asking you several questions about your experience of contracting an infection whilst you were in hospital, and how that makes you feel about going into hospital again in the future. I expect that the interview will last for about an hour. During the interview, there is a possibility that you may feel emotionally affected by the topic we will be discussing. If this happens we will take a break in the interview, or you can request that we stop altogether. When the recorded part of the interview has finished we will have a short de-brief about how you feel and whether you would like some extra support.

What happens if something goes wrong?

If you have reason to complain about any aspect of the study, the NHS complaints mechanisms are available to you. In addition, if there is anything that you are unhappy about in the way that I have conducted the interview you can contact my Research Supervisor Dr Noelle Robertson at Leicester University. Her telephone number is 0116 2231639.

What are the possible benefits of taking part?

There are no direct benefits to taking part in this research, however it will be an opportunity for you to share your experiences of a Hospital Acquired Infection, and how you think and feel about that. This may help to improve services offered to other

patients in your situation in the future. Taking part in this research will help add to the scientific literature around the impact of Hospital Acquired Infections on Patients.

What will happen to the results of this study?

The results will be written up and submitted as part of a thesis which constitutes a significant part of my Doctorate in Clinical Psychology. A copy of the thesis will be stored at the University of Leicester. You are entitled to have a copy of the transcript of the interview I carry out with you, and of the analysis when it is written up, should you wish. The research will also be submitted to scientific journals for publication, and may be presented at academic conferences.

Who is organising and funding the research?

The research is organised and funded by the University of Leicester and Leicestershire Partnership NHS Trust.

Has the research been approved?

Yes. This study has been approved by a research panel organised by the University of Leicester, by my Research Supervisor and formal peer review. [It has also been approved by the NHS National Research Ethics Service].

PERSONAL INFORMATION SHEET

Please answer the following questions which will be used in the introduction to the research report to summarise the demographics of participants who took part in the research.

1. Male Female

2. Age Band

Twenties Thirties Forties Fifties Sixties Seventies

3. How long ago were you diagnosed with MRSA or CDiff?

4. How would you describe your ethnicity?

5. I would like a copy of the transcript of my interview

I do not require a copy of the transcript of my interview

If you would like to receive a copy of the transcript of your interview, please provide your address and/or telephone number so that I can contact you. Thank you.

Name:

Address:

.....

Telephone Number:

Please note that you are not obliged to provide the Researcher with any personal information. Whatever information you do provide is entirely at your discretion. This information will be stored separately to the transcripts and audio files of your interview in a secure location at the University of Leicester and will not be passed on to anyone else.

F. Letters to and from Ethics Committees

05/03/10

Reference Number: 10/H0408/28

Short Title: The Psychological Impact on Patients Acquiring a Nosocomial Infection.

Chief Investigator: Dr Nicola Parker

Date of Proportionate Review Meeting: 22nd March 2010

I enclose the following documents in support of my application;

<i>Document</i>	<i>Copies</i>	<i>Version</i>	<i>Date</i>
Application	1	10/H0408/28	05/03/10
Chief Investigator CV	1		05/03/10
Academic Research Supervisor CV	1		05/03/10
Protocol	4	3	20/02/10
Peer Review	1		10/12/09
Interview Schedule	1	2	20/02/10
Letter of invitation to participant	1	1	05/03/10
Participant Information Sheet	1	1	05/03/10
Participant Consent Form	1	1	05/03/10
Participant Demographic Sheet	1	1	05/03/10
REC Checklist	1		05/03/10

Thank you

Yours Sincerely

Dr Nicola Parker
School of Psychology – Clinical Section
University of Leicester
104 Regent Road
Leicester LE1 7LT

Email: nsp7@mail.cfs.le.ac.uk

Tel: 0116 2231639 (this is a university number where messages can be left for me)

Mobile: 07912882753



National Research Ethics Service
Nottingham Research Ethics Committee 2

1 Standard Court
 Park Row
 Nottingham
 NG1 6GN

Telephone: 0115 8839368
 Facsimile: 0115 9123300

17 March 2010

Dr Nicola Parker
 Trainee Clinical Psychologist
 School of Psychology – Clinical Section
 University of Leicester
 104 Regent Road
 Leicester, LE1 7LT

Dear Dr Parker,

Study title: **The psychological impact on patients acquiring a nosocomial infection**
REC reference: **10/H0408/28**

Thank you for your application for ethical review, which was received on 16 March 2010. I can confirm that the application is valid and will be reviewed by the Committee at the meeting on 22 March 2010.

Meeting arrangements

The meeting of the Nottingham 2 Proportionate Review Sub Committee will be held on 22 March 2010.

The Committee does not require you to attend the meeting in person. However, they may contact you in advance of the meeting with any queries related to your application. Please respond to these queries within 24 hours in order to assist the review committee with making a decision on your application.

Documents received

The documents to be reviewed are as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter		05 March 2010
REC application	47719/104613/1/576	09 March 2010
Protocol	3	20 February 2010
Investigator CV: Academic Supervisor		
Investigator CV: Chief Investigator / Student		
Participant Information Sheet	1	05 March 2010
Participant Consent Form	1	05 March 2010
Participant Information Sheet: Personal Information Sheet	1	05 March 2010
Letter of invitation to participant	1	05 March 2010

This Research Ethics Committee is an advisory committee to East Midlands Strategic Health Authority.
The National Research Ethics Service (NRES) represents the NRES Directorate within the

Interview Schedules/Topic Guides	2	20 February 2010
Referees or other scientific critique report		10 December 2009

No changes may be made to the application before the meeting. If you envisage that changes might be required, you are advised to withdraw the application and re-submit it.

Notification of the Committee's decision

You will receive written notification of the outcome of the review within 10 working days of the meeting. The Committee will issue a final ethical opinion on the application within a maximum of 60 days from the date of receipt, excluding any time taken by you to respond fully to one request for further information or clarification after the meeting.

R&D approval

All researchers and local research collaborators who intend to participate in this study at sites in the National Health Service (NHS) or Health and Social Care (HSC) in Northern Ireland should apply to the R&D office for the relevant care organisation. A copy of the Site-Specific Information (SSI) Form should be included with the application for R&D approval. You should advise researchers and local collaborators accordingly.

The R&D approval process may take place at the same time as the ethical review. Final R&D approval will not be confirmed until after a favourable ethical opinion has been given by this Committee.

Guidance on applying for R&D approval is available at <http://www.rdforum.nhs.uk/rdform>.

There is no requirement for separate Site-Specific Assessment as part of the ethical review of this research. The SSI Form should not be submitted to local RECs.

Communication with other bodies

All correspondence from the REC about the application will be copied to the research sponsor and to the R&D office for University Hospitals of Leicester NHS Trust. It will be your responsibility to ensure that other investigators, research collaborators and NHS care organisation(s) involved in the study are kept informed of the progress of the review, as necessary.

10/H0408/28	Please quote this number on all correspondence
--------------------	---

Yours sincerely,

Miss Susie Cornick-Willis
Committee Co-ordinator

E-mail: susie.cornick-willis@nottspct.nhs.uk

Copy to: Sponsor: LPT

R&D: UHL



National Research Ethics Service

Nottingham Research Ethics Committee 2

1 Standard Court
Park Row
Nottingham
NG1 6GN

Telephone: 0115 8839368
Facsimile: 0115 9123300

22 March 2010

Dr Nicola Parker
Trainee Clinical Psychologist
School of Psychology – Clinical Section
University of Leicester
104 Regent Road
Leicester, LE1 7LT

Dear Dr Parker,

Study Title: The Psychological Impact on Patients Acquiring a Nosocomial Infection: A Qualitative Analysis of the Experiences of Patients Contracting MRSA or CDiff Whilst in Hospital

REC reference: 10/H0408/28

Protocol number: 3

The Proportionate Review Sub-committee of the Nottingham Research Ethics Committee 2 Research Ethics Committee reviewed the above application at the meeting held on 22 March 2010.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>. Where the only involvement of the NHS organisation is as a Participant Identification

This Research Ethics Committee is an advisory committee to East Midlands Strategic Health Authority
The National Research Ethics Service (NRES) represents the NRES Directorate within the

Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.

Sponsors are not required to notify the Committee of approvals from host organisations.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Covering Letter		05 March 2010
REC application	47719/104613/1/576	09 March 2010
Protocol	3	20 February 2010
Investigator CV: Academic Supervisor		
Investigator CV: Chief Investigator / Student		
Participant Information Sheet	1	05 March 2010
Participant Consent Form	1	05 March 2010
Participant Information Sheet: Personal Information Sheet	1	05 March 2010
Letter of invitation to participant	1	05 March 2010
Interview Schedules/Topic Guides	2	20 February 2010
Referees or other scientific critique report		10 December 2009

Membership of the Proportionate Review Sub-Committee

The members of the Sub-Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of

changes in reporting requirements or procedures.

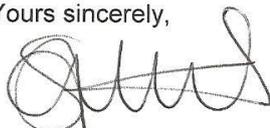
We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

10/H0408/28

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely,



PH
Dr Martin Hewitt
Chair

Email: susie.cornick-willis@nottspct.nhs.uk

Enclosures: *List of names and professions of members who were present at the meeting and those who submitted written comments*

"After ethical review – guidance for researchers"

Copy to: *Sponsor - Dr David Clarke*

R&D office for NHS care organisation at lead site - UHL

NOTTINGHAM RESEARCH ETHICS COMMITTEE 2

Attendance at PRS Sub-Committee of the REC meeting on 22 March 2010

Committee Members:

Name	Profession	Present	Notes
Dr Martin Hewitt	Consultant Paediatric Oncologist	Yes	
Mrs Anita Hughes	Health Services Researcher	Yes	
Mr Glen Swanwick	P.P.I Member	Yes	
Ms Margret Vince	Lay Member	Yes	

Also in attendance:

Name	Position (or reason for attending)
Miss Susie Cornick-Willis	Committee Co-ordinator
Samantha Roper	Proportionate Review Coordinator - observing



08/07/10

Reference Number: 10/H0408/28

Short Title: The Psychological Impact on Patients Acquiring a Nosocomial Infection.

Chief Investigator: Dr Nicola Parker

Dear Sharon,

Following our telephone conversation today, I have emailed to you electronic copies of the following documents

- * Research protocol
- * IRAS Rec Form
- * Researcher CVs
- * Participant Consent Form
- * Participant Information Sheet
- * Participant Invitation Letter

I am now enclosing hard copies of the following documents as required

- * REC letter of favourable opinion
- * IRAS Signed SSI Form
- * Signature of Sponsor
- * Letter from sponsor re: indemnity, funding and trials agreement
- * GCP Training Certificate

Thank you

Yours Sincerely

Dr Nicola Parker
School of Psychology – Clinical Section
University of Leicester
104 Regent Road
Leicester LE1 7LT

Email: nsp7@leicester.ac.uk

Tel: 0116 2231639 (this is a university number where messages can be left for me)

Mobile: 07912882753

DIRECTORATE OF RESEARCH & DEVELOPMENT

Research & Development Office
Leicester General Hospital
Gwendolen Road
Leicester
LE5 4PW

Director: Professor D Rowbotham

Assistant Director: Dr David Hetmanski

R&D Manager: Carolyn Maloney

Direct Dial: (0116) 258 8351

Fax No: (0116) 258 4226

08/10/2010

Dr Nicola Parker
Leicestershire Partnership NHS Trust
104 Regent Road
Leicester
LE1 7LT

Dear Dr Nicola Parker

Ref: **UHL 10939**

Title: The Psychological Impact on Patients Acquiring a Nosocomial Infection: A Qualitative Analysis of the Experiences of Patients Contracting MRSA or CDiff Whilst in Hospital

Project Status: **Project Approved**

End Date: 31/03/2011

I am pleased to confirm that with effect from the date of this letter, the above study now has Trust Research & Development permission to commence at University Hospitals of Leicester NHS Trust.

All documents received by this office have been reviewed and form part of the approval. The documents received and approved are as follows:

Document Name	Version Number	Date
REC Application		09.03.10
Protocol	3	20.02.10
Participant Information Sheet	1	05.03.10
Participant Consent Form	1	05.03.10
Participant Information Sheet: Personal Information Sheet	1	05.03.10
Letter of Invitation to participant	1	05.03.10
Interview Schedules / Topic Guides	2	20.02.10

Please be aware that any changes to these documents after approval may constitute an amendment. The process of approval for amendments should be followed. Failure to do so may invalidate the approval of the study at this trust.

Version 5, 20.04.10

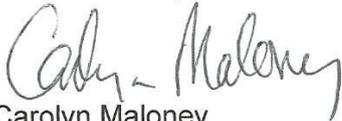
We are aware that undertaking research in the NHS comes with a range of regulatory responsibilities. Attached to this letter is a reminder of your responsibilities during the course of the research. Please ensure that you and the research team are familiar with and understand the roles and responsibilities both collectively and individually.

You are required to submit an annual progress report to the R&D Office and to the Research Ethics Committee. We will remind you when this is due.

The R&D Office is keen to support research, researchers and to facilitate approval. If you have any questions regarding this or other research you wish to undertake in the Trust, please contact this office.

We wish you every success with your research.

Yours sincerely



Carolyn Maloney
R&D Manager

Encs: .Researcher Information Sheet.

Please note that some of the documents may not apply to your study.

Addenda

Anonymised interview transcripts